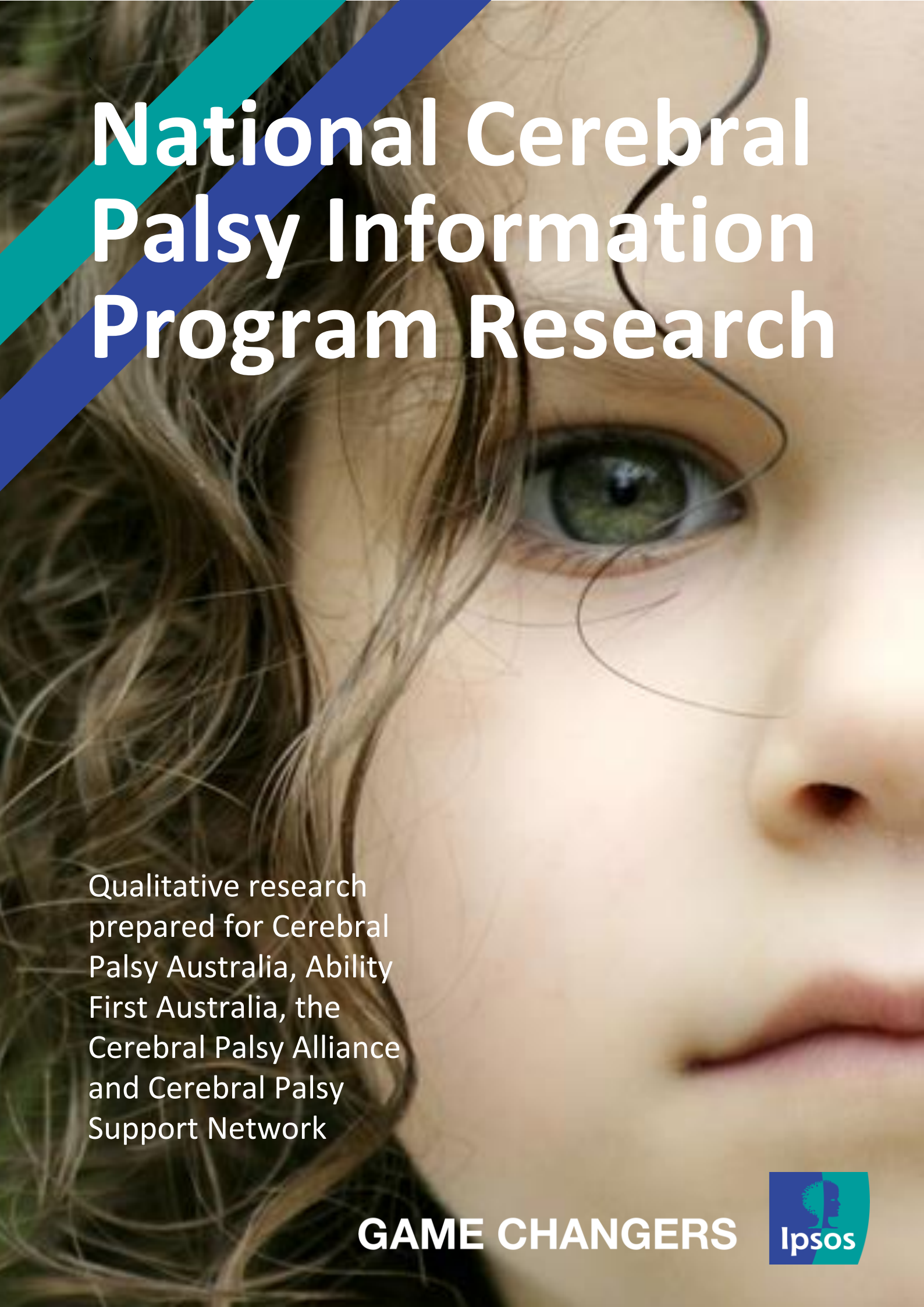

National Cerebral Palsy Information Program Research

Qualitative research prepared for Cerebral Palsy Australia, Ability First Australia, the Cerebral Palsy Alliance and Cerebral Palsy Support Network

GAME CHANGERS

Ipsos

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This research will be conducted in accordance with AS20252 and ISO 9001:2015.

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Ipsos acknowledges the traditional owners of the land and respects their connection to the waters, land and sea.

Ipsos would like to thank the Cerebral Palsy Australia, Ability First Australia, the Cerebral Palsy Alliance and Cerebral Palsy Support Network for commissioning us to undertake the National Cerebral Palsy Information Program research. We also thank the participants with cerebral palsy, their parents and carers, and also stakeholders, for contributing their time to this project.

Contents

1 Executive summary

This study, undertaken for Cerebral Palsy Australia, Ability First Australia, the Cerebral Palsy Alliance and Cerebral Palsy Support Network, comprises three elements:

- A synthesis of four pieces of extant research from Speech Pathology Australia, Cerebral Palsy Support Network and Choice, Passion, Life.
- In-depth interviews with n=40 people with cerebral palsy, their parents and carers.
- In-depth interviews with n=10 key individuals with strategic insight and advice or support roles.

The findings are summarised below.

> *We should be aiming for more proactive support for people with CP; the right information at the right time, when they need it most, to make informed decisions on the level of support they need to be active members of society, to live their lives like everyone else.*
> Stakeholder

Current provision of accurate, useful information for people with cerebral palsy, their parents and carers is inconsistent at best. The breadth, relevance and quality of information they receive is very variable and largely dependent on the quality of health and care settings and professionals they encounter and the persistence of the individual or their parent or carer. This means many feel they 'fall through the cracks' and that there is an undue element of luck in their likelihood of finding relevant, valuable information.

There is a widespread appetite for the quality of information to improve and for access to comprehensive information being effectively curated in a central location. Parents and people with CP are currently dependent on the time and effort they can personally dedicate to searching the internet. Much of what they find is located on international sites, which causes frustration that it may not relate to advice or services available in Australia.

Information needs vary by life stage, however, there are consistent themes that emerge. Parents of children with CP aged zero to two years are looking for a roadmap that outlines their potential routes forward; it is challenging for them to absorb information when they are simultaneously reeling from the arrival of the new baby and the realisation that the child has additional needs, but they want a guide to give them some structure for what the future might look like. Once this period passes, there is a consistent need for more specific, detailed information on CP, the different types and implications. People are critical that the current range of condition-related information that they can access is too generic and, on closer examination, does not relate to their, or their child's, diagnosis.

Funding for therapies, support and equipment is a central concern for all families with a member who has CP. The current information on funding streams is confusing and hard to navigate. It is also very labour-intensive compiling the relevant documentation for funding applications. Not only do parents and people with CP want better information on funding routes, but they would also value more support and a helpline staffed by individuals with lived experience of CP who can personally advise them. This greater clarity of information and more personal support is relevant to all life stages.

Table 1: Information needs

	PROBLEM AND DIAGNOSIS, aged 0 to 2	NAVIGATING EARLY INTERVENTION, aged 3 to 5	SCHOOL THERAPY AND RESPITE, aged 6 to 17	PURPOSE AND INDEPENDENCE, aged 18 to 45	DISABILITY AGEING CARE, aged 46+
'Roadmap'	✓				
CP '101'	✓			✓	
Detailed information on types of CP		✓	✓	✓	✓
Local therapists with CP experience	✓	✓	✓	✓	✓
Comprehensive information on therapies/surgery	✓	✓	✓	✓	
Assistive technology			✓	✓	✓
Peer support	✓	✓	✓	✓	✓
Socialisation and friendships		✓	✓	✓	✓
Mental health information			✓	✓	✓
Funding information and support	✓	✓	✓	✓	✓
Information on employment			✓	✓	
Information on education		✓	✓	✓	
Educate wider population			✓	✓	✓
Information on ageing with CP				✓	✓
Information on legal advice					✓

A central part of life for people with CP, and their parents, is access to appropriately skilled and experienced therapists. This is of most importance for earlier life stages, with adults and older adults making less use of these services. However, all life stages spoke of the challenge of finding local therapists, with experience of CP, and, specifically both knowledge and experience of their CP diagnosis.

In addition, there is significant interest in sourcing comprehensive information on the range of support, therapies, interventions and surgeries that might prove beneficial. Again, there is interest at all ages, but most intensively so on behalf of children and for young adults with CP. There is concern that the progression of their, or their child's CP, is dependent on the scope of the knowledge of the health and care professionals they chance to encounter, and what they recommend. In addition, there is a call for information that includes both traditional and alternative approaches.

As people with CP approach adulthood, there is a range of information they require that relates less directly to the management of their physical disability and more to how they navigate the challenges of adult life and independent living; namely, navigating the health service and therapy, accessing employment, accessing higher education, using public and private transport, becoming a parent, building wider social network and dating. During the 18-45-year age range is when there is also greater interest in information about the range of assistive technologies.

Information needs narrow considerably as people with CP age. There is interest in more information about the ageing process and how it interrelates with CP. Among carers of older people with CP, there is interest in access to information regarding the legal steps for putting in place appropriate legal safeguards for children or siblings with high levels of impairment.

While there is significant need for 'hard' facts relating to CP, and how to meet the challenges of key life transitions – to school, work, or independent living – there is also a huge currently unmet need for parents and people with CP to share their lived experience. This has a practical aspect in that they see peers as the most valuable source of realistic, well-informed advice on day-to-day issues associated with living with CP. It also has a very significant pastoral care aspect, as almost all of those who took part in the research wanted to be able to discuss and share stories with others who were facing the same challenges as them.

There is demand for both in-person support, with more opportunities to meet, discuss and socialise with parents and/or people living with CP, and also online support. The majority of parents and people with CP reported making use of Facebook groups. For many this is a successful route to get rapid access to the experience and advice of a very wide group, with several describing these groups as a 'lifeline' during the early years of their child's diagnosis. There is, however, concern that the advice may not be current, accurate or specific to an Australian setting. Users of these groups are also critical that service providers are present in these online spaces, when actually they're looking for peer discussion and support.

Key to the success of these support channels is that the individuals they are put in touch with have, or care for someone with, the same type of CP. Many of the current channels available are not sufficiently specific, meaning that individuals are less keen to use them because the people they meet

have different levels of physical or intellectual disability meaning that their lived experience is very different. In addition, there is interest in social media, or traditional means, being used to find others with similar lived experience as part of a friendship group. From the age of six onwards there is consistent concern that it is difficult building friendships and social networks, and that there is greater need for support and means of connecting to do so.

In addition to this need for peer support, there is also a need for more direct mental health support. Both parents and people with CP recognise that at various stages of their life there is significant mental strain for them as individuals, as life partners or as families. They would welcome a helpline, staffed by someone who understands CP, that they could reach out to for advice and support.

An information need that becomes more apparent as people with CP age, is the need to provide more information, or education, to the wider public. This presents initially as a need for information to share with educators on what CP is and what it means for any particular child in a school setting. As people enter the workforce, there is a need for employment agencies and employers to have a better understanding of how CP might impact on a person's ability to undertake a given role, and what, if any, additional support would be helpful, or necessary. Furthermore, there is a need for greater understanding among the wider population of what CP is, how it may impact an individual and how the general population can be more supporting and empathetic to people with CP.

There is interest in information provision via a range of different formats:

- **Factsheets** – or clear succinct written information – is particularly valuable for those in both the early and later years of life, as this format lends itself to lifestyle preferences for these age groups.
- A larger range of **age appropriate books** are needed to communicate information about CP to children and their siblings.
- All age groups need better access to information on how to find **local therapists**, with detailed information on their experience with specific types of CP and specific therapies and treatments.
- **Videos** are welcomed by all life stages as an easily accessible way of receiving information. They are seen as particularly valuable in hearing peer stories, and for explaining practical aspects of life with CP
- **Social media** is a channel used by all life stages to access peer support and information, although marginally less so by those aged 46+. The speed and reach of this channel is a major advantage. The majority of people with CP and their parents have made at least some use of CP Facebook groups at some point. While the failings of these groups are recognised (i.e. not necessarily local, accurate or current), most participants felt that it was not necessary and too difficult to create a new social media space for people with CP. Some suggested a stronger presence of skilled advisors with in-depth knowledge of CP in these groups would provide a better way forward.
- There is also interest in the provision of a **helpline**, rather than a chat bot function. There is a desire to be able to speak with a person with a depth of experience with CP, who can direct

callers to relevant information and resources. There is also interest in a helpline that contributes to mental health support for parents.

While there is recognition that it is extremely challenging, both parents and people with CP would welcome the development of a single digital location, that encompasses the broad range of information needs. They currently spend hours searching and being directed between different information sources, which are not necessarily comprehensive and can be contradictory. Knowing that a single platform was trustworthy, comprehensive and up-to-date would be a very significant support for those living with, and caring for someone with, CP.

> *Every person with a disability, every family has a need for timely, reliable and accessible information whether at a transition point or not.*
> Stakeholder

2 Background and objectives

2.1 Background

A diagnosis of cerebral palsy (CP) is one that throws parents into confusion and shock. They have no preparation, and generally will know very little or nothing of what the diagnosis will mean in terms of life implications for their child. From this moment onwards they are on a steady, and often steep, learning curve in understanding the many consequences this will mean for their child, their needs and their family. As the child grows and moves throughout their life journey, potentially taking on greater agency for decisions in their life, it is a learning process for the person with CP that is central to a vast array of their major and minor life decisions.

Central to this learning process is access to high quality information. The consortium of Cerebral Palsy Australia, Ability First Australia, Cerebral Palsy Alliance and Cerebral Palsy Support Network aim to establish a consolidated national platform for information, for people with CP, their families, support providers, key National Disability Insurance Scheme (NDIS) roles, the community and mainstream services. The National Cerebral Palsy Information Program intends to embrace leading and emerging technologies to present and distribute high quality information to people with CP, their carers, and those working to advise and support them.

The consortium has secured funding as part of a recent National Disability Insurance Agency Information and Capacity Building (ILC) funding round and wishes to use this towards better understanding the information needs and experiences of people with CP and their supporters.

2.2 Research objectives

The key objectives are to explore:

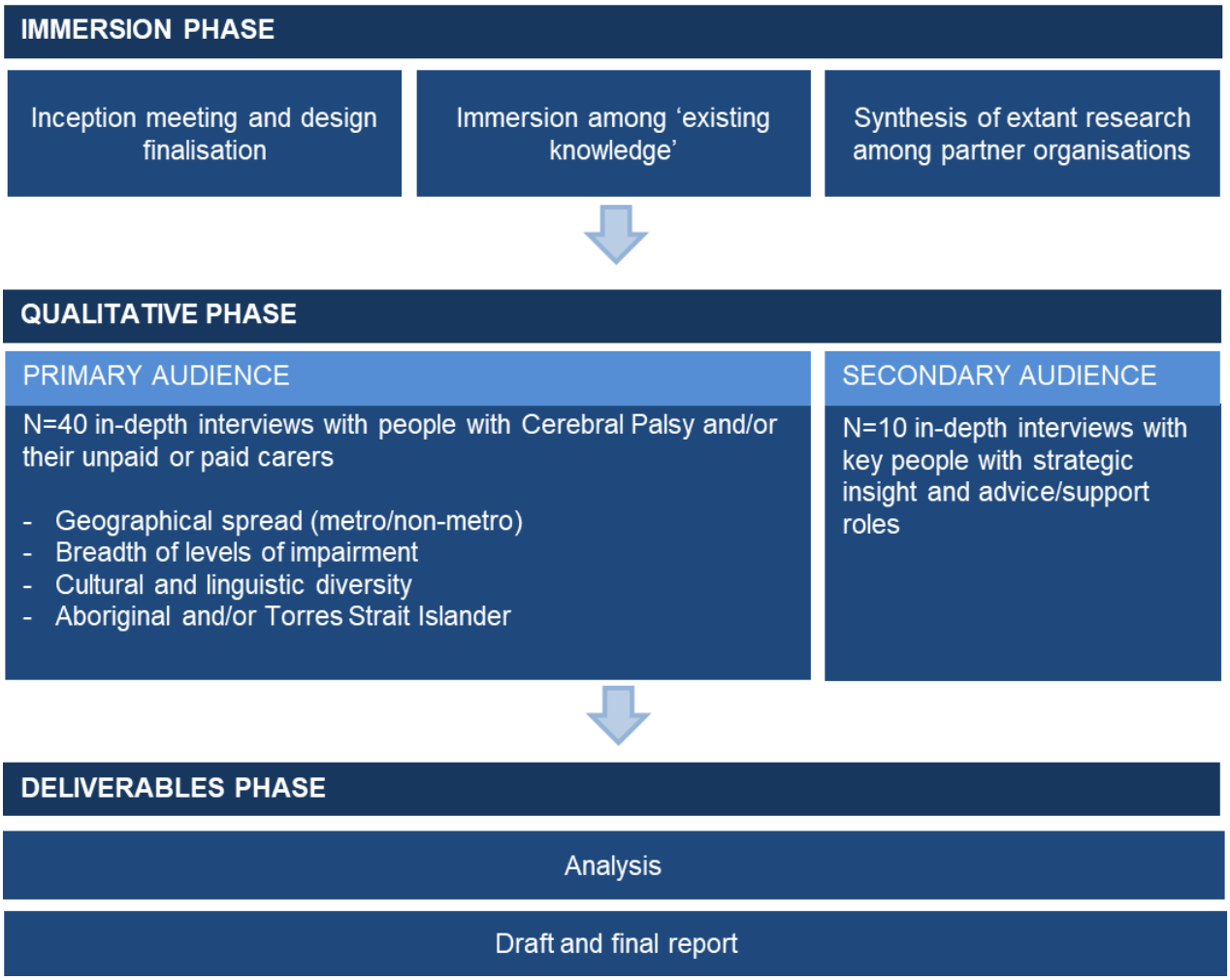
- Life stages/transition points for people with cerebral palsy and, where relevant, parents, to explore experiences and needs at key stages and transitional points to help us understand information needs in relation to these.
- Understanding which institutions, services and people are important at these stages, and the types of information that would most assist them to deliver better outcomes for people with cerebral palsy.
- Current sources of information
    - What information are they finding?
    - Where are they sourcing it?
    - What do they think is useful/not useful, helpful/harmful, good/bad?
- Preferred communication channels and current experiences, e.g. usage of technology, barriers and enablers such as access to devices, adequacy of internet, how they would like to get information.

3 Methodology

3.1 Research design overview

The diagram below outlines the methodological approach adopted for this project.

Figure 1: Research design



Design and recruitment

Immersion phase

Ipsos undertook two initial tasks to ensure this research project was informed by existing relevant information and research; the first was immersion and exploration of existing documents held by the Consortium, and the second was to identify and analyse research held by partner organisations. Ipsos contacted fourteen partner organisations, of whom three had conducted relevant research which they

were willing to share for the purpose of informing this project. The Ipsos team undertook a synthesis of extant research which is provided in section 4.

Qualitative phase

The main data collection was undertaken through in-depth interviews with both the primary audience (n=40 interviews people with CP, their parents and carers) and secondary audience (n=10 with strategic stakeholders and also those working in advice or support roles).

Among the primary audience of people with CP, their parents and carers a design matrix was produced to ensure a spread of participants by location (metro and regional mix, and spread across states and territories), age of person with CP, level of impairment, cultural and linguistic diversity and inclusion of people who are Aboriginal and Torres Strait Islander. Participants were identified via two distinct sources. Of the n=40 interviews, n=18 were identified through project team partners. The remaining n=22 were identified via professional market research recruiters. This mixture of sources ensured a mixture of views of those who were more and less engaged with sector-related organisations.

The recruitment of the primary audience was undertaken using a recruitment screener designed to ensure each of the recruitment criteria were met (appendix 10.1). Primary audience participants were each given $100 to thank them for their time. A table illustrating the achieved sample among the primary audience is included at appendix 10.2.

The secondary audience were identified by the Project team as being individuals with strategic, support or advisory roles that were relevant to the project objectives. Recruitment was undertaken directly by members of the Ipsos team.

Fieldwork

Moderation was undertaken by members of the Ipsos project team, with interviews taking between 30-75 minutes. While the intention had been to conduct some interviews in person, because of the public health situation related to the COVID-19 pandemic and the vulnerability of some participants, all interviews were conducted by telephone or video-conference (depending on participants' preference). Interviews were recorded with participants' permission.

Discussion guides for each audience were designed in close collaboration with the project team. They were informed by extant research, using the life stage structure and exploring information needs in depth. The primary and secondary audience discussion guides are appended at 10.3 and 10.6, respectively.

The primary audience were also invited to contribute a video self-ethnography pre-task. The purpose of this element was to provide an opportunity for primary audience participants to share their experience in their own words and offer wider context for their contribution. Of the n=40, total primary audience interviews, 20 participants chose to submit a video. Participants were given a further

$30 incentive to thank them for this additional contribution to the research. The video self-ethnography pre-task instructions are included at appendix 10.4.

Given the potentially sensitive nature of the interviews with primary audience members, and that the discussion may bring up traumatic issues, moderators were briefed on how to support participants if they became distressed. They were provided with a protocol document, with additional support details, if required. This document is appended at 10.5.

Interpretation of the findings

Please note that this research is qualitative in nature. Qualitative methodologies allow researchers the flexibility to focus on the issues that are most important to participants and to probe in detail on views and experiences. However, qualitative methods do not provide a large representative sample upon which to draw conclusions about the population. Instead, they provide a detailed snapshot of the range of attitudes, behaviours and experiences in the population.

Where possible, terms such as ‘a few’, ‘some’, ‘many’ and ‘most’ have been used to give the reader a sense of the proportion of participants who held a certain view or undertook a behaviour. While these are indicative of the relative prevalence of issues among participants, readers should be cautious in making assumptions about the population based on these descriptions.

Where differences have been identified between the subgroups of participants, these are highlighted throughout the report.

4 Synthesis of extant research

4.1 Context

This synthesis of extant research considers four reports that look into the provision of information for persons with cerebral palsy (CP) and other stakeholders in their lives. Two of the reports were compiled by Speech Pathology Australia (SPA); the third by the Cerebral Palsy Support Network (CPSN); and the last by CPL. SPA is the national peak body for speech pathology; CPSN is a non-profit organisation that is the peak body representing those with CP and their caregivers; and CPL (Choice, Passion, Life, formerly the Cerebral Palsy League) is a Queensland-based disability service and support provider. We would like to thank SPA, CPSN and CPL for sharing this material and allowing it to be used to inform the development of this project. The purpose of this synthesis is to understand the strengths and the gaps in the information provided to aid in the formation of the National Cerebral Palsy Information Program (NCPIP).

The SPA reports include the Executive Summary from a literature review researching communication access standards in Australia, as well as the final plain language research report. The plain language report is highly accessible for those with disability and culturally and linguistically diverse (CALD) populations. These reports provide explanations as to the necessity of ensuring information is available, accessible, clear and CALD-appropriate.

The report from the CPSN consists of the results of the 2019 Member Survey, containing insights from individuals and caregivers regarding the services offered by the CPSN. This report gives an insight, from the perspective of its members, into communication shortcomings and future information provision opportunities. The final reports, the SPA plain language report on communication access and the CPSN results report, are recent and relevant, both published in 2019.

The CPL report includes the findings from a qualitative research study undertaken by Ipsos Australia in 2017. The purpose of the research was to deliver a detailed understanding of their customers' functional and emotional needs during the key life stages in regard to their journey using CPL services. The study explored and mapped the customers' needs along each stage of their life journey, looking at the triggers and barriers to service use, current experience of transitioning from one life stage to the next and how the experience could be improved and also how service provision can continue to be improved.

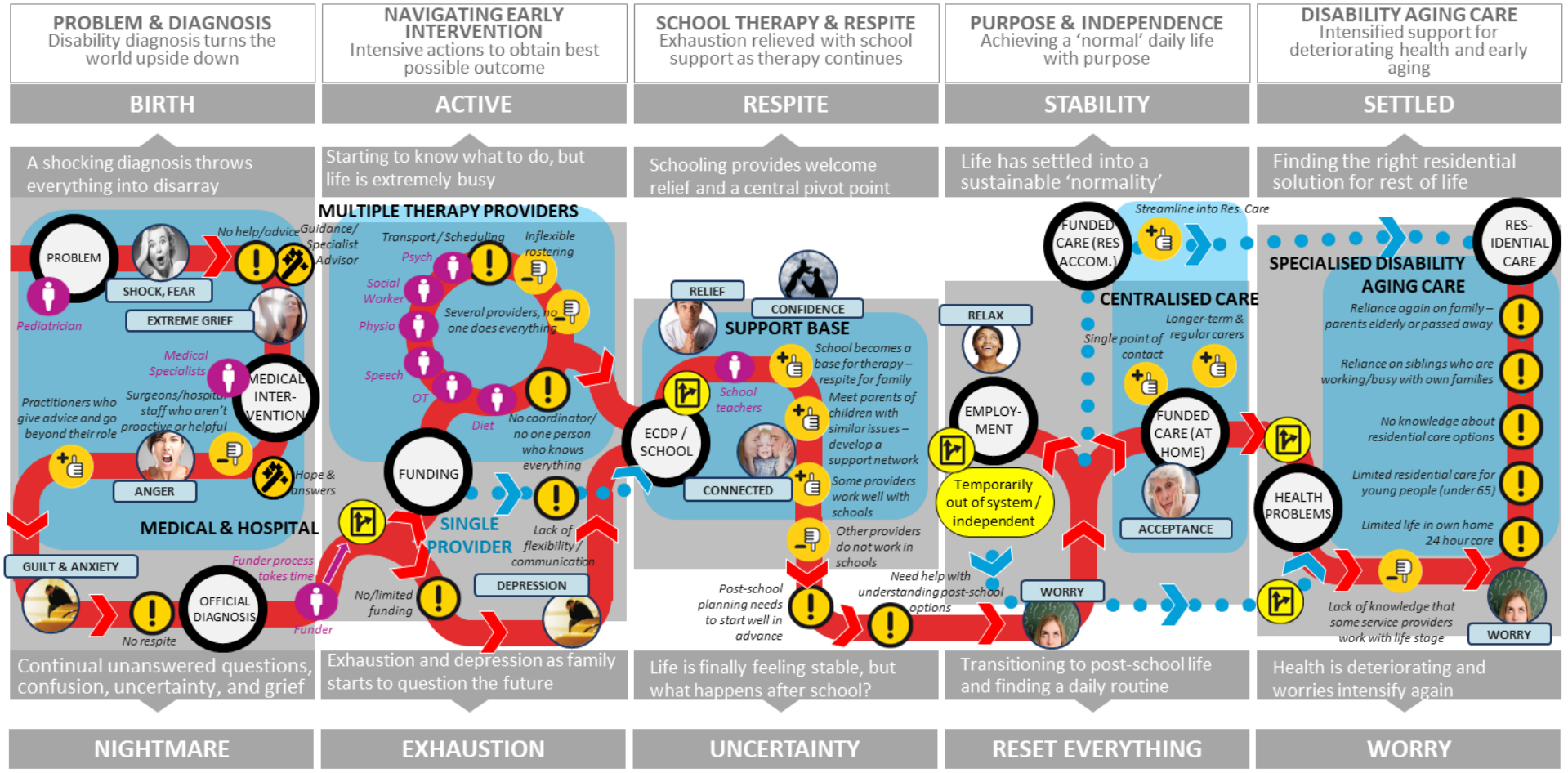
4.2 Analysis

The CPL research illustrated in detail the experience of people with CP, their parents and carers at key life stages. The following summary table and illustration of life stages shows the emotional range, tension points and milestones, turning points and key people or influencers on the pathway. These findings informed the discussion guide and provided valuable information for moderating team for the NCPIP research and allowed this study to build on this structural information.

The macro life stages

	Pre-School		School	Post-School	Post-Family Home
	DIAGNOSIS Aged 0-2	**NAVIGATING EARLY INTERVENTION** Aged 2 to 5	**SCHOOLING, THERAPY & RESPITE** Aged 6 to 18	**LIVING WITH PURPOSE & INDEPENDENCE** Aged 18 to 50	**DISABILITY AGING CARE** 50+
Carer:	Shock, anguish, fear No preparation, no prior knowledge, uninformed and ill-equipped, grief and despair.	Research, information seeking, searching for help, finding resources, making appointments, scheduling a new life, getting organised.	Some relief and respite as school provides daily care and takes some burden of organising therapies.	Life purpose, activities and recreation Planning for future without mum and dad.	Residential care to further alleviate caring burden.
Client:	Oblivious.	Whirlwind of appointments, new therapies, new people.	Early emerging independence, formative socialisation, developing life purpose.	Retreat to home, respite/recreational outings if possible, employment if possible, social life if possible.	Minimal therapy, minimal activities, move to residential care, deteriorating health, increasing medical support required.
Key Need: (what should be happening)	Advice, friendship, guidance, counselling, companionship, information	Resources, rostering, flexibility, streamlining therapies, centralised therapy with one provider.	Working in with schools, transport to appointments, rostering, post-school planning.	Outings, carer flexibility (out of home, in-home), activities, recreational options, employment advice and support, social network & support.	Medical and aged care support as health declines, advice on what to prepare for, residential care and facilitation of finding the right residential care and residential care for those younger than 65.
Situation: (what is happening)	Multiple practitioners, therapist, no carers at this stage, endless appointments and questions, few answers.	Waiting lists, restricted appointment times, inflexible rosters, multiple therapists, multiple providers.	School as a base and central point for therapies works well, falls over if there is a disconnect between provider and school, outside school therapy difficult if there are transport issues.	For those who are more mobile and can work, they can achieve an independent and purposeful life. Those with more severe disabilities have limited opportunities for recreation and social.	Limited residential care options, confusion and lack of knowledge about what is provided. Specific requirement for disability aging care as opposed to aged care residential care.

Map of end to end journey through the disability life stages



The main stakeholders mentioned in these reports are individuals with CP, their parents and caregivers. However, other groups present within the CP information sphere include Speech Pathology Australia, the Communication Access Alliance, the Cerebral Palsy Support Network, support workers, medical professionals, teachers and future workplaces. All of these stakeholders have information needs regarding CP; however, their presence may occur at different transitions through an individual with CP's life.

It is imperative that communication access standards are created and adhered to, in order for those with communication support needs to have equal rights. This will ensure that those with sensory disabilities, such as individuals with CP, can communicate with their community and receive information through a variety of channels, such as face-to-face, written, telephone, digital or with the help of a support person. Australia is falling below other countries in regard to equal communication access rights, as such the NCPIP can aid in ensuring that information is disseminated to all stakeholders in an appropriate manner.

In the CPSN Member Survey, the most common coexisting conditions of the individuals with CP are communication, learning and intellectual difficulties. This highlights the necessity for the provision of information that is sensitive to a range of disabilities.

The CPSN report also uncovers themes regarding gaps in information. Consistently, both individuals with CP and their caregivers were either unsure of exactly what specific services and supports are provided or were completely unaware that these services existed. Within the CPSN framework this includes membership services, the NDIS pre-planning service and support coordination. This suggests that the information explaining what these services offer is either unclear or unavailable and that when these services are advertised, there is a lack of clarity surrounding eligibility criteria. However, when members were asked what is most important to them when making decisions regarding services to use, the response was relevant information about the service and what it offers.

This problem with information dissemination is exacerbated by the fact that the majority of members join the CPSN to receive information and advice for living with CP. This is highlighted by the three most important things for CPSN members:

- receiving support, information and advice
- being kept up to date with current information
- receiving the monthly newsletter

All of these aspects are information-based and ranked higher than any of the more socially based options provided. Members are highly engaged with information provided to them, with three-quarters (75%) of individuals with CP and 92% of caregivers reading the monthly newsletter provided.

Currently, there are some information channels that are provided for support, but members would like to see more materials of this nature in future. Specifically, the most important topics are support for caregivers and support during life transitions. Presently, life transitions during the earlier stages appear to be more thoroughly covered. However, later life transitions, including the transition to high school,

post-schooling options, the transition to independent living and ageing with CP, are all perceived as lacking in sufficient information.

It is also important to members that training and education can be provided to individuals with CP, caregivers and all other stakeholders through an individual's life transitions. This is considered community education and training. For individuals with CP, the preferences for community education are:

- training for young people with CP
- training for health professionals
- training for workplaces
- training for NDIS planning

For caregivers, the preferences for community education are:

- training around life skills
- training for parenting
- training for educational bodies
- training for support workers

Further, members would also like to foster more social connections that help in the transmission of information. These suggestions include forums and online information sessions for individuals with CP and caregivers to provide input and feedback, or possibly even to become a peer mentor for others in similar situations. This highlights how the information provision between organisations and members should be a reciprocal relationship, as those who have CP or are caring for someone with CP, have highly relevant information to share with their community.

The CSPN results report provided valuable information regarding the top challenges for members which could provide initial information themes for the NCPIP. For individuals with CP:

- ageing with CP
- navigating the NDIS
- finding employment

For caregivers:

- navigating the NDIS
- social isolation
- finding quality, long-term support workers

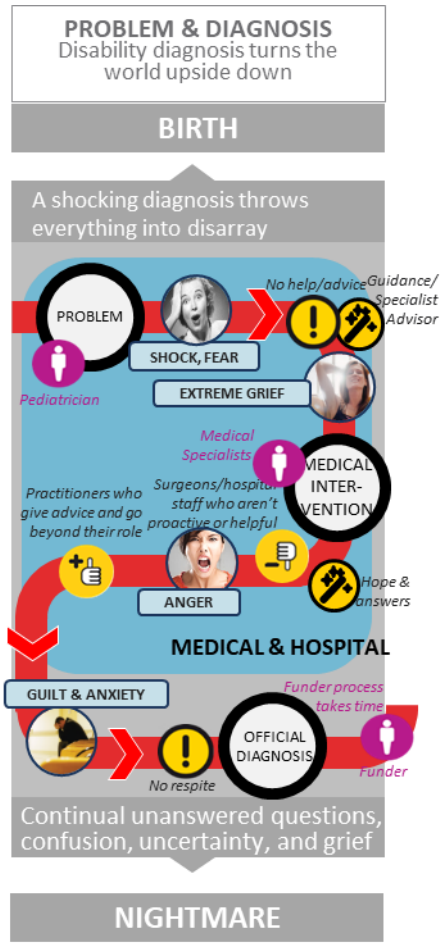
Understandably, as this is an emerging issue, navigating the NDIS is common to both individuals with CP and their caregivers as a top challenge. However, the other challenges presented appear to be more relevant to each population, suggesting that information needs can be quite varied depending on the perspective of the person involved. This highlights the necessity for engagement with the CP community for the NCPIP.

This brief synthesis has provided insights into the importance of ensuring communication access for those with disability, while highlighting the complexities of disseminating education and training to all

stakeholders throughout the CP journey. Individuals with CP and their caregivers are highly engaged with information provided to them, however, there is a lack of sufficient and clear information being provided around a range of topics, including CP life transitions, available services for individuals and caregivers, NDIS support and CP during adulthood.

5 Problem and diagnosis – aged 0 to 2

5.1 Life stage context



This life stage for parents and carers is characterised by shock, confusion, fear and a sense of freefall.

The couple of years following a baby's birth are some of the most uncertain times for parents/carers of infants who go on to be diagnosed with CP. Those we spoke with who were well beyond this stage recalled their child's life from birth to two years old as an incredibly stressful time, especially during the period prior to diagnosis.

The point of diagnosis offered the prospect of clarity for families and a small reprieve for those who suspected CP but struggled to get that diagnosis. Parents generally went from a period of feeling very much in the dark pre-diagnosis to having a slither of firm information to grasp, describing almost a momentary sense of relief. However, although diagnosis provided a label for what their child was experiencing and helped set in motion the early intervention journey, the diagnosis of CP tended to raise more questions than it answered. Compounding this was effectively a period of grieving that parents often encountered, as they came to terms with the potential ongoing issues their child would face.

5.2 Key challenges for this life stage

Upheaval and shock

Parents mostly described that finding out their child had CP (or symptoms suggesting atypical development) was a complete shock, with life feeling like it changed overnight. Those whose babies had arrived prematurely or who had experienced complications at birth were less surprised but still reeling. For those who had had a complicated or pre-term birth, that experience alone was usually very distressing. Subsequently discovering there might be long-term issues for their babies was effectively a second blow while they were still traumatised by the birth.

Coming to terms with their child's likely or confirmed diagnosis of CP was not a discrete event, rather many parents described the process as coming in waves, and the associated grief could be triggered by

seemingly innocuous moments. This can be further complicated by parents' cultural background where differing attitudes to disability can impact their perceptions.

> *They helped with getting the reports typed up, and that was when I saw it in print – even though he looks like a happy little boy, he has issues. It was confronting.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

> *In some cultures there is some shame and stigma attached to disability, and the consequence of that is that parents don't want to recognise or acknowledge that their child has a disability. It is important to have good communication based on respect and understanding. Every family will have a different timing in being ready to get that information and ready for that support.*
> Stakeholder

The complexity of diagnosis

In part, because not all signs of CP are visible at birth and can become more obvious as babies develop, the process of diagnosis can be drawn out and characterised by a period of uncertainty. Some parents felt they had been forewarned of a likely CP diagnosis in a supportive way, meaning the diagnosis was more of a formality. Others experienced the news, or suggestion of CP, out of the blue and found it shattering. Compounding this distress was that a range of specialists were likely to be involved with babies not reaching specific developmental milestones, which meant that the first mention of CP might be delivered informally by someone other than their paediatrician.

> *I think the first person that sort of raised the idea of my daughter having CP was a community physio who, very casually and off the cuff, made a remark at the end of our session, 'But not to worry, i have two sons with CP and it's really not a big deal!'… I was completely bewildered.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

> *[The diagnosis] should have been in private, in the appointment, as part of the appointment, with my husband there. Not in the waiting room, not at the end of the appointment when I've got no options and no way to ask any questions or talk to her about it… That's definitely … a theme … that it was never about considering that we've got some news that might be quite earth shattering for you and we're going to think carefully about how we deliver it. I don't think that happened in any situation.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

Parents of children who have a lower level of impairment, or who experienced other issues that were overriding their experience of CP, sometimes had a slower journey to reach diagnosis. Some felt that they were left with the responsibility of putting together the 'evidence' – things they noticed that weren't quite 'right' with their child and pushing to get doctors to investigate.

> *It was a long time getting to that diagnosis… We would either take some videos of [our son] when we would notice things, just things we didn't think were quite right. We didn't know, because we don't have other children to use as a guideline, so we were told to not Google things or use the internet. We were never given any information at all; just verbal, any information was verbal from them… Because he was so mild, they didn't want us to get worried.*
> Parent of child aged 0-5 with low level impairment, regional South Australia

Isolation

Parents generally feel very isolated in this stage. Extended family was rarely mentioned as a source of support: parents were grappling with what they were beginning to find out about their baby and, with so many unanswered questions, they felt unable to convey what was going on more widely.

> *My family have really struggled to empathise, I think, with what it might be like to have this new information and this child with a diagnosis.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

> *Towards the start, I kept forgetting things, and I had to relay it back to the grandparents or my partner and I would forget, it was really hard, relaying information back. He got his speech report [and it said] nothing's really changed - I can't give you anymore [information than that]!*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

Parents described feeling at the centre of a situation where they didn't know the answers, or the rules of the game, and didn't know who they could turn to.

> *Realistically, navigating accessing funding, we were completely on our own. We were grieving as well as having to do all the admin.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

> *The neurologist asked if we were going to speech therapist and OT yet, and was [my son] progressing? I don't know! There's no support for me or my partner, I can't work fulltime anymore, [my son is] seven days a week with me. There's nowhere I can turn to. His NDIS review is coming up, so I'm getting all the reports from the OT and that, I might have a bit of a cry, is that normal? I don't know! If someone said, 'Here's some information', that would be awesome.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

Adding to the sense of isolation was that, at this stage, parents had not yet met other families in a similar situation, and some felt it was hard to connect with parents of children without disabilities.

> *I think it would be good to meet other parents of children with cerebral palsy, or even other disabilities, because I don't know anyone in our community that has cerebral palsy. And people, I find, just don't quite get it.*
> Parent of child aged 0-5 with low level impairment, regional South Australia

Ambiguity

These very early years are characterised by uncertainty. Parents were unsure about what CP is, and more importantly, what it will look like for their child. This meant that they feel in a state of limbo, waiting for time to pass to understand more about how CP was going to manifest in their child.

Everything from the day dot is 'wait and see, wait and see'. He's making noises and saying 'Mummy' and that's about it. He might say words then they'll just disappear … they just keep saying, 'We don't know'. Is he going to stop walking? They don't know. Is he going to talk at all? Is he going to be able to use his hands? They just keep saying they don't know. So, there's no information.
Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

I guess frustratingly from a parent's point of view, but completely understandable from a doctor's point of view, no one was prepared … or able to give us any stats or facts and figures about what this would mean for her.
Parent of child aged 0-5 with high level impairment, metro Victoria

Looking back on the diagnosis – [we wanted] some kind of resources to give a baseline of what we were [in for] – more of an idea of how differently it can impact children. Rather than a guessing game of 'Is my child going to walk? Is my child going to talk?'.
Parent of child aged 0-5 with high level impairment, regional Victoria

There wasn't a lot [of useful information], because CP is so diverse in presentation. We got given the diagnosis, told CP is 'this' – it was basic, the picture it presented was for high level cerebral palsy, for quite affected people. But for [my son], the picture it was creating wasn't accurate for our experience of what CP is. I realise for some families the literature matches the reality … but doesn't match the child we have. Even today, there's a lack of information about the variance of cerebral palsy. There's a whole load of kids for whom there's no information about.
Parent of child aged 6-17 with medium level impairment, metro Queensland

Lack of knowledge – you don't know what you don't know

Most felt they didn't know where to start and had no idea what to do both in the lead up to and post diagnosis. Overall, they experienced a dearth of information. Although parents who participated had heard of CP and knew it wasn't 'good', it wasn't uncommon for awareness of the condition to be the full extent of their knowledge.

The first time the words [cerebral palsy] were mentioned was by the neurologist. They just asked us, 'Have you heard of cerebral palsy?', 'Yes' and they said it was likely [that's what it was], but that's as far as we got … no one gave us any information, no one told us how you get it, why, what happens from here. … I wasn't handed any sort of pamphlets, I wasn't told here's what you do with a child with CP, so I google – that's sometimes a bad idea.
Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

I didn't know what I was searching for … I felt really stuck.
Parent of child aged 0-5 with high level impairment, metro Victoria

When she first got diagnosed, the paediatrician told me what she had and gave me no information at all … I didn't even understand what CP was, I had to do research. When she told me, I was like 'Is my kid going to die?!'.
Parent of child aged 0-5 with medium level impairment, metro Queensland

> *It would be good to have a form that says, 'This is what cerebral palsy is, this is the type that [your son] has and these are some websites that you could look at and get some useful information'.*
> Parent of child aged 0-5 with low level impairment, regional South Australia

Lack of knowledge about CP, its causes and the way in which it affects people was the main challenge for parents, but lack of awareness and knowledge about the National Disability Insurance Scheme (NDIS) also contributed to the stress parents experienced in the first few years of their child's life.

Fear

Fear was experienced in relation to a range of things but tended to be focused on fear for their child and how challenging life might be for them as they grow older, especially if they were severely disabled. But there was also fear in relation to finances, knowing what to do, and where to go.

> *With the financial side of things, I was in tears; how am I going to afford this? If he can't walk, how am I going to afford a wheelchair? I'm freaking out about the NDIS review – I can't believe anyone didn't mention it to me. The stress was taken off me about how I could afford the sessions, because of the carer allowance.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

5.3 Information needs

While there were significant information needs, some parents were in a state of shock and were not well placed to take in the information they were given.

> *[It needs to be] recognised that people are not necessarily in a state to be absorbing information, [that] needs to be a feature of the sort of program you're involved in.*
> Stakeholder

Cerebral palsy '101'

Parents of infants with CP need introductory level information about CP as a starting point. Some of the parents we spoke with described situations where paediatricians had asked if they'd heard of CP, and – if yes – moved the conversation along from there. One parent in her late thirties recalled the moment she realised that the childhood term she remembered as 'spastic' related to CP.

> *It really wasn't enough of the right kind of literature, it was really medical. I recall thinking, ok fine, but now what do we do?!*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

A challenge for providing information at this stage is that, while parents are desperate for information, they are still coming to terms emotionally with the likely or given diagnosis.

> *I have seen a little bookshop at the children's hospital – I did see a couple of books 'My child has cerebral palsy' and I was going to buy it … um, but then I didn't … not sure why. I think I haven't come to grips with the fact that I have a child with a disability yet.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

Information about what the future will look like for their child

Despite not being necessarily quite ready to absorb information, parents felt hungry for as much information as they could get their hands on. But the dominant theme in what parents of very young children wanted was more specific information about what CP would entail for their child, they wanted more tailored and not generalised information.

> *They need to know their child is going to be ok; that their child will have a very good life, a very productive life. They worry – will my child go to school? Have a job? And what they need is reassurance, with evidence that it can be done, with the level of support that is available.*
> Stakeholder

Parents noted that they didn't know about the different ways CP could affect different children, and those who knew a bit about CP tended to assume that their child would have high impairment.

> *I struggled with it. I used to be a disability support worker, with adults with autism. A few clients had CP. When we were told [our children] were high risk, I didn't know enough about it. I instantly thought of my clients and thought they'd never walk, talk, be wheelchair bound, reliant on us because there was nothing else ever offered to us until we did our own research and understood the different ways it effects people.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Information about services

Some parents reported that they had managed to get access to assistance and support and with it, information, early on, typically immediately following diagnosis, but they often described this as a stroke of luck, that they stumbled upon it, or someone had mentioned a service. Those who had been able to get information and support early on felt that they could so easily have fallen through the gaps and did not get the sense that there was a clear process for linking families with the information they needed.

Information about the NDIS and cost of support

Until someone had time to discuss it with them, most parents had little idea about what specialists might or should cost. Stress about the cost of services and specialists was compounded by the financial pressures of reduced income initially due to parental leave, and then later with some parents – usually mothers – finding they couldn't fit employment around the appointments and care of their child. Others felt in a financially perilous situation having used up sick leave and carers leave to take their child to appointments. A number of parents confided that looking back, they were completely naïve about how the financial side of things would work.

> *I didn't realise I would have to pay, I assumed if a child can't walk, you'd get handed a frame, but it's not the case.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

Initiating their relationship with the NDIS was a specific area of information needs that is currently not working well for parents of very young children with CP. Part of the problem is complete lack of awareness of the NDIS and potential entitlement to funding.

Information about emerging symptoms

Because of the nature of CP (not having a definitive list of the manifestations of the condition), having received a diagnosis (or discussion of likely diagnosis), parents were often left to observe their children and if they saw anything they thought wasn't quite 'right' between medical appointments they would Google the symptoms to see if it was consistent with CP. While parents often cite using internet searches to investigate things relating to their children's health and development, parents of children with CP we spoke with were anxious to confirm whether what they were observing about their child was 'normal' and consistent with CP. This was especially important for those whose children had other conditions such as Autism Spectrum Disorder.

5.4 Current information sources and formats

Paediatricians and other specialists

Most parents' initial formal source of information was their paediatrician. Information from these professionals was trusted, but many felt underwhelmed by the information in terms of clarity and depth, and wanted more tailored information.

Internet searches

Unsurprisingly, given the perceived lack of information proactively provided to them, most parents described relying on internet searches to patch the gaps in their knowledge, check emerging symptoms and provide answers to some of the fundamental questions including what CP is.

Although the internet search was a dominant source of information at this early life stage, parents knew it could be an issue in terms of relevance – both geographically and in relation to their child's unique experience of the condition and level of impairment.

> *Every time I google a symptom it's usually an American medical site, so I take it with a grain of salt because it's American and may not be so relevant for us. There's no particular website I go to.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

Social media

As children got a little older, parents tended to become more engaged with social media, but a number of parents of infants with CP had already started identifying social media groups, mostly Facebook,

through which to increase their knowledge about CP. Those parents utilising these resources found them helpful, 'safe' spaces to ask questions, although most tended to look rather than participate at this stage.

> *When I got the neurologist's report it said he has hypertonic and ataxic something and I didn't want to ask, so I screen shot-ed that – and asked [the Facebook group], 'What does this mean?'.*
> Parent of child aged 0-5 with high level impairment, metro NSW

> *After diagnosis, I jumped on Facebook, came across 'CP parents Australia', for parents. That group has been the best place for information.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Casual incidental sources

Reflecting the feeling that it would be easy to fall through the cracks, parents mentioned getting information in incidental ways. For example, a few mentioned being thankful for seeing posters while in waiting rooms that promoted local services that they wouldn't have come across otherwise. Parents felt that there wasn't a formal pathway for acquiring information.

5.5 Preferred information sources and formats

Experts and specialists

Naturally, professional advice, guidance and therapy is critical throughout life for those experiencing CP, but information from experts is especially important for those at the very beginning of a CP diagnosis when they know very little about the condition. Paediatricians and neurologists are especially critical for the diagnosis stage.

> *There's a lot of focus on early days … most of the tertiary teaching hospitals are producing good information. In those early days there's a strong medical-health interface for the child and the family; that's where a lot of the best information sits … in saying that, there are pockets of better information.*
> Stakeholder

Face to face

Many cited a preference for being able to have discussions in person, which would permit the time to ask questions. This is in contrast to the style of medical appointments where parents often felt they had a short, allotted time with the specialist with limited opportunity to have a discussion.

Peer support

As was the case for many of the families and carers we spoke with across different life stages, the prospect of peer support in the form of families who were in a similar position but just a little 'further down the track' was very desirable.

The logistics of peer support can be complicated though, especially for those with multiple children, balancing different school, care and medical regimes. Furthermore, some mothers who participated in the research noted that it was challenging to find opportunities to develop rapport with other families if you were working.

Written resources

Because parents of infants and toddlers are so new to not only CP but often also to parenting itself, written literature that could be absorbed slowly, over time was regarded as helpful. Written information was considered best in more easily digestible sizes, for example, factsheets and pamphlets were mentioned more than books.

> *Written information is most useful, I get bored with long videos, I love reading. If I don't understand, I can go back and read that again. If I'm looking for critical information, I can read and make notes.*
> CALD carer of child aged 0-5 with high level impairment, metro SA

Social media

Social media is not the primary desired source of information, but social media as a way of accessing a community of people going through the same or similar experience and this is an invaluable resource to parents. As noted above, Facebook groups can be a non-judgmental setting for parents to find out 'basic' information about CP as well as to be reassured that you aren't the only person struggling to navigate life with a young child with CP.

Helpline

The idea of a helpline that could be accessed in between specialist appointments and therapy sessions was very appealing to some, especially to those who felt particularly isolated. Parents often commented that questions would emerge between appointments and a helpline was seen as a way to address queries that cropped up, especially about non-critical topics, between therapy sessions or medical appointments.

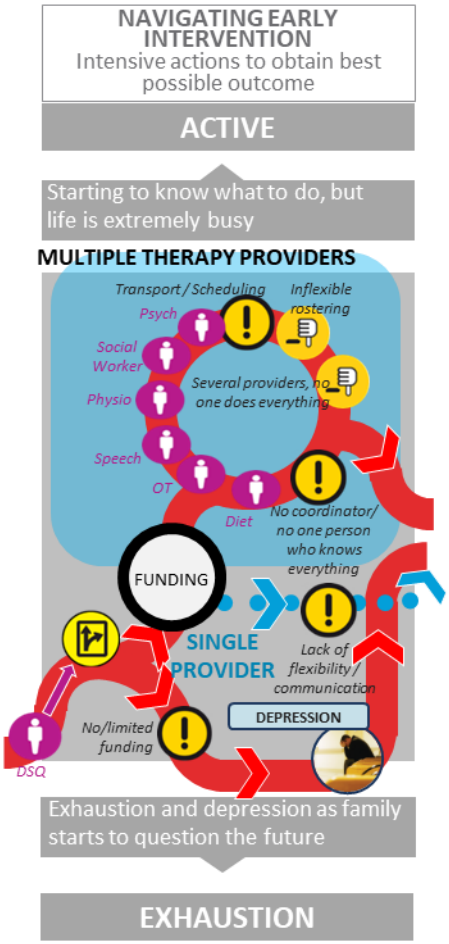
Smartphone app

Although rarely spontaneously mentioned as a desirable way to access information, there was general positivity towards smartphone apps as another way of accessing information. Furthermore, some thought it could be a good way of collating information and sharing it within the family.

> *Because my partner works so much, we don't have time to talk. If he had access to an app he might have a look. The only way he gets information is by email, if he gets notification from an app, I have to tell him, sometimes I forget.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

6 Navigating early intervention – aged 3 to 5 years

6.1 Life stage context



Beyond the very early years and the diagnosis stage, the parents of three to five-year olds with CP were beginning the 'battle years'. Parents had done a lot of emotional processing and grieving in the first couple of years, but a growing toddler meant they had a sense of needing to roll their sleeves up and become proactive in getting started on intervention and actively advocating for their child.

> *You scale back to what's important and what's not important. It's not that you're fighting anyone, but you go on an affront, you become hugely busy. That's been the biggest thing, just so busy 24/7.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

As families settled into life and the demands associated with small children, many felt a greater sense of routine return compared with the turbulence of birth through to diagnosis. However, specialist and therapy appointments make for incredibly busy schedules which was quite overwhelming for parents.

Although many research participants described a journey to diagnosis involving both parents, once early intervention therapies picked up, the logistics tended to fall on one parent, typically mothers.

> *I know he has CP now, but I don't know what the hell I'm doing.*
> Parent of child aged 0-5 with high level impairment, metro NSW

Finding a local service offering early intervention therapies is often lifechanging for families. If services are co-located in a hub, it helped some to reduce the burden of travel to multiple specialists in multiple places.

> *We went through the [named organisation]and saw a speech pathologist. They were amazing, pointed us in the right direction … they had a really detailed brochure, which helped me to be prepared mentally that*

> *things could get worse. It explained (CP), the support services they offered, giving assurance that there were people there who had the information and were there to help, and at the start that was really helpful for us.*
> Parent of child aged 0-5 with medium level impairment, metro Queensland

It seemed common for parents of children aged three to five to have become disillusioned with formal information, especially if they had had negative experiences around their child's diagnosis and increasingly, these parents were searching out information in online settings.

6.2 Key challenges for this life stage

Feeling alone in advocating for their child

Once families become more accustomed to medical and specialist appointments and the routine of attending therapy sessions, it becomes increasingly obvious to parents that no one understands their child's experience of life with CP better than they do and while they may be seeing health experts, they are the expert when it comes to their child. But given families are usually still sitting with many unanswered questions about how CP will affect their child in the future and faced with specialists who don't have all the answers, parents realise they are carrying the burden of getting the best outcome for their child alone. Some reacted to this by trying to create their own child-centred program of therapies with extensive at-home activities and exercises, others were still feeling very lost and not sure where to begin, but either way, a feeling of loneliness and a 'fight mode' was common.

> *Nothing has been provided. I've done all my own research. I've had to record the way he walks and talks. It was only the end of last year [we got the diagnosis], information-wise it's only if I ask questions [I get information] … I rub his legs, give magnesium and give him Panadol. Is that what I'm meant to be doing? [Getting information is dependent on] me asking the right questions.*
> Parent of child aged 0-5 with high level impairment, metro NSW

Feeling overwhelmed and exhausted

There was emotional exhaustion associated with the lead up to diagnosis and coming to terms with the news. While this was still experienced by parents of young children with CP, the busyness associated with a schedule of appointments and the additional preparation often required to help their children interact with the world meant that parents find the demands on their time pretty relentless.

> *It's that difference between going to a birthday party … 'Where do we have to be? Where do we have to park? Do I bring the pram? What are they planning to do? Should I put her in her splints or not?' It's that extra level of thinking that when you're only around parents that don't have those extra layers of complexity to just going out, that gets a bit wearing.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

Pressure on family relationships

Related to feeling overwhelmed and exhausted, the everyday pressures of raising children compounded by the emotional and often physical energy often involved in navigating looking after a small child living with CP could take its toll on relationships. Some of those we spoke with were struggling to connect with extended family and relationships between parents could be especially challenging if the emotional and domestic labour of raising children felt uneven.

> *I wanted [my partner] home with me but he had to work more [to cover the medical costs]. Even today I ask him if he can help me, but he has to work, so it's all down to one person. It's tiring. I sometimes have three or four appointments in a day. You come home and still have to be a parent and do the dinner.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

> *He's clueless. In the reports it's always 'mum said xx' but he earns more money, and so has to work more, he went to the diagnosis appointment … [but] one parent gets more pressure [for coordinating appointments and being up to date with everything], one gets left out.*
> Aboriginal parent of child aged 0-5 with low level impairment, regional NSW

> *Changes in family circumstances – parents separate, moving between households, custody, moving one location to another because of parents' work, grandparents – often more work involved, all those things create transition points, family breakdown – if there's a child with a disability fifty per cent of marriages break down.*
> Stakeholder

> *Family support is critical, and it can be very challenging if they don't have an extended social support network (i.e. people in their life).*
> Stakeholder

Guilt for those whose children have lower levels of impairment

As children continued to develop, parents of those less severely impacted by CP confided in feelings of guilt when they observed other children with CP, and their families, struggling more. Some felt they might get judged for using services that their child might not 'look' as though they required.

> *I felt a bit guilty, silly, showing up for something like that because her CP is so mild. I know some cases are more severe. I didn't want people thinking, 'What are you even doing here?! She's very mild compared to our [child]!'.*
> Parent of child aged 0-5 with medium level impairment, metro Queensland

6.3 Information needs

What early intervention therapies and services provide, and local therapists' details

Although finding a provider in the first place was a main challenge, once parents were connected with a provider offering early intervention therapies, it still wasn't always clear what was on offer and available.

> *I think what would be really valuable [at the Victorian Paediatric Rehabilitation Service, VPRS] would be some sort of orientation process … 'Welcome to VPRS, this is what we do, these are the services that we provide, these are some of the things you can expect from us'.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

Alternatively, some parents were not sure what was available beyond the provider they had been referred to and felt a sense of loyalty or were not confident in seeking additional support beyond one provider. Parents described finding out about specialists they had never heard of previously, e.g. one mother had recently found out about a behavioural optometrist that she had been told would be helpful for her son's development.

Once they had an idea of what they needed for their child, parents often described frustration in trying to find therapists and services that were appropriate, those specialising in paediatric, or specifically CP, that were accessible from where they lived. Parents without access to trusted recommendations said they had spent lots of time searching online or calling around.

> *I wish there was a website for everyone with specialisation in CP, who know all about it. Somewhere I could find all of that information.*
> Parent of child aged 0-5 with medium level impairment, metro Queensland

A 'roadmap' for the next few years … and beyond

As a result of the complete state of confusion most parents found themselves in around the diagnosis stage, they are desperate for some sort of 'roadmap' to help them navigate the next steps.

> *There was no long-term picture, or even a month picture, of what we were aiming for.*
> Parent of child aged 0-5 with medium level impairment, metro SA

> *Even a simple checklist. You fill the information at the back and it sorts of give you a pathway giving you information about who you need to speak to.*
> Stakeholder

While both general, 'introduction-to-CP' information and tailored information was needed by parents of very young children, parents of children aged three to five years old very much wanted to focus on what was in store for their child.

> *Everything hospital-wise and CP-wise was very the same and generic information… not detailed.*
> Parent of child aged 0-5 with medium level impairment, metro SA

Peer support and 'what worked for us'

Peer support emerges as an important information source for parents of babies with CP and becomes increasingly important as children got older. Although some parents didn't want to connect with other parents, for the most part, other parents' experiences were seen as incredibly useful. This was not only for anecdotes of how to tackle critical things (e.g. feeding, weighing up pros and cons to surgeries) but also small 'hints and tips' for incidental situations or daily tasks.

> *Recommendations for groups, forums, Facebook groups, where you can connect with others, some support. A big one would be people recommending places to seek treatment – physios, occupational therapists, and speech if we need it again. Finding the right services for her through other people who have experienced in it.*
> Parent of child aged 0-5 with medium level impairment, metro Queensland

> *Sometimes just random things, like, we're going on a cruise next year, asking what cruise lines you've been on, how have you coped, getting on and off the boat, simple things. Leading up to [our son]'s surgery people were giving me advice on what to take to hospital, how long their stay was, what it was like, medications they were on.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Evidence-based interventions

While parents of very young children were grappling with what CP is and what it was going to mean for their family, as children got a little older, parents were beginning to realise the diversity of forms and experiences of CP. While most parents of three to five-year olds were far more interested in peer advice and anecdotes, some were beginning to become eager for more evidence-based examples of interventions. This was especially the case for those who had come across conflicting advice about treatment or who had discovered treatments and interventions relating to CP that weren't offered in Australia, causing them to question what was best for their child.

> *[Evidence-based practice] is something that, to me, is important. Are we going to be doing the things that we know make a difference? … A lot of the therapy takes a lot of time and with little kids you've got to do it a lot and you've got to do it often; you've got to do it every day … I want to know that there's evidence behind me doing that and the evidence that it's going to help her.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

Approaches beyond the core therapies

As parents become more familiar with the traditional therapies available to children with CP (namely physical, occupational and speech therapy), some begin to search beyond those standard approaches to find a way of helping their child. Some parents hoped of discovering an emerging alternative therapy that would transform their child's life or provide a way to challenge the doctors they were seeing. These parents looked overseas for examples of alternative treatments not offered closer to home.

Generally, when parents spoke about 'alternative' therapies at this stage, they were usually referring to relatively mainstream approaches, but ones that they had only recently come across. Some described 'stumbling' across a treatment they hadn't previously heard of (typically botulinum toxin injections). This common 'accidental discovery' route could make them feel frustrated and suspicious that there was knowledge and information out there that no one had bothered to provide them with. This experience contributed to feelings of isolation, confusion and weariness.

> *I had no idea about Botox. I only found out because the physio recommended a paediatrician who bulk billed. [It] made the most difference. If that physio hadn't known that, and [we hadn't] been linked up with that paediatrician I would never have known about it. If there had have been a website that had all of this information, any treatments that could help improve her situation, but there doesn't seem to be a website that has all of that, that has anything to do with the Botox therapy.*
> Parent of child aged 0-5 with medium level impairment, metro Queensland

Quick turnaround times

Many parents of children with CP, of all ages, complained that finding the information they needed could be very time consuming; time they could ill afford to spare. This was sometimes because they weren't exactly sure what they were searching for, or because they wanted to know things about very specific experiences that they thought were unlikely to be available on CP organisation websites (such as advice about clothing, or holidays). Parents really value the speed with which they could get answers to their queries online from other families.

> *[So that I] don't have to search and search for an answer – I can just put up a post [on the Facebook page] and people answer it from their own experiences. Not having to look on Google, you spend hours searching on google.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

6.4 Current information sources and formats

More defined internet searches

While parents of new babies with CP tended to be searching for any information they could find about CP, some parents of children aged three years and older were beginning to be more specific about what they went searching for online.

Peer support (face to face and virtual)

As parents start accessing early intervention therapies and with it the opportunity to come into contact with parents of other children with CP, peer support starts to become an important source of information. Although the peer support could come directly from other parents they had met face to face, some had started accessing support from online communities too.

> *I can honestly say I got the most useful information and the most thoughtfully expressed information from other mums.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

The experiences of people who were currently, or who had already been through some of the experiences you were facing, is invaluable to parents. Importantly, this information is regarded very differently to the information accessed from specialists. Parents understood peer-advice to be informal, they didn't expect it would be perfect or specific, and they are more willing to filter to the aspects that they think will suit their family's needs.

> *People share different experiences [online] ... Everyone has different experiences, ideas to help with sleeping. On Google sometimes there's one solution or a handful … I prefer hearing about people's different experiences and finding out that way. Not by the book, from people who understand what you're going through and who have been there. Supportive to know that you're not the only person going through certain things.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

A few parents felt like they were on the verge of beginning to connect with other parents just before the COVID-19 pandemic hit and that the restrictions and disruptions of the pandemic had made this challenging.

In terms of more socially focused peer support, although some found this incredibly beneficial, others had resisted these settings including play settings for children. Sometimes this was due to 'guilt' that their child didn't have as high a level of impairment and it made them self-conscious if their child was able to run around when others were using wheelchairs for example. Some felt that to attend these groups forced them to emotionally 'accept' their child as having a disability and they didn't want to, or weren't ready to, do that. Others felt strongly that these scenarios labelled their children as being disabled and felt that it wasn't constructive for their children to only interact with children with CP (and other disabilities).

> *Early on I joined … carer groups and I remember when I first started doing that, I hated it … because I didn't want to be in 'that' club.*
> Parent of child aged 0-5 with medium level impairment, metro SA

> *I want my kids to just be normal and be included as normal people.*
> Parent of child aged 0-5 with medium level impairment, metro SA

Social media, especially Facebook

The most common way of gleaning information from other parents was via Facebook groups. However, the parents of this age group who participated in the research tended to be more observing and learning, rather than posting comments themselves. These communities allowed parents to ask questions they thought of outside of specialist appointments, and the anonymity meant they could also ask questions they didn't want to put to their specialists.

Mostly [I look at] Facebook pages for apraxia, they suggest things … they say certain words and I Google that. My son has bouts of vomiting, it's called something, someone posted something on the CP page saying, 'This is what my child does, somebody help me!' and I Googled it and I was like, 'That's him!' and the neurologist confirmed it.
Parent of child aged 0-5 with high level impairment, metro NSW

[I] go [to the Facebook group] for a range of things. Sometimes just reading other posts and reading comments that may relate to me and to us, you find out so much through that group.
Parent of child aged 0-5 with high level impairment, regional Victoria

I'm [usually] a lurker, I like to read what people write and see if it's relevant. I'd like to have a bit more interaction [on the Facebook groups], but part of me is thinking he's not that severe, and [I have] social anxiety.
Parent of child aged 0-5 with high level impairment, metro NSW

I think most of the information I have got has been social media. Even the surgery in America, I found out about on social media.
Parent of child aged 0-5 with medium level impairment, metro SA

Therapists

As parents find therapists who they develop a good rapport with and trust, these become key sources of information for all sorts of recommendations and advice. Well-connected occupational- physical- and speech- therapists share both core specialisation related advice as well as informal word-of-mouth information about pre-schools and help parents to think through things such as whether mainstream or specialised school might suit their child best.

This preschool has been good, recommended by our speech therapist. Mainstream … it's out of my way to go there, but recommended and I trust the speech therapist, (my son's) bored at home.
Parent of child aged 0-5 with high level impairment, metro NSW

6.5 Preferred information sources and formats

Comprehensive yet succinct written information

Although parents of three to five-year olds were better informed about CP than parents of infants, the level of knowledge varied and some still felt very ignorant about CP and its forms. This meant that there is still a great desire for thorough, but easy to understand, information.

Hospital fact sheets specifically, it's the plain language and it seems to me they are written with parents and carers in mind, and not hospital clinicians. I think they're informative without being overwhelming, they provide a good level of detail.
Parent of child aged 0-5 with high level impairment, metro Victoria

> *No parent in this life has the time to really sift through that amount of information.*
> Parent of child aged 0-5 with high level impairment, metro Victoria

Tailored information

As knowledge of CP and their child's condition matures, parents recognised that they need more detailed information that provides insight into the differing, specific aspects of their child's CP.

> *If you're given a resource pack [like we have in the past] it tells you what to expect, this is the outcome. You read that and that's what you expect, but it's not always the case, everyone is different, reacts and adapts differently … It's not one size fits all.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Local social connections

There is interest in means of connecting with other families in their local area who have a similar lived experience with CP. At this life stage this tends to be more focused on parental peer support, rather than the child's social connection.

> *Something really simple. User friendly, easy to understand. There are so many things out there now. I started using an app for parents of children with disabilities, you put in what disabilities you have and you can match with someone – you swipe like on Tinder. But it would match you with someone in Canada or the UK. Something that's easy to use, sets you up for your local area.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Geographic search functionality

As the intensity of therapy increases during this life stage, parents want to be able to search geographically for local health professionals and service providers with appropriate CP expertise.

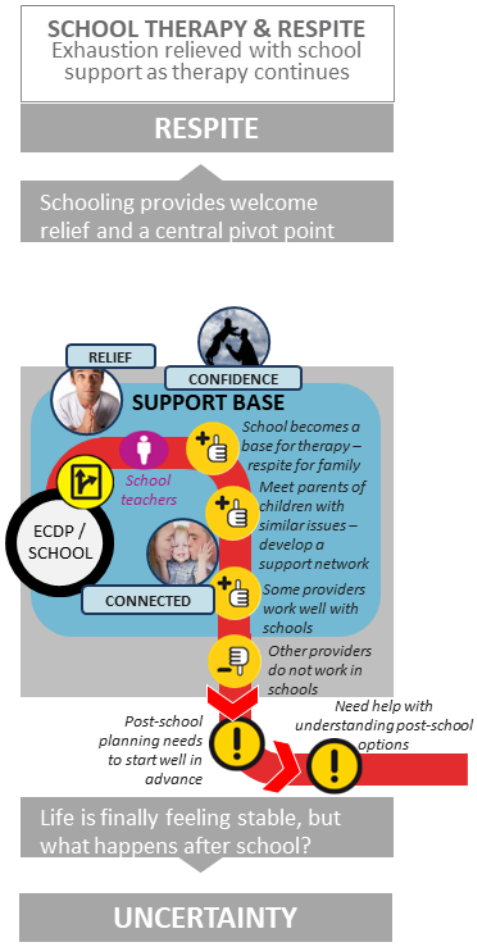
> *Categorised – e.g. therapy recommendation, then under that you have different therapies, can set it to search within 20km of your home, would come up with what's available within that radius, you could search further out.*
> Parent of child aged 0-5 with high level impairment, regional Victoria

Centralised online hub

As is also the case with those at older life stages, parents of children aged three to five recognise either an absence of helpful information or finding information to be very fragmented, commonly mentioned the desire for an online resource that would bring everything they needed together in one place. This was seen as a useful way of reducing the time needed to search for information online or make phone calls to different specialists or services.

7 School, therapy and respite – aged 6 to 17

7.1 Life stage context



As children progress to school age, the trauma of diagnosis and the busy rounds of therapy and treatment tend to settle into a calmer pattern of life. Attendance at school during the ages of six to eighteen provides a structure for daily routine and a ready source of professional support. This daily separation of child and parent provides a degree of respite allowing parents to achieve better balance and wellbeing in their lives.

> *Parents need to look after themselves. It's not just about their children, they need to spend time on their own. You can't be there all the time.*
> Parent of child aged 6-17 with high level impairment, metro WA

Others are very aware of how actively involved they still need to be and, for some, how isolating this is.

> *It's very socially isolating because I don't leave home.*
> Parent of child aged 6-17 with high level impairment, regional NSW

> *I spent an hour contacting Centrelink, then two hours on the phone to service NSW trying to get info. It's very time consuming. One of the reasons I haven't worked is I've got a fulltime job managing his life.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

While parents are sometimes still actively seeking further clarification around diagnoses and pathways, by this stage they generally have a 'bedrock' of information about their child on which to build the next steps. By the age of six, they have some confidence in the knowledge they have gained from the daily care of their child; this personal expertise is sometimes at odds with the medical or therapeutic advice provided by healthcare professionals. Parents tended to be growing in confidence and able to combine this professional advice with their personal knowledge of their child's unique needs. Several parents were also resisting the pressure from health care professionals to prescribe, limit and label their children. As parents, they were focused on seeing their child as 'normal', having fun and not allowing their life to be restricted by their diagnosis.

> *She's just a normal kid with different needs, you just need to modify things a bit for her, but she can still do things … CP isn't central to (our daughter's) identity.*
> Parent of child aged 6-17 with high level impairment, metro Queensland

> *We were given a whole list of affects, things he will and won't be able to do, and at the time (of diagnosis) it was incredibly distressing. I wish that hadn't been part of the process, that's why I resigned. I myself have a visual impairment was told I wouldn't be able to do things, I knew diagnosis doesn't define what you can achieve.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

> *You need to empower that person with CP to believe in themselves, that they can do anything as well as anyone else.*
> Stakeholder

Depending on their child's setting, school can provide a stronger social network for parents. These additional connections further bolster parental wellbeing and their greater connectedness to sources of information, support and resources. As the child progresses to the upper end of this life stage, parental stress again begins to increase, generating significant fear and apprehension, as parents give thought to life for their child beyond the structure of school life.

> *We hate even thinking about the transition from school to adulthood.*
> Parent of child aged 6-17 with high level impairment, regional NSW

7.2 Key challenges for this life stage

The challenges of this stage tend to focus on building the connections and skills for the child to interact more successfully with 'the outside world' and to work towards greater independence.

A child's understanding of their CP

As children are progressing through their primary school years, parents tended to initiate more conversations to educate their child on the nature and extent of their disability. This was to arm them with answers to questions from other children and also to help them develop a sense of self.

> *We've always had a framework and language (for my son) about 'I am someone who experiences CP', it isn't what defines him. It's a big thing for me – what I do and advocate for.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

Some young adults spoke of feeling depressed during this life stage as they wrestled with the impact of CP on their lives, and how this compared to the lives of their school mates. For some this was a further aspect of mourning for what were perceived as lost or restricted opportunities in life.

> *The harder thing is the emotional side of things.*
> CALD parent of child aged 6-17 with low level impairment, regional NSW

There's a risk of (my son) being depressed – I realised I wasn't reaching out enough to the community for support.
Parent of child aged 6-17 with high level impairment, regional NSW

When (my daughter) was younger, there was a lot of 'why me?'. She struggled with not being able to run as fast as other friends.
Parent of child aged 6-17 with medium level impairment, regional NSW

Diagnosis clarification, funding and support

At this stage, some parents are still seeking further clarification around diagnosis, particularly as CP may be an additional, low-level or secondary condition for their child. For these parents, their information and support needs to date have focused on a primary condition (not CP), meaning that they had had few, or no, detailed conversations with health professionals about the different types of CP, the specific type of CP their child had or how it was likely to progress. For some the diagnosis of CP was vital to access a specific school.

The only reason we had a clear diagnosis was because I pushed it and pushed it and pushed it.
Parent of child aged 6-17 with high level impairment, metro Queensland

There was also considerable effort, frustration and exasperation in determining which funding routes would be possible; ECIS, Better Start, NDIS and SWEP, among others.

If you know exactly what you want, the NDIS is great, but you need intellect.
Parent of child aged 6-17 with high level impairment, metro WA

For CALD parents who were not Australian citizens, the search for appropriate funding was particularly challenging. They shared the maze of bureaucracy that other parents experienced, with the additional issue that some funding routes (e.g. Better Start) were not available to them. The time consumed identifying potential funding sources added to parental stress as they sought to meet immediate needs themselves.

New Zealand citizens wouldn't qualify – I panicked – he wouldn't get any funding, so we had to fork out. He needed orthotics at $4,000 a pair and he needed new ones every six months.
CALD parent of child aged 6-17 with low level of impairment, metro Victoria.

There was financial strain in paying for therapies and equipment, where it was not covered by funding, and frustration that services were not able to loan specific equipment or assistive technology. Parents spoke of buying second-hand equipment from friends whose children no longer needed it.

He's been non-verbal his whole life, with limited key signs. We're trialling a device called Lamp, an i-pad style thing. We waited for ages to trial it. NDIS paid for it, but it would have been easier if CPA had owned one and could lease them out.
Parent of child aged 6-17 with high level impairment, regional NSW

Parents were also angry and frustrated by the gap between best practice for their child and what health professionals would recommend, as they tailored their advice in line with their expectations around likely funding or parental engagement.

> *Last year we got NDIS … we found out he needed stretching equipment. We didn't know he needed it, but their thinking was we wouldn't get funding, so they wouldn't mention it … Sometimes they don't recommend things straightway because they don't know if parents have time to invest using the equipment … When I asked why they didn't recommend things they said, 'Well, because you work'. I found that some therapists can be quite mean, they get judgey about whether you do enough for your child.*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

The further gap between health professional and parents was apparent, with parents persistent in pursuing specific positive goals for their child, against less optimistic guidance by doctors. Others spoke of needing a diversity of professionals so that they could triangulate the information and advice they received and, as a family, determine their best way forward. Numerous parents described identifying options that their health professionals or therapists had not known about or brought to their attention. Only a few were overwhelmingly confident and trusting in their therapist advice alone.

> *We had a lot of paediatricians, nutritionists, dietitians telling us that this is the only way. And I'm saying this is ineffective for our daughter. As really young parents in this situation, it was like swimming upstream ... long story short, we wish medical professionals would listen a bit more.*
> Parent of child aged 6-17 with high level impairment, metro Queensland

> *We got a lot (of advice) from the medical world that we have to go down their path, when it was proven many times to be wrong. The doc said my daughter needed a stomach peg, and we proved them wrong. My daughter is feeding orally. If we'd listened, she wouldn't be able to eat … they're too much stuck in the system, they don't look at individuals.*
> Parent of child aged 6-17 with high level impairment, metro WA

> *The therapists are so reliable and thorough and always doing what's in the best interests of (my daughter). I don't need to do any research; it's all fallen into place … I can see the benefits of everything and how well it's working, so don't want to rock the boat.*
> CALD parent of child aged 6-17 with low level impairment, regional NSW

> *Parents and families and individuals with CP should be given more credit, but also I think sometimes we can make, as health professionals, assumptions that there is an understanding without actually making sure that we're hearing what they need.*
> Stakeholder

The use of therapists remains frequent, and often intense, through the early years of this life stage. By the time the child was six, parents are generally clear which therapists their child needs regular treatment from, but they struggle to find a good paediatric physio, and even more so one with experience of CP, or of their child's specific type of CP. There is a greater need for the therapist to be local so that they can easily be accessed after school, without excessive travel. Some therapists avoid NDIS clients because of the related paperwork, which further limits parents' choice of therapists.

> *Don't stick with one professional at the start, maybe go to multiple so you can get different perspectives on the condition.*
> Parent of child aged 6-17 with high level impairment, metro Queensland

Some older children who receive therapy in their mainstream school setting rail against the experience.

> *He hates having an OT coming to the school and work with him who basically tells him how to 'suck eggs'. What strategies he can use to help pack up. He feels embarrassed.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

School

Most parents spoke about finding their own way through the decision-making process of deciding which school to send their child to and did not consistently describe a common information gathering or support process.

> *There was no information and support. There was the local special school as an option … we decided he was too capable to attend special school. We did a lot of our own research as to what options were available – my husband is a teacher. No one helped us make the decision.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

A few parents spoke of getting assessment and support from CPA at this life stage.

> *Through the Cerebral Palsy Alliance once again, they do all the assessments for schooling... I told them I didn't want my daughter to go to a disability school, I wanted her to go to a mainstream school because she has to learn to talk ... They did the assessment on her and they said, 'Yes, she is academically able to go to a mainstream school'.*
> Parent of child aged 0-5 with high level impairment, metro NSW

Those parents who had found a school that met their needs spoke of settings that recognised individual potential and needs, and actively engaged in transition processes (from primary to high school and from high school to employment or post-school education).

> *The school she's in now, they're very supportive. Now she's in transition to high school, a special education centre. Our thoughts are that the college we have chosen has a good curriculum, will teach them how to buy things, take them out to the community, teach them protection … to be independent and have a good quality of life, and to navigate her way through the community.*
> Parent of child aged 6-17 with high level impairment, metro WA

However, some parents were struggling to find a school that met their expectations and hopes for their child. Some felt that the child's disability was perceived by educators as defining them and limiting their expectations.

> *The resources don't focus on self-efficacy. It's more about what they can't do than what they can do. And I think that's really scary and feels really restrictive for people.*
> Parent of child aged 6-17 with high level impairment, metro Queensland

Parents of non-verbal children described finding it particularly challenging to leave their child in the care of an educator.

> *Not easy but felt safe. That has been a constant question – do I feel safe letting him go without me? You can only understand by his demeanour or mannerisms if he's ok.*
> Parent of child aged 6-17 with high level impairment, regional NSW

Some parents were critical of the low level of training and wages offered to educators and that both factors impacted on the quality of education and care provided. Others in regional areas found the distance to appropriate schools very difficult.

> *Department of Education decides where you go - it can be 40km away. We need a school out in Hawkesbury but it won't happen in our kids age.*
> Parent of child aged 6-17 with high level impairment, regional NSW

For those parents whose children were attending a mainstream high school, there were challenges for their child around moving from classroom to classroom, packing and carrying books and negotiating crowded corridors and staircases. Others faced specific problems with handwriting, requiring additional medication and a further NDIS process to seek funding for a school laptop.

> *We find it difficult to process sequences of activities I suppose. The whole idea of moving between classrooms. We can close our books, laptops. For him that is so much more complicated. It requires concentration, mental energy and physical control. It's a lot more difficult for him ... that's a big deal for [name]. He gets knocked over very easily. But the whole set-up of the school can be challenging if there are some stairs.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *When he moved from kindy to primary school was probably one of the hardest ones, because he was pretty fragile still at that stage, he needed an SSO [School Services Officer] in the yard because he'd get knocked over really easily, so they'd have to support him in recess and lunch. It took a bit of hard work to get that support in place at the time. It was more a lack of understanding of what his needs would be, because they've not had a kid like [my son] at school before.*
> Parent of child aged 18-45 with low level impairment, regional SA

For those with children enrolling in mainstream school, there was the additional challenge of whether they were in the appropriate catchment area for a suitable school.

> *Which one to attend? It was difficult because all the secondary schools where we live are zoned, so you are automatically accepted to the nearest school of where you live – and our school didn't have any experience. We did apply to a secondary school who have experience with children with verbal disability and in a wheelchair, but we didn't live in the zone.*
> Parent of child aged 6-17 with high level impairment, metro Victoria

Socialisation and friendships

Building a good social network and group of friends is challenging for many children with CP but parents reported this presenting specific difficulties for children attending mainstream schools. They

spoke of children being left out of sports teams because of their more limited mobility or strength, being unable to join in playground or recess games and of being excluded from social events (e.g. birthday parties). This was a source of real distress for parents.

> *Other kids want to run around after lunch time and burn some energy. He wants to sit down to regain some energy. It's hard to find that friendship group.*
> Parent of child aged 6-17 with medium level impairment, metro NSW.

> *Socialising, trying to find things he can participate in. Young guys like to play sport – cricket, soccer, local clubs. [My son] can do that but they don't want someone who can't pull their weight in the team.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *Opportunities and social outings are hard. The kids don't get invited to parties and outings. I need to make an effort to ensure he is socialised.*
> Parent of child aged 6-17 with high level impairment, regional NSW

Many of these children experienced verbal abuse, discrimination and ostracization by other children.

> *He gets attacks of spasms, which can last for twenty minutes to an hour. It's exhausting, painful, scary. Other kids calling him 'spasms', or who are scared. It takes a long time to negotiate high school.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *No one invites him over. His one good friend used to invite him when he was in primary school. [My son] always invites him to his birthday dinners, but nothing happens in return.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *I got teased every day at school, I had a big group of friends, but you'd have the occasional kid at school who would call you a spastic and that was thrown around all the time and it really hurts.*
> Person aged 46+ with medium level impairment, regional NSW

> *Bullying is a major concern among young people with disabilities, along with mental health and academic success.*
> Stakeholder

Some parents had reached out on Facebook to find other parents and children in their area to meet up, to socialise and support each other, but found it difficult finding others with sufficiently similar CP issues. They found the same problem attending local CP programs.

> *When he was younger a lot of kids had CP but were cognitively normal. Now when he goes to those programs, they're not a match. The gap widens with a friend who is cognitively delayed as they get older.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *He goes to a teens' gym session at CP alliance, which is good for him physically, and he enjoys the company of the other kids. There's one other guy with CP, much more effected than [my son] and not cognitively average. It's hard to strike up a convo and talk about things teenagers talk about with him.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

Some parents are wary of attending CP specific events as they find the setting depressing and limiting.

> *Sometimes when I talk to parents whose kids are more disabled, they don't have a lot of time for me. Often their identity is all about disability which it isn't for me. I'm trying to make their lives as normal as possible.*
> Parent of child aged 6-17 with high level impairment, regional NSW

Transport and learning to drive

While parents are keen to support their child's growing independence, they are worried about the challenges this brings. Making use of public transport raises the need to execute a specific sequence of movements that are difficult, requiring balance, co-ordination and strength.

> *He needs to step on to the bus and have a bus pass in hand. He's only got one hand that he's confident using and he needs to find a place on the bus. It's very easy for the bus driver to not notice his disability. It's hard for a thirteen-year-old man to say, 'Please wait'.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

Those with older teens were aware of the challenges of learning to drive with a diagnosis of CP. Parents spoke of finding it difficult to initially identify what the CP pathway was to learning how to drive, with a lack of transparent information. In addition to undertaking an OT assessment at a driver training unit, parents also spoke of the difficulties of finding a driving instructor who was willing to accept their child as a pupil.

Getting ready for employment or further education

For parents with children with low to medium levels of impairment, by the early years of high school they are already worrying and becoming fearful of their child's employment prospects.

> *He talks about wanting a job. He's an articulate young man. I'm not sure what support we can get him as a first step to employment. After school, a job is only a year or two down the road.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *There's Disability Employment Services that help people with resume writing and job matching. But their expectations aren't high and wouldn't really help get someone a white collar job – may a job at a café, or packing fruit. And that's a symptom of low expectations. But these conversations need to happen as early as possible. Parents need to be aware that you need to start talking about this when someone's a teenager, otherwise it's really really hard to eventually have a good job when you're older. It should be less about focusing therapy every day of the week for kids and teenagers and more about asking people what are you interested in? What university do you want to go to? It's about setting these expectations high.*
> Stakeholder

Interactions with the wider population

Some parents shared the challenges of interacting with the wider population, and that the general public's lack of knowledge, understanding and insight into CP added to the difficulty of raising a young person with CP. They sometimes dreaded going out to public places because of the lack of empathy among other adults.

> *More education within schools, within the general population, so they have a better understanding.*
> Parent of child aged 6-17 with high level impairment, regional NSW

> *Is this project simply about informing people with cerebral palsy and their families about providing them with information that will help them make good decisions? Or is the project about information that will facilitate greater community acceptance of people with cerebral palsy?*
> Stakeholder

7.3 Information needs

Educating children about their CP

Parents are keen to support their child to have a greater understanding of their CP; what has caused it, how the child's body is 'different' from others, and what it will mean as they grow up. They do this in response to a need to start providing the child with greater agency over their lives and enable those who are verbal to better handle questions and interactions with peers.

> *We've always been incredibly upfront on age appropriate information. He understands he has CP, he can list what he has, what he lives with … he knows there's nothing wrong with him, so he can talk to kids if they ask him why aren't you using your hand? Why are [you] using a splint? With my other son as well, in case he gets asked questions too.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

> *I've read books to [my daughter] and stuff like that but it's really hard to explain to her … It's difficult, I don't know how to explain it to her.*
> Parent of child aged 0-5 with high level impairment, metro NSW

> *From a young age when I decided that I wanted to learn more about my disability my mum found it hard to find information. She turned to books and she tried to make them age appropriate, but it was still hard.*
> Person aged 18-45 with low level impairment, regional SA

> *It was probably when he started asking questions as to what cerebral palsy was and what was happening to him and all of that sort of stuff. I could get the information from an adult perspective, but I was trying to find the information that I could put into words for him, like a book or something like that, that would make it easier for him to understand. At the time, I really couldn't find anything. That would have just been internet searches.*
> Parent of child aged 18-45 with low level impairment, regional SA

School

Parents are reaching out via social media to get guidance from parents who are one to two years 'ahead' of them in terms of tips regarding their choice of school. Information needs focus on whether to send their child to a mainstream school or not, and what this might mean in terms of the practicalities of accessing the school (e.g. ramps) and the amount of teacher support their child will receive.

> *Schooling decision time… no information about what everyone else does. I know there's not a 'norm' but what other schools do to make teaching adaptive for kids in mainstream schools, making uniforms accessible, helping peers and schools to understand CP.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

> *The school was next door to her preschool… so I rang the school and asked them… and they were more than happy to take (my daughter) on because they already had a child with a disability in a wheelchair there … She's got an aide with her pretty much all the time… It's a mainstream school with no support unit in it, but they have a support worker in the classroom with her.*
> Parent of child aged 0-5 with high level impairment, metro NSW

> *No-one really assisted us. We looked at colleges around our area and that's about it. We asked other families with special needs where they were going.*
> Parent of child aged 6-17 with high level impairment, metro WA

They are also searching for information and suggestions for how their child best manages school.

> *I spoke to a few mums about what to look out for with school – they all said a flat surface, welcoming, flexible. You get different things form different people, like I never thought about needing to ask about making sure he sits up front in the middle (of the classroom).*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

Parents are also aware of the need to inform both educators and other students about their child's diagnosis. They are critical that there's no ready website to refer them to but created reference materials themselves.

> *I used Google, 'What CP is? What type?' and my personal experience. I put a one-pager together with a picture of [my son] with really basic and easy to understand information.*
> Parent of child aged 6-17 with high level impairment, metro Victoria

> *I remember in primary school, every new teacher I met I was literally introducing myself and saying, 'Look I've got cerebral palsy, if I need to make my life easier, can I tell you how to do that please?'.*
> Person aged 18-45 with low level impairment, regional SA

> *I suppose in the schooling system, having that information available for teachers so that you didn't have to necessarily give them the basic rundown of cerebral palsy and so on would be handy… So that it was less expectation on the parents to give that information.*
> Person aged 18-45 with low level impairment, regional SA

Preparing for employment

Parents recognise how central a meaningful job is for their child's independence and wellbeing and are keen to understand the range of support and resources available to help their child after they graduate school. They are keen for any additional information they can access at an early stage (from year 8 onwards) to help prepare their child for this step.

Specialist therapists and support

Parents continue to need detailed information on local therapists – physiotherapist, occupational therapists and speech therapists – that have experience of CP. Furthermore, they would value information on the therapists experience with the different types of CP so that they can work with someone who has insight into their child's specific needs. While lists are available, they lack the detail parents need.

> *[The NDIS list of providers] is quite huge. Overwhelming. We don't really know where to start.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

As parents are time poor, they are also interested in knowing whether therapists are co-located so that they can work with a practice that can meet their multiple needs and reduce their need to attend many locations and appointments.

> *Different physios, speech and OT in one building is really helpful, with appointments back to back so I don't have to drive between places.*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

Parents are looking for online content to help them to engage their child in the regular exercises they are set by their physio and to vary or extend those exercises to improve the effectiveness and reduce the monotony.

> *I was googling how to motivate him to do stretches, how to distract a child when doing painful stretches, how could I get him to cooperate. You go to a physio for forty-five mins, but that's once a week; stretches have to be done every day.*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

> *We try and do a half hour stretch on a wedge – extra pressure for getting everything done. I get called a mean mum but I want them to be independent and do things themselves.*
> CALD parent of child aged 6-17 with low level impairment, regional NSW

> *[My daughter is] supposed to do thirty minutes of exercise every afternoon but will do anything to get out of them. We need to look at other ways of exercising to make it a bit more fun.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

> *I just kind of Google it – e.g. CP hamstring stretches, muscle tone. I just narrow it down to a specific topic and click on random links. I put info together myself from multiple ranges of websites. Sometimes it's factual, and sometimes a personal opinion. If [I] find a stretch that isn't working that's prescribed by the OT, I do a bit of a look about why it doesn't work, what do other people say.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

They are also searching for recommendations regarding good quality equipment or assistive technology.

> *One of the things that would be great – recommending services, we recommend this orthotic provider – great shoes or helmets, then I don't have to waste ten to twenty hours to compare what's good, compare prices, know that you can trust, other parents' feedback and reviews, that's always helpful.*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

They would also welcome a forum where they are able to discuss NDIS with others in a similar position

> *A forum about NDIS – what you can say and how to word it to actually get items and services you would need for your child. Instead of sitting on hold for forty mins and get told, 'No'.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

Health-related issues

There are a variety of different areas where parents are looking for information during this life stage:

- Parents want to be able to search for very specific aspects of their child's conditions. By this life stage parents are generally very knowledgeable about their child's CP and complain that much of the health information is too generalised.
- During this stage parents are continuing to actively engage services and, if appropriate, acquire equipment. They need information to reach decisions on these and some are sceptical of the information offered by service providers.

  > *Eighty per cent is word of mouth – parents and networking. If you have a child with a disability you can't just listen to centres. They're just trying to sell you their services, or medical [solutions].*
  > *Parent of child aged 6-17 with high level impairment, metro WA*

- They continue to search for information relating to diet and nutrition that will best meet their child's diagnosis.
- As children mature, parents are keen to find information that addresses the specific challenges of puberty for children with CP, e.g. behavioural and mood changes, body changes, relevant medication, intimate relationships and masturbation.

  > *While the diagnosis doesn't change, his body does change.*
  > Parent of child aged 6-17 with medium level impairment, metro NSW

  > *Whole new world, it's the next stage of life for him.*
  > Parent of child aged 6-17 with high level impairment, metro Victoria

> *Sexual relationships and intimacy for people with CP - parents find this a difficult topic. The young person with CP has been quite a vulnerable person we need to protect so a lot of parents find it difficult to accept that they've moved on.*
> Stakeholder

- A few parents were aware that their child's CP meant that they tired easily, meaning they exercised less. They saw their children putting on weight and were interested in support and information on how to help their child exercise and manage their weight.

> *Maintaining a healthy weight, it's been a big deal for us for a long time. He doesn't use as much energy as other kids … But after school he's very tired. He wants to sit down and not do much over the weekend.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

- Some parents want information on alternative therapies, having become frustrated by the response from traditional health professionals.
- Some parents specifically mentioned the need for more information or aids to support toilet training, incontinence and bedwetting.

Social life

There is a gap in support and information that relate to social activities and means of connecting with other young people with CP.

> *The vacuum of formal info means you need to rely on Facebook groups.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *When they get to [my son's] age, there's this huge gap in access to anything social.*
> Parent of child aged 6-17 with high level impairment, regional NSW

Parents spoke of using their local knowledge or connections to help their child, with very little formal information available. They were able to access activities such as Nippers aimed at children with additional needs, and a drumming program provided by the Cerebral Palsy Alliance..

> *Inclusive spots programs for kids – dance, swimming – become more of an issue the older he's gotten, when he was little it wasn't a big deal. Programs and options for being a part of the community.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

This is particularly challenging as parents and children want to meet others with the same, or very similar, levels of both motor and cognitive function. This need is exacerbated by the loneliness some children experience within a mainstream school setting. Parents want more information on activities outside of school for their child to socialise and create friendships.

> *For years I tried to get him to go to the local theatre workshop – he wouldn't go, he struggled with anxiety. In the end, booked him in, paid for a term … he has loved it. Drama group, film group, other young people his age. Some of them may have issues, but all of them can converse and all have an interest [in] creating a performance.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

While parents are aware of some camps or workshops offered by specialist providers (e.g. Cerebral Palsy Alliance), some are considered expensive. Those with lower level CP are more likely to say they find it difficult to find a group of similar people.

> *CPA have great sounding camps and things away for young people, but they're very expensive, $3,000. It can come out of the NDIS, but [my son] isn't given that much money because it's a mild form of CP, and we wouldn't pay that much to go away as a whole family. Once the NDIS came in and CPA opened up to everybody else, it was hard to find a group where [my son] would fit in.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

Some parents simply spoke about not knowing any other children in their area who had CP, and that knowing others would put their child's, and their other children's, minds at ease.

7.4 Current information sources and formats

Hospitals, paediatricians, GPs and local area co-ordinators

The availability of suitable information varies hugely from these sources. While parents are generally positive about factsheets provided by large metro hospitals, those living outside of capital cities tended to find it difficult to access high quality, useful information. Hospital information is generally praised, but there is a need to keep the language straight forward and to minimise the use of medical jargon.

How parents perceive local area co-ordinators (LACs) as a source of support and information varies. A few see them as a vital portal to a good, reliable range of information, but many are critical that staff are not sufficiently experienced or trained, and that the rate of staff turnover is too high to build trusting, ongoing relationships.

> *We're on to our sixth local area coordinator. They can't maintain staff. I've had one person I thought came up with some good ideas and suggestions, what we could use funding for. The rest don't know what they're talking about, I knew more.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *The local area coordinator was quite new. She didn't have the concept of disability spectrum, assumed [my daughter] was in a wheelchair and incapacitated. She didn't get that she was mild … couldn't grasp our needs. You need people with a background in disability, more personalised.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

> *The people [from NDIS] who are your managers or planned coordinators have … very little knowledge about living with a disability or being the parent or carer of someone with a disability.*
> Parent of child aged 6-17 with high level impairment, regional NSW

There is also considerable frustration among parents for being passed between these different care professionals, depending on their information need and the funding stream for each professional.

> *Every time he changes campuses, the OT has suggested the sort of help, do an assessment, tell the school how to help him, and helps the school get funding. We rang the previous local area coordinator and she said nothing to do with education is funded by the NDIS and that the school should provide the OT to do the assessments. No way school can do that! She sent me the COAG agreement. There's a constant theme of not getting a straight answer.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

Age-appropriate books

A few parents had sourced books that explained CP in an age-appropriate way. However, many felt that this type of resource was scarce, and given the very heterogenous nature of CP, it was very difficult to find a book that successfully reflected the similar experience of their child.

> *CP fictional books based on facts. One of the stores is about a teddy staying with the girl … that's been helpful – (my daughter) has taken them into school, 'Tess's best friend'?*
> CALD parent of child aged 6-17 with low level impairment, regional NSW

Skilled therapists

Parents are either using a search engine, social media (Instagram) or word of mouth, to find appropriately skilled and located therapists, or suggestions for home-based therapeutic exercises. A few mentioned GPs who, while not expert in CP, were supportive and able to make valuable recommendations about information and services.

Many parents are seeking therapists through organisations (such as Cerebral Palsy Alliance). Some speak highly of these services and at various stages of their child's life consider this support a 'lifeline'. Others are critical of the quality of therapists and staff turnover. Parents consistently stress the importance of building a long-term relationship with their physio.

> *A physio for example … It's essential to have a rapport, for the parents, and to have trust for [my child] to want to see the person.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *We had the same physio from the beginning, she's part of the family! It's positive to have had consistency in the hospital team and consistency with the physiotherapist. They've provided excellent info, they guide us to websites, booklets. I have a personal relationship with the physio. She's good at listening to the ups and downs, looks after you as a family unit, and was supportive through my divorce. She treats [my daughter] like her own.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

> *If you had inconsistent healthcare workers, you can get lost in the system.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

Word of mouth and peer support

Frustrated by the limited, or absent, information from health professionals, some parents had formed long term peer groups that would meet either in person, or virtually, to provide support to one another and recommendations on information sources, resources and materials. Personal recommendations

from other parents, who understood the local options and the realities of caring for a child with CP were invaluable.

> *When you can see where other people are going through similar things, it puts your mind at ease.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

> *Going to CPA, the most valuable thing that they did was the parent support group and in that we had … a group of us with kids the same age as [my son], and then there were a few parents who were two years ahead of us and they led us.*
> Parent of child aged 6-17 with high level impairment, regional NSW

> *My biggest thing was word of mouth, like talking to other people... Connecting to people whose kids had CP and finding information from them.*
> Parent of child aged 0-5 with high level impairment, metro NSW

> *When I had my [older children without CP], I had a lot of friends, and then … they started having kids, they'd do birthday parties without me… I don't know what it was… They just sort of left me out because my daughter was different.*
> Parent of child aged 0-5 with high level impairment, metro NSW

7.5 Preferred information sources and formats

Diverse range of books

For younger children, the story book format is valuable, and a means of information provision that parents are comfortable with, however the range available is limited and needs to better reflect the breadth of lived CP impairments. Parents also felt books were necessary to help siblings understand their brother or sister's needs, or to provide answers to questions they might not know how to ask.

> *What would have been good would have been a children's book, having more children friendly resources. Perhaps they're out there, things to help them have a positive narrative.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

Social media

Parents make use of Facebook groups, and social media more generally, for a wide range of information needs. They value the speed of response, in contrast to more traditional sources because thousands of parents are in the groups, and that at least some peers are likely to have significant insight into their needs. Parents use social media to find information they're failing to find elsewhere, and also to seek reviews on particular equipment before making a purchase.

> *It was easy to ask other parents because someone would reply in 5 minutes, if you call hospital it would take hours.*
> CALD parent of child aged 6-17 with low level of impairment, metro Victoria

> *NDIS self-management hub – joined that when we started managing [my son's] NDIS. People chat on that – e.g. asking whether zipper Nike's can be claimed on the NDIS. A lot of people have experience and different info. Very broad, there will be a few different answers.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *Reached out, posting on those groups asking if there's anyone who would be happy to talk to me about boys in particular with CP and going through puberty … how is [my son's] facial hair going to be looked after? Electric razor? Or getting somebody in to help with his daily shave?*
> Parent of child aged 6-17 with high level impairment, metro Victoria

> *Through the tracheotomy Facebook group found it you could use blended diets rather than just milk.*
> Parent of child aged 6-17 with high level impairment, regional NSW

> *Like [the parents of kids with CP] helped me, I helped others. It's like a pay it forward, you always seem to be helping someone else through your experiences. That's where Facebook pages are really good.*
> Parent of child aged 0-5 with high level impairment, metro NSW

> *Facebook is extremely good because it's got knowledge about everything… From therapies, to doctors, to specialists, everything's on there.*
> Parent of child aged 0-5 with high level impairment, metro NSW

However, the downside is that the information is not always sufficiently local or specific to a person's needs, nor is it always accurate.

> *Cerebral Palsy Parents Australia Facebook page. When I was first thinking about [my son] getting his license, I asked if anyone knew the process. A few people came up with ideas. That's a very big wide group, everything from ventilation and peg feeding to people with quite mild CP like [my son]. Always a good source of info. But not always specific or local.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *There's a lot of information online. I'm a bit concerned about some families getting most of their information from groups on Facebook, and a lot of the information is incorrect, not relevant, inflammatory and scary. Finding reliable information is challenging.*
> Stakeholder

Parents value specific social media groups associated with services they are using. Some are enthusiastic about the prospect of an app designed to link them with other parents, or people with CP; others feel they have sufficient contact and information and are loath to take on additional connections that they may feel obligated to.

Those who are specifically worried about their child's social network or limited friendship group are interested in a platform where their child could connect with people their age, with similar levels of CP impairment.

> *That's what's lacking here. There must be other teenagers with CP, but we haven't connected with any … you're looking for people who have CP in a similar way to [your child].*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *If I could find a family to buddy up with another teenage boy with CP. Talk to and ask specific questions. I think that would [be] wonderful.*
> Parent of child aged 6-17 with high level impairment, metro Victoria

A number of parents of teenagers and/or young adults referenced seeking out social media or Instagram influencers with CP as positive role models for their children, as a way of demonstrating the opportunities that the next stage of life might hold. These included R J Mitte, Robyn 'The T-Rex' Lambird, Emily Prior and 'Ohh Bulldust'.

> *My son was able to talk to RJ Mitte from 'Breaking Bad' through this. [My son] is at the stage where he's very aware [of his CP] and refuses to know about the good things ... He gets angry at me. But talking to someone else who also has CP, helps show him that there are still cool things to do because of CP.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *Seeing people's stories of people with CP in media, really positive, this is my story – it's different, good for him.*
> Parent of child aged 6-17 with medium level impairment, metro Queensland

> *A guy who did climbing with cerebral palsy – like a day-to-day diary. Really nice to see what he was capable of, I'd show [my daughter].*
> Parent of child aged 6-17 with medium level impairment, regional NSW

While many parents were happy with the information and advice they accessed via Facebook – and felt that an alternative CP social media space would be competing or repetitious – others welcomed a dedicated forum.

> *A forum for people to jump on for questions, a bit like a Facebook, put questions and get advice from people ... Health professionals could jump on and give advice too (if they're legally allowed?) ... Not everyone wants to use it Facebook – you don't want people to see what you're asking. Within a website you could make it a private chat room. You could speak to an administrator, could be anonymous, still getting info, from likeminded people.*
> Parent of child aged 6-17 with medium level impairment, regional NSW

> *I know where those parents are at (on Facebook), and they're wanting answers or they want reassurance that things are normal or whatever, and then with everybody putting their two cents' worth in, I don't think it's great.*
> Parent of child aged 6-17 with high level impairment, regional NSW

> *NDIS grassroots is a very large FB group, where parents and people go to ask questions … if staff members from this project went on their and answered questions, generated discussion, that would probably provide more support …. They'd reach more people than trying to build an audience, it takes times to build a new social media audience. It's about posting where people already are, rather than expecting people to find*

you.
Stakeholder

Peer support groups

Some parents had not found a useful group of peers to connect with either in person, or via social media, and were keen to connect with a local group of other parents dealing with CP, with whom to share worries and difficulties. This was particularly the case for parents whose children were in mainstream education; they reported feeling alienated from, or angry with, parents of children who did not have CP, and they were not able to compare experiences with these parents.

It's really hard. A portal that not only connect to private providers but also where people can talk and share stories. But talking to other parents who have kids with CP about what they have success with really would really help.
Parent of child aged 6-17 with medium level impairment, metro NSW

Really useful to have stories … a life saver when [my son] was first diagnosed.
Parent of child aged 6-17 with medium level impairment, metro NSW

There was also interest in social activities that would help their children meet and connect with other people with CP.

I am trying to find people, a community, so [my daughter] can be friends with somebody … and I don't know how ... I need to connect with some people who have kids her age who have CP to be able to go to the park.
Parent of child aged 0-5 with high level impairment, metro NSW

For those who are struggling, parents also suggested that there was a need for a manned helpline to provide mental health support. A stakeholder recommended the 'Head to Health' website, but this was not mentioned by participants.

Often people are at the end of their tether with high needs children. [You need] a mental health line for people confined to the house looking after children who don't get respite.
Parent of child aged 6-17 with medium level impairment, regional NSW

I didn't have that support … like someone asking if I need someone to come and have a talk with me… Support for parents as well as for kids.
Parent of child aged 0-5 with high level impairment, metro NSW

Mental health is an important issue for both parents and young people. It tends to be in that leaving school period, leaving university and that adjustment period is quite challenging. There's lots of counsellors out there but often they don't know what to do in relation to CP. There are no psychologists that specialise in CP.
Stakeholder

One platform

Numerous parents spontaneously expressed the need for a single, unified, interactive platform that comprehensively addresses the range of information and support relating to CP.

> *Having a one stop shop can help you understand what's in your area.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

They acknowledge that this is a very challenging prospect, given the diverse umbrella of impairments, other associated conditions and lived experiences for people with CP.

> *Somewhere that would be so huge, CP is a spectrum as well like autism is. My son's needs are as individual as anyone else's. Something centrally available and you could get all the info online.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *Central website would need to have NDIS, Centrelink, therapy, [then you] could narrow it down by state, areas. A big project, hard to make it easy to navigate. I'm well educated, grew up in Australia, don't have a disability. I can't imagine navigating it if that isn't the case.*
> Parent of child aged 6-17 with medium level impairment, metro NSW

> *The challenge is the diversity of accessibility needs within this group of people with Cerebral Palsy. So, it's about understanding the needs and those with intellectual disabilities as well … I think it's particularly difficult to broadly comment on that as a specific diagnostic group without doing some quite significant mapping.*
> Stakeholder

The concept of a one-stop-shop, or centralised platform, was raised repeatedly across all life stages. Stakeholders referenced a number of examples of where this is done well.

> ***Dementia Australia**, fabulous website. Clearly dementia's getting a lot of money and they're investing; it's got a very look and feel contemporary feel, it tells me they're up to date, whereas CP Australia looks daggy and old fashioned. Even if they are up to date, they don't look like they're up to date ... We want something that says we value you, we value the information you need, we're trustworthy, we're modern.*
> Stakeholder

> ***Health Direct** have a fantastic governance structure at the back, they do a lot of due diligence of any other information providers. We had to jump through a lot of hoops to be a link on their website … how we write, develop, maintain our information. That stood out for me. They have a whole clinical governance team and they don't just link to anything … It has to be a trusted source. Integration and seeing a person as a whole, will involve a lot of work at the back end. When I look at different CP sites, I get pretty underwhelmed. It looks daggy, it looks out of date. Whereas Health Direct has a personality, it looks current, you can trust it, you can call the doctor at the end of it if you want to. It speaks volumes 'I think I'm in the right place, with the right information'.*
> Stakeholder

> *'Enable Me' are doing a good job. I like their portal and their approach. The navigation … it's just clear and obvious, that's it … I want it to be a place where people can go to connect and share, and I feel that's what*

Enable Me does for their community.
Stakeholder

'The Loop', that's for muscular dystrophy … they have an app that's really good … its less about the information … what I like is the way, the modern feel of the website, it doesn't have this disability or allied health feel about it. It's really modern, clean and crisp and its really clear how to get into it … I always admire their accessibility, especially 'The Loop'.
Stakeholder

Summer Foundation, a good combination of outreach to professionals and disability providers, and also do good work with the lived experience with videos and resources.
Stakeholder

Valid (Victorian Advocacy League for Individuals with Disability), they do lots of grassroots peer support work and facilitate people themselves dictate what happens.
Stakeholder

Videos

Hearing first-hand experiences, via video, was broadly welcomed as a means of communicating to both parents and children during this life stage.

Watching interviews with people who have CP, kids and adults talking about their needs. They've been very useful, because it's about hearing their experience.
Parent of child aged 6-17 with medium level impairment, metro NSW

Videos of people explaining … demonstrating certain things. How to sign up for myGov, how to find what you're looking for on Centrelink, e.g. on myGov can go and find local therapists? How do I find a local therapist? A video stepping you through, or steps to do with self-managing, filling out Centrelink forms.
Parent of child aged 6-17 with medium level impairment, metro NSW

Videos are a really good source of information for the kids to have. And parents as well. I know some people don't feel comfortable watching videos but that's part of their journey.
Parent of child aged 6-17 with high level impairment, metro Victoria

Some parents referenced existing videos that they found valuable.

Cerebral Palsy Alliance have videos once or twice a week that you can do at home with the bands. Simple videos, just one minute long, they're good to watch.
Parent of child aged 6-17 with medium level impairment, regional NSW

During this life stage parents are still considering – or opting for – a variety of surgeries to enhance their child's long-term prognosis. They mentioned videos being particularly valuable for illustrating the 'before and after' of common operations.

One area that would have been helpful to have some information on, particularly for (my son), was when he had his hamstring release surgery. Having someone that has actually been through it, talking about what it was like and what to expect, how long it might take to recover and all of that sort of stuff, I think

would have probably been helpful for him.
Parent of child aged 18-45 with low level impairment, regional SA

Podcasts

While a few parents like the podcast format, others find it a less accessible format.

For me, nothing like podcasts – too time intensive. I want quick easy access to information.
Parent of child aged 6-17 with medium level impairment, metro Queensland

Apps

A parent referenced an app called Zingo, that allows therapists to load and share content with her child, providing support she can access at home and school.

It's an app the physio and therapist can load things on to … its been awesome … I can see what she's meant to be doing, sometimes video of Raya's doing things, sometimes generic. It's so motivational compared with me saying, 'Let's do this'.
CALD parent of child aged 6-17 with low level impairment, regional NSW

Chat bots

Opinion of chat bots varies.

Real people would be much better. I'm not keen on automated chat bot, you get stupid answers, and its frustrating to not get a proper response.
Parent of child aged 6-17 with medium level impairment, regional NSW

Websites

Parents during this life stage found the following digital sources useful:

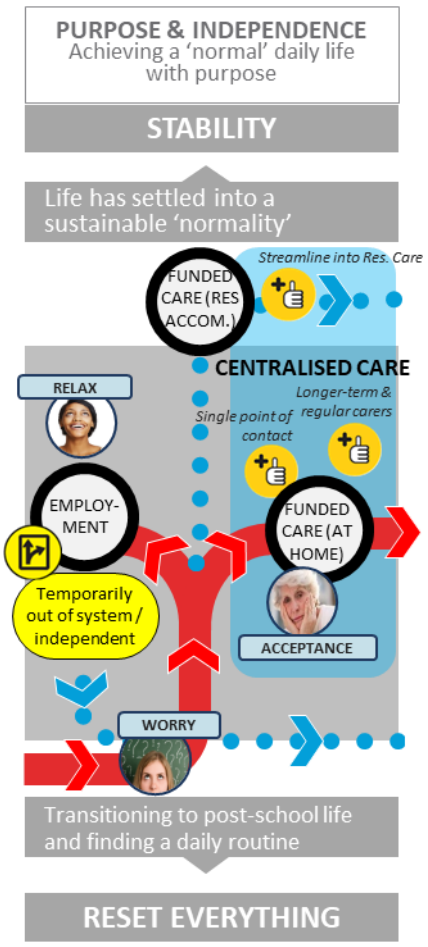
- cpaustralia.com.au
- atchat.com.au/about-us/what-is-at-chat
- beyondblue.org.au/get-support/online-forums

They value interactive functions, allowing them to leave questions, post videos and make comments.

Some parents were critical of current online resources in Australia, preferring to make sure of international platforms, e.g. cerebralpalsy.org.uk

8 Purpose and independence – aged 18 to 45

8.1 Life stage context



This adult life stage lacks the trauma of earlier life stages and the level of worry and stress become less burdensome. Depending on the individuals' level of impairment there is a shift towards greater independence, taking increasing responsibility for many central aspects of life; education, employment, housing, health, transport and relationships. This can initially be challenging for parents to step back and let their child take steps towards adulthood.

> *Letting a young person be a young person and be independent; it's hard to let go of your child who has vulnerabilities.*
> Stakeholder

> *Achieving independence and try to find a life outside of their family home. I think that can be a challenging time.*
> Stakeholder

At the beginning of this life stage individuals enter a steep learning curve about both their condition and how to interact with the wider world. Knowledge that has been developed and held by the persons parents needs to be understood by the person with cerebral palsy as they transition from paediatric services to adult services. Simultaneously, as they look for answers externally, they encounter information and resources that are largely focused on babies and children with CP and their parents.

> *I was under the care of [named organisation]. I aged out and then there's nothing at all. There was a long period of nothing at all, then NDIS came in … it was a whole mess trying to figure out where to go.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

8.2 Key challenges for this life stage

Identity

Some adults with lower severity of impairment reach teenage or young adulthood before their parents shared their diagnosis with them. They tended to credit this with giving them a positive attitude and a

determination not to be held back by their CP, but it also meant they weren't consciously developing a knowledge of their condition.

> *There was a moment when I was twenty-two, my aunty was drunk at a Christmas party. She said 'You're a little spastic … your mum and your dad spent so much time and money doing physio for you' … I turned to mum and said, 'Is that true?' and she said, 'Oh yeah'. So, it made me realise it was an ongoing thing to get me to where I am now.*
> Person aged 18-45 with low level impairment, metro ACT

> *My parents didn't even tell me I had CP until I was eight or nine, even though I was going to more appointments than others. It was good, but also to my detriment, I didn't learn about it.*
> Person aged 18-45 with medium level impairment, metro NSW

For those aware of their CP diagnosis, there is also a journey in how their disability impacts on their identity and outlook, and in what ways it determines their choices in life.

> *My parents are more deniers! They were adamant I wasn't going to be in a wheelchair, that I would be in mainstream school, it has given me determination, not how society expects someone with a disability should behave – gave me attitude that a disability doesn't stop you from achieving things in life.*
> Person aged 18-45 with medium level impairment, metro NSW

> *When parents discover their child has CP – or any kind of disability – they see their child differently, they become a lot more over-protective … they treat their child like someone with a disability, not just a normal child with additional needs. This can have a very big impact on how the child will look at himself when they grow up; being able to experience life like everyone and to have the same opportunities like everyone else.*
> Stakeholder

Navigating the health system

As people with CP reach adulthood, those with low to medium levels of impairment who are seeking greater independence, start to build greater knowledge about their condition. They frequently lack a detailed knowledge of their own medical history or their condition, as their parents have dealt with this aspect of their life for the last eighteen years.

> *It's explained to your parents, not to you as an individual, so it's assumed you know what CP is.*
> Person aged 18-45 with medium level impairment, metro NSW

> *There's all this stuff that I suddenly had to learn when I started doing physio and my mum wasn't always there. This terminology I had never absorbed or wasn't interested in.*
> Person aged 18-45 with medium level impairment, regional Victoria

> *When talking about an infant with CP – the voice is the parent. [The challenge is] how one facilitates that increasing voice and agency of the person with the disability. You know it is vital but can also lead to stress and disagreement because the person who had the voice and the agency may not be ready to let go of that voice.*
> Stakeholder

Similarly, for those with high levels of impairment, there is a parallel transition with the role of carer eventually moving from a parent to a sibling, as either parents die or become too frail to continue as the primary carer.

> *Used to be just mum and dad taking the reins, but my father died in 2018, and as soon as he died, I had to take over … it's challenging. Government programs … confusing, there's no single point, no source of truth of information. You rely on social workers that come along and say how come you aren't participating in X Y and Z? I'm taking over all of it. What I needed to know – what she's entitled to, what support she actually needs – I'm learning every day … It's very time consuming – you want to have all the right information, to make sure you get the best.*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

This greater responsibility and independence also mean that while people with low to medium levels of CP have spent much of their lives interacting with the health system, it is their parents who have the knowledge of how to manage and co-ordinate medical and therapeutic needs. These young adults were on a steep learning curve about their condition and the need to maintain their skills and mobility. This is exacerbated by the transitioning process from paediatric to adult services.

> *A bad experience with a specialist kick started it for me. They didn't tell me to bring anything, 'You just told me to turn up'. II missed my first appointment because I couldn't find the place ... I now know how to be an advocate for myself.*
> Person aged 18-45 with medium level impairment, regional NSW

> *The medical transition can be very difficult. You leave school and leave children's hospital at the same time. You leave all our resources and move onto the adult service – and the adult service isn't particularly good about CP. There are no CP specialists in the adult world.*
> Stakeholder

> *You fall off a bit of cliff when they leave paediatric system – everything becomes fragmented where you had something under a paediatric umbrella now, you might have your lungs and your respiratory issues sit with the Austin and then you're going to go and see such and such for your rehab coordination and … so all becomes very disjointed and difficult.*
> Stakeholder

For older adults with CP there has also been a substantial readjustment over the course of the introduction of NDIS.

> *No support to figuring out which supports are available – figuring out has taken up the whole last two years.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

Furthermore, for those who are now living independently in a new location, they need to establish a new health network (of GPs, physiotherapists, occupational therpaists and neurologists). This can be challenging for those in regional areas with fewer specialised health professionals and services to access and challenging in metro areas where there are waiting lists.

> *Before, I was in a smaller town and was able to get physio at the hospital really easily, but since I've been [on the Gold Coast] my GP put me on the waitlist for the physio at the hospital and it's been three years and we've heard nothing.*
> Person aged 18-45 with low level impairment, metro Queensland

> *The physio I see is mainstream, a private physio. He's treated me on and off for ten years. He's got to know my case, but he had no experience with CP. In some ways I've helped 'educate' him … I've been referred to a horrible rehab …the pitfalls of being in a regional area.*
> Person aged 18-45 with medium level impairment, regional NSW

Some young adults initially significantly reduce the frequency with which they receive physiotherapy or other therapies. Others continue but some wish the focus of the therapy was more functional to enable them to manage greater independence.

> *Around their late twenties young people with CP begin to discover the normal wear and tear on the body and start going back to therapy. The young ones go, 'I don't [have] anything to do with CP world' and then come back to it in their late twenties. Their balance is not good. It happens quicker with CP, everything is magnified*.
> Stakeholder

> *OT, physio and speech therapy, I still do but I feel like it is not focused on functional things, like, for example, opening jars. It's more focused on normal exercise. They need to combine motor and function so I'd really get more out of it.*
> CALD person aged 18-45 with low level impairment, metro Victoria

As with other life stages, it is important that there is consistent care from a therapist and that they have some experience and understanding of CP.

> *Some therapists are really hard to talk to. They don't really understand you. They don't understand the situation. I think some of them have never had friends with a disability … I'm still not a hundred per cent comfortable with my physiotherapist.*
> CALD person aged 18-45 with low level impairment, metro Victoria

A key part of navigating the health system, is understanding and accessing different funding streams. Again, this takes considerable effort, time and persistence that can feel overwhelming as young adults take this over from their parents.

> *I went on a care plan [for the physio] but the trouble with that is it is only five sessions for the whole year which is not enough because I should be going weekly … I recently looked up the Cerebral Palsy League and saw that now they do have services for adults, but it's mostly through NDIS and I'm not linked with NDIS … I haven't actually… signed up for [NDIS] just because… I'd need reports from my physio, reports from my OT, and I don't have a regular OT or regular physio, because I've moved and I'm on a waitlist for so long, so I don't know what to do.*
> Person aged 18-45 with low level impairment, metro Queensland

> *With NDIS, we've given choice and control to people, but you only need to look at utilisation rates to see people don't have time to make good decisions, because good information is not there in a form that facilitate a good decision.*
> Stakeholder

For those with lower severity of impairment, CP was sometimes a secondary diagnosis and they were more focused on managing and living with another condition that had a greater impact on their day to day life.

> *I have a mental illness as well – impacts me more than CP. If it was just CP, it wouldn't stop me, but it's the other things combined.*
> Person aged 18-45 with medium level impairment, metro NSW

As a new parent with CP, one participant was worried that her CP was hereditary and may be passed onto her child. She also had significant worries about being able to safely manage the care of her baby.

There were also very significant challenges for a sibling carer, whose sister with CP still lived in the family home with an ageing parent carer. He was investigating respite or residential options for his sister as the strain of caring was becoming too much for his mother, but he had very serious concerns about the quality of residential care available for his sister with CP.

> *It's hard to trust the people in the system, I've encountered people with bad intentions. It's the same as aged care health facilities; spy cameras and abuse. How do you trust the system?*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

On-going education

Several of the adults interviewed were prospective, current, or recent university students. They all spoke very highly of the support services in place to help them negotiate student life, describing these university services as flexible, open-minded and supportive.

> *Uni was a good introduction to living independently. The staff were great … they renovated a room. I use my wheelchair full time, so I needed accessible entrance. Disability services at Uni … there were great, made sure my classes were accessible.*
> Person aged 18-45 with medium level impairment, regional NSW

> *My university is one of the best for people with disabilities. There are a lot of students with disabilities and they are very flexible, they are very open-minded and they are very supportive. Their layout of the university is good for someone like myself … it's very convenient. The people are really friendly compared to the more competitive universities, very open-minded.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *I wouldn't need to talk about anything unless it came up. I might need to talk to them about more time on tests and maybe talk to each lecturer about if there's going to be any hands-on tasks and it's going to be fiddly, if someone can assist me.*
> Person aged 18-45 with low level impairment, regional SA

> *I made contact with the accessibility people within the uni. I talked about needing extra time, space, accessing lectures ... Uni of Sunshine Coast have that info listed very well on their website - easy to understand, easy booking system … They're emailing and ringing me quite regularly to check in to see if there's any extra support I'm needing or areas I'm struggling with. Very proactive in making sure my plan is working for me. A lot different than when I first studied over 10 years ago, trying to find disability supports then was a lot more difficult than it is now.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

Meaningful employment

A central pillar of adult life is finding and maintaining employment; both for financial support but also to give life greater purpose. This can be a slow and challenging process, that lacks clear signposts for young adults with CP.

> *There's no comprehensive system specifically for adolescents who experience transition issues from school to work opportunities … they have to take it on themselves to find out what's available.*
> Stakeholder

> *A lot of young people will say leaving school is like falling off a cliff … they don't naturally have the same pathways, school to uni, or school to work. Because of some of the challenges they might experience getting into the workforce, it can be a very isolating and stressful time. What do I do now? What are my options? That transitional support, some young people and their families find [it] very distressing. School leaver pathways. … a very worrying time for parents around their young person's mental health.*
> Stakeholder

The adults with CP were mostly able to find work with the assistance of specialist employment support – or for those with low level CP, sometimes independently. Older participants regretted the ending of some specialist employment agencies who would actively support people with CP transition from education to the workplace.

> *The main frustration for me is that… the Cerebral Palsy Alliance used to have its own employment agency … due to government funding, the service was stopped and at the time, because I'm an older person, I wasn't really concerned about me, but all of these young ones who have just exited from school and they need help, that service is gone.*
> Person aged 46+ with medium level impairment, regional NSW

> *My first few days at work, they took me into the hospital, set me up, acted as my liaison, sat with me for a day to help out and identify any issues. They were really good, a godsend, but they're not there anymore. I'm not sure what I would do these days.*
> Person aged 18-45 with low level impairment, metro Queensland

However, those receiving support from a specialised employment agency report a mixed experience. While some are satisfied with the work they secure, others feel that they are largely put forward for relatively low skilled roles, and that employers misconstrue their physical disability for cognitive disability.

> *That's one misconception that I hate that people have about CP – it's that they think that we're mentally retarded. They don't understand that it's a physical thing more than being intellectual disabled.*
> Person aged 46+ with medium level impairment, regional NSW

> *The expectation society has about people with CP is very low and this is what we need to change and provide the same opportunities to everyone. And show that people with CP can have the same goals and dreams in life as everyone else.*
> Stakeholder

> *Australian Disability Enterprise jobs are sub-minimum wage, factory or cleaning work. There's not much career progression - people can get a bit stuck.*
> Stakeholder

Those in employment spoke of the challenge of communicating their condition to their employers, especially for those with relatively low levels of impairment. They are aware that their disability may not be very obvious to their employer and find it difficult explaining how their CP impacts on their movement, strength and energy levels.

> *If I was getting an in-office job there are things that I would need, maybe like a special chair or certain break times so I can get up and stretch. I can't work a job where I'm standing… I have to be sitting down. And that can be hard sometimes, advocating for myself … because I don't look disabled, trying to figure out when to bring it up is hard … I don't want to be constantly harping on and feeling sorry for myself, but also, they need to know that I have limitations.*
> Person aged 18-45 with low level impairment, metro Queensland

> *I'll be fine at the start of a shift, but at the end I'll just be spent.*
> Person aged 46+ with medium level impairment, regional NSW

> *Part-time jobs – any time I feel like getting a part-time job after year 12 that will probably impact me because of my CP. They'll probably end up needing to know what I can and can't do. I've got a quote from Maxima to help me set up an application for a job and support me to get a job and teach me work life.*
> Person aged 18-45 with low level impairment, regional SA

Living independently to parents

The timing and speed of moving to independent living varies considerably, depending on the individual's level and type of impairment. For those with lower level of CP, it is an easier step, but still requires consideration that their housing is compatible with their disability, e.g. close to shops, near to public transport, a ground floor property to negate the need for stair use and with access to a good GP. For many this first move will be made to a location where they know people or have an existing support network in place. Bringing these together with the likely rent an individual will have at their disposal makes this challenging.

> *You can't move out of home. The rental market you can afford, is generally inaccessible – old, steps, terrible bathrooms - certainly wouldn't be open plan. The only thing you could afford is an old little house that he couldn't live in.*
> Stakeholder

Establishing where they sit on the housing needs spectrum is also difficult. For example, many with lower levels of CP impairment are aware that they will not be eligible for NDIS Special Disability Accommodation, but yet they have specific accessibility needs that are very difficult to match or afford, in the private rental market. This leaves them with few options and limits their choice of where they can live. For those with higher impairment, the process to independent living takes longer, as the options are scarcer, and may only come about as parents become too old to be primary carers.

> *In the past putting your child into accommodation, an STA, a Department of Human Services house felt like a relinquishment that you couldn't cope any more. There was the real impression that you only moved your high needs child out because you couldn't manage it, lots of a sense of failure and guilt. But it's an opportunity for me as a younger ageing carer … enjoy it with him rather than be in my eighties and him to be taken off me because I can't do it.*
> Stakeholder

In addition, to the major challenge of finding and acquiring an appropriate property, adults with CP were very aware of the self-care skills that they would need to live independently and that there were some aspects where they would need ongoing help and support.

> *Most of my self-care needs are pretty normal but I think when it comes to cleaning, I think there are some modifications I'll need.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *Learning the skills to manage a house or building up the support that I would need to make that work … I can cook a whole meal by myself. But it's like, realistically, it's a long and tiring process for me if I have to cut up any vegetables or anything. And some of it I just can't do ... Realistically I will still need support, so it's about what do I choose to have more support in and what do I choose to be more independent with.*
> Person aged 18-45 with medium level impairment, regional Victoria

> *Independent living, moving out, what are my options, where can I live, how can I get funding? That's a really big one, quite complicated for people to understand … often for young people they may need more support to practice that in a safe way. What's the scaffolding support that you can help set them up for success?*
> Stakeholder

Transport

Participants were dealing with the difficulties of both public and private transport as aspects of adult, independent life. Younger adults were exploring the possibilities of learning to drive, and the additional steps required as a person with CP. Others were viewing the advent of self-drive cars as bringing huge personal benefits, while another participant had been given an adult tricycle which gave her new freedom.

> *Learning to drive? I'd love to drive one day but I may not be able to … I think the technology is really changing. There are a lot of self-drive cars that are coming out and I hope that one day I can buy one. It's amazing for someone like myself. I think driving gives you a lot of freedom. I currently have support*

workers to drive me, but I think it'd be nice to drive on my own one day.
CALD person aged 18-45 with low level impairment, metro Victoria

People with disabilities often live more of a sheltered life than able-bodied people, you don't necessarily learn the skills that everyone organically learns. Budgeting skills because you aren't necessarily independent enough to get out and go on a bus and go to the movies with your friends. Even how to catch public transport. It kind of has to be more structured and you rely on your parents teaching you that.
Person aged 18-45 with medium level impairment, regional Victoria

My grandparents gave me the tricycle and my parents are looking into getting one with a motor under the NDIS. Basically, I ride every day, I use it constantly.
Aboriginal person aged 18-45 with medium level impairment, regional Queensland

Friends and dating

Building a good friendship group and wider social network is a focus for those in this life stage. For some they are already well connected through a variety of activities that connect them with others facing similar personal challenges. Others find it more difficult connecting and shared feelings of loneliness.

We pretty much meet with the same people every week [at weekly gym group]. So, without intending to, you make a lot of friends through that group and you end up making a lot of connections with the physios as well.
Person aged 18-45 with low level impairment, regional SA

A minority of adult participants raised the issue of dating, and the additional challenges faced as a person with CP.

For some people, they want to go on a date. They might feel scared or anxious. I think there needs to be something … to help people meet other people in a safe environment. I think that's really important for someone like myself. When we are in our mid-adulthood we're looking for that someone, and I think we should be able to pursue that if that's what we want, because we are a little bit scared when it comes to dating stuff. I don't think I'm ready for a relationship for now because of my studies, but maybe in the future.
CALD person aged 18-45 with low level impairment, metro Victoria

They're worried they won't get a boy or girlfriend. Meeting someone's a little harder; judgements are a little bit hardy. They go through this body awareness and confidence. You can learn about the physical aspects of sex, but it's all the other stuff that goes around it that's a bit of a challenge.
Stakeholder

8.3 Information needs

Information deficit

An overarching theme to emerge in this life stage is the widespread perception that it is harder to access appropriate and useful information than at earlier life stages. Adults with CP, and their carers,

comment that much of the information that is easily accessible are too focused on the diagnosis and childhood life stages.

> *I've found that just getting any information on CP has been hard as an adult. When I was a kid it was easy… but they said that once I turned eighteen, they couldn't help me anymore.*
> Person aged 18-45 with low level impairment, metro Queensland

> *The biggest thing for me is that adults aren't forgotten. There's a real lack of information for adults on the assumption that it kind of finishes when you stop being a child.*
> Person aged 18-45 with medium level impairment, regional Victoria

> *I found that most of the specialists who focus on CP, focus on children, most of the research is on children, when I look things up, like… what to expect with cerebral palsy as you age, it's all about children or information for parents of children with CP.*
> Person aged 18-45 with low level impairment, metro Queensland

> *I tried looking for a cerebral palsy Facebook group, but again it's all for parents … of kids with cerebral palsy.*
> Person aged 18-45 with low level impairment, metro Queensland

There is also a perception that much of the information and resources focus on people with a higher level of CP impairment.

Working with health professionals and therapists

As adults began establishing more independent lives, and working with new health professionals or therapists, they reported frequently encountering people who know relatively little about CP, and lack any detailed expertise about specific types of CP. In this way individuals began to take on the role their parents had previously had of being specialists on their own history and diagnosis. They felt the lack of easy to share information sources that they could direct these doctors and therapists to, to better understand their condition.

> *Even if I go to a GP, or sometimes a physio, I have to explain what cerebral palsy is and how it affects me. I know it affects me and how I feel, but I don't really know all the physiological stuff behind it and what other parts of my body it can affect.*
> Person aged 18-45 with low level impairment, metro Queensland

These adults also found it challenging to communicate their health needs. It is something their parents had previously done, and they are unsure of what they should be doing to maintain their health. Reflecting the broader lack of information aimed at adults with CP, people in this life stage also commented that it was hard to find comprehensive, detailed information on the range of therapies that are appropriate to their condition. As with younger life stages, adults comment that they frequently have to drive the conversation about new treatment or choices.

> *It can kind of be hard to articulate what I need, when I don't even fully know what kind of support I need.*
> Person aged 18-45 with low level impairment, metro Queensland

> *I want to know if there's different therapies I should be looking at.*
> Person aged 18-45 with low level impairment, metro Queensland

> *I find that sometimes you have to say to doctors, 'Hey can I try this? Or see this type of doctor?' Rather than them suggesting it to you. But it can [be] hard to find about this stuff.*
> Person aged 18-45 with medium level impairment, regional Victoria

They would also welcome definitive information on new treatments from an authorised source.

> *I look every few months to see if there are any miracles, but there's nothing miraculous that's occurred. It'd be good if a central website [included] new approved advancement, new treatments for muscle stiffness beyond Botox. Instead you read an SMH article – attractive headlines, about that kind of thing.*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

> *Some information – [might be a case of] 'this is the best early intervention technique', vs. others where 'the science is divided'… some of it [information] is relatively stable, other bits will need to be updated regularly … [there needs to be an] expert advisory board needed to oversee what should be included*
> Stakeholder

As with other life stages, adults with CP also struggle to find local information that can direct them to local health professionals with expert CP knowledge.

> *I want to know… if there are specialised physios who know about CP… [My GP] can't look up on her system physios or podiatrists who know CP and what to do with it.*
> Person aged 18-45 with low level impairment, metro Queensland

> *Finding a good physio? That's very hard – we don't know where to go for help. A lot are only used to dealing with a normal life. I ask friends to recommend people.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *We probably didn't do enough research into finding someone who knew about cerebral palsy. He's a neurologist so he has knowledge of it, but I think he forgets that having cerebral palsy is relevant.*
> Person aged 18-45 with medium level impairment, regional Victoria

> *I think I'd like to use it also to have a database of doctors, medical professionals, who have knowledge of CP.*
> Person aged 18-45 with low level impairment, metro Queensland

There was preference for this information to include short summary information about these providers, rather than solely relying on links to their sites.

For younger adults, taking over management of their care from their parents, there are challenges with how to manage the relationships with the variety of health and care providers they interact with.

> *Building relationships with providers and support staff is something that is new to me and something I would like more information on. It's not always easy to find information on.*
> Person aged 18-45 with medium level impairment, regional Victoria

A minority of adults with CP comment that they lack information not only on their current condition, but also how their condition is likely to impact them as they age and what their ongoing health management should include.

> *A place that has information on perhaps what to expect, as a person with cerebral palsy, for different life stages.*
> Person aged 18-45 with low level impairment, metro Queensland

> *Trying to find that further information is hard. My neurologist is a quick five minute appointment – I can't have a long conversation about it, he just gives the Botox … I noted that you do decline and age quicker, but these things aren't told to you, they aren't explained medically … I want to be prepared.*
> Person aged 18-45 with medium level impairment, metro NSW

> *I've only just recently found out that some of the aspects of my health is related to my CP that I didn't know. I need basic info about CP and what that can mean and how it can impact your life.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

> *Recently my sister has had these seizures. We went to hospital, they asked which neurologist we're seeing – we're not, should we? It's challenging, it's very, very unclear. Seeking western medical advances and Chinese, acupuncture anything that provides a glimmer of hope.*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

Those with lower levels of CP impairment also felt that resources, such as day programs, tended to be aimed at those with more severe CP and were not appropriate or engaging.

> *It's more been access to services [info needs], appropriate exercise programs, and research into potential day programs – if they'd be suitable. But there are lots of day programs that aren't intellectually stimulating. I don't know anyone else with CP, so I was looking for ways to connect – I was looking for groups, but never found something appropriate. There's stuff for people with severe CP – so once again, I'm falling through the cracks.*
> Person aged 18-45 with medium level impairment, metro NSW

Those caring for family members with high levels of CP impairment also wanted more information relating to respite care and what was locally available.

Becoming a parent

For the participant who was a new mother, she would have welcomed practical information about the physical challenges of being a new parent with CP, e.g. bathing a newborn or changing a nappy. She was fearful that her impaired motor skills might mean she would drop her baby, so that she could not safely take care of him. She would have liked to have seen videos of other new parents with CP discussing the difficulties and making suggestions of how they've managed to take care of their baby.

> *Videos would be really helpful ... to see other mums with CP would be excellent. There's nothing out there from the other person's perspective, from right along the spectrum from mild to severe … Stories from other mums about pregnancy, how it did go from start to finish. In the hospital they were showing us how to bath him, I worried I'd never be able to do that and broke down in tears.*
> Person aged 18-45 with low level impairment, metro Queensland

Living dependently from parents

There are many aspects that need to come together to enable many people with CP to move into independent housing – and there is a lack of information and guidance on how to achieve this.

> *They need somewhere they can tap into to find this information – somewhere that's not biased by a service provider, accurate, up to date and current. I'm sick of hearing a good idea but you ring up – you're not in the right area, you're not the right classification, or that opportunity is no longer available, it was a pilot project. There are a whole lot of barriers.*
> Stakeholder

People are not only looking for information and support on how to get a suitable property for their needs, but also for information on how to put in place personal care, and to develop skills for independent living.

> *Some other things that would be good on the website would be housing or support to find housing… It's hard to get information on.*
> Person aged 46+ with medium level impairment, regional NSW

> *Sometimes I dive into it and I try to figure stuff out and then I leave it for a bit because it gets overwhelming or boring or seems like so much extra work. I just want someone to say it's worth going down a certain track, it's worth exploring certain parts of accommodation.*
> Person aged 18-45 with medium level impairment, regional Victoria

Several of the adults with CP who were either currently living independently or aspiring to live independently, spoke about the motor challenges of cooking, and specifically of cutting up food or opening food containers. They needed information on tools or assistive technology to help them and were conscious that this was a significant barrier.

> *I try and do things on my own but it would be better if there was more technology to help me … it makes my life a bit harder, especially in the kitchen, when I have to open jars and my hand strength isn't there.*

> *They need to start making more accessible stuff that can help people with a disability to be independent.*
> CALD person aged 18-45 with low level impairment, metro Victoria

They were looking for better information on which equipment they should use to help them with day to day life and where to buy it.

> *Even now I'm not too sure where to go for good equipment. I'm not able to go and try out stuff; I don't really know where to go … I can order online but I don't know whether it will suit me. How do I know if it'll work for me? …There's nothing like trying before you buy and knowing it suits your needs. We need like a really big warehouse where we can try stuff. Even like a seminar or exhibition for things that would be useful.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *The other thing, NDIS provides opportunity to purchase consumables, if I look at website, I have no idea… great if some sort of shop for those with CP – show the equipment that people with CP typically need. It can be overwhelming.*
> Person aged 18-45 with medium level impairment, metro NSW

A distinct aspect of independent living information is that adults with CP want to see peer examples that demonstrate the range of aspects of life that people with CP can engage in, and that their disability is not holding them back.

> *It would be awesome to have an individuals' story. It might make someone see they could go to uni or start working out in a gym.*
> Person aged 18-45 with medium level impairment, regional NSW

Educating employers

Adults with CP would like more information to be made available to employers to explain CP and how they can best employ people with CP. There is frustration with the common assumption that those with physical disabilities, also have intellectual disabilities, meaning that they are only put forward for low-skilled roles.

> *That whole employment situation … examples of how to employ people. I don't think employment services do a good job at all; they see someone with two degrees and intellectually capable, but they're used to putting someone on to a packing line. We have to look to ways to modify the workplace, incentivise, educate employers to enable employment to happen. Implement ways to ensure that employment is sustainable.*
> Person aged 18-45 with medium level impairment, metro NSW

> *Employment – if everything was in the one place, a one-stop shop to go to. Employment options, how to deal with employers once you do get a job, how to explain your disability [noting range]. It's hard to explain it to employers sometimes. Helping you to describe to them what it's like for you.*
> Person aged 18-45 with low level impairment, metro Queensland

Educating the wider world

Again, people with CP comment that there is a significant lack of understanding of CP among the general population that they come into contact with, and this ignorance negatively impacts on their daily life.

> *The main impact of CP on life as a student is the lack of awareness among students and lecturers. They don't really know how to accommodate me. That's really important. Even in my lab, I'm often not really included … but [my colleague] really stood up for me, she really wanted me to have a go. She also had a disability and I think she understood that it's really important for me to have a go. Her belief in me really changed a lot in the labs and I'm so grateful for her.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *With kids as well, they were quite often confused, especially the little kids. I quite often almost wished that I had a sign on my shirt saying 'I have cerebral palsy, that's why I've got these splints on my legs'.*
> Person aged 18-45 with low level impairment, regional SA

A distinct aspect of how people with CP engage with the wider world relates to advocacy, and several of the adults spoke about wanting to engage more in advocacy and felt that information on how to do so needed to be more readily available.

> *Access to links about disability advocacy, that's an area in general life that's really missing, not much representation in parliament, not much talk about ableism. That's one of the reasons that I'm studying what I'm studying – very keen to speak up about this issue.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

> *More information on advocating for yourself as a person with a disability, because I know even just for myself especially when I was younger, it's hard to speak up and you don't want to make yourself feel othered.*
> Person aged 18-45 with low level impairment, metro Queensland

Relationships

As with other life stages, those aged 18-45 have unmet information needs in relation to personal relationships. Some individuals expressed interest in being part of a mentoring or 'buddy' scheme, where they can meet and get advice from an older person with CP who has faced similar challenges as they have.

> *I'm lucky to the extent that I have a good mentor with a similar type of disability … I can go to them for advice, but I think a really good mentoring program would be nice, or even like friends. Like a buddy program where you mentor someone who has gone through the same thing as you.*
> CALD person aged 18-45 with low level impairment, metro Victoria

Others are looking for more support and information on meeting and making friends with people with similar CP diagnoses and widening their social network.

Sometimes it's difficult to talk to friends about having a disability. If there is a group that you could contact that would be great. They'd offer you support. Just being able to talk and run through day-to-day troubles if you have any. Someone to have a vent to, people who don't have a disability sometimes don't understand your daily struggles.
Person aged 18-45 with low level impairment, metro Queensland

But for me in my twenties, a social aspect to it, a forum, other young people, where you're from and have a meet-up group, because it's CP, not just disability – that would be helpful.
Person aged 18-45 with medium level impairment, regional NSW

At least for myself it feels a bit lonely. I have a struggle where I'm obviously quite independent, but CP is such a spectrum, I wonder which category I'm in? Am I in the 'normal people' category? Making an online support network where you can make connections with other people like me who need support but can live a functional life.
Aboriginal person aged 18-45 with medium level impairment, regional Queensland

A few participants also spoke directly about appreciating more information or opportunity to date and develop intimate relationships.

8.4 Current information sources and formats

People in this life stage are searching for information less intensively than their parents were in earlier years. They refer generally to using the internet and googling, and many make use of the CPA website or call CPSN or CPL.

I'm fairly computer savvy and I know where to search for stuff if I need to. The main page for me is the Cerebral Palsy Alliance.
Person aged 46+ with medium level impairment, regional NSW

Some of CPSN's staff have lived experience, like they have CP themselves or have family members with CP, so they understand where it's coming from and tend to use some of the resources themselves. So that's helpful.
Person aged 18-45 with medium level impairment, regional Victoria

In terms of CP related information, since I turned 18 and left Royal Children's, I've not accessed any specific CP information … I've been in a regional area, there's a lack of info … and you kind of figure it out for yourself.
Person aged 18-45 with medium level impairment, regional NSW

CP Alliance website coupled with government websites. They're the ones I trust. CPA has been around some time – trustworthy, anything else I'm a bit sceptical of. Since Gov established NDIS – a lot of providers out there – hard to see who you can trust, if stumble across a website, is that a source of truth?
CALD carer of person aged 18-45 with high level impairment, metro NSW

A participant commented that the algorithms within Google, mean that by searching for CP related information, they are constantly prompted with other disability related material which can be depressing.

> *Google can be overwhelming. I may have liked a disability page … I was doing NDIS searches too. When you're on social media, you don't always want to be reminded about what you have, don't want constant reminder of your conditions.*
> Person aged 18-45 with medium level impairment, metro NSW

As found in earlier life stages, those using Facebook groups find them useful, but also frustrating as recommendations may come from international group members which are potentially not relevant, or available, in Australia.

> *Local Facebook group meets my needs 100%.*
> Person aged 18-45 with low level impairment, metro Queensland

> *There's a lot of very good Facebook groups. I mean the ones for Cerebral Palsy which are specific ones are international which sometimes can be a bit frustrating because you'll get all the Americans responding and you have to respond 'I'm in Australia' … someone was like, 'You can use this app' and I'm like, 'This is a US based app' and I'm Australian so I'm not going to use an American app.*
> Person aged 18-45 with medium level impairment, regional Victoria

There is also frustration that service and support suppliers are members of these groups, offering their services, when adults with CP are actually looking for discussions and recommendations from peers. That said, there are also limitations to information gained from peers, with the awareness that their knowledge may not be current or relevant.

> *Peer support is really fantastic, but sometimes you need an answer that is correct rather than someone's opinion.*
> Person aged 18-45 with medium level impairment, regional Victoria

> *It would be beneficial if there was a more active community to go to and trust, and share, carers, people with CP themselves… useful and interesting. Then you could borrow ideas, behavioural management for example, synonymous with parent blogs.*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

> *A lot of information has become attached to service providers which they deliver with their own slant.*
> Stakeholder

The NDIS is also a current source of information, however, as mentioned previously people find it very hard to navigate, slow to respond and, depending on who you contact, inconsistent.

> *And thought should be given to what info is NOT provided, [and consider] to what extent will this link to NDIS information, the NDIS changes its rules as often as I change shirts [therefore risks dating very quickly], so need to define boundaries.*
> Stakeholder

For younger adults learning about their condition and support needs, the NDIS is a very steep learning curve.

In relation to housing and independent living, adults are making use of information from the Summer Foundation and 'Way Home'.

One participant had attended a Disability Support Expo and found this an extremely helpful process. Being able to attend in person and hold multiple conversations with multiple providers allowed her to better navigate what was available and determine what best met her needs. She felt a future CP portal should incorporate an online version of this expo, within the site.

> *What really changed that was the Disability Support Expo … I got to actually talk to people, found out a disability support coordinator was a thing. Being able to go to booths and talk to people and find out what you could do was so helpful … being able to go to virtual booths and get an overview rather than clicking out to their specific site*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

Some participants with other conditions, in addition to CP, reflected that other health areas are better at communicating the impact of the condition and how to manage it.

> *Mental health does information much, much better. It's written out, explained, practitioners spend time spelling out how you can manage, and how you can cope. This is what your experience is likely to be this is how you manage it ... Every other condition I have has been easier to find info, with CP it's more 'could be…' and it's the broad spectrum.*
> Person aged 18-45 with medium level impairment, metro NSW

8.5 Preferred information sources and formats

Social media

Social media preferences vary, as per other life stages, with some finding it a useful source and others less so, but it is also apparent across this life stage that there is divergence on preferred social media platforms, with older people making greater use of Facebook and those under thirty more likely to use Instagram.

> *I'm not on Facebook, I'm more on Instagram ... I think Instagram is a really good creativity outlet, that's what I use it for.*
> CALD person aged 18-45 with low level impairment, metro Victoria

> *Instagram … Facebook is dead.*
> Person aged 18-45 with medium level impairment, regional NSW

Some recommended Facebook groups including 'Disability Melbourne East' and 'Accessible Melbourne'.

One comprehensive portal

As mentioned by those in other life stages, there is a wish for their breadth of information needs to be brought together in one place, with strong navigation, focused around life stages and search functions.

> *I get services, as I said, through the NDIS. So, if you go onto a central website and just say that you needed speech therapy, or you needed a support group, you could just go onto the website and just find what you need. So, you could have all of the sources in the one spot.*
> Person aged 46+ with medium level impairment, regional NSW

> *A one stop place where you could get all the information you needed – that would be the best thing. You wouldn't get frustrated going to multiple agencies, multiple groups or people. You'd only have to tell your story once and get all the information around that from the one place.*
> Person aged 18-45 with low level impairment, metro Queensland

> *I like the idea of being able to go to one place and at least be pointed in the right direction. I see that as a support coordinator role, even if you don't have your own support coordinator.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

> *All about having a well set-up search function, as long as you can bypass the subcategories with a search. Very accurate and intuitive search function.*
> Aboriginal person aged 18-45 with medium level impairment, regional Queensland

> *Australians are desperate for good quality health information - they google and go offshore. They weren't being pointed to anything reputable that is produced by Australians … Core, foundational information. It makes sense to me that you'd have a generic disability gateway.*
> Stakeholder

Participants spoke about a single portal being interactive, with a streamlined process to help people navigate the content. They also suggested that the site should make use of voice activation for ease of use, and all written content must be in plain English.

Design and assistive technology

Adults spoke of the challenges of some websites, i.e. the motor skills required to accurately click small boxes with a mouse or use small menu bars. They preferred layouts that work well with a screen reader and are compatible with speech recognition programs like Dragon.

> *Some people absorb complex information differently, for some video is great, but others might have a huge appetite for information so long as they can convert it from text to voice on the iPad; literacy can be low but comprehension ability can be high, may not be able to turn page, but can read online. Once you have material in digital form [that] can converted to lots of different formats.*
> Stakeholder

Tinder style app

To address the need to meet others with similar lived experience, there is interest in an app that could link people in their local area. Current social networks are either felt to be small or are among friends who don't understand what life is like with CP.

> *I do like that idea, there needs to be connection. I have lots of friends, but they don't know what it's like. That's why I started my blog. For mental illness – I have a group that I connect with, but they don't understand the other conditions I have. Mental illness and CP are common to go together but there isn't that avenue to connect and support one another – especially for those who have mild CP.*
> Person aged 18-45 with medium level impairment, metro NSW

Videos

Adults with CP are looking for concise online content, making use of video and first-hand accounts by peers, and only limited textual content.

> *[You want] really good, easy to understand videos, documents, and not find information here and land on a twenty-five page pdf. Information presented by people with CP, coming from a familiar place, empathy.*
> Person aged 18-45 with medium level impairment, regional NSW

> *The NDIS websites … to get the information you need to download the word document or pdf, and I find that not great. I want it to be a lot more easy, a lot more immediate.*
> Stakeholder

This age group also referenced making use of video conferencing technology, like Zoom, as a mean of making better social connections.

Videos would also meet the needs of older CALD carers who have lower levels of literacy.

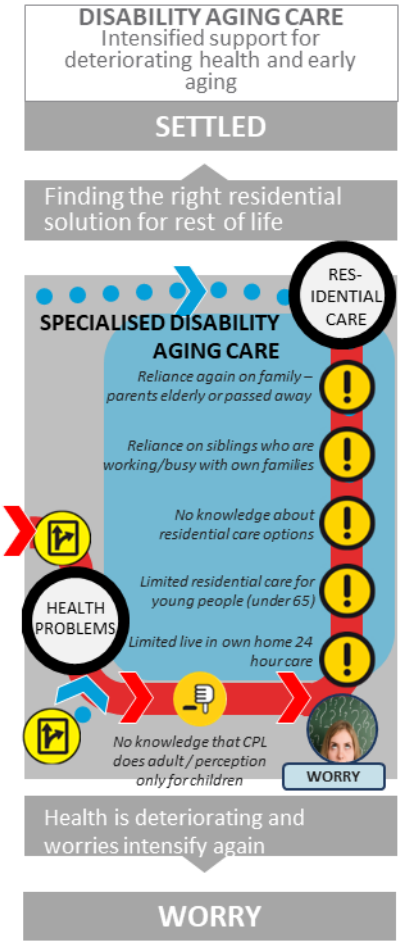
> *Not just language [barrier for parent carer] but if you told her to read a factsheet in translated Chinese, she'd still struggle ... If she had someone speaking to her in language would be better. That's the case for numerous other carers in my mum's position.*
> CALD carer of person aged 18-45 with high level impairment, metro NSW

Helpline

While a minority like making use of a chatbot, most adults with CP preferred dealing with a real person, preferably with some lived experience of CP.

9 Disability aging care – aged 46+

9.1 Life stage context



The older adults who participated in this research had very varied experiences of life (and consequently information and support needs) depending on their levels of impairment and their age. For those who were settled in their home or residential facility and in a routine, this tended to be the most stable period of life.

However, older people with CP and their families had concerns about aging and what the future would look like as both them and their support network became frailer and encountered health issues associated with getting old. Fear of isolation, especially contemplating the likelihood of families changing, and older family members dying, was top of mind for older participants.

> *Getting up is [hard] agony, toes… feet…. Doing up buttons take a long time… At our age, cerebral palsy makes you do things very slowly, get very frustrated.*
> Person aged 46+ with medium level impairment, metro Victoria

9.2 Key challenges for this life stage

General wear and tear of aging

Many of the participants, including those at the younger end of this age group, described how they had noticed some physical decline in their bodies in recent years.

> *[He] can walk but is losing that ability. He recently got a walker … he's got a bit of mobility. If dementia sets in, that could be an issue. They [the accommodation service] are confident in looking after him [as he ages].*
> Carer of person aged 46+ with high level impairment, metro Victoria

> *As I've gotten older more day to day pain, sore joints, in knees a bit more painful, exacerbated by not being as active. Used to walk around a lot, now not really walking so much.*
> Person aged 46+ with low level impairment, metro NSW

> *As you get older things break down, but I keep myself relatively active … [physio] we don't automatically get it, we have to source it … either in house or outside, we have the choice.*
> CALD person aged 46+ with medium level impairment, metro WA

> *We know that although it's non-progressive or a non-degenerative condition that that doesn't mean that there isn't deterioration that isn't significant compared to others at the same age who do not have CP.*
> Stakeholder

Family members and carers are also aging and the physical demands of caring for an adult family member with a physical disability was very tiring for them, and something that was an increasing struggle.

> *He's a real handful for us. I'm physically wrecked whenever he comes over, by the time you get him up out of bed and showered and fed. We're finding it more difficult as we get older.*
> Carer of person aged 46+ with high level impairment, metro Victoria

Those with lower levels of impairment and a relatively stable health situation had tended to reduce their interaction with therapists with some doing little to actively manage their CP. They were responding to their condition as it evolved, and several reflected that they would have benefitted from doing more in their thirties or forties to maintain their strength and mobility through therapy.

> *Growing up I had a lot of operations on my legs from the age of five to sixteen, corrective surgery on my legs and feet. But the physio, I haven't had that for a long period of time. I just manage for myself and work out what I can do, and I can't do.*
> Person aged 46+ with medium level impairment, regional SA

> *When you have cerebral palsy as a child they give you intense physiotherapy because they're trying to work with your body as it grows… you get to the end of adolescence and the attitude is kinda 'we've done all you can', but the truth is you can keep working on keeping things strong. For 25 years I didn't see a specialist or anything, all that happened in that time are muscles got weaker and weaker until I was unable to walk unassisted, but it's something that could have been halted ... I pushed and pushed and pushed to find somebody because I thought 'I'm not going down without a fight!'.*
> Person aged 46+ with medium level impairment, regional Victoria

Some also reduced therapies because of financial pressure.

> *Income security is an issue … it gets harder and harder to get the disability support pension. So being able to afford housing, and things like shoes, go to the pool three times a week, with a taxi. It [gets] harder. And it's more expensive to be healthier. That's something people worry about.*
> Stakeholder

Others may have reduced their frequency of therapies in response to their childhood experience.

> *There's a big focus on getting young kids to walk … some can walk, but others can't, and some kind of feel pressured by parents and therapists to be more 'normal'. It can be scarring; not living up to those expectations.*
> Stakeholder

Isolation

Some older participants with CP reported feeling increasingly isolated as they were getting older. They were losing contact with some of their social network and their increasing health issues meant they were being less mobile, which was reducing the social interactions. While there may be social interaction with support service workers, there is a lack of independent friendships.

> *Lots of friends of mum and dad's they met when Colin was young at Spastics centre, they met frequently, socially, BBQs and things. We don't know any other families now – maybe we could reach out to an organisation like Scope and get put in touch with other families.*
> Carer of person aged 46+ with high level impairment, metro Victoria

> *Parents often give that support, so it can mean there's a lack of wider social support. They might be friends with the paid support running the programs they go to, but that's more of a co-relationship, with boundary issues. It's less of an organic kind of friendship. There's a lack of mainstream opportunities to have as many friends as they'd like.*
> Stakeholder

For others, a sense of isolation was a theme that had continued throughout life. Several of this older generation spoke about never having known another person with CP, or CP type like theirs.

> *I wished I knew other people who had it. It's a fairly common disability, to be able to talk to other people, I wished I had been able to talk to people about issues they'd had. A guy approached me on the train and provided advice about shoes, connections with someone else is nice.*
> Person aged 46+ with low level impairment, metro NSW

> *I feel a little bit on the outer, there isn't that outlet for someone in my situation, I know there must be lots of other people out there, [who] would benefit from the emotional support.*
> Person aged 46+ with low level impairment, metro NSW

Intergenerational transition of support, care, and responsibility

For older people with CP, there is a recognition of the value that family can bring in providing ongoing support and help with access to information and resources.

> *Family, if you have a family, your children can help you, [can help you use the] computer more.*
> Person aged 46+ with medium level impairment, metro Victoria

> *We have no family backup and no friends, it's very hard.*
> Person aged 46+ with medium level impairment, metro Victoria

For those caring for an older person with CP, there is an increasing awareness of the passage of time and the need to give full consideration to who will continue in a caring role if they pre-decease their family member with CP. As a sibling, they inherited their caring responsibility from their parents on

their death, but do not wish to pass this responsibility on to their own children. That said, they were delaying putting in place the necessary legal safeguards because of the sombre nature of the process.

> *We don't want to wish him away first but might be easier [if he dies first in terms of looking after brother with CP and addressing his needs] … It would be too much for our children to look after him, they won't take over as guardians … My wife and I are trying to ignore it, we're getting older, we haven't really addressed the question. We need to sort out powers of attorney, how we'd hand over the care, probably to the State Trustees, we need to address it, but we haven't.*
> Carer of person aged 46+ with high level impairment, metro Victoria

9.3 Information needs

In terms of information, a key frustration for this age group was that the available information relating to CP felt as if it was aimed at parents of children with CP and younger adults. As a consequence, older adults felt left out. If things were going well, however, information needs were very low.

> *No, I haven't [read up on information about CP and getting older] … I just take it day by day, whatever happens, happens. If something comes up, but otherwise I'm not going to worry. The GPs [have] not raised it.*
> Person aged 46+ with medium level impairment, regional SA

> *Knowing [my brother] and people he's [living] with – they're so different, general information can't be useful. Information about [suitable options for] holidays perhaps?*
> Carer of person aged 46+ with high level impairment, metro Victoria.

General advice on ageing with CP

Older adults are aware that they know little about the impact of ageing on CP, and vice versa. When prompted, they acknowledged that more information would be valuable.

> *Then the maturer adult, it's about ageing well, maintaining function and mobility ... You don't see a lot promoting older people to age well when they have a disability.*
> Stakeholder

They are aware of their increasing health-related issues but don't disaggregate these from the general ageing process. They would welcome greater information about how the ageing process impacts CP and learn about ways in which others have managed changes in their condition. While they recognise some good sources, they are critical that little is focused on their age group.

> *I'd like to know how other people manage; people have families that back them up.*
> Person aged 46+ with medium level impairment, metro Victoria

> *Cerebral Palsy Alliance send out a weekly thing of medical papers, I look through and see if there's anything relevant, mostly there isn't because 99.9% is for kids, research of kids … It's interesting, but nothing I could actually use.*
> Person aged 46+ with medium level impairment, regional Victoria

> *We would like to know what research there is happening, when you get to our age, what's going to happen to our ageing, and we don't know how bad we will get, nobody can tell us how bad we'll get.*
> Person aged 46+ with medium level impairment, metro Victoria

There is interest in advice on functional ways to keeping active and sustaining their optimal health, through exercise and therapies.

> *One obvious way is group fitness. There's a lot of research I now know from CPA that exercise is really beneficial and important. I respond very well to physical treatment, osteopathy, gym. Doing that in a group environment with other people with CP. Doing exercises together, could be an online chat group, in person chat group.*
> Person aged 46+ with low level impairment, metro NSW

> *If somebody could have told me, I thought it was natural progression, but with CP you use your body incorrectly because you can't use it the way you're supposed to. Certain muscles don't get used so they get weaker, so [during] my rehab we do a lot of strengthening work, but if I'd known, I'd have started it ten years earlier and I wouldn't have declined as much as I have – but nobody ever said that to me… I just thought it was the natural progression, but it didn't have to be like that.*
> Person aged 46+ with medium level impairment, regional Victoria

NDIS funding

As with other life stages, there is a need for easier navigation and access to NDIS related information, and greater clarity and consistency about what can and cannot be funded using NDIS money. This is an area where peer advice is frequently valued above 'official' guidance.

> *[I only] thought about NDIS because I met someone from Ability Links … I rang them, they said I should apply, it never occurred to me that was something I could do. But I was incurring increased health costs … shoes getting expensive. I was trying to find out information about what it can do for me. I had to keep asking that question, it was incredibly hard. I would talk to the call centre at different times and were told different answers. There aren't absolute answers and it just depends on who you speak to on the day … all the good information on the NDIS comes from other people in the community, not the NDIS … [The challenge is] knowing where to get information about the NDIS that's CP specific.*
> Person aged 46+ with low level impairment, metro NSW

Legal advice

For carers making end-of-life plans, putting in place appropriate legal structures to protect their family member with CP in the event of the carer's death, there is a need for comprehensive information on what is required. Clear guidance on the range of protections recommended and the route to do so would be valuable.

> *[Where would you go for info?] our solicitor for legal, for other things, probably Scope and the State Trustees to find out what can be done? These days you google. Probably have to sit down with someone*

and figure out best course of action.
Carer of person aged 46+ with high level impairment, metro Victoria

Information for the rest of society

Those with medium or high levels of impairment were less likely to comment that they needed information, but that the rest of society needed information about CP. Their lived experience would be improved by greater understanding of CP among the general population and patience when they are communicating.

The area that is missing is parental education outside the disability area … because we don't mind people asking us questions, but it's often the parents that say, 'Oh don't, leave alone' and we don't mind inquisitive kids … otherwise we get treated as some sort of old git and not part of the community. We don't want the next generation to look at us and think we're some sort [of] creature out of no-where, so I'd rather people ask me questions. If you have a greater understanding, you'll be more accepting.
CALD person aged 46+ with medium level impairment, metro WA

I don't like communicating with people. We tried going to things … but [our] CP … makes it very hard … people can't understand me often.
Person aged 46+ with medium level impairment, metro Victoria.

9.4 Current information sources and formats

Those older adults with CP living independently were only tending to seek out information directly in response to a specific physical need or change in their condition. They were not proactively seeking out information about their condition, the impact of ageing or available therapies, despite articulating that they would like to know more.

They were less likely than other life stages to have an ongoing relationship with a physio or therapist, so their GPs was frequently a starting point.

CP organisations

In order to access resources via NDIS funding, older adults were making use of information and guidance from organisations such as CPSN, Scope and Cerebral Palsy Alliance. These were also useful sources for practical information.

I've come across an organisation called the Cerebral Palsy Alliance on Facebook actually … pretty good, pretty interesting to read … I found out about the disabled parking permit, which is a big thing.
Person aged 46+ with medium level impairment, regional SA

Residential facilities

For a carer of an older person with CP living in residential care, the care provider was the main source of information about their sibling's condition and needs. They attended regular meetings with the care provider and had a relatively strong and trusting relationship with them. They were comfortable that the care provider was best placed to advise on their sibling's care and did not proactively seek out further information.

> *I don't get anything [information / support] other than from Scope. Recently, since the pandemic, there's been more communication … newsletters and how they're coping with the virus, not an awful lot else.*
> Carer of person aged 46+ with high level impairment, metro Victoria

> *We catch up with other house residents' guardians when we can … we talk about any problems that crop up. Officially catch up every couple of months, but whenever things crop up, might chat if we bumped into them [when visiting their relatives]. Every few months, we meet with the house coordinator – they'd run the show, bring people in from the Scope region, a group called housing choices – someone from there would talk to us… most people [were] happy with how residents were going.*
> Carer of person aged 46+ with high level impairment, metro Victoria

9.5 Preferred information sources and formats

Peer and social support

Being able to connect with others living with CP was cited as important for most of these participants. While most of the older people who contributed were not relying on peers as sources of information per se, the common ground shared and ability to (continue to) share anecdotes and advice of what 'worked' for them was highly desired.

> *I'd like to have access to some of these things … information, chatting online to other people in similar situations, expanding my access to ways of getting support and information and talking to other people, feeling less on the outer.*
> Person aged 46+ with low level impairment, metro NSW

> *Community – would be really amazing to build a community around that information hub, similar to the community NDIS groups, for people with CP to have a chance to talk to each other, being able to share info – not just a site, community around it. I'm amazed at how good the NDIS grassroots groups are, incredible, speed they move at … people find NDIS so overwhelming, would be good to peer up and get support through the process, someone on the NDIS could talk about how they're using different categories of funding to get support*
> Person, aged 46+ with low level impairment, metro NSW

> *[Medical professional] tried to understand what [CP] is, but they fall short. They understand a little part of it, but they only take ten minutes. They can't realise how frustrated you get. I get so upset … They look horrified when you explain [how you feel] … I want to sit down with a real person…. [get support to] make you part of the conversation, a good conversation.*
> Person aged 46+ with medium level impairment, metro Victoria

> *People with CP, we don't care about the stats, we don't want to know about the medical, or sad, demographics … maybe for parents. Adults with CP would much rather hear from peers – you don't always want to see inspirational people.*
> Stakeholders

Easily referenced written communication (online and hard copy)

Reflecting the wide age range of this group and different levels of technological comfort, there was varied interest in different formats. While most were comfortable searching for information online, there was a stronger preference in this cohort for written communication over other formats that seemed less tangible.

> *[I like to] Read on screen. Read and read, over again if you want to... read online, and print if I wanted, [I like to] print things, want hard copy and remember what it said. Videos you can [watch them] but can't print.*
> Person aged 46+ with medium level impairment, metro Victoria

Some told us about Facebook groups they were part of, or consulted from time to time, but this was less common than amongst the younger participants.

10 Appendices

10.1 Primary audience recruitment screener

Job No.	20-041283-01
Job Name	National Cerebral Palsy Information Program research
Job owner	Jessica Elgood, Florence Le Guyader and Jen Brook
Version	1

General notes

This screener is designed to identify IDI leads that Ipsos will then follow-up:

- Recruit n=40 participants for whole project, but this also includes those we'll recruit via the client sample.
- Participant leads can include people with Cerebral Palsy, their parent or their carer. All are eligible.
- All ages, locations and impairment levels are eligible.
- In-depth interviews will run c.1 hours
- **Incentives will be $100 per person**, with an optional **additional $30** for those who undertake the video pre-task. (We will be covering additional costs for the use of support worker, interpreter, child minder or speech pathologist, if necessary).
- With participants' permission, the in-depth interviews will be audio recorded
- The discussion will be about Cerebral Palsy related information needs and experiences at key life stages.
- The majority of interviews will be conducted by telephone – however, there is scope to conduct some in-person interviews for participants located in metro Sydney, Melbourne and Brisbane (Covid-allowing).

Screener

Hi, this is [NAME] calling from [IPSOS/RECRUITER], can I please speak with [INSERT NAME]?

We are currently undertaking a research project for a range of organisations that work with people who have Cerebral Palsy. The organisations are Cerebral Palsy Australia, Ability First Australia, Cerebral Palsy Alliance and the Cerebral Palsy Support Network.

They have asked us to research the information needs of people with cerebral palsy, their parents and carers – and the findings will be used to inform the development of a National Cerebral Palsy Information Program. This program aims to ensure there is high quality information available to people with cerebral palsy, their families and carers.

[IF RECRUITING IN REGIONAL/RURAL]: These interviews will be conducted by phone, or if you prefer, by video conferencing (e.g. Zoom, Teams, Skype).

[IF RECRUITING IN METRO]: These interviews will be conducted either by phone or in-person.

It will involve an informal discussion with a researcher for around an hour. The discussion is confidential, and your responses will remain anonymous. We hope you will find it interesting.

Those who take part will be given a $100 [EFTPOS FROM IPSOS/ E-GIFT VOUCHER FROM THN] to thank them for their time. Are you interested in participating?

[IF YES, CONTINUE]: I just have some questions for you, to make sure that you qualify, as we need to speak to a good cross section of people as part of the research.

[IF QUERIED ABOUT BONA FIDES OF RESEARCH] I can provide the names of people who will verify the legitimate nature of this research project.

- The first is the Australian Market and Social Research Society enquiry line on 1300 364 830, who can verify that we are a legitimate market and social research company.
- The second is the research project manager, Jess Elgood at Ipsos, the organisation managing this research project, who can discuss the specifics of this research. Her phone number is 0431 656217.

[IF ANY CONCERNS ABOUT THE PROJECT OR WANT TO KNOW MORE] If you would like to know more about the purpose of this research, I can ask Michael Bink, from Ability First Australia, to get in touch.

[ONLY IF NECESSARY]: This is strictly SOCIAL research. Your responses will remain completely confidential. We are not promoting or selling anything. If you would like to verify the validity of this research you can call the Australian Market and Social Research Society's survey line on 1300 364 830).

[If not available, arrange time to call back to speak with them, or **TERMINATE**]

RECRUITER NOTE: PLEASE REMIND INDIVIDUALS THAT THE INFORMATION THEY PROVIDE IS TOTALLY CONFIDENTIAL AND WILL ONLY BE USED TO DETERMINE THEIR SUITABILITY TO PARTICIPATE. IT MAY BE NECESSARY TO REMIND POTENTIAL PARTICIPANTS OF THIS AT SOME OF THE MORE SENSITIVE QUESTIONS.

1. For this project we need to talk to people with Cerebral Palsy, their parents and their carers. Do you have Cerebral Palsy, or are you the parent or carer of someone with Cerebral Palsy?

Yes, I have CP	1	**CONTINUE**
Yes, I have a child with CP	2	**CONTINUE**
Yes, I care for someone with CP	3	**CONTINUE**
No	4	**TERMINATE**

2. We need to get a mixture of people for this study, so I'd like to ask a couple of questions about [PARTICIPANT/FAMILY MEMBER WITH CP]. What is [YOUR/YOUR FAMILY MEMBER'S] age?

Aged 0-6	1	**CONTINUE**
Aged 7-17	2	**CONTINUE**
Aged 18-30	3	**CONTINUE**
Aged 31-45	4	**CONTINUE**
Aged 46-65	5	**CONTINUE**
Aged 66+	6	**CONTINUE**

We're keen to speak to people with a range of differing impairment levels. I'm going to ask a couple of questions that are aimed at trying to identify this mixture of people with Cerebral Palsy. Firstly …

	Not at all	**Sometimes**	**All the time**
3. Do [PARTICIPANT/FAMILY MEMBER WITH CP] require support, devices or aids to be understood when communicating?	1	2	3
4. ASK ONLY OF PARENT/CARER. Does the person you support or care for require any communication devices or aids or assistance to understand people communicating with them?	0	0	0
5. Do [PARTICIPANT/FAMILY MEMBER WITH CP] require any assistance or use any equipment to be mobile such as a walking stick, wheelchair, walker or scooter?	1	2	3
6. Do [PARTICIPANT/FAMILY MEMBER WITH CP] require any assistance, support or services to undertake daily life such as getting ready for the day, preparing meals, housework, accessing the community or getting around?	1	2	3
TOTAL	=		

CODE TOTAL BELOW

High (score of 7-9)	1	**CONTINUE**
Medium (score of 4-6)	2	**CONTINUE**
Low (score of 0-3)	3	**CONTINUE**
Prefer not to say	4	**TERMINATE**

7. Is any language other than English spoken in your household?

Yes	1	**CONTINUE**
No	2	**CONTINUE**

8. Are you of Aboriginal and/or Torres Strait Islander origin?

Yes, Aboriginal	1	**CONTINUE**
Yes, Torres Strait Islander	2	**CONTINUE**
Yes, both Aboriginal and Torres Strait Islander	3	**CONTINUE**
No, none of these	4	**CONTINUE**

9. In which town or suburb do you currently live?

Town or suburb:

.....

State:

.....

Postcode:

.....

CODE AS METRO OR REGIONAL/RURAL

Metro	1	
Regional/rural	2	

[IF QUALIFIES, CONTINUE]

To recap …

- This research involves participating in a one-hour telephone/in-person interview.
- An incentive of a $100 will be offered to everyone that participates.
- To assist the researchers in their analysis and report the interview may be audio recorded. All information gathered during the discussion is used for research and training purposes only, unless stated otherwise.

  Are you still happy to participate in this research?

No	1	**TERMINATE**
Yes	2	**CONTINUE**

IF NO è

- **DISCONTINUE WITH THANKS**
- **[TERMINATION SCRIPT]** Thank you for your interest in participating in this research, unfortunately you are not eligible for this particular study.

IF YES ➔

Thank you so much for your interest in participating in this research. We'll now pass your contact details to our colleagues at Ipsos who'll be back in touch sometime over the course of the next week or so, to let you know whether or not they'd like to arrange an interview.

Do you have an email address and phone number that we can use for future contact?

Respondent name:

.....

Email:

.....

Phone:

.....

THANK YOU VERY MUCH FOR YOUR ASSISTANCE WITH THIS PROJECT

Just to remind you, I'm [INSERT NAME], on behalf of Ipsos. In accordance with Privacy Principles, your responses to the questions will remain anonymous. In case I need to check something with you, can I just confirm your name, telephone number, etc.?

Respondent name:

Telephone number:

Email:

Postal address:

Postcode:

Date of interview:

Time of interview:

I certify that this is a true, accurate and complete interview, conducted in accordance with IQCA standards and the ICC/ESOMAR International Code of conduct. I will not disclose to any other person the content of this questionnaire or any other information relating to this project. Signed as a true and accurate interview in accordance with all briefing instructions:

Interviewer name and number:

Signed:

Date:

10.2 Primary audience achieved sample

	METRO/NON-METRO		STATE/TERRITORY					
	Metro	Regional/ rural	New South Wales/ACT	Victoria	Queensland	Western Australia	SA/NT/ Tasmania	TOTAL
AGE OF PERSON WITH CEREBRAL PALSY								
Aged 0-5	8	3	3	4	1	0	3	11
Aged 6-17	6	4	6	1	2	1	0	10
Aged 18-45	6	4	4	2	3	0	1	10
Aged 46+	4	5	3	3	1	1	1	9
LEVEL OF IMPAIRMENT								
High (7-9)	9	3	5	4	1	1	1	12
Medium (4-6)	8	8	6	3	4	1	2	16
Low (0-3)	7	5	5	3	2	0	2	12
CULTURALLY AND LINGUISTICALLY DIVERSE								
	6	1	2	2	1	1	1	7
ABORIGINAL AND TORRES STRAIT ISLANDER								
	0	2	1	0	1	0	0	2
	24	16	16	10	7	2	5	40

10.3 Primary audience discussion guide

Briefing information

The handling of a moderation guide

As an open method of exploration, in-depth interviews are not completely standardised. Listing of relevant questions in the interview guide covers relevant subjects and leaves enough space for discussion in the sense of an open approach. The questions mentioned below are not necessarily meant to be literally asked. Likewise, the order must not be strictly followed. In this sense phrased questions describe the different subject areas and are meant to control the discussion process. Each subject area is firstly explored openly. Then more detailed probing by the interviewer follows, with regard to subjects that were not spontaneously mentioned by the participant, but that are relevant.

Study objectives

OBJECTIVES:

Reminder to moderator: The key objectives are to explore:

- *Life stages/transition points for people with cerebral palsy and, where relevant, parents and carers, to explore experiences and needs at key stages and transitional points to help us understand information needs in relation to these.*
- *Understanding which institutions, services and people are important at these stages, and the types of information that would most assist them to deliver better outcomes for people with cerebral palsy, their parents and carers.*
- *Current sources of information*
    - *What information are they finding?*
    - *Where are they sourcing it?*
    - *What do they think is useful/not useful, helpful/harmful, good/bad?*
- *Preferred communication channels and current experiences, e.g. usage of technology, barriers and enablers such as access to devices, adequacy of internet, how they would like to get information.*

***Note to moderators:** keep a digital focus throughout, understanding/exploring how perceptions, needs and expectations may map to a digital solution.*

Introduction to the interview

5 minutes

- Thank you for taking the time to participate in this important project; your contribution is greatly appreciated.
- My name is …. I work for Ipsos, and we are an independent social research company.
- This project is being undertaken for a consortium of organisations; Cerebral Palsy Australia, Ability First Australia, Cerebral Palsy Alliance and Cerebral Palsy Support Network.
- The findings from this research will inform the development of a consolidated national platform for information for people with cerebral palsy, their families, support providers, key NDIS roles, the community and mainstream services.
- This discussion will take around an hour. Your contribution is anonymous and the final report will show the combined responses of all the different people we speak with.
- And you'll receive $100 by EFTPOS/e-gift transfer to thank you for your time. [IF APPROPRIATE MENTION 1) COVERAGE OF OTHER ASSOCIATED COSTS AND 2) $30 PRE-TASK ADDITIONAL INCENTIVE]
- EXPLICIT PERMISSION FOR AUDIO/VIDEO RECORDING, AS APPROPRIATE.
  - The recordings will be listened to by members of the Ipsos project team;
  - The recordings will be stored securely for up to two years and then destroyed.

Background

5 minutes

- IF UNDERTOOK PRE-TASK, ACKNOWLEDGE , BRIEFLY DISCUSS AND RECAP PERSONAL DETAILS.
- IF DIDN'T UNDERTAKE PRE-TASK
  - Can we start with you telling me a bit about yourself/about [NAME OF FAMILY MEMBER WITH CP]? ESTABLISH AGE, LEVEL OF IMPAIRMENT, LIFE STAGE, LIFE STYLE.

Understanding key transition points

10-15 minutes

- We're aware that there's a huge amount that you can tell us about the needs of people with cerebral palsy, and how this can help this research project. But in order to make the most of the time we have talking with you, I'd like to start by thinking about your current stage of life. AS APPROPRIATE, REFERENCE MOST RECENT TRANSITION POINT:
  - DIAGNOSIS
  - PRE-SCHOOL, CHILD-CARE
  - PRIMARY EDUCATION
  - SECONDARY EDUCATION
  - TERTIARY EDUCATION
  - EMPLOYMENT
  - INDEPENDENT LIVING
  - OLDER AGE

- Thinking about [RECENT TRANSITION POINT], what are the issues or 'hot topics' that you are dealing with, or have recently had to deal with, in relation to your/family member's CP?
- Who's been involved, or supported you, as you've dealt with these issues? Which services or organisations?
- What helps these services/organisations work well together to support you, parents or carers negotiate this stage of life?
- And what caused problems with how well everyone worked together?
- Looking back, what needs to be improved to help other people with CP when they're approaching this life stage?

Sources of support and information

20-30 minutes

- Thinking again about [RECENT TRANSITION POINT], can you give me some examples of the range of information you were looking for at that time?
- And what different sources of information did you find? FOR EACH SOURCE, what was most/least useful about that information source? Why? PROBE:
  - CONTENT
  - STYLE
  - CLARITY OF VISUAL PRESENTATION
  - COMPREHENSION/PLAIN ENGLISH
  - TIMING
  - DISTRIBUTION
  - CHANNEL
  - CAPTIONING
  - EASY ENGLISH (WITH SYMBOLS)
  - COMMUNICATION BOOKS AND BOARDS
  - TRUSTWORTHINESS
  - ACCESS TO PEER STORIES
  - ACCESS TO LIVE CHAT
  - ACCESS TO A HELPLINE NUMBER
  - FACT SHEETS
  - CHECKLIST/SURVEY
  - RESEARCH PAPERS
  - USE OF VIDEO
  - USE OF PODCASTS
  - USE OF SOCIAL MEDIA FORUMS
  - AVAILABILITY OF OTHER LANGUAGES
  - ABORIGINAL & TORRES STRAIT ISLANDER SPECIFIC MATERIAL

- Thinking about going through this stage of life, with hindsight, what was the most useful information that you needed to know at the time? Why?
- Was there information that would have been useful, that you couldn't find?
- And how would you have liked to have been able to access the information you needed? PROBE USING SOURCE LIST ABOVE, AS APPROPRIATE
- What would have made it easier for you to find out what you needed to know?
- And now thinking more generally about when you go looking for information, some information sources provide … is that something you've previously used? it is helpful? IF YES, why is that? IF NOT, why not?
  - FACT SHEETS
  - EASY READ INTERACTIVITY
  - GAMIFICATION (THE USE OF GAMES TO HELP SOLVE A PROBLEM OR REACH A GOAL)
  - A FUNCTION WHICH READS ALOUD WHAT'S ON THE SCREEN
  - A FUNCTION TO SHARE CONTENT
  - APPS OR VIRTUAL REALITY TECHNOLOGY
  - ONLINE HELPDESK
  - ONLINE COMMUNITIES (EG MODERATED SOCIAL MEDIA GROUPS)
  - CHAT BOTS
  - WEBSITE FUNCTIONS THAT QUICKLY HELP YOU FIND THE INFORMATION MOST RELEVANT TO YOU
  - DETAILS OF CP RESEARCH AND ADVOCACY ORGANISATIONS
- The National CP information Program is aiming to use innovative digital solutions.
  - We've mentioned a few, but do you have a view on what channels or technologies they should consider?
  - What do you see as the pros/cons of each of these?
- And in, say, three years' time, what would you see as indicators that the National CP Information Program has been successful? What would be different for you/your family/the person you care for?

Thank and close

- Those are all my questions. In terms of thinking about the information that people with CP need, and your experience, is there anything else that you think the organisations building the National CP information Program need to know?
- And any final comments?

- Ipsos and the consortium led by Cerebral Palsy Australia; Ability First Australia; the Cerebral Palsy Alliance; and Cerebral Palsy Support Network, and Ipsos, thank you for your generosity with your time and contribution to this important project.
- IF RECRUITED VIA THN: We'll let THN know that you've taken part in the interview (and video pre-task) and they'll transfer your e-gift to you shortly. Thanks again for your help.
- IF RECRUITED VIA CLIENT SAMPLE: We'll be sending you an EFTPOS gift card for $100 (interview only) / $130 (interview and video pre-task) to thank you for your time. Could I take your postal address? RECORD ADDRESS. Thanks again for your help.

10.4 Primary audience video ethnography pre-task

Short personal video

Thanks for agreeing to take part in this research project – we really appreciate your help.

In addition to taking part in an interview, everyone contributing to this research is also being asked if they would be interested in making a short personal video, answering 3 brief questions. This is really informal; we'd just like to hear from you in your own words. And if you don't want to make a video, no worries, we're still looking forward to chatting with you in the interview.

If you're interested in making a short video, please follow the instructions below, and send it through to us **at least one day before your interview**. And once your interview is done, we'll add $30 to the gift voucher we send through to you.

Thanks again, from **Jess, Flo and Jen**, the Ipsos National Cerebral Palsy Information Program research team

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Before you start recording …

- Before you start recording, please read each question overleaf so that you've got a good understanding of what to cover in your video before you start.
- Please can you start a new video for **each** question so that the video does not become too large to upload. For each question, please keep your video to around 1 minute. If you want to talk for longer, stop recording and start a second video and continue answering the question.
- When it comes time to upload the videos, it is best to upload one at a time directly from your phone, using Wifi.

Video recordings tips

- Ideally, have someone from your household help by filming your video clips. If you're flying solo, place your camera in a stable spot that will capture you and your environment clearly.
- Find a well-lit place. If possible, avoid aiming at windows with your camera (especially when it's sunny outside).
- Please speak loudly if you can and eliminate background noise, where possible.
- Hold your phone on the side so the video is in landscape.
- Please don't feel the need to clean up or put your best self forward – real life is great!

Privacy and confidentiality

Only the Ipsos team members will be able to access your video, which will be stored securely and deleted after the research is complete. Your name will not be associated with your video (unless you choose to do so in the video). Please note that parts of your video may be shown to our client at a presentation. Please let us know if that's not ok.

QUESTION 1 – Tell us a little bit about **yourself**.

Prompts that will help you answer this question:

- Your name, age
- A bit about your life – family situation, living situation, work, study, hobbies and interests etc
- A bit about you – what are you passionate about? What do you find challenging in life? What are the values you hold?
- And please tell us something unique about yourself, or about the person you care for.

QUESTION 2 – Getting **information** about cerebral palsy.

Please tell us about <u>one</u> example of where it's been really difficult to get useful information about some aspect of your care or needs, or the person you care for with cerebral palsy.

Prompts that will help you answer this question:

- What was it you were trying to find out about?
- Where did you turn to for the information?
- And in what different ways was it hard to get good information?

QUESTION 3 – A **positive example** of accessing information

Finally, please give us one example of a really positive experience of accessing information. This doesn't need to be about cerebral palsy – it could be about anything.

Prompts that will help you answer this question:

- What information were you looking for?
- How did you find the information?

- And what was it about that example that made it a really good experience for you?

When you've finished, please upload directly from your smartphone (using Wifi)

1. Upload each file using this link: https://liquidfiles-au.ipsos.com/filedrop/preinterviewtask
2. Once at the site, enter your email address in the top box titled 'From'. We will not email you, however a valid email is required to use the site.
3. In the 'Subject' box, type in your first name and the first letter of your last name, and the area you are from. For example: Jack W, Tamworth.
4. If you made multiple videos, please label them with numbers (1, 2, 3 etc).
5. Click 'Add files', select your video. Click 'Send'.
6. As videos are large files, it may take a moment for it to upload. Please be sure you have a strong connection and upload directly from your phone and one video at a time.

10.5 Primary audience protocol

Protocol for qualitative research interviews for the National Cerebral Palsy Information Program research

Discussion guides for the National Cerebral Palsy Information Program have been carefully designed by Ipsos and the consortium staff to ensure the research is carried out in a respectful way. The guide complies with the AMSRS Code of Professional Behaviour for when conducting social and market research: *"Nobody shall be adversely affected or harmed as a direct result of participating in a market research study."*

However, we acknowledge that thinking about the challenges of accessing information in relation to their, or their child's, cerebral palsy diagnosis, and the challenges they have faced, has the potential to be distressing, or raise future fears, for some respondents.

Specific measures have been put in place in this project to support respondents and interviewers with these issues, should they arise:

- The moderating team will be trained on the specific sensitivities and ethical issues raised by this research. Training will include, where possible, specific language guides and dos and don'ts for the primary audience. The consortium team have provided documentation to support this training.

- During the interview, interviewers will 'check in' with respondents and ask, *"Are you okay going on with these questions?"* as appropriate. At the end of the interview, the interviewer will make a second assessment, and if needed, refer the participant to support services.

- Following the procedure recommended by AMSRS, respondents will be referred to counselling if they are upset or disturbed by interview questions.

- Referral to these procedures are also available for interviewers themselves - if they encounter distressing or disturbing stories or accounts from participants in the course of the in-depth interviews.

- All participants will be given the opportunity after the interview to still withdraw their permission to participate - i.e. they could contact Ipsos and ask for their responses to be destroyed during this time period. This will reduce the danger of participants retrospectively regretting their participation.

- If appropriate, information sheets can be provided to participants after interviews, which are tailored to include a note encouraging participants to seek help from a professional if needed. The information sheet will also include a list of helplines available.

In addition to the above, interviewers will follow these guidelines:

- As soon as they are aware of any distress, they should not go on with the interview.
- They should not probe or open up distressing issues any further.
- They can offer to refer the person to Lifeline/support line themselves, with a phrase such as *"This is not part of the interview, but would you like to talk to someone about these issues?"*
- Other agencies, such as their local community health centre, should also be offered as alternative referral points.
- They should then terminate the interview as sensitively as possible and ensure the respondent has the support they need.

  - Lifeline Crisis Support – phone **13 11 14** (24 hours/7 days) or chat to a crisis supporter online (7pm – midnight/7 nights).
  - Beyond Blue Support Service – phone **1300 224 636** (24 hours/7 days) – provides free, immediate, short-term counselling, advice and referral to anyone in Australian via telephone, webchat or email 24/7.

1. Complaints about services

Each state has a government authority which can provide support if complaint relates to provision of service.

Provided before 1 July 2019, including;

- NDIS
- Local Area Coordinators (LACs)

For services provided after 1 July 2019;

- Funded or contracted by DHHS
- In-kind support
- Funded by the Transport Accident Commission (TAC)

VICTORIA	https://www.odsc.vic.gov.au/	1800 677 342
TASMANIA	www.ombudsman.tas.gov.au	1800 001 170
NSW	http://www.ombo.nsw.gov.au/	1800 451 524
QLD	www.ombudsman.qld.gov.au	1800 068 908
WA	www.hadsco.wa.gov.au	1800 813 583
NT	www.hcscc.nt.gov.au	1800 004 474
SA	www.hcscc.sa.gov.au	1800 232 007

For complaints after 1 July 2019, relating to the provision of NDIS funded services, participants can contact NDIS Quality and Safeguards Commission 1800 035 544 www.ndiscommission.gov.au

2. **Support for carers** https://www.carergateway.gov.au/
3. **Support for parents** Parentline 13 22 89
4. **Family violence support** 1800Respect 1800 737 732
5. **Information and referrals for people with disability and their supporters about coronavirus (COVID-19)** Disability Information Helpline 1800 643 787
6. **Counselling support for people with disability affected by violence, abuse, neglect or exploitation** National Counselling and Referral Service **1800 421 468**
7. **Support for people with disability to help understand and protect your rights** National Disability Advocacy Program

10.6 Secondary audience discussion guide

Briefing information

The handling of a moderation guide

As an open method of exploration, in-depth interviews are not completely standardised. Listing of relevant questions in the interview guide covers relevant subjects and leaves enough space for discussion in the sense of an open approach. The questions mentioned below are not necessarily meant to be literally asked. Likewise, the order must not be strictly followed. In this sense phrased questions describe the different subject areas and are meant to control the discussion process. Each subject area is firstly explored openly. Then more detailed probing by the interviewer follows, with regard to subjects that were not spontaneously mentioned by the participant, but that are relevant.

Study objectives

OBJECTIVES:

Reminder to moderator: The key objectives are to explore:

- *Life stages/transition points for people with cerebral palsy and, where relevant, parents and carers, to explore experiences and needs at key stages and transitional points to help us understand information needs in relation to these.*
- *Understanding which institutions, services and people are important at these stages, and the types of information that would most assist them to deliver better outcomes for people with cerebral palsy, their parents and carers.*
- *Current sources of information*
  - *What information are they finding?*
  - *Where are they sourcing it?*
  - *What do they think is useful/not useful, helpful/harmful, good/bad?*
- *Preferred communication channels and current experiences, e.g. usage of technology, barriers and enablers such as access to devices, adequacy of internet, how they would like to get information.*

Introduction to the interview

5 minutes

- Thank for taking the time to participate in this important project, your contribution as a subject area expert is much appreciated.

- This discussion will take no more than an hour.
- Your contribution is anonymous, unless you particularly wish to be identified, the final report will show the combined responses of the people we speak with.
- EXPLICIT PERMISSION FOR AUDIO RECORDED.
  - The recordings will be listened to by members of the Ipsos project team;
  - The recordings will be stored securely for up to two years and then destroyed.
- To confirm the background of this research: The consortium of Cerebral Palsy Australia, Ability First Australia, Cerebral Palsy Alliance and Cerebral Palsy Support Network aim to establish a consolidated national platform for information, for people with cerebral palsy, their families, support providers, key NDIS roles, the community and mainstream services. The Program aims to adopt innovative ways to distribute high quality information to people with CP, their parents and carers, and those working to advise and support them. You've been identified as someone with valuable insights relevant to the objectives of this research.
- Ipsos is an independent social research company. You can tell us exactly what you think.

Background

5 minutes

- The consortium or organisations that commissioned this research identified you as someone with strategic insight into the needs of people with cerebral palsy, their parents and carers, and the systems and services that most impact on their lives, so I'd like to start with you giving me a bit of background about yourself: your role with [relevant organisation] and your connection with the CP sector?
  - [May need to probe for professional history as relevant, involvement in different groups / peak bodies etc.]
  - [If appropriate] While this study is about information for those with cerebral palsy, can you provide me with any context around the broader national approach to information provision for and about people with disabilities?

Understanding key transition points

10 minutes

- We'll be interviewing people with cerebral palsy, their parents and carers, about their experiences of different life stages and transition points – what that experience is like and the implications for their

information needs during transition periods, but I'd like your perspective on this too. In your role, or from your perspective, how do you think people with cerebral palsy and their carers experience this?

- What do you perceive as the key transition points?
- For each:
  - What are the issues / 'hot topics' in relation to this?
  - Who's involved in these transition points?
  - [probe for what makes different people's experiences of this different… e.g. metro / regional; role of parents / carers; family resources available; etc.]
- Where / in what situations do you think these transition points work better/worse?
- What's key to successfully supporting people through transition points?
- Where are the 'weaker' spots? What needs to be improved?

Key institutions, services and people

10 minutes

- Let's go a bit deeper now, can you tell me more about the institutions, services and people that tend to be involved in the life transition points for people with CP, and their parents and carers?
  - Are there particular institutions, services and people critical to different life stages / transition points?
  - How do these different institutions, services and people interact? Do they work effectively together?
  - What facilitates these institutions, services and people working well together to support people with CP, their parents and carers negotiate these transition points?
  - What hinders them from working well together?
  - What do you think could be done to improve this interaction?

Sources of support and information

20-30 minutes

- In terms of support and information, what do you think is key to improving the experience of people with CP, their parents and carers navigating through life stages and transition points?
  - What sources of information and support are effective at the moment?

  - What is it about these that work well? [Probe for content, style/comprehension, timing, format, distribution, channels, trustworthiness etc.]
  - Who is responsible for effective sources of support and information?
  - What is it about these organisations / sources that enable them to create and share effective support and information?
- What are the major gaps?
  - Who does this affect most acutely / less so?
  - Where is support and information most needed?
  - [probe for demographics / characteristics of those most in need]
- And overall, what is most important in terms of effective support and information? [Again, may need to probe for timing, format, distribution, channels, trustworthiness etc.]
- Given your view of current information and support, what are your thoughts on how the National CP Information Program should best provide information?

- The National CP information Program is aiming to use innovative digital solutions.
  - Do you have a view on what channels/technologies they should consider?
  - What do you see as the pros/cons of these channels?
- And in, say, three years' time, what would you see as indicators that the National CP Information Program has been successful?

Thank and close

Those are all my questions. Do you have any final comments?

Ipsos and consortium led by Cerebral Palsy Australia; Ability First Australia; the Cerebral Palsy Alliance; and Cerebral Palsy Support Network, and Ipsos, thank you for your generosity with your time and contribution to this important project.