SUPPORTING THE DEVELOPMENT OF ADVOCACY IN THE PARENT/CARERS OF QUEENSLAND CHILDREN WITH DISABILITY

A Thesis submitted by

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Abstract

This body of research takes a pragmatic approach to supporting the capacity of parents to effectively advocate on behalf of their children with disabilities across complex systems. It demonstrates an understanding of advocacy in this context and defines the complex role of the parent caring for a child with disability. It consists of a robust background and literature review and four subsequent studies, each building on the knowledge base provided by the previous.

The first study is a systematic literature review that examines the research related to the parental experience of engaging on behalf of their children with the National Disability Insurance Scheme (NDIS), a fledgling Australian program of individualised disability support delivery. This was a necessary focus because the NDIS is new and literature is only now being published as the program is enacted region by region. The NDIS represents a significant shift in the delivery of support and services to persons with disability in Australia and its focus on individualised funding demands more of persons with disability and their families than previous system-led models.

The second (primary) research study explored the collective experiences of ten parents in developing and exercising advocacy skills and included a broad range of family structures, disability types, and children's ages. Building on the thematic findings of these interviews, the third (primary) research study explored the experience parental advocacy from the perspective of service providers. Thematic analyses highlighted similarities and differences in the experiences and expectations of the parent-professional partnership.

The final (primary) study involved the design and delivery of a parent-focussed, peer-led capacity building program. It included pre- and post-intervention measures and questionnaires to evaluate the benefits of the program. The research found that the health

system – as primary responders to the presence of disability – is organically well placed to partner with families in capacity building at or around the time of diagnosis or significant transition. It further found that the structured design framework resulted in support that targeted the needs of the family participants in a way that was perceived as relevant, topical, and timely. Participants demonstrated and reported improved empowerment and perceived self-efficacy and a trend towards reduction in the frequency and impact of situational stressors. They reported increased confidence and beneficial outcomes associated with their acquired advocacy skills and knowledge and the value of a peer base of support.

Thesis certification page

This Thesis is entirely the work of **Fiona Frances Russo** except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

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Publications under Review

Russo, Fiona (2019, August) Parental experiences of engaging with the NDIS on behalf of their children with disabilities, Journal of Disability Policy Studies, resubmitted with minor modifications following review August 2019

Conference Presentations

Russo, Fiona (2017, May) *Advocacy in parents caring for children and young people with disabilities,* Presented at the National Disability Summit, Melbourne Australia

Russo, Fiona (2017, November) *Supporting the development of advocacy skills in the parents caring for children with disabilities,* Presented at the Children's Health Queensland Research Symposium, Brisbane Australia, Children's Health Queensland

Russo, Fiona (2017, November) *The role of advocacy in the lives of Queensland parents of children with disabilities,* Presented at the Fellowships Fund Incorporated Annual General Meeting, Gold Coast Australia

Russo, Fiona (2018, March) *Parent empowerment and the NDIS,* Presented at the Children's Health Queensland Professional Development Videoconference Series, National Access Clinical Program

Russo, Fiona (2019, March) *The experience of the parent advocate – partnerships that produce results,* Presented at the Australian Paediatric Rehabilitation Conference, Brisbane Australia, Queensland Paediatric Rehabilitation Service

Russo, Fiona (2019, August) *Champion Your Child (or 'getting what you need in a complex system'),* Presented at the Deafness and Mental Health Queensland Seminar, Brisbane Australia, Child and Youth Mental Health Queensland

Chapter One: Introduction

1.1. Background

Children with profound disabilities require a considerable level of care, support coordination, and advocacy. The Australian Bureau of Statistics' (ABS) *2009 Survey of Disability, Ageing and Carers* found that of the 187,600 children aged 0-14 with disabilities living in Australia, approximately 108,000 reported a disability with a profound/severe core limitation and 96,000 parents identified as primary carers for their disabled child/ren (Australian Bureau of Statistics, 2012). A child with complex health needs requires an effective champion but defining advocacy in this context is as complex as the child's condition and the environment in which they live.

The guiding principle of advocacy is to promote general and public welfare (Datta, 1999). The single advocate does this by taking a position of representation, whether for an individual, a group, or a 'for the collective good' cause. The Oxford English Dictionary (2011) lists no less than five broad definitions of the word "advocate". The earliest of these, first defined in 1340AD, refers to "a person or agent believed to intercede between God and sinners". As the word has evolved, its core meaning remains unchanged. A modern advocate is still an intermediary - one who "pleads for or speaks on behalf of another" (Oxford University Press, 2011, p. 3022). Advocacy has since worked its way into professional life, where advocates are employed in the legal, social services, medical, and political spheres - to name just a few. The very act of advocacy implies a level of vulnerability on the part of the subject. If a person was able to successfully promote or meet their interests, one could argue that the role of advocate would become unnecessary.

Parental caregiving is 'informal care' in that it is nonprofessional and largely unpaid, but it was assigned a replacement value in the United States of US$196bn almost twenty

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years ago (Navaie-Waliser et al., 2002). At the time, this figure far outstripped the total national spend on home health and nursing care. In Australia, the replacement cost of informal caregiving has jumped from AU$19.3bn (Winch, 2006) to AU$60.3bn (Deloitte Access Economics, 2015) over the past decade. This replacement cost does not consider opportunity costs such as the unrealised skills and experience that could be contributed by the carers and the cared for if the situation were different. The scale of activity and the economic value of the caregiving itself build an excellent fiscal case for supporting these carers in developing the skills required to actively advocate as well as care for their children. This is a multi-billion dollar 'industry' that is largely ignored in economic terms.

Understanding the complexity of the parent carer role is an integral first step in designing effective support offerings. Whilst there have been many academic publications regarding specific legal, educational, and medical advocacy for children with special needs, there is a limited understanding of the role of the parent carer in this context and where they 'fit' in systemic interactions. This thesis will focus on the advocacy role in the parent carer population and aims to improve the understanding of the challenges faced by parent carers in achieving recognition for their role as advocates for their children in a system that some argue is designed to exclude them.

This program of research examined the experience of raising a child living with disability in Australia today by applying an interpretive lens to qualitative interviews and focus groups of key stakeholders in the childhood disability landscape. Each study built on the preceding one to produce a deep understanding of the challenges and opportunities for parents and families as they sourced, negotiated, accessed, and funded the medical, educational, therapeutic, and physical resources required for the children to access all the opportunities of full community citizenship. The culmination of the program was the design, development, and implementation of a capacity building intervention that aimed to assist

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families in taking their first steps towards peer networking and advocacy skills development. This intervention was delivered within an action research framework with a live and evolving feedback loop that enabled real-time optimisation of the program. The initial phase in building a robust knowledge base was to examine the existing literature and explore the current understanding of advocacy in this context.

This program of research aimed to examine more closely the development of advocacy skills in the parents of children with disability in Queensland, Australia. This was achieved through two primary research studies involving parents and carers of children with disability and the professionals with whom they partner to meet the needs of their children. In the first study, parents participated in individual semi-structured interviews with the researcher, which encourages free flowing discussion about the phenomenon of caring for a child with lifelong complex needs as well as exploring their relationships with service providers, their support structures and coping mechanisms, their skills and perceived efficacy in advocacy, and their feelings toward imminent systemic changes. The second study considers the thoughts and perceptions of those professionals to whom parents are advocating by involving a variety of service providers in small focus group sessions exploring similar themes.

The findings from the first studies inform the design and development of a capacity building program which supports the development of the advocacy skillset and mindset in the parents of children with disability in the Queensland community. This program is delivered and outcomes measured with the intent that it act as a pilot program for consideration by Queensland's public Health system as the logical first responders when disability is suspected.

Chapter Two: Literature Review

2.1. A brief history of parental advocacy

The notion that parents are best placed to raise children with disabilities and to advocate on their behalf is a relatively recent development in Australia. In contrast, in our cultural neighbours with similar climate and policy environments - the United States and the United Kingdom - there has been considerably more research activity into the phenomenon. Mere decades ago, the care of children with disabilities was considered a 'social problem'. Leiter (2004) discusses the pervasive climate of institutional vs community- and family-based care family that existed from the 1800s to the late 1970s in the United States. The culture of the time actively promoted the institutionalisation of children with disabilities from a very early age. Parents were counselled that these institutions were the only providers of the support and services their children would require, and it was further suggested that parents who opted to keep their children at home were depriving them of opportunity as they couldn't possibly meet their changing needs in the home and in the community. Leiter's research studied the movement of parent activists in redefining childhood disability from a social problem to a family issue. These parents were further able to present the family as the child's natural ecology – that is, the environment in which they naturally belong and which offer the best chance of thriving - thus invoking family values as part of the solution and helping to destigmatize the issue of childhood disability. This activism led to the development of federally funded, family-centred early intervention programs in the United States. These programs offered a viable option for families wishing to keep their children in the family home, and the public discourse began to change in favour of family-centred care.

This trajectory was mirrored in the United Kingdom, where Walmsley, Tilley, Dumbleton, and Bardsley (2017) describe the pervasive control exerted by the institutions that limited the capacity of parents and families to make decisions in relation to their child's

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care. Walmsley and Rolph (2002) discuss the impact of isolation on these families, suggesting that the nature of the controls employed by institutions discouraged families from meeting one another, limiting the opportunity for them to share knowledge or develop a collective voice. Walmsley et al. (2017) describe a changing public discourse during the mid-twentieth century that saw families of children with disability as objects of pity, a worldview at odds with today's push for equal citizenship but one that helped to destigmatize the experience and the public began to engage more charitably with families. Churches and other charities began to provide services in the community, which supplied much improved opportunities for parents and families to meet others in similar situations. This development of the collective voice emboldened parents to advocate more fiercely for their children to be viewed less as pathetic wretches and more as children deserving of education and opportunity. Significant legislative changes to the provision of public education and community-based services to children with disability were enacted in England, Wales, and Scotland during the 1970s. Similar attitudes began to appear across Europe, enacted into public policy in Denmark in a similar time frame (Bylov, 2006). In Australia, the Commonwealth Disability Services Act (1986) first described a range of new service types including community-based supports for Australians with disability, marking a shift from the prevalence of 'government jails or asylums' (Braddock, Emerson, Felce, & Stancliffe, 2001). Advocacy services were first defined and provisions for funding declared in this Act (p.2) (Australian Federal Government, 1986):

> (a) self advocacy services to assist people with disabilities to develop or maintain the personal skills and self confidence necessary to enable them to represent their own interests in the community;

> (b) citizen advocacy services to facilitate persons in the community to assist

(i) people with disabilities; or

(ii) the families of; and other persons who provide care for or assistance to, persons with disabilities, to represent their interests in the community; or

(c) group advocacy services to facilitate community organisations to represent the interests of groups of people with disabilities.

Deinstitutionalisation was the initial banner that spurred the movement, but the parent voice continued to develop and mature alongside the voices of adults with disabilities advocating for themselves. Self-described 'disabled academic' Michael Oliver (1983) espoused and widely disseminated the social model of disability, first described by the Union of the Physically Impaired Again Segregation (UPIAS) in the United Kingdom. The social model of disability asserts the view that disability is a construct of society rather than the result of individual impairment. These events saw the focus moved towards the more modern expectation of full and equal citizenship for people with disability.

In today's deinstitutionalised Western societies, it is difficult to find a large-scale 'residential school' designed for young children with disability. In the handful of decades since the 1970s, the shift in public policy in areas such as health and education has been monumental. Australia enacted the Disability Services Act to introduce robust disability services - particularly in the area of equal economic participation - in 1986, followed by the Disability Discrimination Act in 1992 (Meekosha & Dowse, 1997), and became a signatory to the United Nations Convention for the Rights of Persons with Disability at its inception (United Nations, 2007), which sets out the rights of people with disabilities as full and equal members of the community. Cooper (1999) espoused the power of self-advocacy when she summated the Australian disability rights movement thus (p225):

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While the political power of people with disabilities is most easily seen in national specific disability organisations debating issues with government policy makers, a greater power is with the myriad of individuals and small groups, working mostly without funding, but armed with anti-discrimination legislation, and engaged in access battles. Maybe this is how our diverse society works best.

More recently, the National Disability Strategy and one of its key activities, the National Disability Insurance Act of 2013 (Australian Federal Government, 2013) moves Australia closer to a model of disability supports and services that are genuinely person- (and family-) led (Bonyhady, 2014). However, with this step comes a shifting of the burden of responsibility from the professional sector to a more client-led paradigm. Under the National Disability Insurance Scheme (NDIS) provided by the Act, if a person with disability (PWD) or their agent (commonly a parent among the child population) cannot research, understand, and prioritise requests under the individualised funding arrangement they are unlikely to receive the correct funding packages for the services they need. Empowering and supporting people with disabilities and their families to develop and exercise the skills they need to source and secure equipment and services is central to the Scheme's success – and more importantly, to the pursuit of positive outcomes for PWDs.

Both Leiter (2004) and Walmsley et al. (2017) found that parental advocacy and activism have emerged during times of change, crisis, or where there is a growing dissatisfaction with the status quo, all of which might be applied to the current Australian context. Their studies each espouse the importance and the power of parent collaboration and peer support in providing the platform on which parents can build skills, establish priorities, acquire knowledge and confidence, and effectively advocate for change.

2.2. Supporting parental advocacy in service delivery for children

Many studies have found that the majority of parent carers are already engaged in advocacy through a wide range of activities resulting in varying levels of success (I. Brown, Anand, Fung, Isaacs, & Baum, 2003; Crowe & Florez, 2006; Dempsey & Keen, 2008; Glang, McLaughlin, & Schroeder, 2007; Green, 2007; Hess, Molina, & Kozleski, 2006; Kingsnorth, Gall, Beayni, & Rigby, 2011; Neufeld, Harrison, Stewart, & Hughes, 2008; Resch et al., 2010; Ryan & Runswick Cole, 2009; Trainor, 2010). Common among the findings of these studies was a sense of frustration about systemic barriers facing the families of children with complex support needs (Green, 2007; Hess et al., 2006; Neufeld et al., 2008; Resch et al., 2010; Ryan & Runswick Cole, 2009; Trainor, 2010). I. Brown et al. (2003) asked families about their current advocacy activity. Of the 34 respondents, 25 said they were advocating for disability related services *some*, *quite a bit*, or *a great deal* of the time. The majority of the remaining nine families reported that their responses of *hardly at all* or *a little* were indicative of a lack of knowledge about how to engage in advocacy rather than any disinclination to do so. Although a small sample, this result supports the position that most parent carers are either actively advocating for their children or would be if only they knew how.

This finding logically precedes the question – how can parents gain the knowledge that would allow them to become the champion that their child needs? Family empowerment was identified as a principle of strengths-based practise in the late 1980's (Weick, Rapp, Sullivan, & Kisthardt, 1989), and has subsequently become a central focus for many of the services that support the families of children with disabilities (Koren, DeChillo, & Friesen, 1992).

"Empowerment must be viewed as a complex, multidimensional construct that incorporates much more than components of personal control. Knowledge about

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resources and alternatives, positive attributions about personal and family circumstances, as well as the demonstration of relevant and appropriate behaviour are crucial features of empowerment" (Dempsey & Dunst, 2004, p. 49).

S. M. Brown, Humphry, and Taylor (1997) described seven distinct levels of family involvement in the context of therapeutic service delivery for children (eg. physiotherapy, occupational therapy, speech therapy, and psychology). These were:

1. no family involvement – the child client attends sessions without parents or family members and therapeutic decisions are based largely on observation;

2. family as informant – family may attend at assessment stage or sporadically throughout treatment, and is able to provide information of relevance;

3. family as therapy assistant – parent/family member regularly attends and supports child at therapy sessions;

4. family as co-client – therapeutic decisions are made with the whole family in mind and services are delivered to the family as a unit;

5. family as consultant – parents or family members provide information and offer advice and decision making support to the therapist/s;

6. family as team collaborator – parents or family members are actively involved in developing plans and making decisions; and

7. family as director of services – parents or family members take the lead on planning and goalsetting and engage therapist/s accordingly.

There is a clear increase in the depth and intensity of advocacy engagement as one moves through the levels. A fully empowered parent advocate would be likely to engage at the upper levels of this scale. The next logical question, then, is whether a fully engaged parent actually improves therapeutic outcomes for their child?

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Dempsey and Keen's (2008) Australian discussion of effective family-centred help-giving identified successful child outcomes as being directly related to the locus of control - that is, the extent to which parents/families feel in control of the events that impact them. This is as important as the extent to which parents/families feel they are positively influencing outcomes and is related to their satisfaction with the support received. Dempsey and Keen (2008) clearly demonstrated the value of effective system-family partnerships in achieving positive wellbeing outcomes for the child/ren, their families, and the benefits even extended to the service providers themselves. These findings present robust evidence for the need to support the role of parental advocates in directing their child's care and supports, as they imply a direct correlation between the resulting family empowerment and improved outcomes for children. However, parental advocacy requires considerable resources on the part of parents and families. Understanding this cost is a key success factor in the provision of services aimed at supporting parents to effectively champion their children in the new Australian policy landscape.

2.3. The cost of advocacy

Advocacy engagement has been identified as a drain on parental resources, including emotional (I. Brown et al., 2003; Crowe & Florez, 2006; Neufeld et al., 2008), financial (I. Brown et al., 2003; Resch et al., 2010), and socio-cultural assets (I. Brown et al., 2003; Crowe & Florez, 2006; Green, 2007; Neufeld et al., 2008; Resch et al., 2010; Ryan & Runswick Cole, 2009; Trainor, 2010). Parents in Green's (2007) study entitled 'We're Tired, Not Sad' reported that their emotional resources are less impacted than their socio-cultural ones. They spoke about the burden of paperwork and the intensity of negotiations with medical and education professionals associated with having a child with complex needs. When resources are being consistently depleted, parents must find a way to refill their

proverbial buckets. Green's study found that parental social networks were highly valued but were negatively impacted by these extra demands on their time and attention.

Many parents caring for very young complex children are new to the world of *typical* parenting, let alone the additional demands of the carer role. Leiter (2004) suggests that parents may be assumed unwilling or incapable of participating in advocacy in the Early Intervention setting because the developmental aspect of advocacy is not well understood. Parents caring for children with complex disabilities spend significantly more time on direct child-care activities than their peers with neurotypical children, and this occupational gap grows wider as the child ages (Crowe & Florez, 2006). Crowe and Florez (2006) also found that many children with disabilities will require basic self-care supports such as bathing, feeding, and toileting far longer when compared with others among their age peers. In addition to this, developmental delays necessitate an increased level of care across all aspects of the child's daily life including social and educational inclusion. The intensity of this care provision leaves very little time for leisure or social interactions (Green, 2007). This is a trade-off generally expected and accepted during the first few years of parenting, but in the case of disability it may stretch relentlessly into the future, negatively impacting parents' emotional wellbeing over time as members of their social networks are perceived as moving onto stages of life that they cannot follow (Neufeld et al., 2008).

Many parents find that they are barely managing to cope with this parent carer role without adding the further pressure of developing advocacy skills and researching the rights and obligations of children, families, and complex systems (Leiter, 2004). These parents may have been assumed unwilling or incapable of participating in advocacy in the Early Intervention setting because the developmental aspect of advocacy is not well understood. Advocacy is a learned skilled honed over time and an expectation that the parents of very young children would be able to successfully exercise these skills would be unreasonable.

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However, it is equally unreasonable to assume that these same parents do not have the will and the capacity to develop advocacy skills. Inevitably, though, advocacy becomes a necessary component of the provision of care when needs are identified by parents and services must be sought, negotiated, and financed. This suggests that providing gentle (not overwhelming), effective supports aimed at developing an advocacy skillset and mindset in the parents of very young or recently diagnosed children will provide long term benefit across the child's life.

It is acknowledged that parental advocacy requires a certain amount of personal and family resilience as resources must be available for the activity. Heiman (2002) identified three main factors present in resilient families where childhood disability is present: (1) open discourse with family, friends, and professionals; (2) a positive bond between co-parents; and (3) continuous professional supports for family members (eg. educational, therapeutic, and psychological). Another common characteristic was positive parental feelings, not only toward their child but also about coping and family relationships. Of the thirty-two (32) respondents in Heiman's (2002) study, the majority of parents expressed positive feelings such as joy, satisfaction, optimism, love, acceptance, and strength. It is important to note that parents in other studies also reported positive feelings and experiences when parenting their children (I. Brown et al., 2003; Crowe & Florez, 2006; Green, 2007; Retzlaff, 2007). An American study by Scorgie and Sobsey (2000) focussing on the transformational changes experienced by the parents of children with disabilities found that three major positives were reported. These were in the areas of personal growth, improved relationships, and deeper, more meaningful philosophical or spiritual values.

These positive feelings toward their children described by parents did not immediately follow the presentation of disability (Heiman, 2002; Retzlaff, 2007). Receiving a life-altering diagnosis brings with it an avalanche of information that shell-shocked parents

are unable to absorb. Parent carers are thrust into the additional role of advocate without preparation. In the words of one parent: "…you start at the overwhelmed stage. I have absolutely no idea where to begin. I can't even believe this." (Stebnicki & Marini, 2012, p. 229). In most cases, effective advocacy develops over time as parents come to understand their child's needs and learn how to navigate within the medical, therapeutic, and educational systems. Although it could be argued that all parents advocate on behalf of their children, the parents of children with disabilities must engage in advocacy more regularly, for longer, and with much higher levels of complexity (Ryan & Runswick Cole, 2009).

2.4. Advocacy skills development

There are numerous elements that could be considered barriers to the development of parental advocacy skills. Leiter (2004) outlines five of these elements:

1. professional socialisation – citing a lack of professional acknowledgement of the role of the parent-as-advocate;

2. professional power – the structure of services sees knowledge and resources in the control of the professional sector rather than the families;

3. parent-professional intimacy – prevalent in the early intervention space, service providers may develop close intimate relationships with families that often encourage dependence;

4. parents' limited awareness of rights – a lack of knowledge about the systems and processes that surround their children and their role/s within them; and

5. parental/family constraints on parents' ability to exercise rights – individual impacting factors such as language or socio-cultural barriers.

Researchers are exploring ways to educate and empower parent carers outside of their child-specific systemic engagements and are successfully developing advocacy skills through

peer-led supports (Dennis, 2003; Kingsnorth et al., 2011). During their participation in a Transition Peer Support Group led by a parent facilitator, parents reported increased skill in identifying and articulating their child's support needs and noted a sense of empowerment when experiential knowledge within the group was received as expert (Kingsnorth et al., 2011). Many parents reported applying for and in some cases receiving services as a direct result of participation. Positive results also included parents reporting (1) an increased awareness of challenges and shifts in views on future orientation; (2) increased active planning; and (3) noting the particular value of experiential knowledge freely shared. Many parents engage with peers to support their advocacy and help one another, and Kingsnorth et al. (2011) demonstrated a direct correlation between peer support involvement and increased advocacy capacity. However, while peer support was highlighted as a useful advocacy tool, participants also noted limitations such as a lack of individual support.

Other research has focussed on the formalised delivery of parent education around advocacy. Glang et al. (2007) developed and delivered two multimedia training modules to the parents of children with traumatic brain injuries: one designed to provide information about childhood brain injury and ideas for educational supports (control group) and the other focussed on parent advocacy training in communication skills (treatment group). Subsequent surveys considered skill application, self-efficacy, and behavioural intention in the parents following their viewing of the material. The treatment group demonstrated considerable improvements in identifying and understanding key communication strategies. This study, although limited by size (n=31), clearly demonstrates the potential for effective parent training in advocacy planning and techniques.

In another approach, the instructive text "Six Steps to Successful Child Advocacy" (Wright & Jaffe, 2013) took a self-education position, in which potential advocates and

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activists are offered a framework for planning and executing advocacy projects. The six steps outlined are:

1. Knowing Your Issue

2. Research for Background and Impact;

3. Preparing Effective Materials;

4. Making Meetings that Work;

5. Conducting Strategic Follow-Up; and

6. Reinforcing Successful Advocacy Outcomes.

As a project planning tool, this work provides insightful direction to the potential advocate or advocacy group. As parents, though, advocacy is less a project than a lifestyle. It would be easy to dismiss the advice of Wright and Jaffe (2013) on this basis, but the idea of breaking parent-carer advocacy into teachable units is not new. A simple internet search offers online training from organisations such as the A G Bell Academy; Parent Educational Advocacy Training Center; Parents' Advocacy in the School; the Council of Parent Attorneys and Advocates; the Parent Consultant Training Institute; and the PACER Center. It is noted that these offerings are primarily US-based and concerned with advocacy in the special education space. This may be an indication that the education sector is proactive in acknowledging and supporting the role of parent carers as advocates, but it may also point to a growing concern over breakdowns in family-school relations.

2.5. Parent advocacy in the education sector

The special education sector and its interactions with families has been the subject of a considerable volume of literature, particularly in the United States where it has spawned a new practitioner: the Special Education Advocate/Consultant (Heitin, 2013). Families employ these consultants or lawyers to intervene on behalf of their child, often when the relationship

between the school and the family has broken down. Heitin (2013) notes that there is no agreed skillset or accreditation for this role, so essentially anyone can offer a fee-for-service. If this sounds like a criticism of the role, she further asserts that parents need the support of advocates more now than ever before. Two US programs currently in their infancy are aiming to close this professional gap by offering education and recognised accreditation (Burke, 2013). Although both programs are available to fee-paying parents, they are not the primary target market. This systemic response provides for an intermediary between the person with disability and the supports they require. This trend toward professional support implies a worrying lack of confidence in effective parental advocacy, whether on the part of the education system or the parents themselves, and strained family budgets will likely bear the brunt of the cost. This professionalising approach appears to consider parent carers not as advocates but as consumers of disability supports. In fact, it is the children with disabilities who are the users of the services, and teachers/doctors/therapists who deliver them. Service provider administrators and parent carers are already acting as intermediaries, and it could be argued that inserting yet another 'middle man' into this complex space is not an ideal solution.

Hess et al. (2006) studied twenty-seven families' systemic interactions in the US and identified a dichotomy between being an effective advocate for a child and passively accepting decisions made for the child by professionals. This dichotomy was present in the language used by parent carers to describe their interactions: "*we*" vs "*I*" and "*they*". Hess et al. note that each of the stakeholders' – student, teacher, parent, family, class, school, education department – success is dependent on the others'. Central to creating a more collaborative, balanced experience is the need for more equal partnerships between the system and parents.

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"At the most fundamental level is the need to assist families in learning to be advocates for their children through education, support and family mentors. If we only give voice to the idea of empowerment without taking action, we are not truly providing families with opportunities to become equal partners in decision-making for their children." (Hess et al., 2006, p. 29).

Parents in the Hess et al. (2006) study further suggest that their advocacy does not always have to be family vs system, reporting occasions where it could be used instead to bolster existing infrastructure such as sourcing equipment or para-professional resources in schools, thereby supporting an inclusive environment for all children. This type of advocacy moves parents towards activism, a common extension of the parenting role in this context.

2.6. Consumer advocacy in the health sector

In Canada, inclusive policies pertaining to children with disabilities and their families are on the public health agenda. Provincial governments are beginning to acknowledge feedback from families expressing frustration about professional-dominated decision-making with regard to their disabled children. In these provinces, a 'family-centred' approach to childhood disability policy and supports prioritises the needs of the child and their family above strictly medical or therapeutic goals (Valentine & Network, 2001). In the family-centred care model, parent carers are empowered to prioritise supports and make decisions about their children in partnership with service providers, rather than at the mercy of them.

In the case of medical care management, Schwartz (2002, p. 37) considers that "the concept of [patient] advocacy imposes a suspicious appearance on the relationship between patients and caregivers". Schwartz suggests that the promotion of medical advocacy implies that there is a fundamental conflict between patients and practitioners and that practitioners may not have patients' best interests at heart. She does, however, acknowledge that patients

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may require support or assistance to understand their treatment options or to articulate their needs and preferences. In this context, Schwartz suggests that the best medical advocate may be the patient or a family member, but could also be a separate professional role, or an extension of the doctor or nurse responsibility. Stone (1979) outlines the American Psychiatric Association's principles of advocacy from the medical perspective as championing the medical needs of patients but notes that this is often at odds with the legal notion of advocacy, which champions instead the legal rights of their client. Two recent examples of this in the broader medical context exist in legal proceedings brought by UK hospitals Alder Hay and Great Ormond Street against the families of Charlie Gard and Alfie Evans respectively. The British courts were asked to consider the medical and humanitarian interests of the boys by supporting the hospitals' recommendations to withdraw medical treatment without parental consent, both cases resulting in the death of the child (Wilkinson & Savulescu, 2018). These cases may represent the worst case scenario regarding medical disagreement but they are worth noting in the context of parental advocacy – where the best interests of the child may be in dispute.

In the Australian context, patient and family advocacy is generally supported by the health department. Non-government organisations with consumer engagement and advocacy at their heart exist in most States and Territories. Health Consumers Queensland (HCQ) is the peak body in the State of Queensland, which is where this program of research was undertaken. It exists to support patient advocacy in the health system and outlines five levels of co-operative service design and delivery from the larger strategic perspective on healthcare: (1) inform – patients and families are informed about decisions made by health service providers; (2) consult – patients and families are consulted following the design of services; (3) involve – patients and families are actively involved in the feedback processes and their advice is incorporated in the final product/service; (4) collaborate – patients and

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families work together to plan and design services and resources; and (5) consumer led – consumers identify gaps or areas for improvement and request the support of service providers to develop and implement a solution (Health Consumers Queensland, 2017). These principles are reflected by Payne et al.'s (2011) evaluation of collaborative health research, which champions the role of consumers and communities in designing and developing truly impactful projects.

Payne et al. (2011) described a process of consumer engagement as part of a public health research project conducted in Western Australia. They followed the project across its three-year life cycle during which consumer engagement was embedded at every step. These consumer-researcher collaborations contributed positively to the scientific and ethical standards, recruitment and participation, and legitimacy and credibility of the research, and ultimately improved the project outputs and community outcomes. The Australian National Health and Medical Research Council expects researchers to engage in consumer and community partnerships and continue to evaluate and report the positive contribution to the research outcomes (Saunders, Crossing, Girgis, Butow, & Penman, 2007). From the perspective of mental health and wellbeing, this increased engagement of consumers in research offers participating families a sense of positive action, which can provide significant benefit to parents who may be feeling helpless about their child's condition.

2.7. The parent-as-advocate

Trainor (2010) identified four categories of advocacy used by parents within the special education sector that could be logically applied to any systemic interaction. She notes that each has its limitations, and that many parents identified with more than one, suggesting that they are often utilised in combination. The four categories are (1) the Intuitive Advocate; (2) the Disability Expert; (3) the Strategist; and (4) the Agent of Change.

The 'Intuitive Advocate' relies heavily on knowing their child better than anyone else in order to exert more influence over decisions relating to support requirements, service access, and contingency planning. It is difficult to argue that a parent's intensive understanding of their child could be exceeded by any other party, but Trainor (2010) notes that this strategy is limited when professional expert knowledge might arguably be considered more pertinent in settings such as medical and educational. This approach is therefore sometimes discounted by professionals and other stakeholders when important decisions are being made.

The 'Disability Expert' seeks to impart knowledge of the child's disability and associated problems. It was noted in Trainor's (2010) research that parents of children with autism were the most likely to identify with this approach. However, it was also noted that this strategy had the potential to inadvertently create a deficit view of the child by focusing heavily on challenges rather than opportunity and potential.

The 'Strategist' is well-versed on systemic policy and legislation. They understand their role/s and rights, and their children's rights. The Strategist confidently prioritises needs and sets goals, and then manipulates the system/s to achieve them. Trainor (2010) found that parents identifying with this type of advocacy report gaining a 'troublemaker' reputation among the professionals with whom they interact. There is also the potential to relentlessly pursue a chosen course of action without acknowledging alternatives as Strategists often find themselves in combative scenarios.

The final approach described by Trainor (2010) is that of the 'Agent of Change', who identifies a gap in the system or delivery processes, and lobbies for change. Community-minded activism – improving the system not only for their own children, but for the families that follow – is their mission. If there is a limitation associated with this approach, perhaps it

lies in the possibility that such external focus may result in a lack of attention on the individual child.

Trainor (2010) found that parents would identify with more than one of the above advocacy strategies, using them interchangeably dependent upon the circumstances. Parents may initially assume responsibility for monitoring their child's condition, but as empowerment increases the role expands organically to include educating themselves and others, negotiating (fighting) for resources, and campaigning for change. Parents often begin to assert themselves in response to unsatisfactory interactions with established systems, such as taking control of a strained relationship with a health professional. These negative or nonsupportive interactions may in fact provide the catalyst for advocacy development (Neufeld et al., 2008) and eventually move parents beyond the scope of advocating purely for their own child and into the realm of activism.

2.8. From advocate to activist

Landsman (1998) described the indiscriminate nature of childhood disability and its effect on traditional notions of mothering, noting that mothers from diverse backgrounds and of differing ages and ethnicities describe their experiences and perceptions of disability in remarkably similar ways. Landsman's study included observations of a group affiliated with the NICU at Albany Medical Center called 'Parent Outreach and More" (p75). This group was made up of a revolving membership of parents whose children were hospitalised and provided peer and crisis intervention supports to families through a peer-professional partnership model. Although this group dissolved after two years and never quite reached the parent-led, self-sustaining aspiration, it did demonstrate that parents were both willing and able – even in the earliest days of disability – to reach out to and connect with others. Ryan and Runswick Cole (2009) suggest that advocacy and activism occur in the parent carer population in tandem. It is difficult to separate the roles of parent/carer/advocate/activist

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because they aren't often engaged in isolation. Wright and Jaffe (2013) suggest that advocacy can be broken down into micro, mezzo, and macro activities – micro involving the single child in a single setting, mezzo involving multiple settings or a small group of people, and macro moving into large scale activism. The parent-carer is often actively involved in all three levels as described by a UK study involving mother-carers, which identified a significant portion of mothers whose advocacy had become 'enhanced' as part of their caring role, either independently or via community groups (Ryan & Runswick Cole, 2009). Although a mother caring for her child may not fit the role as it is generally perceived, activism is a largely unrecognised part of caring for a disabled child, even among the caring community.

It is interesting to note that the mothers in the Ryan and Runswick Cole (2009) study did not largely self-identify as activists, perhaps illustrating that parents caring for children with complex needs consider activism an ordinary extension of the parenting responsibility. This conclusion is echoed by Panitch (2012), whose book on 'accidental activism' in a similar cohort of Canadian mothers describes a notion held by parents that good mothering (of children with disability) includes social activism. Panitch and Ryan & Runswick Cole further describe the evolution of the mothers' activism as having roots in peer support activities. Mothers discussed the support and guidance provided by and to groups of peers as having significant positive impact on their sense of empowerment and self-worth as well as their mothering and support of their own children. These peer groups often became activists as they identified gaps in services and supports and set about enacting and lobbying for solutions. Whilst parent activists come from many different backgrounds, Sauer and Lalvani (2017) describe one key predictive demographic regarding levels of activism: education. As two professional women and mothers of children with Down Syndrome, they describe deliberately using the "privilege of relative power" (p52) afforded them by their education to

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improve quality of life for persons with disabilities across the world. Education and knowledge gathering is also a significant positive factor in the peer support groups described by Panitch (2012) and Ryan and Runswick Cole (2009). Their members reported personal satisfaction linked to increased skills in professionalism, communication, and a deeper understanding of complex social systems. This suggests a three-fold benefit to activism in parents caring for children with disability: improved outcomes for their child/ren; personal and professional benefits for the parents, many of whom reported a reduction in workforce participation as a result of their child's needs; and improved services and supports for the larger community.

2.9. The changing face of Australian disability policy

There are two main schools of thought around global disability policy and practise. The traditional - often referred to as the 'Medical'- model of disability considers disability in terms of individual impairment or deficit, for example, a missing limb or the absence of sight. The socio-political – or 'Social' - model takes the position that disability is a societal construct, the product of one's interactions with a hostile environment (Hahn, 1985). These two prevailing constructs can be considered in terms of the words disability (impairment) and disadvantage (societal constraint). In the case of a person with a hearing loss, for example, is it the inability to hear that causes disadvantage or is it that the wider environment is designed for the hearing community? With reasonable adjustments, would the disability continue to present disadvantage to the individual? How much adjustment is reasonable and who would decide such a thing? Who is responsible for making the adjustment – the wider society or the deaf community/individual? These are provocative questions, and the answer is not always clear. Governments around the world are grappling with these ideals, underpinned by the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Harpur, 2012), the central tenet of which is full and equal participation in

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society. Australia has been a signatory to the Convention since it was enacted in 2007 (United Nations, 2007).

The National Disability Insurance Scheme (NDIS) is arguably the most significant social policy reform in Australia since the introduction of Medicare in 1975 (Walsh & Johnson, 2013). It is built on a platform of full and equal citizenship including equality of community access for all Australians living with disability that echoes the principles of the UNCRPD and fits reasonably well within the framework of the social model of disability. The National Disability Insurance Act (Australian Federal Government, 2013) supports the social model as it acknowledges that people with disability are often disadvantaged by inaccessible infrastructure and other societal constraints. The Scheme seeks to mitigate this disadvantage by providing funding for self-directed supports to Australians living with disability that align with their own individual goals. However, it also addresses the criticisms of the model – primarily its tendency to homogenise a rich, diverse community of disabled people and ignore the issue of individual impairment (Oliver, 2013) - by providing for therapeutic supports that aim to maintain or improve capacity in areas directly related to individual impairment/s (eg. communication, mobility, occupation, and mental health and wellbeing). The medical management of disability is not addressed by the NDIS and remains the sole domain of public and private health services. This is also the case with education-related supports, which in the main are still provided by public and private education providers. The reality for the parents of children entering the Scheme is that they are likely to be navigating the health, education, social services, and NDIS systems in tandem.

By individualising funded support plans, encouraging participants and their families to choose, direct, and manage their services, and ceasing the block funding arrangements previously entrenched in the support industry, the NDIS represents a fundamental shift from a professional-led mode of support to a consumer-directed paradigm with all the complexities

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of a free and open market. It is not difficult to infer a significantly increased level of

responsibility and accountability for persons with disability and their families as they seek to

secure appropriate funding, services, and equipment in this new landscape. For children

entering the Scheme, this responsibility falls largely to their parents (Ranasinghe, Jeyaseelan,

White, & Russo, 2017; Sheppard, Lefmann, & Crowe, 2013; Tracey, Johnston, Papps, &

Mahmic, 2017). The National Disability Insurance Agency (NDIA) – the federal agency

tasked with administering the NDIS – has delivered more than AU$85.9M to community

organisations via the Information, Linkages, and Capacity Building grants program (National

Disability Insurance Agency, 2018) aimed at improving readiness and capacity in participants

and service providers as the Scheme is fully enacted. This is additional to the Agency's own

direct series of events and workshops designed to assist people with disability and their

families to understand and engage with the Scheme. These activities are planned to extend

just beyond full Scheme implementation (2019-20) to the 2021-22 financial year. Whilst this

may assist to prepare the current participant and provider population, it cannot address the

needs of the future participants who have perhaps not yet been born or whose disability is not

yet evident. For these families, there is likely to be little support from the NDIA.

2.10. Summary

Current research supports the position that parent carers are already actively involved

in advocacy. Parents report engaging in a range of activities with varying levels of success,

but many do not identify themselves as advocates or activists. Researchers agree that

advocacy is a natural augmentation of the parent carer role, and are positive about the

potential benefits when executed effectively. There is agreement around the need to better

support the development of advocacy in the parent carer population, although the best

delivery method is still being considered. Peer-led parent education and support and flexible

delivery of 'training modules' are just two options that have reported successful outcomes for families.

The level of frustration when attempting to engage with the system – medical, educational, allied health and other services – is consistently reported as high, and a lack of recognition for their role is identified as a significant source of this. There is very little in the current literature around the 'systemic fit' for parental advocacy in the care of children with complex health needs or disabilities. It is difficult to identify where parent carers fit into the current system, which pays lip service but offers no official role to parents as advocates. For example, the referring General Practitioner is considered the integral member of a child's medical team and copies of investigative results, reports, and imaging are forwarded to him/her as a matter of course. This occurs even when the referring GP is not a regular member of the child's circle of support (e.g., locum). There is no such recognition for the role of parents, who must request – and are often denied – copies of the same. Parent carers must sign a consent form for information to be shared between the education department and a child's therapy team but are often excluded from the correspondence that follows. Perhaps the problem lies with the fact that parents are considered 'informal carers'. With this understanding, is it any wonder that an 'informal' role would have an 'informal' position in systemic interactions?

The idea of formalising the role of a parent carer as advocate may raise issues of qualification. How would parent-carers prove competency? Would the onus be on them to do so? Should an educational qualification be undertaken by parent carers, and if so what would it look like and how would it be delivered or funded? Where performed by a parent carer, should the role be financially supported? How much and by whom? If a parent carer did not have the competencies required for the role, what then? Should a profession pop up to fill that gap? What would that mean to the parent's caring role, financial burden, and decision-

making capacity? It soon becomes clear that formalising the advocacy role presents some particularly provocative questions. Perhaps, then, it is not a matter of formalising the role so much as recognising, respecting, and supporting it.

Parent carer advocacy is not merely a position of representation for a child with disabilities, but one of direct care and activism as well. If one were to consider traditional professions such as a disability support worker (carer), a lawyer or social worker (advocate), or a political lobbyist (activist) – these roles are well delineated and understood. The support worker may provide physical or social assistance to a client but is under no obligation to support the greater community. The lawyer or social worker may speak on behalf of a client in court, but never takes them home afterward to feed and bathe them. The Greenpeace activist may board a whaling ship or address parliament on behalf of a species but doesn't coordinate ongoing veterinary care for any one animal. The parent carer must be all things to their children, and the lines between roles are blurred. One cannot consider advocacy among this group as an isolated activity but as part of a much larger, more complex role that is not well understood but deserves recognition – and perhaps a new name.

2.11. Gaps in the research

It is notable but perhaps unsurprising that the participants in studies on raising children with disabilities are overwhelmingly mother-carers (female respondents). This aligns with the widespread research that finds the burden of childrearing around the world has historically been – and still remains - largely the domain of women (Barusch & Spaid, 1989; Case, 2000; Folbre, 2006; Hervey & Shaw, 1998). The political and economic emancipation of women progressed in the United States, the United Kingdom, and Australasia into the early 1900s (Evans, 2012) and the movement reached its zenith during the 1960s and 1970s (Humphries, 1983) when real legislative reforms were introduced to support the ethos of full and equal citizenship for women. This timeline is aligned with the growing movement

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towards the deinstitutionalisation of children with disabilities and the demand for better services in the home and in the community. As mothers were afforded the right to a political voice in line with the feminist movement of the time, it appears that the mothers of children with disabilities made this a key priority.

There is very little research in the Australian context about the development of advocacy skills in the parent population, and by extension how the disability systems and processes are affected by parental advocacy. The role and its systemic 'fit' is not well understood by parents or service providers beyond a vague acceptance that it is has the potential to be a positive contributor to improved outcomes for children (Dempsey & Dunst, 2004; Dempsey & Keen, 2008; Fereday, Oster, & Darbyshire, 2010). There is very little in the current research that considers ways in which the development of these skills can be supported or encouraged. This program of research aims to improve the understanding of advocacy in the Australian childhood disability context, its fit and function in systemic interactions, and to design and implement a framework for supporting its development in the parent population. It will seek to answer the following question: How can Australian systems support the development and exercise of critical advocacy skills in the parents of children with disability?

Chapter Three: Parental Experiences of Engaging with the NDIS for their Children: A Systematic Review

3.1. Introduction

The National Disability Insurance Scheme (NDIS) is a new piece of public policy. As such, there is very little to draw from when attempting to build an understanding of the way that parents experience or would seek to experience their engagement with the Scheme. This systematic literature review will close that gap in the knowledge base by examining the current literature available in the context of the parent experience. The Australian government will soon release recommendations from the review of the National Disability Advocacy Program (NDAP), under which "people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation" (Australian Federal Government, 2016b, p. 2). The NDAP acknowledges that not every person with disability is able to effectively advocate on his/her own behalf and funded fifty-eight individual advocacy agencies across Australia in 2015-16 a total of AU$16.4M (Australian Federal Government, 2016b) to provide support on a number of levels. It is reasonable to assume that some of these finds will be required to support parents as they engage with the Scheme for the first time.

An Australian discussion of effective 'family-centred help-giving' (Dempsey & Keen, 2008) identified successful outcomes as being directly related to the locus of control, that is the extent to which parents/families feel in control of the events that impact them. This is as important as the extent to which parents/families feel they are positively influencing outcomes and their satisfaction with the support received. This aligns well with the National Disability Insurance Scheme (NDIS), which is being progressively rolled out across the

country between 2013 and 2019 and represents a substantial change in disability policy in Australia (Bonyhady, 2014). An individualised funding scheme delivered within an insurance model, its central tenet is choice and control for persons with disability (PWDs) (Australian Federal Government, 2016b). Under the Scheme, a PWD (or their agent) may request any support or equipment that meets the "reasonable and necessary" test (Australian Federal Government, 2016, p.39). With respect to the current focus of this paper being on children, the annual planning process requires the family of a child PWD to have a working knowledge of therapies, equipment, and supports available before they can request them. This systematic review presents the literature regarding parental experiences of the NDIS as it is implemented across Australia. The research question posed is 'How do parents of children with complex health needs experience their engagement with the Australian National Disability Insurance Scheme (NDIS)?

3.2. Method

The systematic review was completed in accordance with PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). This ensured a rigorous and repeatable process to identifying and assessing articles for inclusion in the review. The search was conducted independently by three reviewers to ensure reliability in the search outcomes from the databases. Articles identified in this initial search were then reviewed by two reviewers, then the final selection of articles were reviewed for final inclusion by two reviewers. Any disagreements were discussed and resolved through reference to the inclusion and exclusion parameters established before the search commenced.

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3.3. Eligibility criteria

The search parameters were kept deliberately broad for this review due to the anticipated small numbers of articles currently published about parental experiences with NDIS service provision.

3.3.1. Criteria for inclusion

An article was considered suitable for inclusion in the review if it met the following criteria:

- The prime focus for the paper was on the NDIS;

- The prime focus of the paper was on parental experiences with NDIS services;

- The paper presented empirical research on parental experiences within the NDIS;

- No restrictions placed for the age of the child;

- No restrictions were placed on the category of disability but the disability focused on in the article needed to qualify for NDIS service provision.

Criteria for exclusion.

An article was considered not suitable for inclusion in the review if it met the following criteria:

- Did not have an NDIS focus but rather a broader education or health focus;

- Primarily focused on the experiences of other NDIS users such as adults, plan managers, and other professional groups.

3.4. Search strategy.

The databases selected for searching were PubMed, EBSCO Host (all databases), Psych-Articles, Psych Info, Psychology and Behavioural Sciences Collection, Proquest, Web of Science, and the Cochrane database. In addition, given the relatively new research focus on the NDIS, a search was also conducted on Google Scholar to ensure the reach was as wide

as possible. The searches were limited between 2013 and present due to the date of initial rollout of the NDIS being 2013, with the search taking place on 17th August 2017. The research string included the terms "Australia* AND parent* AND advoca* AND experie* AND NDIS AND Scheme AND disab*" and these along with the overall search strategy were independently reviewed by a research librarian.

3.4.1. Data extraction.

A data extraction form was created to extract the data following initial screening. This included the authors, date, full reference, main findings, and assessment decision with rationale for its acceptance or rejection to move forward for full inclusion or exclusion.

3.4.2. Quality assessment.

Due to the focus of the review being that of parental experiences with the NDIS, the articles returned and selected for inclusion in the final review were qualitative or mixed-methods in nature. A quality assessment was conducted to assess the methodological quality of the articles. Given the mixed-methods and qualitative methodology adopted by the article authors, the Critical Appraisal Skills Programme (CASP, 2006) was utilised. The CASP score attributed to each paper can be seen in Table 3.1 which summarises the main characteristics of the articles.

3.5. Results

3.5.1. Article selection.

The initial search on 17th August 2017 returned a total of 713 records from the search string "Australia* AND parent* AND advoca* AND experie* AND NDIS AND Scheme AND disab*". All records returned were considered for their merit in meeting the inclusion and exclusion parameters set. Six hundred and fifty records were subsequently excluded on the basis of not meeting the inclusion criteria. Following the removal of duplicates, 64 full

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text articles were assessed for eligibility. On reviewing the full text of these articles, 57

papers were excluded because they did not have a primary focus on the NDIS, were not

research articles that presented empirical data, were not sufficiently focused on the voice of

parents, and were not primarily experiential in focus. This resulted in seven articles being

included in the final qualitative synthesis. Figure 3.1 outlines the flowchart of article

selection and methodological decisions.

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│   650 records excluded based on title and abstract     │
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│   Not NDIS focused = 29                                │
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│   A journal commentary not a research article = 1      │
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│   Not parental focused = 22                            │
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│   Not experience focused = 5                           │
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              │  7 articles included    │
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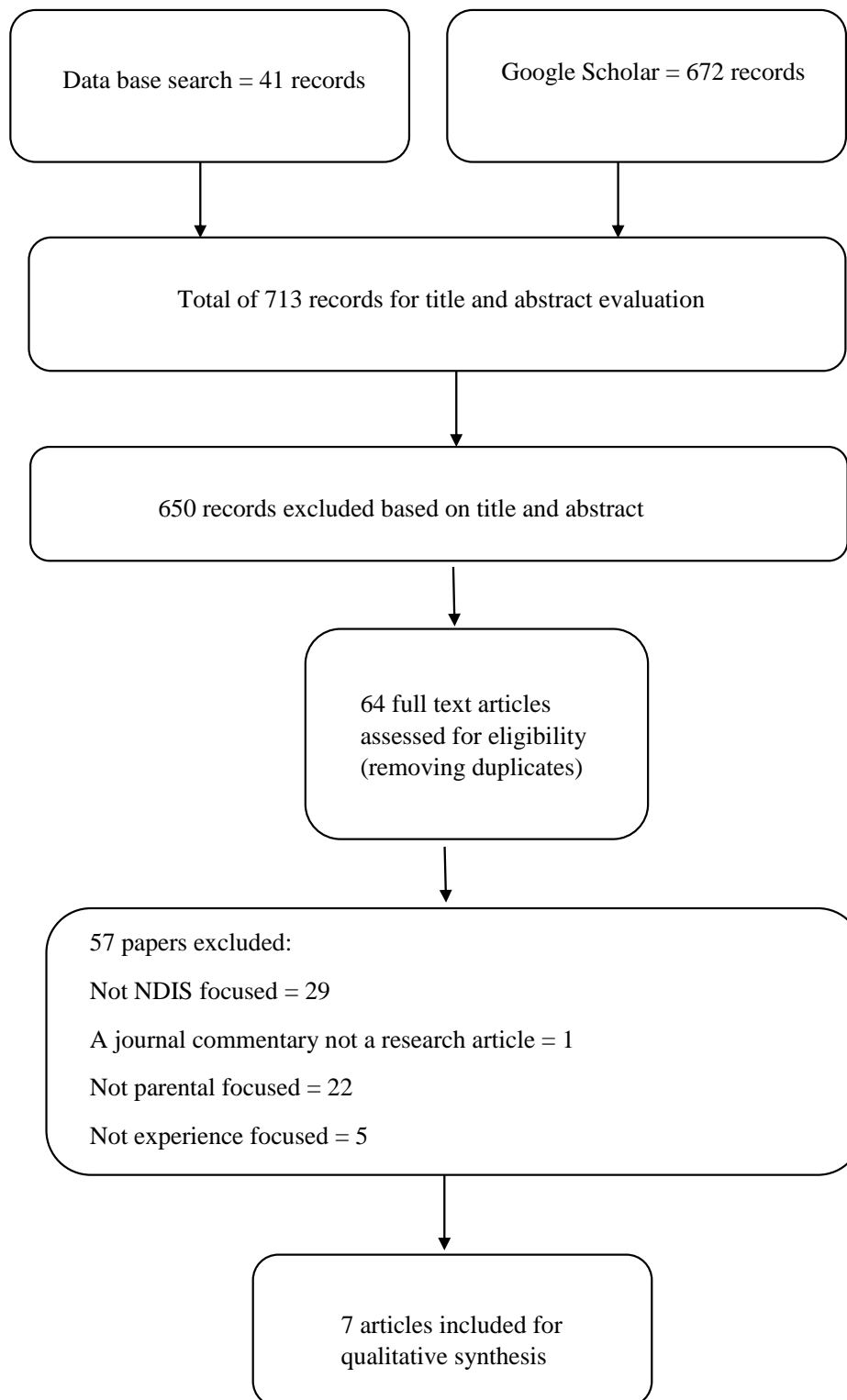
Figure 1. Flowchart of article selection

3.5.2. Summary characteristics of included articles.

The seven articles retained for inclusion in the final review were broad in focus on

types of disability, with only one paper, Simpson, Stewart, and Douglas (2016), focusing

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specifically on the singular disability of hearing loss. Two studies - Howard, Blakemore, Johnston, Taylor, and Dibley (2015) and Johnston, Tracey, Mahmic, and Papps (2013) - were mixed methods, Ranasinghe et al. (2017) primarily used a survey, and the remainder were qualitative in methodological approach, drawing on interviews and focus groups. The quality ratings of the articles retained for inclusion in the final review indicated a general high quality in research being undertaken concerning parental experiences within the NDIS. Table 3.1 summarises the key aspects of each article and main findings from each paper.

Table 3.1 *Summary characteristics of the final selection of articles*

Author, year	Participants	Disability	Research Method	Findings	Quality Rating
Dew et al. (2013)	10 carers; 60 service providers	Range	Focus groups and individual interviews	Positive findings in greater access to choice of therapy; negative findings in limitations of range of therapies available, complexity of self-managing packages, and higher costs	8
Howard et al. (2015)	75 surveys; 34 individual interviews	Range	Mixed-methods: surveys and individual interviews	Identification of several policy assumptions about parents/carers impacting on impacts of NDIS in regional towns.	9
Johnston et al. (2013)	306 parent surveys, 344 professional surveys; 21 parent focus group participants	Range	Mixed methods: surveys and focus groups	Challenges of sourcing reliable information online; importance of a skilled case manager/key worker; challenge of jargon and clarity of information	9
Ranasinghe et al. (2017)	42 parents	Range	Survey	Mixed experiences in ease of accessing funding,	8

				communicating with the NDIA, and general satisfaction	
Sheppard et al. (2013)	12 parents and carers; 13 physiotherapists; 8 health and disability policy advisors	Range in physiotherapy services	Individual interviews	Focused discussions concerning relevance, relationship building and choice	8
Simpson et al. (2016)	11 caregivers	Hearing loss	Individual interviews	Perceived transfer of responsibility onto families for care; importance of preparation in making a strong case for resources; difficulties in working with professionals; information overload	9
Tracey et al. (2017)	291 parent surveys; 56 parent focus groups	Range	Mixed-methods: surveys and focus groups	Importance of experiential knowledge of other parents; challenge of sourcing reliable information on the internet; importance of early intervention	9

3.6. Thematic synthesis

Four major themes emerged upon analysis of the articles included in this review. These are: (1) access to information and services; (2) system complexity; (3) family (self) advocacy; and (4) effective support systems.

3.6.1. Theme 1: Access to information and services.

All articles included in the final sample discussed the importance of access to appropriate and timely information for participant families in the lead up to, and implementation of, the NDIS. Dew et al. (2013) and Howard et al. (2015) reported that parents in their studies felt 'overwhelmingly uninformed' and each discussed the perceived lack of information and advice available regarding the management of individualised funding. Howard et al. (2015), Johnston et al. (2013), Tracey et al. (2017), and Simpson et al. (2016) found that even when information was made available, parents found it indigestible, not tailored to their family or their child's needs, culturally inappropriate or insensitive, and often causing information overload. Parents speaking with Howard et al. (2015) and Johnston et al. (2013) further suggested that information for families needed to be offered in lay, jargon-free language and made available in easy English and other languages where appropriate. For example, "Families are keen to have more state-specific information regarding service providers on the NDIS website and more personalised interaction with the NDIA." (Ranasinghe et al., 2017, p. 26)

When seeking information, parents were likely to look to their peers (Johnston et al., 2013; Sheppard et al., 2013; Tracey et al., 2017), existing relationships with early intervention service providers (Simpson et al., 2016; Tracey et al., 2017), and the internet (Johnston et al., 2013; Ranasinghe et al., 2017; Tracey et al., 2017). It was acknowledged that online sources were less able to be relied upon due to difficulties in judging credibility and

accuracy (Simpson et al., 2016; Tracey et al., 2017). It was further noted by Simpson et al. (2016) that parents tended to procure information about the NDIS from third party sources rather than the NDIA directly. Although the value of online information was generally acknowledged, every article reported that parents preferred person-to-person contact.

In the context of access to services, Dew et al. (2013) discussed the concerns of rural and remote families regarding the availability of local services. They identified a need for additional support in these regions to build capacity and skill in the local community, but added that financial support was necessary in the short term to enable PWDs and their families to overcome geographical barriers to service seeking. Parents reported a desire to have services aligned with their child's interests and related to their contribution to their community (Sheppard et al., 2013) – an issue compounded where choices are limited from the outset. Ranasinghe et al. (2017) found that better communication with local NDIA representatives could assist families to locate and choose appropriate service providers once their child's funds were in place. For instance, "According to participants in this study, a lack of choice and limited capacity were associated with less access to therapy. Participants also reported increased costs due to the need to travel long distances to access services" (Dew et al., 2013, p. 440).

3.6.2. Theme 2: System complexity.

Ranasinghe et al. (2017) surveyed parents of children under 7 years old about their experiences in entering the NDIS via referral from a health service and found that close to half of the families required follow-up or other support during the registration process. Dew et al. (2013) and Howard et al. (2015) found that families struggled with the complexity of managing individualised funding within the NDIS' difficult-to-navigate processes. In exploring parental experiences of an early NDIS trial site, Howard et al. (2015) also found that many parents cited the complexity of planning conversations and the eventual

management of funds to be a source of stress and highlighted the need for support from local, consistent NDIS contacts. This issue was a central theme of the study by Simpson et al. (2016):

> I got to my meeting and there was a completely different person. I asked where my original planner went and they simply said oh they're gone now. I understand people move on and that work places have employee turnaround but to not even be told was rude and then the new planner knew nothing about my child. She seemed disinterested it made me really angry and it felt like a waste of all that time we had previously put in. (Simpson et al., 2016, p. 154)

Ranasinghe et al. (2017)found a relationship between the complexity of a child's needs and parental satisfaction with the Scheme. Parents whose children had complex disabilities reported higher levels of dissatisfaction with their NDIS experiences. Existing relationships with early intervention service providers were found to be extremely important in navigating the complex processes of NDIS registration, assessments, and planning (Ranasinghe et al., 2017; Simpson et al., 2016; Tracey et al., 2017).

3.6.3. Theme 3: Family (self) advocacy.

Parents reported growing tensions as responsibility for advocacy, coordination, and management shifted from the system to families themselves (Simpson et al., 2016). A sense of physical, mental, and emotional fatigue was reported by families with respect to attending multiple appointments and having to explain their child's disability and its functional impact over and over again to many stakeholders whose level of understanding, knowledge, or interest was often perceived to be minimal (Howard et al., 2015; Ranasinghe et al., 2017; Simpson et al., 2016; Tracey et al., 2017). For example:

> "If I ever call the NDIS about a question, they never understand because they have no background in disability or have no idea who I am or know how to answer the

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questions so they get someone to call me back but they never do."(Simpson et al., 2016, p. 154)

Studies discussed the importance of keeping professional supports available for families who struggled to develop the skills or capacity to advocate for themselves and their children. Family advocacy services were considered necessary to combat the overreliance on families to identify and procure appropriate supports, equipment, and services (Howard et al., 2015; Tracey et al., 2017). For example, from the paper by Tracey et al. (2017):

There's a lot of parents with a high level of literacy who are very good at working on the system, but there are a lot of parents with a very low level of literacy who can't use the web who can't use those things, and that's what these case workers need to really be there particularly to support those people because they can't advocate for their children effectively. (Tracey et al., 2017, p. 7)

Many parents reported satisfaction around the increased choice and control available under the Scheme (Ranasinghe et al., 2017) and expressed a willingness to develop the skills and resources needed to effectively advocate for themselves and their child/ren (Sheppard et al., 2013; Tracey et al., 2017). Parents spoke about the importance of peer relationships in sharing skills and knowledge to enable families to advocate for themselves and each other (Howard et al., 2015; Johnston et al., 2013; Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), but also noted that the Scheme was limited in its support for parents and sibling carers (Howard et al., 2015). For example, Tracey et al. (2017, p. 6) found: "…the resource that has fed me best and nourished me and helped me has been getting together with other mums . . . I get together with . . . I just share their experience of walking the same road, and that's where the resource is."

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3.6.4. Theme 4: Effective support systems.

Every study included in this review highlighted the need for effective family supports in the context of individualised funding schemes like the NDIS. Supports discussed included professional services such as family advocacy programs (Howard et al., 2015), early intervention services (Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), health services (Howard et al., 2015; Ranasinghe et al., 2017), peer groups and organisations (Howard et al., 2015; Johnston et al., 2013; Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), and structured supports within the Scheme itself (Dew et al., 2013; Howard et al., 2015; Johnston et al., 2013; Ranasinghe et al., 2017; Simpson et al., 2016). For example, from Howard et al. (2015, p. 1378):

> …research demonstrates that any child and family initiative must recognise that already intensive everyday demands on parents and carers are compounded when their child's development and support is dependent on a convoluted system, potentially based on inaccurate assumptions about what it takes to support and develop parent and carer knowledge to gain the best possible results for their child.

Another key theme emerging from every study was the strong preference for direct person-to-person contact with support providers. These could take the form of face to face local meetings (Dew et al., 2013; Johnston et al., 2013; Simpson et al., 2016; Tracey et al., 2017) or online/telecommunication (Dew et al., 2013; Ranasinghe et al., 2017; Tracey et al., 2017), but in all cases parents strongly asserted their need for consistent points of contact – people with whom they could build relationships.

Parents also reported feeling that support was not always provided in an appropriate way for families, citing jargon-heavy communication (Howard et al., 2015), and support not tailored to their child's needs or stage of diagnosis (Johnston et al., 2013), and cultural insensitivities (Tracey et al., 2017) as issues that must be resolved if the NDIS is to

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adequately support the inclusion of young children and their families. For example:"...if it's another Koori worker they just connect straight away, 'oh that's a Koori person', you know, they know how we are in our culture everything, so it's just a connection" (Tracey et al., 2017, p. 7).

3.7. Discussion

The Australian NDIS commenced in 2013 with four trial sites - including South Australia, the first to include young child participants – which tested policies, systems, regulations, and processes in anticipation of the full Scheme rollout from July 2016 (Reddihough, Meehan, Stott, & Delacy, 2016). It is therefore plausible that parents in these studies experienced slightly different eligibility and planning processes as trials progressed. However, the central themes of their experiences carry through the various iterations and provide valuable guidance for policymakers as the full Scheme is implemented across the country.

Individualised funding packages for disability supports and services have been available to eligible Australian children under the Better Start for Children with Disability (BetterStart) and Helping Children with Autism (HCWA) programs delivered by the Australian Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) since 2007 (Dew et al., 2013). These programs each provide up to $12,000 for eligible children under the age of seven with which to secure therapies and equipment through a registry of approved providers. The NDIS will progressively replace these programs as children join the Scheme. Traditionally block funded supports for children with disability will also be replaced as the NDIS rolls out. Parents whose children participate in them are more likely to have existing relationships with early intervention services than those who have received no funded supports prior to the NDIS. In the context of this discussion and the research findings, it is concerning that the eventual closure of these programs means that

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new families entering the NDIS are far less likely to have these important supports during the eligibility and planning stages. It is crucial that the NDIA acknowledge this gap and provide sufficient safeguards for early intervention engagement prior to Scheme entry. This has been partially addressed through the development of the Early Childhood Early Intervention (ECEI) pathway (O'Tarpey, 2016) but this concession still does not allow for the development of meaningful relationships with early intervention services prior to engagement with the Scheme. It will take time for this issue to be fully appreciated but it is likely to become apparent when families who have not had access to other services (closed as the NDIS reaches full saturation) join the Scheme.

It is plausible that families whose children have received services through the (simpler) FaHCSIA individual funding programs will have gained skills and experience that enables more confident engagement with the NDIS – an analogy might be riding a bicycle with training wheels before joining the Tour de France. The research presented here clearly demonstrates a shift of responsibility from the system to individual families, and the capacity of a parent to effectively advocate on behalf of their child/ren is influenced by many factors. Successful advocacy in this context requires a skillset (e.g. information management, health literacy, communication, and negotiation) and a mindset (e.g. family resilience and optimism) that advantages some families over others. There are many external factors that also influence advocacy capacity such as socio-economic status, parental education, family structure, English proficiency, and availability of informal support networks.

Parents who are less able to advocate for their child/ren must be able to access advocacy support services to ensure that no child is disadvantaged. It is important that these services are available to all families who need them regardless of regionality and independent of the NDIS, and that these services empower families to develop their own advocacy skillset and mindset. This is in line with key themes from the Consultant Report on the Review of the

National Disability Advocacy Program (Australian Department of Social Services, 2017), which will inform development of a new NDAP from 2018. Successful advocacy faces further barriers in the female-dominated parent-carer community. Female negotiators often suffer backlash because assertive behaviour is perceived as a masculine characteristic, viewed as arrogant or aggressive in a woman. Women who adopt a less assertive position are received negatively due to perceived feminine characteristics such as weakness and gullibility (Amanatullah & Tinsley, 2013).

The research presented in this paper demonstrates a clear preference among families to be provided with a consistent key contact throughout the process of application, planning, and Plan implementation. This will improve participant experiences by offering clear and consistent information tailored to families by someone with whom the family has established a working relationship. The NDIA has recently acknowledged this feedback by announcing a pilot program to begin in Victoria in December 2017(National Disability Insurance Agency, 2017a) that aims to improve communication and information channels for new and existing participants. However, as the roll-out of the NDIS continues, more work will need to be done in the area of facilitating family negotiations with the NDIS and service providers in order for effective and fitting individual packages to be crafted.

The need to understand more about individual experiences is therefore evidenced by this review, and its importance crucial for the successful development of an advocacy program. The second study in the following chapter therefore builds on what is known in broader literature as discussed in this chapter and seeks to explore individual experiences of advocacy.

Chapter Four: Parent Experiences of Advocacy

4.1. Introduction

Building on the findings of the literature review presented in the previous chapter, the second study (Study 2) aimed to enrich the understanding of the personal experiences of parenting children with disabilities specific to the Queensland context. This study sought to explore these experiences with a variety of families whose children range in age and diagnoses. It also sought to identify areas of commonality (or significant differences) in their perceptions of themselves as advocates and of the factors that contribute to these perceptions and abilities – and ultimately, to positive quality of life for their children and their families. A secondary focus was on the imminent arrival of the NDIS to Queensland (July 2016), and the thoughts and feelings of families as it grew closer. In the context of the complete program of research, this study provided the rich, experiential understanding of managing disability in the complex landscape of Australian supports and services. It offered meaningful insight into the development of advocacy skills in the parent population and the factors that lead to positive child and family quality of life. These insights were considered invaluable in the development of the capacity building program delivered at the culmination of the project.

The overall aim of this study was to develop an understanding of the experiences of parents advocating for their children with disabilities in Australian systemic interactions.

4.2. Method

This primary research study sought to understand the experience of parents within the context of the Australian disability landscape. Taking a hermeneutic phenomenological approach - where 'being a parent caring for a child or young adult living with disability' is the given phenomena – the first phase of this study collected rich, experiential data and applied an interpretive lens to the analysis. This approach is consistent with Laverty (2003)'s

assertion that the interpretivist paradigm does not assume any one 'truth', but rather that there are multiple versions of the reality experienced and interpreted by the 'knower' (in this case the respondent). Yin (2015) describes the hermeneutic phenomenological method as being "strongly devoted to capturing the uniqueness of events" (p14). With this framework in mind, in-depth individual interviews were conducted with the parents of Queensland children with disabilities. Ethical approval for this study was obtained through the University of Southern Queensland's Human Research Ethics Committee on 15th November 2016 and is recorded as project H16REA245.

Turner III (2010) stressed the importance of a robust knowledge base prior to conducting research using the semi-structured interview in order to provide substance to the area of study, formulating the guide in a way that encourages participants to tell their unique story in their own words and still address the study's aims. A researcher must have a predetermined set of assumptions and evidential understandings to assist in guiding the interviews in real time without diluting the experiences being shared. The narrative and systematic literature review reviews were key in providing this knowledge base prior to the conduct of any interviews. A series of guiding questions for these semi-structured interviews was developed and is presented in Appendix 9.1.

The interviews themselves were conducted over a three-month period in 2017. Each involved the researcher and a single respondent, and interviews ranged from one hour to 150 minutes in length. This large difference in time frames can be explained by the format of the interviews, which were semi-structured and encouraged participants to speak freely and openly about their experiences. Kallio, Pietilä, Johnson, and Kangasniemi (2016) conducted a methodological review of the use of semi-structured interviews in qualitative research and developed a framework for designing an interview guide – a list of open-ended questions that guided the development of the interviews. Kallio et al. (2016) described the four stages of

development as (1) identifying pre-requisites that point toward the appropriateness of the method; (2) retrieving and utilising previous knowledge; (3) formulating the preliminary guide; and (4) pilot testing the guide. In the case of this study, those steps were conducted as follows:
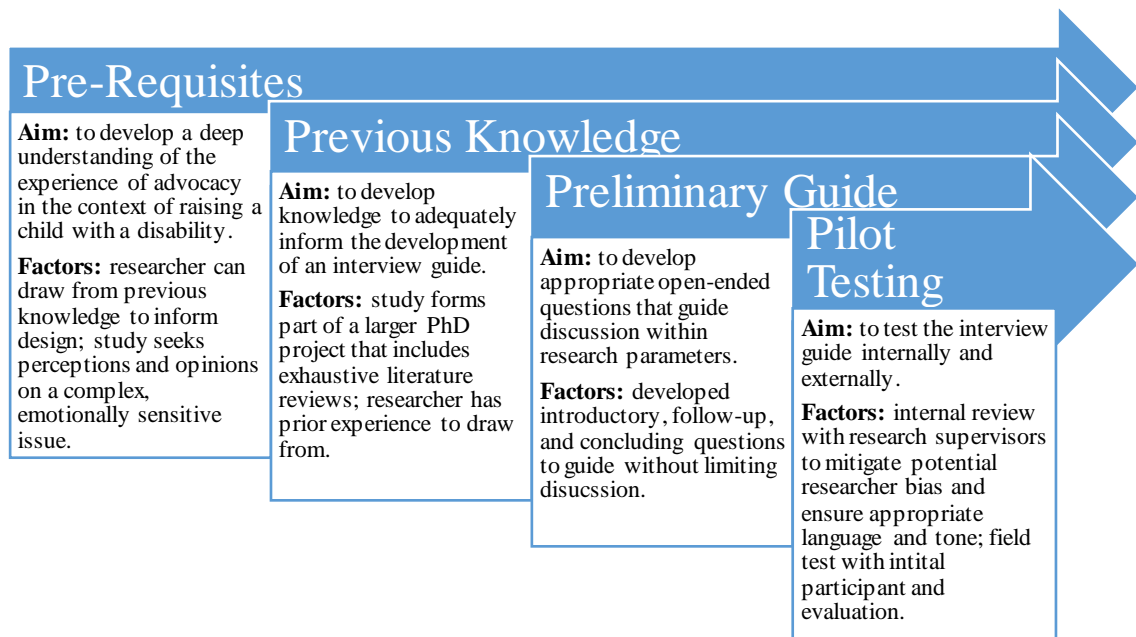

Pre-Requisites
Aim: to develop a deep understanding of the experience of advocacy in the context of raising a child with a disability.
Factors: researcher can draw from previous knowledge to inform design; study seeks perceptions and opinions on a complex, emotionally sensitive issue.

Previous Knowledge
Aim: to develop knowledge to adequately inform the development of an interview guide.
Factors: study forms part of a larger PhD project that includes exhaustive literature reviews; researcher has prior experience to draw from.

Preliminary Guide
Aim: to develop appropriate open-ended questions that guide discussion within research parameters.
Factors: developed introductory, follow-up, and concluding questions to guide without limiting disucssion.

Pilot Testing
Aim: to test the interview guide internally and externally.
Factors: internal review with research supervisors to mitigate potential researcher bias and ensure appropriate language and tone; field test with intital participant and evaluation.

Figure 4.1 adapted from Kallio et al. (2016) describes the development of the interview guide.

Barriball and While (1994) suggest that semi-structured interviews are particularly suited to areas of study where the aim is to explore a complex or emotionally sensitive issue. The disability landscape in Australia is historically disparate and undergoing a period of change. Seeking rich, experiential data in this context must allow for deviation from a rigid set of questions. Parents of children with disability are also subject to significant stressors and are highly invested in the wellbeing of their child/ren, marking the potential for an emotionally sensitive discussion. Given these two factors, this study is well suited to the semi-structured interview as a rich form of data collection.

4.2.1. Development of the Interview Guide.

The preliminary interview guide was developed from the knowledge base provided by the review of the literature and comprised general introductory questions including "Can you tell me a little about your family?" and "Can you tell me a little about your child (with a disability)?", and provided a set of follow-up questions pertaining to the experience of parenting their child:

- What kind of (paid and unpaid) supports do you have available to your family?

- How has your child's disability impacted daily life in your house?

- How would you describe the kind of advocacy you engage in on behalf of your child?

- Was there anything that happened early in your experience of disability that made things easier/harder for you?

- How do you know when your advocacy has been successful?

- Do you believe there is such a thing as negative (bad) advocacy?

Although the National Disability Insurance Scheme (NDIS) represents a paradigm shift in the way that disability is managed under Australian policy, the experiences of families prior to its inception will continue to have relevance in the context of the considerable self- and family-advocacy required to source, negotiate, and fund the disparate supports available in each Australian State and Territory (Crowe & Florez, 2006; Green, 2007; Neufeld et al., 2008; Resch et al., 2010). The next set of guiding questions were designed to include discussion of the incoming NDIS where participants had not naturally discussed it:

- How do you feel about the NDIS?

- How much do you know about what the NDIS can do for your child?

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- Do you feel ready to engage with the NDIS on behalf of your child?

The final component of the interview guide was concluding questions such as "Do you feel you are a good advocate for your child overall?" and "What positive changes would you like to see in your child's life over the next few years?" This design aimed to begin and end each interview with a positive tone to mitigate the potential for negative emotional impact caused by discussing difficult subjects at length. Interview were conducted face-to-face with the exception of two regional respondents, who were interviewed by telephone.

Ethical approval was obtained from the University of Southern Queensland Human Research Ethics Committee on 15 November 2016 (H16REA245).

4.3. Participants

This study was conducted within the South East Queensland region but sought to include some rural/regional participants as Queensland is a vast State with a concentrated metropolitan population but a whole-of-State health system. Participants were approached via existing Australian peer support groups through newsletters, flyers, and social media. None of the respondents were known to the researcher prior to their engagement with this program. Diversity was sought in the respondent group to enable the research to identify features within the given phenomena (parenting a child with a disability) that carry across a range of stakeholders. This strategy follows the purposeful sampling method of maximum variation (Palinkas et al., 2015; Patton, 2002; Suri, 2011). Families who responded to the call for participants provided some preliminary information that allowed the researcher to achieve maximum variation in the sample. The final participant group of ten parents included:

- Single parent families
- Dual parent families
- LGBTIQ parent families

- Culturally and linguistically diverse families

- Foster and kinship carers

The children in these families ranged from 18 months to 24 years old and their disabilities ranged in terms of visibility and the significance of impact to the child and their families. Some acknowledged limits of the sample were the lack of indigenous Australian voices and the fact that all respondents were female.

Table 4.1 *An overview of the families in Study 2.*

Mother's name (*pseudonym*)	Household / Family Structure	Education (completed – High School, Diploma, (college), Bachelor (University)	Age of child with disability	Disability type
Charlotte	Single parent	Bachelor	7	Neurodevelopmental
Anna	Two-parent multi-child	Diploma	7	Neurodevelopmental incl. Physical Impairment
Carly	Single parent, multi-child	Bachelor	6	Neurodevelopmental
Nhi	Two-parent multi-child	High School	4	Neurodevelopmental incl. Physical Impairment
Diane	Single parent, multi-child	Diploma	6	Neurodevelopmental
Jo	Single foster parent	Diploma	8	Acquired Brain Injury, Amputee
Katie	Two-parent, multi-child	High School	12	Epilepsy, Intellectual Impairment
Lisa	Single parent	Bachelor	24	Cerebral Palsy
Siobhan	Two-parent	Diploma	21	Neurodevelopmental incl. Physical Impairment
Sarah	Two-parent	Bachelor	1	Cerebral Palsy

4.4. Findings

Ten (10) in-depth semi-structured interviews were held with the parents of children with disabilities in Queensland. These parents (all mothers) represented their children aged from 18 months to 24 years throughout a variety of public and private systemic interactions and shared their experience of advocacy as it applied to their own family situations.

Verbatim transcripts were analysed using NVivo qualitative research software and themes identified and grouped by the researcher and the principal supervisor independently. Three significant themes and eight subthemes were identified as prevalent in the collected data. These eight elements covered three major areas of importance when forming a robust understanding of the experience of parents in developing and exercising advocacy in the Australian system.

Table 4.2 *Themes evident in the collected interview data of Study 2*

Superordinate themes	Subthemes
Understanding the role of advocacy	The impact of caring
	Understanding advocacy
Experiences influencing advocacy skills development	Positive influencers on advocacy skills development
	Barriers to advocacy skills development
	Activities of parent advocates
The role of effective support systems	The role of formal (paid) supports
	The role of informal (unpaid) supports
	NDIS perceptions and readiness

Parents in this study universally acknowledged the importance of a good advocate in the life of a child living with disability, and the natural extension of their role as parent to encompass this element. The Australian systemic environment is multilayered and complex, and even the largest government systems such as health, education, social security, and the National Disability Insurance Scheme (NDIS) fail to agree on a single definition of 'disability'. In the experiences of the parents, this has meant that applying for supports on behalf of their child/ren subjects families to multiple assessments for eligibility because each provider's verification process applies different criteria. A family may repeat this process for a single child within the contexts of health, social services, education, the NDIS, and multiple disability support providers in the first difficult months following the identification of developmental delays or ill health. All of this is likely to be required before the family can access any supports at all. Therefore, the advocacy skills of parents in securing and accessing services will be crucial.

4.4.1. Understanding the role of advocacy

4.4.1.1. The impact of caring

The advocacy role was considered by all respondents to be a natural, intuitive extension of the caring role. However, it was also acknowledged that both the caring and the advocacy roles require significant parental resources. Participants spoke about the extra energy required of the typical parenting function of their roles before they moved into discussing the development of extra skills.

Parents confidently discussed the challenges facing their children but struggled a little more to articulate the impact of disability on themselves and their families. Discussion of the family routines and ordinary activities quickly revealed a considerable amount of support provided by parents that would not be required by a typically developing child of the same

age. Anna offered a very detailed narrative about the "simple" routine of getting her family ready for the school day:

> I check [child] because she gets leg cramps and sometimes in the morning she'll have her legs stuck up under the sheet, so I need to fix that immediately and check that her face is not down in the pillow, because she sleeps on her stomach. This has been brought about because of [child], but I now do this as standard procedure for everyone - we make all of our food from scratch. So, our breakfast routine – I'm too tired to clean up the kitchen at night, so I have to do that in the morning. Then, start prepping the food for breakfast. It can be anything from bacon and eggs to sausages and eggs. It's always got sauerkraut probiotic food, sometimes rice, there's always eggs. So, that process takes half an hour to cook the food. Then [child] wakes up generally around 6.50-7.00am. She needs to be helped out of bed, walked across to the bathroom, which has since been modified so we've got good access. We've got a shower/toilet chair and it's a fully open bathroom now with shower curtain. So, sat on the toilet, help to do her wee on the toilet. Take her off and walk back to the bedroom, get her dressed in her clothes and then walk out to the dining table or lounge chair to wait for breakfast. We feed her. Feeding can sometimes take up to half an hour, depending on how good she is that day. She feeds through the mouth, which is great. Her food is chopped up or it's basically the consistency of like a 12- to 18-month-old. During the week we leave a lot of equipment at school. But, she has a wheelchair that's got to be in the car, her walker, which we leave at school during the week, but bring home and take back to school Monday and Friday. The same with the large Bumbo chair that's an upright, child right seat that she uses for floor time at school, and any other equipment like making sure she's got her – she's got a peanut allergy plus all the extra information in her little band thing that she's got about Rett Syndrome and what to expect if you're an ambulance officer. Plus, arm bands, orthotics suit and all that stuff. You make sure she's got all of that ready. That bit in itself in getting [child] ready to go anywhere takes time and really needs one person just to do that. In addition to that, you're trying to get the other two kids ready, so my sister's daughter and my son. Feeding them the right food and making sure they've got their homework packed and bottles and all that sort of usual stuff. I'm lucky, my sister makes lunch for those two and brings that, and then I just make [child]'s and pack that up. - Anna

Diane's son has a twin brother, so she was able to benchmark the level of care she provides on a typical day. It is worth noting (for context) that Diane's son's physical support needs are not as high as those of Anna's daughter (described above). Diane said:

> Self-care. Reading, understanding, connecting with the outside world – that's a huge thing. But he's getting there, and the teachers are getting there, too. I would say it's like a 70 percent. Whereas a newborn baby takes up 100 percent of your time; I would say that he takes up 70 percent. [Twin brother] takes up probably 30 percent of my time.

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In reflecting on her daily activities, Sarah discussed her role in the family unit comparative to the other members:

> I think that for them it's business as usual, they just see her as [child]. Especially my son, he doesn't – I don't think he really knows that she's different to the other kids, but yeah, my husband's very supportive of all the things that I do, but the majority of it falls to me.

The impact on the family unit was often referred to as significant, and two parents spoke about the strain on spousal relationships:

> I suppose after the diagnosis and everything that I've gone through with him, I've made the decision not to go back for any more children. And yeah, obviously what we went through placed a lot of strain on the relationship with [child]'s Dad and myself, and yeah, that's why we had to go our separate ways, I suppose. – Charlotte

> It put an impact on the relationship and having to put her first with everything because of those issues puts strain on everything. – Carly

Charlotte and Anna also discussed the impact on their work life:

> I've got high unplanned leave at work. Which obviously puts pressure on me from time to time. I have to often work odd hours to try and fit everything in and organise alternate care for [child]. – Charlotte

> I was working part-time after having children and full-time before that, in management for consulting. After having kids, I went into part-time work for the government. Then, due to [child] having her diagnosis and flexibility needed in the workplace for me having to drop the ball at the last minute because she's been sick or the childcare centre has called me… or because of appointments. I ended up getting discriminated against at work and lost my job when they restructured. – Anna

> This last week and today, I feel like screaming and driving off into the sunset, to put it bluntly. It's not because I don't love my family, it's not because I don't appreciate [child], I love the fact that she's here and she is the way she is, because if she wasn't, we wouldn't have learnt half the stuff that we have… So, I'm thankful, but damn it's hard. I get overwhelmed and feel like screaming, but it's a really big effort not to snap at people. – Anna

It is important to recognise these 'daily demands' of parents because they have a direct impact on the amount of intrinsic resources left in the proverbial tank. A parent functioning on very little sleep, existing in a perpetually heightened state of anxiety, and physically managing tasks beyond the 'norm' cannot reasonably be expected to find the extra

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resources required to develop and exercise advocacy skills. However, every parent in this study is doing exactly that.

4.4.1.2.   *Understanding advocacy*

The role of a parental advocate - that is, a parent acting as advocate on behalf of their child – was generally perceived to be an evolution of the typical parenting role. Families in this study discussed everything from the need to fulfil basic physical, social, and emotional needs to the complexities of coordinating professional care and promoting the interests of their child/ren at home, at school, in systemic interactions, and in other public settings. All of these activities were perceived to be the role of a parental advocate.

Anna spoke about the layered evaluations she makes even during the simplest of moments with her daughter:

> Whenever you look at her, you try and look at her and smile and just be a parent, but at the same time you're running your eyes over her body thinking is she pale, is she looking at me, is she flailing, is she eating enough, is she whatever? Is her movement still what it should be or has she lessened? It's a constant assessment every time you look at her, and it's that analytical thought process and all that stuff that is going on in my head, which I don't share with anyone unless I see an issue and then we might have to do something about it. - Anna

Most of the parent participants perceive their role to include considerable crossover into what might be considered the 'professional domain'. In this capacity, parents discussed coordinating medical and allied health care, a role often filled by a case manager. They also discussed directly providing inclusion supports at school or in the community when providers had been unable to provide them. Many families delivered written reports and practical training on significant issues such as medication management, manual handling procedures, and assistive technologies to the people with whom their child/ren regularly interact. This is quite separate and in addition to the perceived 'ordinary' information such as allergies, likes

and dislikes, calming techniques, and communication preferences that a parent might need to provide for their other typically developing children.

> …negotiating things with day care for my daughter, like at the moment we're discussing what equipment she'll need at day care next year, how she'll be supported when she goes up a room. So, I've been her advocate through all of that. Enrolling her in day care in the first place, you know, making sure that they had epilepsy training and knew about cerebral palsy before we started, and it's also, I guess, helping other families with advocacy too, like I talk to them about what is available for them, not just for my daughter. - Sarah

The participants spoke about the disadvantage inherent in being differently abled in any way, and about their perceived responsibility to mitigate that disadvantage for their child/ren. Emotive and sometimes confronting terms such as 'fighting', 'exhausting', 'hammer and tongs', 'arguing', 'demanding', 'pushing', 'relentless', and 'not backing down' were common among the cohort.

> We need to be empowered, our children deserve the right to be included, we're not asking for anything special, we're not asking for special favours, don't go 'every child deserves the right to the same education', and then not give it to them. Don't go 'every person deserves this', and then not give it to them, not give them the tools to empower them to have it. - Siobhan

Diane discussed the importance of her role in her son's development and in facilitating his access to his community and the world. She described a sense of being more than just her child's voice – extending and enhancing his abilities in every area to enable him to reach a level playing field with his typically developing peers:

> Roar. Roar loud. To utilise the services around you and obtain tools, skills, surgeries… everything that my child needs, and he can't say for himself. So it is literally that, but it does mean more. It makes me bigger – you know what I mean? I'm not just his voice. I'm his hands when he can't reach for what he wants – all those sort of things. It's not just dealing with medical professionals; it's dealing with school professionals… Give him as many opportunities as I would give my other children.

For the parents in this study, advocacy therefore means many things. However, every parent spoke about the pressure they felt to be the best advocate they could be, to secure the supports that would enable and empower their children in a world that is largely stacked

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against them. Every parent also discussed the perception that the systems designed to provide support are difficult to engage with. They spoke about the significant investment of time and resources required, and of the skills they had to develop to enable effective advocacy.

4.4.2. Experiences influencing advocacy skills development

4.4.2.1.   Positive influencers on advocacy skills development

Most parents in this study discussed the period of adjustment that follows the discovery of disability. They talked about the grieving that accompanies a difficult prognosis and spoke about the need to develop coping mechanisms for themselves and promote resilience within their family unit – for parents, grandparents, siblings, and especially for the young people themselves. Many respondents discussed the importance of this family resilience – expressed as a mixture of positive thinking and behaviours along with traits such as tenacity, patience, and kindness – as a key factor in the success of their advocacy, but also a challenging one to maintain at times.

> It's making sure that you build your resilience. I went to this brilliant mental health OT session one time and she said most carers are [gesturing with a hand held high] here's the red line, up here you are coping, down here [moving her hand lower] you're not. They are under that red line and I realised I was under the red line a lot of the time. She said, 'what happens is people do something to get themselves above the red line and then they think, oh, I'm good now, and they keep going and doing a whole lot more and they are quickly below the line'. - Lisa

Another significant element identified was prior experience – that is, a person's advocacy skillset developed via personal and professional experiences gained before the child was born. This was a position shared by a number of participants, for example:

> …my work/life career and having to deal – starting as a graduate in an organisation going from industry to industry, business to business, learning about how different people operated in different roles in different structures, different processes and different systems and knowing all that stuff exists and learning how to be a chameleon and how to work your way through each system and learning how to build rapport

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with different types of personalities and recognising different personality traits and all that stuff. That has all helped me with this, and not everyone has that. – Anna

I think having the opportunity to be a consumer rep at the hospital has given me more skills to be able to do it. Knowing what happens inside out and processes. And just once you're in there, having those conversations with the therapists, the doctors, and showing them that you really want to make change. I think you have to be 100% in it, you can't, you have to put your fullest into it. – Katie

Years ago, when I was in my 20s, I did an assertiveness course. You need to learn to be assertive, not aggressive. You need to know your stuff inside out. You need to know your rights… as a social worker, I've always dealt with crisis really well, and difficult situations. – Lisa

As well as skills developed in professional roles such as those described above, Diane

discussed her experience of caring for another family member before her son was born. She

highlights the difference between caring for someone with decreased or declining self-agency

versus a child with little or none:

I cared for my mother. She's still alive, but during her… she's very ill, chronically ill. I've cared for her for a lot of years. So… I've gone to meetings doctor's appointments with her. So I've done the same thing – in a different way, though. For me, it's **for** [child], but with Mum, it was **with** Mum. Because she was verbal, and she could speak her own mind, as well. So it was **with** Mum – in unison with Mum, getting the stuff that she needed. But definitely, yeah, had it [advocacy experience] before. (emphasis by speaker) - Diane

The support of wider networks was also cited as a positive contributor, and peer

support was identified by a number of participants in the context of the development of their

own advocacy skills and positive mindset. For example:

 It's helpful to talk to other people; it's helpful for them to share their stories and you listen, and then say, 'How did you get A from this person?' … Peers – definitely. Yes. Peer support is huge. In teaching you and giving you confidence and support. That is the biggest thing. If you haven't got it [confidence and support], that's where you'll get it from – definitely. – Diane

I was fortunate that we had QPPD [Queensland Parents for People with Disabilities], and that's where I—I was thinking about it on the way here, that's where I met with other parents who were older than me.…We supported each other amongst ourselves. For example, if [child] was at school and there was an issue you could always tap into one of the other people. – Lisa

Diane also discussed the need to balance peer and professional supports in empowering parents. She spoke about the importance of having parent education and capacity development available in tandem with peer support options:

> With a newbie, I would steer them towards peer groups as well. I think it would be of equal value to have peer support and formal training with advocacy.

Formalised parent-focussed training was the third significant element that emerged as a factor contributing positively to skills development. Respondents spoke about the need to have up-to-date, topical, and timely information provided by credible experts and suggested that it isn't always possible for that to come from peer support alone. The upcoming NDIS was a good example of this – as a new piece of complex legislation, the parent community was largely uninformed and unable to rely on each other as a source of information and support. The need for formalised information and support sessions provided by people with knowledge of the new system could not logically be met through traditional peer support channels but needed to be provided by professional and paraprofessional services. The National Disability Insurance Agency (NDIA) itself was recognised as an important source of truth during the transition and knowledge dissemination period. However, the need for information about specific programs and supports was not the only potential area of focus parents were looking for. Some parents specifically discussed the value of broad advocacy development supports as part of the capacity building required in their role/s:

> [Advocacy] can be taught, it can be a learned skill. It's empowering people to have a voice and have confidence enough to use it and if they don't like the results then keep seeking elsewhere until they get the result they want. – Carly

> [Formal training] would have to be time-sensitive and malleable around their timeline – their timeframe schedules and all that sort of stuff. But yes, I think some people would benefit from that. I think that if you've got – I don't know, it's a formal – some people need formal teaching, in what I think are life skills. I think it's a life skill to have it. – Diane

> Yeah, parenting courses. No, I think all the information you can get is beneficial. And if I went to a course that would help me self-manage, it would give me better ideas

and information and know how to do it better, because in the end it's for my children, and if I can educate myself in how to be a better advocate for NDIS [National Disability Insurance Scheme], why not? Yeah, definitely. – Katie

These statements emphasise the powerful elements of resilience, peer support, advocacy skills training, and prior advocacy experience that contribute to the development of positive advocacy skills. Parents in the context of peer groups would each bring their own wealth of knowledge, experience, understanding, and empathy that makes peer support so vitally important in reducing isolation and developing family resilience.

4.4.2.2. *Barriers to advocacy skills development*

Parents contributing to the study identified a number of barriers to positive advocacy and also discussed their perception of 'negative' or 'harmful' advocacy, two distinct concepts for participants. One of the barriers most often cited was the complexity of disparate systems and unnecessarily bureaucratic requirements. As put so succinctly by Lisa, "The devil is in the details." The policies may be built on positive foundations and exist as they should, but they fall apart at the implementation stage because of a variety of factors including unnecessarily bureaucratic requirements, human error, poor systems and processes, misinformation, poor management, miscommunication, extended timelines, reduced funding, and limited access support for parents and families.

> I mean just the simple things … it should be in the system, you know I'm her parent, why do I have to take down all my passports, citizenships and proof of bloody ID? I'm her representative you know. Just shouldn't have to be doing - parents have got enough, carers have got enough to deal with without having all this bureaucratic bullshit. – Siobhan

> When you're in a lot of bureaucracies or systems that you have to navigate, they all have their own secret code. – Jo

Siobhan spoke about the lack of coordination between departments, and the inability of systems to anticipate or manage the effect their action might have on other critical services

accessed by families. She described a recent encounter relating to her daughter's access to medication:

> 'Her Health Care Card has been cancelled.' 'What!' They said, 'Her Health Care Card has been cancelled so we can't give her medication at a reduced rate.' 'What do you mean her…?' The chemist man goes, 'It's all right, I know what's happened - you've just applied for her pension, haven't you?' I went, 'Yeah.' He goes, 'So now what you have to do, you have to apply for a temporary Health Care…' This is my pharmacist telling me what I'll have to do because this happens to every one of their pension clients.

Jo further discussed the difficulty of reaching decision-makers in complicated bureaucracies. She spoke of her frustration with platitudes and agreements that mean nothing in practical terms when nobody seems to have the authority to act.

> I've written to ministers, anyone that – anywhere with an ounce of power behind them, I have knocked on their doors, the – yeah, because everyone in the whole – that comes into our lives goes, 'Wow, wow, amazing. In principal, we agree that this should happen'. What does that mean?

Another barrier to positive advocacy identified was a feeling of isolation and of being a small voice in a loud world – a theme that resonates with the previous discussion concerning the importance of peer support as a positive factor in advocacy support and development. It was noted by some parents that there is a natural tendency to self-isolate during the early stages of grieving and coping. Diane spoke about the price of this self-isolation:

> Not reaching out. If you don't reach out – if you… I have got friends, peers, who are in this boat, and they don't reach out. They think they can do it on their own. And that's destructive, I think, because you are not on your own – no one's ever on their own. So, yeah, not reaching out and asking for help, or listening to other stories – would be a hindrance [to advocacy]. Major hindrance, yeah. Definitely. - Diane

Lisa spoke about her concern over recent defunding decisions made by government agencies regarding established, long-standing peer support networks.

> Now that QPPD [Queensland Parents of People with Disabilities, a defunded peer network] is not there, it's really worrying. Where are parents going to get this information and support from? - Lisa

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Parents noted the critical importance of formal and informal networks of peers in enabling and empowering parents in effective advocacy. They suggested that these barriers presented by closed bureaucratic systems can in fact be offset by good peer supports. Sarah explained:

> Some people just get stuck with the system – 'I have to do things this way because this is what I'm being told' – whereas, you know, I talk with other families and find out how they've done things so we can say, 'okay, how about we try, you know, other ways of doing things?' so, yeah, a lot of things aren't common knowledge. Because a lot of it just seems like, you're stuck with just the DSQ [Disability Services Queensland] pathway or with CPL [Choice, Passion, Life - formerly Cerebral Palsy League], or…it's other parents who can show you the alternatives. - Sarah

Developing peer relationships can however present difficulties for families who may be struggling with the time and energy required of them in their caring role. Some rural and regional parents are geographically isolated and finding a local peer group is impossible. For others, communication barriers can present issues in reaching out to other parents. For Nhi, whose native language is not English, this can present significant disadvantage:

> In the disability parent group I am not really close with anyone. I don't know how to start a conversation or how to ask a question, but maybe [other parent] was the one to start ask me [sic] before, and that's why I got more contact than the other parents. - Nhi

Katie and Siobhan discussed the culture of fear among the parents of children with disabilities – the fear of not being believed, or that that their advocacy activities might negatively impact the level of care given to their child/ren. Siobhan mentions a common observation of newly diagnosed families that approach her peer group: "They've been too scared, they haven't had the power or the strength to fight the system." It seems that this feeling of fear is a potential driver of peer support in its early stages.

Katie echoed these experiences and further stated:

> Fear hurts it. Fear that you're not going to be listened to, fear that they're not going to believe you. Fear of retribution, yep. Fear that, yeah, that your child's care will be

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worse ... so I think it's one thing they learn that it won't be, and another that they know how to advocate properly.

Building knowledge, skills, and confidence are some of the commonly described benefits of effective peer supports, but Anna suggests that this is but one aspect of positive advocacy – the other being the willingness to engage in a solutions-focussed manner:

Not all families or people have an open mind to take on that [advocacy role] yet and may never have it. They are the glass is half empty, the world is out to get me, how could you do this to me universe and give me a child that's like this, it's not fair – that attitude doesn't work. - Anna

This raises concept of 'good' and 'bad' advocacy: when might advocacy be a bad thing? Parents in this study had some clear ideas about what constitutes negative behaviour. Some respondents spoke about the only negative form of advocacy is to take no action at all:

Bad advocacy would be not doing anything or relinquishing the power to give to somebody else to solve the problem because then you're not speaking for that person, you're letting someone else speak for that person. – Carly

Conversely, other respondents discussed negative behaviours that they have witnessed or engaged in that could be considered 'bad' advocacy:

I think bad advocacy is going to the media, being passive aggressive and nasty at meetings, and even though you're so frustrated, you still have to be calm and show dignity and respect for those staff. And I learned that, I think I probably learned that the hard way, by being sometimes that frustrated you're in tears, but you still have to be respectful. – Katie

It is perhaps due to some of these negative behaviours – or stereotypes that anticipate these negative behaviours - that parents often find their expertise, advice, or opinions discounted by the professionals around them. Katie has experienced this when seeking support related to her daughter's behaviours of concern:

I need them to believe me, and I don't think they believe me, I think they just sort of think I'm a parent and I don't know what I'm doing. - Katie

Siobhan theorises that there is also a misguided tendency toward protectionism among the professional sector:

> That's the frustrating thing you know, it's like they don't want to empower us, they want us to be the minions because heaven forbid that we might become more educated than them and actually show them up. To show their incompetence as if that's even what we're doing. It's like that in so many things. It's just crazy. - Siobhan

Jo also experiences this phenomenon as a long-term foster carer for her son, meaning that she must first justify her own position as his advocate before she feels she is able to act for him:

> Things might be going well for a while but then occasionally you get a new CSO [child safety officer] who comes in and goes, 'Well you're just a carer; we need to control all this" and they just bugger up everything.'

Barriers to the development and exercise of positive advocacy such as systemic complexity, unnecessary bureaucracy, fear, professional mistrust, and isolation continue to prevent families from effectively influencing the care and support for their child/ren. In the best case, this results in an increased financial burden on governmental departments to provide these lynchpin services. In the worst case, the result is delayed or denied supports leading to negative outcomes for children. It is therefore critically important that families be empowered to develop and exercise advocacy skills as their children grow.

4.4.3. Activities of parent advocates

The activities of advocacy are as varied as the parents engaging in them, but some thematic elements were apparent throughout the respondents' anecdotes. For example, many parents spoke about being a liaison between the services accessed by their child/ren. All of the children in this study were involved with more than one service, many discussing their experiences across a handful of systems or more. Parents spoke about the need to 'translate' the requirements or recommendations of one service into the language of another to ensure

that the supports provided were holistic, appropriate, and timely. Some families have provided permissions for services providers to speak directly with one another, particularly within the allied health industry. Parents also noted the trust required for this to be a workable arrangement – and the importance of building and maintaining positive relationships with the people in their child/ren's lives.

> [It's important to] be thankful for what they're trying to do or what they've done. If they need to be guided differently, then give that guidance gently with constructive feedback and make sure... I always make sure I let everyone know who helps us that we're grateful. – Anna.

Two parents in the study spoke specifically about the importance of having reciprocal trust between families and service providers. They discussed the difficult situation of having conflicting goals or objectives around an area of service or support and the importance of resolving these effectively. For example, Sarah spoke about a situation where her advocacy was focussed on obtaining a walking aid for her son because she was aware that a source of funding was approaching its expiry. To enable access to the funding, her son's occupational and physical therapists were required to support the application. Both felt that pushing for a walking solution in the short term was not in her son's best interest clinically and encouraged Sarah to focus instead on kneeling and crawling development. The positive relationship fostered by the parent and therapists in this case allowed them to have a constructive discussion that avoided arguing their positions (what they wanted) and allowed them to address instead their interests (why they wanted it). Sarah expressed her gratitude for the realistic discussion of her son's therapeutic trajectory and skills development ("I'm very proactive with it but I do take on board when we need to adjust the goals to make them more realistic rather than just focussing on the big picture stuff"), and the therapists – upon understanding Sarah's concern regarding the funding - supported the application for a walker that her son could grow into rather than one intended for immediate use.

All respondents discussed similar instances where they too had partnered in the provision or coordination of care. Many also recalled situations where they were more assertive, directing the professionals around them. For example:

> The diagnosis was actually driven by us. The paediatrician hadn't seen Rett Syndrome before, so we pushed them to test for that. – Anna

> And I clearly, without emotion, said, 'No. That [procedure] is not going to happen. That, to me, is the most ridiculous thing on earth. Because…' and I stated why: 'he falls over.' I gave all the reasons why it wasn't a good idea, and they did – they stood back, and they said, 'Yes, okay, that's right. Let's go this way.' So they decided on surgery. – Diane

An added challenge is the limited availability and access to services in regional Queensland, which has been highlighted in the new ten-year Children's Health and Wellbeing Services Plan (Queensland Health, 2018). This required an assertive and resource-intensive decision on the part of Charlotte:

> I definitely manage his care, I'm definitely, you know, the driver, literally as well as figuratively…they couldn't meet his needs here [regional Queensland] so now I take him to Sydney. – Charlotte

Although parents universally acknowledged the importance of developing rapport and positive relationships with service providers, combative language was occasionally evident when describing the actual activities they were engaging in. This suggests that there is a persistent 'us vs. them' dynamic at play when advocating for their child/ren. Some examples of this:

> I'm actually fighting with the Department of Education at the moment, and having meetings with the Principal, his current teacher, the aides at the school, the counsellor, to try and basically plan him for next year. – Charlotte

> I call it the Dragon Lady. You can become the Dragon Lady without even trying, just by speaking up, you are the Dragon Lady. The thing to learn is how to contain—it gets very emotional and it gets very personal and the best way, if you were to navigate these systems is to really know your information before you go into a testy situation. – Lisa

> I rang up the up the chick and I just went cray cray [crazy - sic] lady on the phone and said that is discrimination. I said you have discriminated against us and our daughter.

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You have forced us now into the private sector. We now have to pay to go to private. I said, 'I tell you what lady you might've screwed me over, but you will never screw over another family again if I have my way.' They were like oh oh, and within an hour I had, they were ringing, they'd organised two different meetings with guidance officers. -Siobhan

On other occasions, the same parents spoke very positively about their advocacy and relationships, indicating that the experience was more nuanced than either wholly positive or negative. For example:

She's [occupational therapist] one of the best things that's happened to us. Yeah, he's got a pretty good medical team now, and they all communicate with one another. Obviously our family GP, he's pretty integral in making sure everything works, and doing any enhanced care plans, mental health plans, referring us here there and everywhere, but he keeps track. I can go in and he'll say "Oh, I just got a report from Dr Such and Such", and he'll know all the information, I feel like it's so much better managed now. I don't have to explain things again and again and again. – Charlotte

'Yes, this is not working and what can we do?' Wherever possible you try and enter into a really cooperative process. People appreciate that. If people see that you are cooperative and you want to work it out. – Lisa

We've been really really fortunate with our service provider, they are an amazing bunch of people and the end of financial year will be approaching and they'll be on the phone, Heather you've got this much funding you need to use" … "They're always always in our corner, so we've been really really lucky. – Siobhan

The benefit of building and maintaining those positive relationships came through clearly in some of the successful outcomes discussed by Anna:

I haven't actually found anyone that's come into our life or [child]'s life that we've decided to reject or move away from for any reason; they've always contributed something. - Anna

Anna believes that approaching these relationships with a positive attitude from the beginning has been key:

The big thing about advocacy is that you need to maintain, consistently, every day, for every single person that's involved in your life and your daughter's life… they are just trying to do their best; that's it. They're not out to intentionally harm or do the wrong thing or make the wrong decision or choice, they try and do their best based on the knowledge that they have, and you've got to remember that.

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Parents generally discussed advocacy in terms of the professional sector – health, education, social services, and other service providers. However, many identified a 'softer' form of advocacy in their toolkit, used to support their children in developing their own resilience and self-advocacy skills. Jo discussed supporting her son as he developed his own assertiveness.

> I've seen my little boy turn round to people and go [holds up hand clearly indicating 'stop']. And they'll just do it anyway and it's like, 'No, hello?' and I've got to stand up over him and go, 'Stop. Did you not hear him?' He has a voice. So yeah, he will be empowered when he's an adult, and if they don't listen to him, god help them. - Jo

Jo also spoke about her drive to instil a sense of worth and expectation in her son – to support his developing self-belief. Of her role, she said:

> His self-esteem bucket is filling up … that is the most rewarding thing on a daily basis, when I see it, I hear it, I feel it. … and there's no injuries or wounds or holes in that bucket, so that's a good thing. It's going to be a strong, solid foundation because it's a – there are going to be people who come along and shoot the crap out of that bucket. But hopefully he will have enough in there, if not overflowing, to sit back and work. And learn the skills to refill it when he needs to. So that's crucial, and that's an unconscious type of advocacy that you do, completely unconscious. I think a lot of good advocacy is just gut feelings. - Jo

Jo was not alone in her acknowledgement of this type of 'unconscious advocacy'. Diane spoke about advocating for her son within the family unit when she said:

> Even in home, too, I'll advocate for him to be spoken to by the other people in my house as an equal – not as less. It's different. Yes, we have to say things differently, but not less.

Parents discussed examples relating to advocacy that occurs at the playground with other children, at shopping centres with staff and members of the public, in car parks, at soccer clubs and scouts and swimming lessons, at the movies, and anywhere you can imagine a child might ordinarily go. It is easy to understand, then, why so many parents report carer fatigue beyond the physical demands of the caring role (Crowe & Florez, 2006; Green, 2007).

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It is perhaps because of their innate understanding of the challenges faced by families living with childhood disability that so many parents choose to actively support and provide assistance to other families.

Diane runs a charity dedicated to raising awareness for rare chromosomal disorders, Lisa was for many years involved in the executive of a large not-for-profit peer organisation, Charlotte has plans to open a "one stop shop and mobile therapy service" for parents struggling to find services in her regional town, Jo is actively lobbying the government for better supports for children in out of home care, Katie is an active consumer representative at a large health service, Siobhan has co-written a book detailing her experiences with a view to helping other parents. Given the extra requirements of the unique caring and parenting role, it is perhaps surprising that so many parents are spending their energy on broader pursuits beyond their own families.

What is it that pushes some parents into the realm of activism? Ryan and Runswick Cole (2009) suggest that advocacy and activism occur in the parent/carer population on a continuum. Drawing on this idea, and extending based on the findings of the current research, it is possible to visualise the activities of the parent/carer as a number of roles within one:
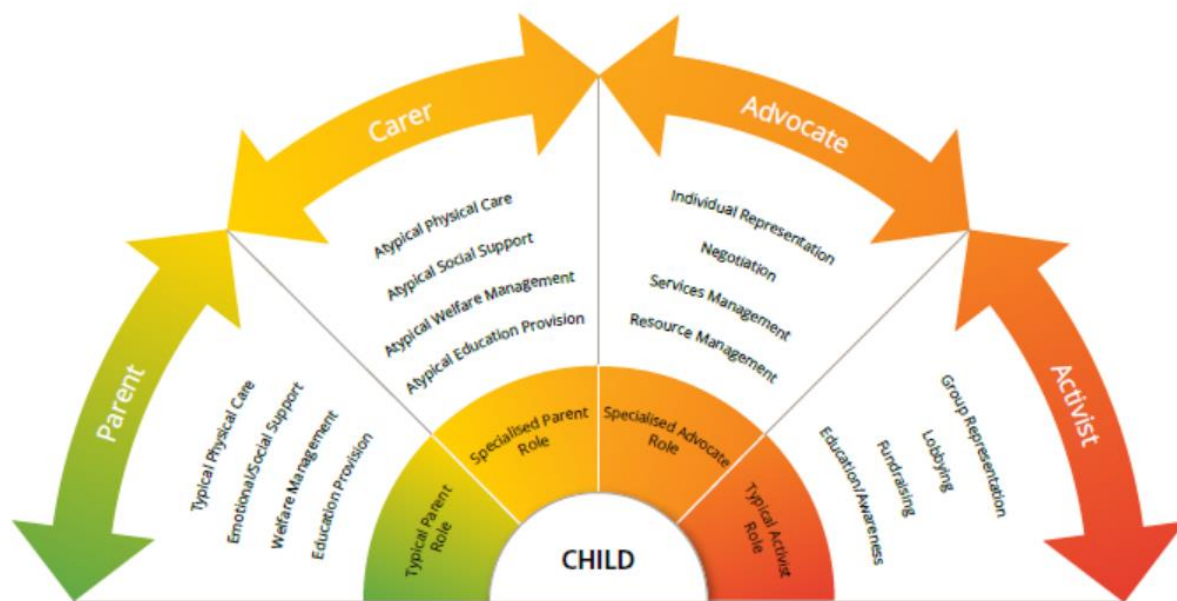
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Figure 4.2: conceptualisation of the parent/carer Role based on current findings

The responses from parents in this study support this theory in that parents who perceived themselves to be capable advocates were the ones most heavily involved in activities that cross into activism. For example:

> We're good advocates for [child], we're a supportive family and we're willing to work with you, we're not going to work against you, was the message that we were taking to the school. – Anna

> (Do you feel you're a good advocate now?) At times. If I'm well informed of the topic, and I often do that by researching myself. Yeah, at times, definitely. – Charlotte

> When I've given the information that I need to give for them to understand what [child] needs. And that's it – that's what advocacy is, for me. Yep. In that professional world, definitely. – Diane

> I still don't know whether I'm a good advocate. I like to think I am. I know I'm the only advocate. I'm probably a lousy advocate for me. - Jo

> I always get told I'm a good advocate because I voice my opinion, and don't settle for, not having results. – Katie

> I have fought so hard for services, everything, all the services we've got we've fought so hard to get. People turn around and say to me, 'You're lucky you've got what you've got.' I go, 'Well, there's not a lot of luck involved in it really.' I had to do hammer and tongs to get what I knew we needed. - Lisa

It is notable that the two parents with the youngest children in this study were the only two whose responses were more hesitant relating to their perception of themselves as 'good advocates':

> English is my second language, and I'm not good at the words like the medical stuff, like a particular one that I miss and then I read information and I get more confused, more nervous, more scared. - Nhi

This suggests that advocacy is a skill developed and honed over time, further supported by the increase in activist activity in the more experienced parents. If advocacy is developed over time, it logically follows that continuing support throughout all stages would be of benefit to families and children. Australia has a robust disability landscape with many funders and providers. This provides excellent opportunities for the delivery of advocacy supports for parents, but the complexity of the systems themselves also present challenges.

4.4.4. The role of effective support systems

4.4.4.1.   The role of formal (paid) supports.

Parents were asked to discuss the professional (paid) supports they accessed on behalf of their child/ren. Every family in the study accesses some form of professional support. Some of those most often identified included doctors and allied health professionals, teachers and other educators, sporting coaches, spiritual supports, and domestic and personal support providers. This is by no means an exhaustive list, but it quickly becomes clear that these children are accessing a large variety of supports that must be sourced and funded, assuming that eligibility requirements are met. Some families had been self-funding very expensive programs of therapy and support such as Applied Behaviour Analysis, a particularly intensive form of therapy that Siobhan and her family could only afford because they made significant sacrifices including the sale of their family home. Other families had received individualised government funding from sources such as the Better Start and Helping Children with Autism

(HCWA). Such programs offered by the federal government enable eligible children under 7 to access approved allied health services and equipment in the critical early years. Your Life, Your Choice – considered by some to be the precursor to the NDIS in Queensland – allowed adult Australians with disability (including the young adults in this study) to largely self-direct their allotted financial resources (Queensland Government, 2018).

For some families, traditional block funding arrangements allowed the child/ren to access services via the Queensland Department of Disability and Community Services (DSQ) and their Family and Early Childhood therapeutic service (FECS). Other large non-government service providers (NGOs) mentioned by families such as the Cerebral Palsy League (recently renamed Choice, Passion, Life) and Equity Works' Respite Plus program also operated under block funding models. Block funding is a funding model targeted toward organisations rather than individuals, and in the context of disability services provides a number of individual 'places' in a given program of support. Most block funded services in Australia have struggled to deliver appropriate services with long waiting lists and rigid support offerings (Bowers, Danner, Powers, & Neu, 2011; Spall, McDonald, & Zetlin, 2005). The NDIS aims to replace these block funding arrangements with individual packages that allow families to tailor their supports and choose their providers, theoretically offering an opportunity for exponential growth in the best performing services. This reflects the central tenet of the NDIS – choice and control for people with disabilities.

For the parents in this study, formal supports provided the treatments, therapies, and physical supports that enabled their child/ren to participate in the community and continue to live in the family home. Parents discussed the different ways they use formal supports. For example:

> When we realised that I was going to be a sole parent and I called on to see what was around. I ended up getting supports when he was three years old, some of which is

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still in place. One of them is a service which is block funded. Since [child] left school, we also have a little bit of post school options funding, which covers about one day of support a week. Then the other support is Your Life Your Choice, which has kicked in. I had to advocate to get that, very strongly. – Lisa

I have funding at the moment for a mental health care plan for her through the government, and Medicare I have for her psychology sessions which she currently engages in and I still get some partial funding for paediatrician appointments, although I still have to pay upfront and I get a rebate. Nothing is fully funded. – Carly

We do Riding for the Disabled [horse riding – hippotherapy], and it's good for coordination but you can see how much it calms him. – Charlotte

With him coming into my life, we now have two – three bureaucracies; a non-government agency which I'm attached to, the child safety officers which he's attached to, and of course, the hospital. The hospital was the biggest support, still is to this day. – Jo

We use Your Life Your Choice [individualised government funding]. We also have a Respite Plus package, which is awesome, has good flexibility, but can only be used for the workers that are registered with them. Most of my workers I work through the Your Life Your Choice because I have more freedom with that money so I can, you know, pay my own rate type thing. - Siobhan

Whilst the availability of formal supports was gratefully acknowledged by every parent in the study, many also spoke about the gaps and issues they have experienced in developing these important relationships. Some of these issues related to a lack of funding support, but there were other concerns as well. Anna, Nhi, Siobhan, and Carly each raised concerns around the level of training or competence of the staff they rely upon:

Some teachers are so scared, they don't want to have a child like that in their classroom, because they don't know what to do. - Anna

I've got a really good work team now, but man it's been hard. We've had some fruit loops along the way and that's a really hard thing for a family to have to go through all that to have to do all that employing. Not everyone can do it. I got to the point well it would've been last year that they pushed me to the edge where I had a breakdown so I just sacked them all. I thought I can't do this, so got rid of them all. – Siobhan

Adding to the complexity is a feeling that the choice of provider is determined not only by availability, eligibility, and funding, but also by other social factors. Nhi explains feeling limited to a single local provider who speaks Vietnamese, her first language. She

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feels this is necessary so that she can absorb and understand the medical information but is not convinced that this provider is right for her family:

> I go to the Vietnamese GP and I feel at the moment that they work for the money, not work for the passionate [sic] of their job. So when you get there it looks like they don't give you time to explain or give you time to talk on your children, and it seem like you have twenty minutes or half an hour and then you go. – Nhi

Further to this concern around the knowledge and expertise of professionals in their lives, Jo, Lisa, and Sarah spoke of their frustration about their lack of control around decisions being made about their child/ren and the flexibility of supports they could access. They discussed the gap between what they perceive as being the right supports for their children and the decisions made by professionals who did not understand or appreciate their needs:

> So they're [Child Safety] more than happy for me to care 24/7, but they will not – well, they have not recognised that he needs permanency and I need decision-making powers for all the issues in his life that - we live in this twilight zone. I have been asking for long-term guardianship to other for over six years now, really fighting the past three years, and the original reason I was given; not going to happen due to his complex needs. Right. That's discrimination under the Federal Law, that's discrimination under the Child Act, that just does – that just takes away his right to a fair and just system. – Jo

> I don't have the level of support for him to have a support worker of his own age to take him up to meet ups, to meet new people, to engage in social things on the weekends… That's the biggie in our life. We've got everything else going really well, the biggie is the opportunities for him to meet—keep up with old friends. – Lisa

> …if there was, like, options of weekends every now then or… that would be good, but at the moment it's pretty set that it has to be those particular hours, so, yeah… it's not really flexible support as such. – Sarah

4.4.4.2.   The role of informal (unpaid) supports.

Under the terms of the National Disability Insurance Act (Australian Federal Government, 2013), parents are generally considered the primary informal support providers for a child with disability. Interestingly, none of the parents interviewed in this study identified themselves as 'informal supports' for their child/ren. Perhaps it is indicative of a

different level of care and investment these parents are making in their child/ren that the informal supports they identified were more likely to be those outside the family home. This may suggest that the National Disability Insurance Agency (NDIA) and families are misaligned regarding the mindset to view parents as informal supports. The NDIS is not intended to replace informal family and community supports. However, it does acknowledge that it must take into account the support reasonably expected of parents and families in making decisions about funding (National Disability Insurance Agency, 2017b). For a parent caring (as the primary carer) for a child with a disability, the notion of what can reasonably be expected is skewed by the level of investment a parent naturally makes in a child.

It is difficult to qualify the level of 'reasonable' support to be expected of unpaid members of a community. Many of the respondents spoke about the limitations of their existing informal supports:

> I just have my sister who is older than me, so you know it gets a bit hard, like she can look after [child] for a day or overnight, but I don't like to ask too much more of her, because [child] is getting less mobile and that sort of thing. Mum was our other support and she passed away a couple of years ago. – Siobhan

> Emotional support is jagged, sometimes. It's not … it's not committed. Like, I'm committed. When I'm tired, I still have to go and look after [child]. There's no one that's committed to me in that way" … "Physical support for me, like saying, "Here, you do that, and I'll go take a week off" or whatever – that's non-existent. There used to be, as they were growing older, the twins were growing older, my sister used to take them for weekends, but I think it got a bit too hard, now that he's older. - Diane

> I have one sister that lives at the Gold Coast and her partner is a quadriplegic, beautiful role model. He has his own business, he drives his own car and his business is earthmoving equipment, all done by remote control. They travel all over the world, that's why I can't use them as support. - Jo

> My mum does still provide informal supports, but she's getting old and my father now has Parkinson's, so she is now, technically, a carer for him and I can't pull her away from that. – Anna

Within their own homes and family units, a few of the mothers in this study acknowledged that the bulk of the care was provided by them although they did discuss their family members' contributions in positive terms:

> He [husband] just doesn't get the opportunity all the time to always be involved with everything that I am. So, I manage [children]'s portfolio of stuff, and when I need help I pull him in to help me, and when he's had to stand up to the plate, he has. – Anna

> My eldest boy. He's 23. He's in between jobs at the moment, so he's helping out. Helps out in every way he can. And vice versa, you know what I mean? So, yeah. It's good. It's good to have him home. – Diane

> Everyone's on board, like my husband as well. Although, he had to ask me the other night about how much medicine she has and I was like, 'how come you don't know this?!' – Sarah

Most respondents, while discussing spouses and siblings – family members living in the same home – did not consider this group part of their child's 'informal support' network as the NDIA would view them, signalling a disconnect between the systemic perspective of informal supports and the parent perspective of family. However, when asked about other informal supports, respondents mentioned grandparents and other extended family, along with community supports such as church, social, and sporting groups. Perhaps this better represents the parent understanding of 'informal support' in the context of the NDIS. For example:

> …the rest of my family is New South Wales. And every school holidays, we go – my mother has a little farm, so we go down there, it's beautiful. Little fellow loves it, he gets to do lots of things that people would put as high risk and he would never, ever, ever get permission to do. Everyone's got their own quad bike, everyone's got to sit on the tractor. – Jo

> Being a single mum and then studying my degree was already a challenge in itself and having no idea, had not much family support around and I met my neighbours which you know when I first moved in they knocked on the door and said hi you know if you need us to help if you need me to help with the kids I'm happy to. They've become surrogate Grandparents and great friends. – Carly

> There is support; there's great support from the special needs community, because you can talk and you can relate, and you can share stories, and you can have emotional support that way. – Diane

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> We have a circle of support. While the circle doesn't give actual physical support most of the time, they are there for—through social and informal support. – Lisa

> Basically, here, we've got friends at church, and we know really well the Pastor's family and they support us quite a lot. - Nhi

This discussion of informal supports provides insights into the lives of the families in the study, but also highlights the differing expectations and experiences of families when it comes to the provision of supports and what might be considered 'reasonable'. This is an area of concern for the operationalisation of the NDIS, which has reportedly taken inconsistent approaches to determining reasonable informal support expectations, particularly for child participants. An Australian Institute of Family Studies (AIFS) report (Edwards & Edwards, 2008) found that carers in the 18 to 50 age group (those most likely to be raising children, and representative of all parents in this study) as those most likely to present with the lowest levels of vitality and the highest levels of depression. Positive family functioning requires healthy, functioning adults with the capability and emotional capacity to foster healthy family relationships. The expectations likely to be imposed by the NDIA around informal care provision are a source of concern for many of the parents in this study.

4.4.4.3.   *NDIS perceptions and readiness.*

The NDIS is in the early stages of rollout in Queensland, and none of the parents in this group had yet had any direct interactions with the Scheme. Many parents in this study had a largely negative initial reaction when asked about their feelings regarding the upcoming NDIS.

For example, Anna spoke about the lack of time and headspace to prepare for this new policy that will impact her family:

> [I'm] scared. Really scared and it's just because I don't know enough about it yet. I haven't had time to go and work out what it's going to do to impact us. - Anna

Charlotte had similar feelings about her perceived lack of knowledge:

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I'm not real comfortable with it all yet… a little bit anxious at the moment, because I don't really know what it is, what it entails, what I need to put in an application, yeah, I don't know a lot about it. – Charlotte

Anna also spoke of a lack of knowledge but was thankful to have an existing relationship with a service provider she feels able to rely upon:

I feel bad for the families who don't currently have a coordination support organisation in their life. We're getting heaps of help from Equity Works to get ready for this, and they will be our advocates for this; I know they will. They will help me work through the system, but other families don't have anything. They don't know what they're doing, and they're going to end up with less than us, again. Which is shit. - Anna

Carly had a more positive feeling about the Scheme, saying she "can't wait for it to roll out." However, she expressed concern about the lack of support for vulnerable families:

I know it's individualised and it's good for some, but I guess not good for others. If others don't have the educational background to know how to advocate for themselves or advocate for their loved ones then they won't be able to get what they're entitled to. - Carly

Diane expressed her concern about upsetting the proverbial apple cart and disrupting the life she has so carefully crafted for her son:

I think… I don't think they're trying to invent the new wheel, but I think they're changing the wheel. I think the wheel was working quite okay before; I think you should just leave it alone. - Diane

Nhi also spoke of her trepidation around changing supports:

I'm scared because we're losing our own team for [child] here for four years already, and then starting with a new one I don't know what's going on with that. They know him really well and support us – will it or not? That's why we worry. – Nhi

Despite the fear and anxiety felt my many of the parents, there was still an element of cautious optimism around the intent of the new policy and the promise of a long-term, tailored, national approach to disability supports:

I'm one of the few people that actually like NDIS and give a damn. It's a brave new world coming in, I get it, I want to capacity-build him to embrace that, not be scared of it. For five years – if NDIS stays true to its fundamental cornerstones, in five or ten years it's going to be awesome. – Jo

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I think I feel good because they said when we enrol, we will have a whole package. We can take that package everywhere in Australia, so they don't need to do assessment again for my child from the beginning. Another thing is I feel is really good is that maybe – if we think about WA and maybe going back there – I'm not scared about assessment or processing the paperwork from the beginning again. - Nhi

Overall I'm positive about it because it's all about choice an control rather than going, 'no, this is your provider because you've got this disability, because you've got this disability this is the amount of support that you get, and no there's no negotiation'. So, knowing that it's about the individual and not about the disability is a big positive but let's hope that some of the finer details are ironed out between now and then. – Sarah

Siobhan was particularly hopeful that the NDIS will improve things for younger families:

I'm excited that there's going to be something for the young ones, because once you hit six [years old] you're dropped like hot potatoes … we shouldn't have had to have sold our house, and live with my sister for 12 years to do what we have done, people shouldn't have to do that. That's what puts pressure on marriages, that's what causes suicide, it's just not right. Hopefully NDIS will save that.

It may seem a stretch to suggest that the introduction of this Scheme might reduce marriage breakdowns and suicides, but in light of the AIFS findings described above, perhaps it isn't an unreasonable expectation.

Some of the other expectations discussed by the parents were more practical, but highlight again the variety of supports families are seeking, even among child cohorts with similar challenges as they grow alongside their age peers:

I hope it covers more than just the occupational therapy, because now they're talking about speech therapy and all this other stuff, but it becomes, like I've had to apply to my super a couple of times just to get money to help pay for things to meet his medical needs. – Charlotte

I would like her to go to the movies with a carer close to her age, or just make her a little bit more independent. – Katie

I hope that once we get to that point that all my supports can be managed and flexible. We have an ongoing issue with a provider that we can't get out of. Roll on the NDIS and hopefully we'll be away from them. – Lisa

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However, service delivery was raised as a potential issue and Siobhan raised concerns around the readiness and growth of the disability services market, and the dangers of a fast rollout when she said:

> People have got planners that really don't know really anything about disabilities and we're going to have this bunch of carers coming through that are going to have a three buck qualification off an online course" ... "so the Cert III that parents are going to use in vetting their carers, putting their kids into community activities, what are these carers going to be like? - Siobhan

Some respondents reported discussing their expectations and anxieties around the NDIS with trusted existing support providers with mixed results. Whilst some had been positive and knowledgeable, others had been more negative. This is perhaps an indication of just how influential these established relationships can be, when Diane's expectation of the NDIS was that it is ambitious but doomed to failure. She cites this piece of advice received by her child's treating specialist: "My paediatrician, being so supportive – his advice was, 'If you register – doesn't matter what you think of it – just register. And then any benefits that are left once it explodes, you will get them.' And that's my view on it, because that should say everything that I think of it."

Despite the palpable mixture of fear, hope, and caution evident during the interviews, all parents had intentions of applying to the NDIS when it became available to their children. Some discussed their efforts to prepare for its arrival, and Anna spoke about her confidence that an existing relationship with Equity Works (an NGO service provider) would continue to be a source of support for her family throughout the NDIS processes. This was a sentiment echoed by many of the parents, who almost universally expressed concern about families without those existing relationships to depend on.

Siobhan spoke about her perception that attending readiness sessions too early would not be helpful:

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> I've been to NDIS workshops. I've had one on one meetings, Horizon [existing support provider] had a lovely guy, he was really good, but I'm the sort of person that I'll go to someone like that and if it's not happening straight away so much more happens then I lose momentum, and they do seem to move the goal posts. - Siobhan

Many of the parent participants in this study had attended NDIA-funded introductory workshops delivered by a variety of local NGOs. They reported a spectrum of information and advice ranging from the very low end to a moderate level of support. Sarah had attended a number of sessions herself and offered feedback that highlights this inconsistency well:

> Some of them were good, Some were a bit airy fairy, like one was 'what do you know about NDIS?' and that's what the whole three hours was about, and they were saying 'oh, that sounds like a good idea…', and one had families talking about what they've gone through with the process in the trial sites in South Australia, so getting their positive stories was good. - Sarah

Jo's little boy is in her long-term foster care, and their challenges with NDIS are unique among this cohort but common among children in out of home care. Jo has spent considerable time and effort attempting to clear the way for parents like her to engage with the NDIS on behalf of their children:

> Now everyone goes, 'But Jo, you have to come to the planning meeting'. 'Yeah, I know, I know. Haven't got an invitation'. I have now. I marched for the NDIS 30 years ago, so I'm a big fan of it. When they first announced it what, four years ago, and then Queensland hadn't joined… but two years ago, they brought in the Queensland NDIS check-up. Jumped online, yeah of course, right, brilliant. Made a few phone calls to the NDIS every now and again, went to a lot of workshops; and again, a workshop where I can't stand up and go, 'What about this cohort? [children in care]' so I've – you know, tried to educate myself around it, I think I'm up to Version 35 of the plan before the planning meeting, hoping to get long-term guardianship to avoid this migraine that's coming along. Thankfully all the services – I've had years and years of rapport with them, they do get the situation, but because of the rules around NDIS, they now have to talk to Child Safety instead of me, so I'm just being left out. At the end of the day, that is just going to have a negative impact on the little fellow. - Jo

All parents in this study were aware of the existence of the NDIS, although some had not yet engaged with the Scheme on any level. They cited reasons ranging from fear and anxiety to a lack of local NDIS events, but all were looking for opportunities to educate themselves about it over the coming months:

I still haven't had any conversations, I still haven't done anything… we're doing a program meeting in the next couple of weeks to go through what I feel we need to be providing to the NDIS for our support. If I can educate myself in how to be a better advocate for NDIS, why not? Yeah, definitely. – Katie

I need to register with them first… and then, no, there's no preplanning available here yet. - Diane

A lot of it is not new to me, but yeah I do have fears – and for other people. I know that it's going to be a difficult time in our lives. I'm not looking forward to it. Also, this is the biggest change that we've had—but I've had 20 years of different systems thrown at me: 'Now you've got this, now you've got that.' – Lisa

It is interesting to note the recurring theme of concern that parents had for their peers, further articulated by Sarah when she said:

I do worry about those who aren't informed or don't' have the capacity to get the best plans for themselves … it's definitely worrying for those who don't have the experience, people who are unable or unwilling to attend meetings around NDIS or aren't even aware that there are meetings happening. - Sarah

This concern for others reinforces the suggestion that most parents – even those not currently engaging directly in activism – are considering their peers and those who will come after them, identifying issues in the system. This supports the conceptualisation of 'parent carers' existing on a continuum such as Figure 4.2 presented on page 77 of this document.

4.5. Discussion.

The parent respondents to this study were recruited and interviewed individually. The interview guide was semi-structured and allowed each respondent to speak freely about their experiences. Despite their differing backgrounds and family structures, the variety of ages and diagnoses of their children and young adults, and their locations across Queensland, their stories shared some common thematic elements. All parents believed advocacy to be a natural, intuitive, and necessary function of parenting a child with a disability. Although they reported differing levels of skills, activity, and confidence, all were actively engaged in advocacy. Activities described ranged from advocating for their own child to a single person in a single situation such as a doctor's appointment or parent-teacher interview to activist

activities such as the establishment of incorporated not-for-profit peer support organisations or lobbying the government for change.

Every respondent spoke about the need to develop the skills and confidence necessary to ensure that their child/ren had every opportunity to succeed. They identified peer support as a significant factor in building their capacity to advocate, driven by common factors such as a lack of information, a fear of speaking up in intimidating environments, and social isolation. The benefits of peer support were clear and common among respondents – a reduction in feelings of isolation, an increase in knowledge and confidence, sounding boards and advice from credible sources, physical and emotional support, and the ability to pool and share resources. Parents did acknowledge the limitation in any peer group of the members' collective knowledge and experiences. All participants spoke of the importance of structured or professional input into their capacity building such as education and workshops provided around particular topics of interest. This was considered particularly important during periods of change or transition, and many parents cited the NDIS as an example of this.

The supports around a child with disability must extend well beyond the scope of parents alone. Respondents discussed the role of professional supports and services such as doctors and other clinicians, therapists, teachers and educators, support workers, coaches, pastors and others. These roles are generally well understood although many parents reported challenges in accessing them. More difficult to qualify were the informal supports such as grandparents, extended family, friends, neighbours, teammates, church communities and the like. All respondents spoke about the importance of having these people involved in their child's life but reported different levels of association and activity. Some parents reported a large group of informal supports but none having a daily presence in the home, whereas others spoke about a single supporter such as a grandparent or sibling etc whose support was regular, physical, and/or manifest. This implies that it is not simply a matter of how many

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informal supports exist around a child but how much of which kinds of support they provide and the quality of that care. It is also worth noting that satisfaction with informal supports is very individual, with some parents whose support base was quite small feeling that it was enough and others with a large pool of support feeling they needed more. This is likely to be a complex area from the perspective of the NDIS.

Although the distance between the role extremes illustrated by Figure 4.2 - a typical parent and a typical activist – could be considered dichotomous, they are joined by the intermediary roles of specialised parenting and specialised advocacy. Each subsequent role demands a particular set of skills and attributes that a parent/carer must develop in order to effectively pursue their child's interests. It could be argued that parents who become confident advocates are best placed and more likely to move into the activism space, which moves their focus beyond their own needs and necessitates the development of positive partnerships with other community members and service providers.

All parents in this study spoke about the importance of building and maintaining positive relationships with the professional supports their child accesses. They spoke about the benefits of clear and open communication and proactive planning. However, they also spoke about the experience of negative or poor relationships and their impact on the quality of care they perceive their child to be receiving when the relationship is not one of reciprocal trust and respect. It is important to consider the concept of parental advocacy not just from the parent perspective but from the service provider perspective as well to optimise the opportunity for positive, productive relationships and improved outcomes for children. The next study in this program of research sought to understand the perspectives of those service providers and professionals to whom parents direct their advocacy. These perspectives are presented in chapter five.

Chapter Five: Service Provider Experiences of Advocacy

5.1. Introduction

It is impossible to examine advocacy effectively without considering the perspectives and experiences of the professionals to whom parents direct much of their advocacy effort. These relationships range from occasional contact such as funding providers and service coordinators to very close, ongoing, and long-term associations with families, particularly in the context of education and direct therapeutic supports. Whilst the level of contact a provider has with any one family may shape the type of relationship they are able to form with them, Sheppard et al. (2013) reported that parents do not universally present to long-term therapists as willing advocates for their children. They discuss a range of presentations such as parents who are generally disengaged from the service and do not attend appointments with their child/ren or have contact with therapists; those who perceive themselves as an extension of the client (patient) to whom services are being delivered; and fully engaged partners, directors, and coordinators of/in their child's care. These differences in approach by families necessitates a variety of responses from the service providers, key to which is the ability to accurately assess a family's needs and expectations.

Trainor (2010) described a further variety of advocacy styles presented by the parents of children in the special education sector in the United States, suggesting that there is more to consider than simply the willingness of parents to engage in advocacy. She outlined four broad parental advocacy strategies that have been consistently observed within the interactions of educators and parents and their strengths and limitations. These were introduced in the Literature Review chapter but (briefly) they are (1) the intuitive advocate, reliant on knowing their child/ren; (2) the disability expert, educating providers about the child's diagnoses; (3) the strategist, focussed on understanding and exploiting the system/s; and (4) the activist, concerned with improving the circumstances for larger groups or those

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yet to come. This implies that beyond the willingness to engage in advocacy, there is considerable diversity in the ways in which parents exercise their skills.

Many service providers throughout the world have responded to these complexities by engaging in family centred care practices, particularly after the Surgeon General of the United States publicly called for "coordinated, family-centred, community based care for children with special health care needs and their families" (p25) at a family-led conference in 1987 (Kuo et al., 2012). This was followed by sweeping policy changes starting in 1989 when the Maternal and Child Health Bureau's mission statement was altered to better reflect the role of families in the delivery of care for children with special needs. Whilst there are some consistent principles applied to the practice of family centred care, there has been no strict consensus on its meaning (Johnson, 2000; Jolley & Shields, 2009). Some of the broader underpinnings of family centred care include information sharing, partnership, collaboration, and negotiation.

There are many research studies that demonstrate the improved outcomes associated with effective family advocacy – and specifically the influence of service providers in empowering parents to engage (Brookman-Frazee & Koegel, 2004; Dunst & Trivette, 1996; Rosenbaum, King, Law, King, & Evans, 1998). The approaches of the service providers in these studies draw from the principles outlined above by implementing parent education initiatives, a partnership approach to decision-making, and a flexibility in the way services are delivered including individualising programs to suit the specific needs and expectations of families. Every study was able to demonstrate improved satisfaction ratings from families regarding the service and – more importantly – improved health and wellbeing outcomes for the children. It is demonstrable that service providers and their approach to family centred care and parent advocacy is a critical piece of the proverbial advocacy puzzle.

5.2. Method

The third study in this program of research sought to explore the collective professional experience of a group of disability support service providers to identify the factors that influence – both positively and negatively - family-system interactions. Focus groups provide an opportunity to economically and efficiently collect data from multiple participants in a socially oriented session that facilitates and encourages open discourse (Krueger & Casey, 2000). The subject of this study – parental advocacy and it systemic 'fit' – touches multiple systems, and the ability to consider the perspective and approach of a variety of service providers at one time reflects this complexity. This study received ethical approval on 15th November 2016 from the University of Southern Queensland's Human Research Ethics Committee and was included in project H16REA245.

Two 2hr focus group sessions were held. Each included at least one regional representative, and videoconferencing was offered to support attendance. Each group was limited to a handful of participants, offering a breadth of experience but so as not to silence any individual voices (Krueger & Casey, 2014; Moreland, Levine, & Wingert, 2013; Onwuegbuzie, Dickinson, Leech, & Zoran, 2009; Ritchie, Lewis, Nicholls, & Ormston, 2013). A multiple category design was implemented (Krueger & Casey, 2014) whereby the three participants represented a variety of normalised levels of family interaction in their roles, i.e., little or no contact, occasional consultations, or close working relationships. Using this strategy, the research was able to address the position that there may exist a relationship between the frequency and quality of contact with families and alignment of priorities and values between providers and the families they work with. Heterogeneous sampling yielded a broad cross-section of experience (Ritchie et al., 2013), in this case ensuring that a variety of organisations were represented, each with differing levels of family contact.

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Collected data was analysed using NVivo to code for major thematic elements and patterns in keeping with the frameworks provided by Braun and Clarke (2014). Analysis sought common understandings about family advocacy, its development, strengths and weaknesses, and its fit within systemic interactions at each level. Commonly repeated phrases or terms were highlighted as well as individually powerful statements relating to the themes. Themes and perceptions were consistent across the two groups so rather than present separate analyses, this chapter will approach the analysis of the data corpus as a whole.

5.3. Participants

Participants were recruited via a purposive, targeted recruitment strategy that sought to include all large Australian mainstream services for children and a variety of non-government services. A total of eight participants contributed to two focus groups, representing numerous service provisions and levels of engagement with families. Details of the participants can be found below.

Table 5.1 *An overview of participants contributing to the focus groups in Study 3*

Name (pseudonym)	Role	Sector	Level of ordinary interaction with individual families
Group 1			
Helen	Early Childhood Educator	Public education	Frequent
Louise	Registered Nurse/Midwife	Public health	Limited
Eliza	Occupational Therapist	Private practice	Frequent
Ashley	Disability Funding Administrator	NGO	Occasional
Group 2			
Ciara	NDIS Transition Officer	Public health	Limited

Suki	Rehabilitation Physiotherapist	Public health	Occasional
Stephanie	Visiting Advisory Teacher	Private education	Occasional
Shannon	Carer Support Officer	NGO	Occasional

The professionals in these focus groups between them represent the public and private sectors of health, education, and disability service organisations. They self-identified levels of ordinary interaction with individual families (that is, repeated interactions that enable relationship-building) at either frequent, occasional, or limited. However, all respondents did report regular interactions with parents as a normal function of their role/s.

5.4. Findings

There were three main themes evident in the service provider focus group discussions. These were (1) advocacy in practise – the consideration of what advocacy means in the context of their service; (2) factors impacting advocacy in service delivery – the use and success of family advocacy and the factors that affect this; and (3) family readiness for the NDIS – a discussion of both provider and family expectations and family preparedness for the incoming NDIS.

5.4.1. Advocacy in practise.

The first theme to be identified in the focus groups concerned the practice of advocacy as experienced by the professional sector – in other words, the sort of activities parents were engaging in that the providers considered advocacy in practise. Some participants spoke about the pragmatic, practical approach to advocacy:

> You have some parents that are clear and know exactly what their child can travel to and really they come in and say, 'Well you know, you need to start funding this year, we can access this, this, this', you know, 'I meet the criteria and he should be able to get this…' – Helen, Early Childhood Educator

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I know one single mum who's got seven children and a couple of grandchildren and a young man with significant disability who is amazing. Like absolutely amazing, and she lives in [a regional Queensland town], which isn't the most service-riddled area, but she's really good at it, because she had that consistent information and is – and now goes, 'well this needs to continue'. – Suki, Paediatric Clinical Physiotherapist

For some families, though, a more holistic support is required. Eliza discussed her sense of responsibility in supporting the whole family, not just the child, in her role:

…it's a lot more counselling and support sort of for mum and dad rather than the child. I guess it's just shown in different ways, but I think parents always want the best for their child, and it's just what state they're in and what grieving stage they're in as best as I can tell, how quickly they can jump in and you know, follow strategies. – Eliza, Paediatric Occupational Therapist

The participants reflected that families present at appointments in very different ways, and the professional response must therefore reflect this. Every focus group participant acknowledged this challenge and described an almost triage-style approach to their professional practise when it came to expectations and support of advocacy in the parents they work with. For example:

…it's really based on how much knowledge the parent has…"; "some parents come to therapy and they're in that really early stage of grief…"; "every parent's experience is different and it just depends on how receptive they are to that sort of information…"; and "I think there are a lot of other factors and others for the parent being able to access the help they need at home and it's not being – well, there are just bigger things that end up being a priority for their family… Eliza, Paediatric Occupational Therapist

All participants noted that despite the differing presentations, the underlying interest that they recognise in all families was best summed up by Helen:

It varies from parent to parent, but I think they're all invested in supporting their child the best they can. – Helen, Early Childhood Educator

It is important to note that all respondents – regardless of the level of family interaction they had – espoused the importance of working in partnership with parents. However, examples offered reflected the differences in the depth of these relationships well. For example, Eliza worked as an occupational therapist in private practise and saw most of

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her clients regularly over a long period of time. She was therefore able to develop meaningful relationships with parents. Of her role in supporting parent advocacy, she said:

> I felt that if you were supporting a new family with advocating and they weren't doing the best job that you, as a therapist, felt they could be doing, I think I would personally then reflect, 'Okay, how can I grade this down so the parent does feel still empowered and is advocating for their child on a smaller level?' I feel like it's my responsibility then as a therapist, to support that family. When you support a child, you don't support just the child, you support the whole unit. Advocating for your child, I think, is super empowering for mum and dad - so I would really want to think of a way that I can still do some ground work so mum and dad still feel that they are advocating, and it is them. – Eliza, Paediatric Occupational Therapist

Helen, an educator in a public early year's program for children with disabilities had a similar level of opportunity to form lasting relationships with families. She spoke about the value of peer support for parents and her ability to influence and facilitate helpful peer interactions. This was also a key finding from the parent interviews and it is important to note the alignment:

> I was talking to a mum and she said, 'You know, we all sit outside the building, waiting for the children to come out, and we don't talk to each other,' and she was talking about - I think they felt so judged for so long, that they don't want to put themselves out there, and they don't want to build those relationships. And I said to her, 'But you are all here for the same reason. You're actually all in the same boat', and I said, 'Maybe you need to be the one who does say hello first' and she was like, 'Oh, oh I don't know about that.' – Helen, Early Childhood Educator

Eliza agreed, reflecting on the tangible benefits of parents supporting one another:

> It really empowers– when that social connection is made, so many other of those mums then feel empowered. I had an example of one child's mum who said can she get access to this type of appointment? And I said, 'Yes, we can put that through x and y…' and no joke, about 10 minutes later, I got a phone call from one of the other mums who was friendly with the first mum and said, 'Hey, I've heard that you've accrued this for this child, is my child eligible for that?' and they all kind of network and support each other advocating. Because sometimes it's scary to be – stand up and be brave by yourself, but if you know someone else has done it or you know, you're doing it together with someone else, it's easier. – Eliza, Paediatric Occupational Therapist

Suki – whose role as a paediatric physiotherapist in the public health system affords her contact with families that ranges from the short, intense treating periods to the long-term occasional support – offered an example of parent-led advocacy:

> One dad is an IT engineer, and I'm not quite sure what mum does professionally, but they have done an amazing job at actually pulling all services and all teams within the hospital together to actually have a weekly family meeting, so – and they come with their list and their notepads of questions and research that they've done, and what they think and what they feel. – Suki, Paediatric Clinical Physiotherapist

Louise's role as a nurse working within the child and youth mental health service is similar to Suki's in that her client relationships vary from the short-term intensive support to the longer-term outpatient environment. She provided another example of a parent driving her child's care:

> I started reflecting and trying to figure out what impacts her capacity to be such a good advocate for the child? And I tried to break it all down, and I think the things that come to mind as to why she's so well-equipped was that she has a really switched on – a really good, supportive – social network, she's got extended family involved, she's got a really good group of friends, she taps into – she builds with social supports, even in new situations. So this year, her child's moved schools. There was only one other – one or two other kids at the school with a disability, and right in the first week, she got in contact with those two parents, organised a morning tea at her house, invited some of the other kids' parents that were going to be in her child's class, and started building this beautiful network of support. She was super-confident, she went in and she really involved her child's therapy team in all of those steps, so going to the school meeting, 'This is my child's OT, this is what he's been doing, and she's going to talk about how you, as a school, can support [child] from an open perspective' and she had his physio, she had his speechie [speech therapist], she had everyone involved, and I think she's a good advocator because she really taps into all of these supports. – Louise, Registered Nurse, Child and Youth Mental Health

Ciara and Ashley – whose more administrative roles within the public health and NGO sectors respectively – spoke about the parent population more holistically, in terms of the supports that could and should be available to enable families to more confidently navigate complex systems.

> Sometimes the different services have a tendency to think of themselves in a silo. So parents can often seem combative to, say, the school, or to health, and sometimes we forget that parents aren't just advocating for their child in that one area, that they are advocating within Centrelink [federal social services], they are advocating within the

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school, they are advocating with the NDIS, and then also within health, and just the amount of time that that can take alone, let alone the emotional and physical demands that it takes, that sometimes people are seen as combative when it's actually just really stress. – Ashley, Disability Funding Administrator

I think that parents should be – need to be the case manager, but it's about the supports that are put in around families to be able to do that. Like there's – you know, I absolutely believe that all families have got the capacity to make decisions in their best interests, and every family is going to need a different level of support around them to do that. – Ciara, NDIS Transition Officer

It is possible to view these examples in the context of the levels of advocacy as described by Wright and Jaffe (2013) – micro, mezzo, and macro. Wright and Jaffe refer to the subject of the advocacy – micro being one child, mezzo a small group, and macro a large population – but it fits with the above examples to consider these levels in terms of the closeness of the relationship between families and providers and its effect on joint or complimentary advocacy practises. The professionals with the very close relationships with families appear more likely to be direct participants in the advocacy, fitting the micro scale – advocating for one child at a time. Occasional family contact appears to lend itself to a partnership approach involving other service providers where parents are capable drivers of their child's care. Those with less direct family contact appear to be considering the role of the system more generally in supporting all families to develop and exercise their skills, particularly as they do not have the opportunity to become involved in any one child's care.

5.4.2. Factors impacting advocacy in service delivery.

Participants in the focus groups each discussed the impact of advocacy on the delivery of their services. Discussion centred on the way in which the level of advocacy skills and the parents' willingness to engage them influenced their professional practise. Many respondents spoke about the difficulties presented by the sheer availability of information accessible to families, not all of it reliable or accurate. Some parents were considered to have the capability

to discern the information presented to them and look for second and third sources before

committing their energy, but others were not able to do this. Suki explains:

> …they [parents] can do a lot of Googling which gives them misinformation because it's not all credible sources, and it's not the exact fit of information for their child, so then they often just find the worst of everything. – Suki, Clinical Paediatric Physiotherapist

Helen offers a similar cautionary tale regarding the spread of misinformation:

> [Parents often] bounce ideas off other mothers or other families they know that have children with similar diagnoses… to predict how this will impact their child, 'Oh, my child has this, which is what your child has, isn't it? Oh, is this what I'm up for?' Like looking at the future going, 'Your child behaves this way, does this mean that my child is going to behave this way or is this how it's going to be?' – like they sort of anticipate a future of difficulty when it doesn't have to be that way.- Helen, Early Childhood Educator

Helen also spoke about the need to dispel myths and misinterpretations in her role as

an educator. She discussed one example where a child was transitioning from her early year's

specialist education service into prep (mainstream schooling). The child's mother had

concerns about her son's sensory issues manifesting as negative behaviours in the classroom.

Helen said (to the parent):

> 'That's something that maybe we need to think about and work around when you go in for your prep interviews, that you need to tell them … so that they know right from the beginning, they can plan for him.' And she [the parent] said, 'Oh, can they do that?'

Helen discussed experiencing feelings of sadness when she realised that this parent

had assumed that her son would be placed wherever the school wanted him to be, that she

wouldn't be able to influence or inform it because it was their local zoned public school:

> She was shocked that she could go into the interview and say, 'This is my son, these are his needs and what he requires to be managed, and can you facilitate something around that?'

Stephanie was a visiting advisory teacher in the area of special education for the

private education sector. She had also experienced difficulties relating to a lack of

information or even acknowledgement of the issues facing the children she must make recommendations for. She discussed a remote rural area where many children experienced hearing loss caused by local environmental factors that have been plaguing the community for generations.

> It's really difficult because it's one of the invisible disabilities; it's been an area that's extremely difficult to gain traction with - with families first and then within the school and the community. Making sure those children have access in our classroom, making sure that the schools are prioritising sound field systems and all those kinds of things that again, I suppose when the parents have perhaps been in similar circumstances, they don't view it as a disability, it's just something that just happens and you just deal with it. - Stephanie

Stephanie also spoke about her experiences in two remote Queensland towns where the largely Indigenous parent population presents with a cultural reluctance to engage with the system.

> Very quickly, they actually give up their power by assuming they don't have any power when they do, so that creates a lot of concerns as well, and it's very difficult then to engage them in the process of NDIS or whatever because of their whole experience of trying to interact with agencies or systems which haven't often been positive. – Stephanie, Visiting Advisory Teacher

Ciara works within the public health sector, developing a consistent systemic response and transition service to assist families into the NDIS. She spoke of the destabilising influence of changing or unpredictable conditions in the development of advocacy skills.

> Children in services like our rehab service or our oncology service or our palliative care service where they are newly applied or newly understood, all conditions that have sudden unexpected changes in function, that I think that that's really – that's really destabilising for families as they're developing the skillset and the mindset to advocate for their child's needs – that instability that just comes with childhood full stop and then the additional instability that can come with certain conditions and uncertain trajectories. – Ciara, NDIS Transition Officer

In each of these examples and others like them, the professional response has been to redouble the effort to support the families through their systemic interactions, a role with which all the respondents are confident and comfortable. However, the participants also acknowledged that this advocacy support is often perceived, by the establishment if not the

professionals themselves, as an extension to an already-stretched mandate to provide hands-on teaching, clinical, or administrative supports for children.

The two groups discussed the difficulties caused by disparate systems, each with their own rules and regulations, and their own language and interpretations of legislation. Most of the providers in these focus groups worked within a single service, but Ciara's role was focussed on where two major services (health and the NDIS) meet. She said:

> We've had a lot of families where health says this is a stable condition, this is lifelong, this is whatever, and then NDIS are saying, 'Well no, not necessarily, and we need more information around why that is. Why is that health professional saying that this is definitely lifelong, all these things, but there's nothing to – well there's no evidence,' or the NDIS can't accept that evidence, but the poor parent is in the middle going, 'I just don't know because five different people have now told me five different things.' - Ciara, NDIS Transition Officer

The NDIA has published guidelines that delineate the responsibility mainstream systems and those of the NDIS (National Disability Insurance Agency, 2014). However, families continue to report gaps between the largest systems such as health, education, and the NDIS that directly affect their children's wellbeing (Foster et al., 2016; Mavromaras, Moskos, & Mahuteau, 2016; McIlwraith, 2014). These ill-defined boundaries also negatively impact the ability for those around the child – parent and service provider alike – to effectively advocate on the child's behalf when it is difficult to identify the decision-maker at the outset. A very robust understanding of the various legislations and policies that underpin these complex systems is often required to work within them, but this presents an unrealistic expectation of families and specialist service providers.

Given the limited availability of specialist advocacy support services for the parents of children with disabilities – especially cross-system advocacy – it is concerning to observe such a high level of need occurring among the populations serviced by this group of professionals. This clearly demonstrates the existence of a significant gap in the services

available to children and families – not simply the frontline clinical or educational services, but those less tangible supports required before some children even arrive at the provider's doorstep. The NDIS may provide some opportunity through building a community of supports around a family that enables full and equal access to citizenship for the child – a central tenet of the Scheme. However, these supports cannot be implemented until a child is successfully participating in the Scheme itself.

5.4.3. Family readiness for the NDIS.

It is clear that the providers in these discussions saw the need for supportive professionals and communities throughout the NDIS rollout process. For example:

> You just don't give a kid a bike and expect them to ride it; someone has to walk beside them with the bike and set of training wheels on and you go to a safe place, and it's a process. Some kids learn to ride the bike a lot quicker than other people who've tried it, but there's a lot about that trust and relationship building that is required in terms of the person learning to ride the bike. If we're talking about newly acquired or newly diagnosed disabilities, then I think trust and relationships is key. – Ciara, NDIS Transition Officer

Ciara also discussed the NDIA reports showing that children are the largest group of NDIS participants enrolled so far (National Disability Insurance Agency, 2016). She theorised that it is their parents' experiences with other individualised funding schemes, such as Better Start and Helping Children with Autism (HCWA), that have provided the 'training wheels' that give families the confidence to become early adopters of the NDIS.

> I would love to see some research that looked at why has the 7 to 14 age group in the NDIS have been super-uptakers? And my theory is because it's that group of families who saw the benefits of having some control and making informed and active decisions for their children, and they've stepped up to continue that. – Ciara, NDIS Transition Officer

Stephanie agreed with this observation, adding:

> I also wonder if they've actually had a positive experience as well in terms of – so I'm thinking of some of our rural kids who've been given the opportunity to actually fund private therapists through Better Start, whereas before they would've had access to nothing. So I think they've kind of been placed on this treadmill that's like, 'Right,

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well therapy's been great, this is what we've seen, this is where we've – what we've achieved, therefore I want this to continue.' – Stephanie, Visiting Advisory Teacher

Ciara spoke about her hope that the NDIS would progress a long-stalled conversation about holistic responses to complex needs in the community. She has observed that services are often compromised not by a dearth of resources or knowledge but by the complexity of a multiagency response:

> Multisystem navigation has been a massive issue for a really, really long time, and I don't know, maybe I'm Pollyanna [sic] about these things, but I'm actually excited about the conversation that the NDIS is starting. For the first time that I can remember as a health professional always working with children, we've actually now got this conversation happening, and I'm kind of excited that we can be shaping and informing this conversation, and I think that families, and particularly families of young children – I do think we see a difference in the skills and capacities– you can buy into that different generational thing or not, I guess; but I do think that young families have got a different sense of empowerment around understanding building networks around themselves, learning about the systems and working out how they engage. – Ciara, NDIS Transition Officer

However, for families whose children's disabilities are newly diagnosed or recently acquired, some providers expressed concern about the confronting discussions the NDIS forces onto unprepared parents. Suki sees this regularly in her paediatric rehabilitation role:

> One of the concerns that our rehab services had around the NDIS in terms of parent advocacy is that it's actually forcing the conversation about lifelong disability much earlier in a family's experience… so what used to maybe be a gentle handover to an NGO that was block-funded to provide those services and supports to that family in the community, is now an upfront discussion about the fact that your child is not going to recover fully from the injury or the accident that they've had, and that actually, we now need to make an application to a lifelong disability service sector. – Suki, Clinical Paediatric Physiotherapist.

It is observable in the shared experiences of the service providers here and the parents in the previous study that the support offered to families through these early funding schemes is a significant influencer of confident engagement with the NDIS. It is also a key finding of the systematic literature review that existing supportive professional relationships result in more positive engagement and improved outcomes in the context of the Scheme. This is an important point because as the NDIS rolls out, the earlier funding sources will cease to exist.

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Families who do not have the capacity to privately fund support will not have the opportunity to build these crucial professional relationships ahead of their engagement with the NDIS.

5.5. Discussion

It was the intent of this study to examine the perspectives and experiences of the professionals to whom parents advocate. It is evident, however, throughout the tone and content of the data corpus, that the professionals themselves also identify as advocates for the families they provide services to as well as the target of parental advocacy. It is interesting to consider, then, whether advocacy in this context is almost cyclical or at least chain-like in nature, even when there is a clearly defined target, objective and/or timeline. Families advocate to the service providers on behalf of their children and service providers advocate to the larger system on behalf of families, while the system's decision makers and policy writers are engaged with family advocacy through political lobbying (politicians in turn advocating for communities) and other forms of direct activism.

The principles that underpin family-centred care are evident throughout the collected data. Service providers across the spectrum of family relationships spoke about the importance of sharing information with families. Some of this was related to tracking service performance – giving information to enable families to recognise issues or monitor progress at home. This in turn allowed providers to indvidualise the service to better meet the needs of the child and their family. Some information sharing was more directly geared towards improving service outcomes, providing information to assist families in partnering and collaborating with them in the provision of care. This may involve giving parents the tools to implement plans in the home and in the community or providing formal education opportunities such as parent information sessions or hands-on workshops on specific subjects. Central to the themes of parent empowerment was the understanding that you must "meet parents where they are" (Eliza, Paediatric Occupational Therapist) – that part of good service

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provision is understanding what the family expects from them and having a variety of tools and techniques to help them respond to the diversity of needs.

All respondents spoke about the challenges of cultural and linguistic barriers in service delivery and the need for services to better integrate inclusive practices to mitigate these issues. The root of this issue seemed to be in effective information sharing and its role in building positive and productive relationships despite these barriers. Other socio political factors such as parent education, economic participation and resources, health literacy, and complex family situations were challenges experienced by all participants, and all expressed concern about the supports available to disadvantaged children and families. A shared feeling of responsibility for helping families – especially those experiencing disadvantage – was evident. The biggest factor in the success of partnering effectively with families was perceived to be quality of service provider relationships with the adults in the children's lives. This was a theme that came through most strongly in the group of service providers whose contact with families was long-term and regular in nature, although it was acknowledged by all. Service providers whose direct client contact was occasional or limited spoke more about the larger systemic perspective of parents' advocacy than those with closer relationships, whose advocacy was more direct and specific.

Many service providers acknowledged the challenge in balancing the sometimes-competing interests of the families, their own organisations, and the larger system. However, they universally perceive their highest responsibility to be that owed to their client and their families. The move to individual funding means that many therapy providers will need to move to hourly billing of services. Some of their activities identified during the focus groups would normally occur outside of the therapy room. Under the individualised funding arrangement, it is conceivable that organisations may exert pressure on therapists and other providers to maximise their billable hours. This may come at the expense of other family

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supports such as making phone calls on behalf of clients that often involve a lot of wait time or coordination. This could present an impediment to the positive, supportive relationships they nurture with families, which was perceived as an addendum (albeit a natural and critical one) to their service delivery.

The knowledge acquired from this and the previous study as well as the broader understandings from the literature reviews informed the design and delivery of a pilot capacity building program, which is presented in chapter six and makes up the final study in this program of research.

Chapter Six: Capacity Building Program

6.1. Introduction

The notion of training parents in the skills and competencies of advocacy is not new. In the early 1980s Baker and Brightman (1984) delivered a four-week program of training in the United States aiming to upskill the parents of developmentally disabled children in one of two areas – Parent as Teacher and Parent as Advocate. Parents in their program/s were randomly assigned to a stream and subsequently evaluated for knowledge and skill across two areas: behaviour modification and advocacy. Baker and Brightman found in their evaluation that all participants demonstrated gains specific to their training program (teaching or advocacy). Since this time, parent training in the ethos of the first stream – Parent as Teacher – has developed to empower parents as partners in the delivery of clinical services, especially in the case of intensive delivery such as Applied Behaviour Analysis (Keenan, Kerr, & Dillenburger, 2000; Smith, Buch, & Gamby, 2000; Van Houten et al., 1988).

The development of parent advocacy training across a similar timeframe has however been less robust. Perhaps this is because the benefit of such training is not as tangible or easily measured as clinical improvements in children. The United States has recently seen an upsurge in parental advocacy around the provision of special education following the introduction of the Individuals with Disability Education Act (IDEA) in the 1990s (Telzrow, 1999). Parents are experiencing varying levels of inclusion in public schools across the United States and advocating for individual children as well as for large-scale consistencies and change have spawned a new practitioner: the Special Education Advocate (Heitin, 2013). These professional advocates have largely been experienced special educators or attorneys, but an increasing number of programs aimed at providing parents with education and skills suggests a turning of the tide (Burke, 2013; Glang et al., 2007). The programs are many and varied and tend to be regional in focus, perhaps in keeping with the state-based structure of

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education provision in the US. They range from formalised, certified courses of up to six months' duration (Burke, 2013) to short workshops aimed at developing skills in particular cohorts such as the parents of children with acquired brain injuries (Glang et al., 2007).

The final study in this program of research comprised the design, development, facilitation, and evaluation of an intervention that aimed to provide parents and carers whose children were transitioning into the NDIS with some tools and strategies to confidently advocate for their children with disabilities. The program delivery aligned with the intended introduction of the NDIS to Queensland, so it was both timely and topical to include a focus on effective engagement with the Scheme.

6.2. Method

The program itself evolved over time as it drew on the expanding knowledge base provided by the previous studies and as the practical challenges of implementation were addressed. The design of the program drew on the principles of action research described by Davis (2018): "…the process, however, is not as neat as suggested as stages overlap, and initial plans can become obsolete or altered in the light of learning from experience." (p. 595)

Kemmis (2001) described the reality that the process of action research is likely to require more fluidity and responsiveness. He describes the measure of action research not as faithful adherence to the steps in a framework, but rather a strong and authentic sense of development and evolution in practice. Each study in this program of research builds upon the knowledge provided by the previous ones, and between each a period of reflection and planning included. The delivery of the final capacity building program was broken into three regional cohorts of parents and carers whose children were likely to be eligible for the NDIS, between which adequate time for reflection and moderation was allowed.

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When research moves beyond the theoretical and into the practical, it is critical to involve consumers in a meaningful way (Payne et al., 2011), even before the project's inception, including the identification of research priorities. In the context of Payne et al.'s framework, the parent interviews and provider focus groups might have been conducted in a more formative stage of the research - outside the parameters of the traditional research participant framework. However, in this case the overall research program required an iterative process approach to acquire a robust understanding of advocacy on which to base the capacity building program. This was built on knowledge gained initially from previous studies providing the background; the interviews with parents offered rich insight into the benefits, techniques, and challenges of advocating in the context of raising a child with disability in Queensland; and finally the views on advocacy from the perspective of those professionals to whom parents and carers are advocating added context and provided both common understandings and divergent viewpoints. It is these insights from a broad range of consumers and partners that informed the design of the program.

This capacity building intervention took a strengths-based approach that aimed to provide practical, timely support to empower families as they prepared to engage with the NDIS for the first time. The luxury of action research is its flexibility and evolving nature, affording the opportunity to identify and respond to changing participant needs and preferences as well as identifying, verifying, or challenging hypotheses and assumptions that may be present in the proposed research design. The program was offered three times at three different locations over six months, allowing for the cycle of observation and reflection to finetune and strengthen the offering as the project was enacted.

6.3. Participants

Participants were the attendees of the four-week capacity building program. They all self-identified as parents or guardians of children with disabilities. The Children's Health

Queensland (CHQ) Hospital and Health Service and the Queensland Centre for Children's

Health Research (CCHR) issued ethical approval for the program via their Human Research

Ethics Committee on 12th October 2017 under HREC/17/QRCH/241. The University of

Southern Queensland (USQ) subsequently issued a reciprocal HREC approval with the same

designation. This study is the result of a research partnership between USQ, CHQ, and Fiona

Russo as Principal Researcher. Recruitment took place over a six-month period from

February to August 2018 for three program offerings in May, July, and September

respectively. Parents responded to advertisements placed on paediatric disability social media

forums, through the Early Childhood Development Program peer group, and via the

Children's Health Queensland Paediatric Rehabilitation Service newsletter. Criteria for

inclusion in the group required participants to be self-nominating, over 18 years of age,

parents or guardians of a child with disability, and to have a reasonable expectation that their

child would be eligible for the NDIS. All participants signed an informed consent form that

allowed the facilitator to take notes during the sessions and report on activities and outcomes.

Participation across the three groups comprised 37 families represented by 44

parent/carers. Most of the respondents were women, very much in line with the literature

review which found that mothers are more likely to be primary carers for children with

disabilities (Barusch & Spaid, 1989; Case, 2000; Folbre, 2006; Hervey & Shaw, 1998).

However, it is notable that four fathers attended the program with their partners and three

others signed up and attended independently. A further two attendees were grandmothers

supporting their participant daughters. The key intent of the capacity building program was to

provide practical, timely, and topical supports and information to parents prior to their

engagement with the NDIS. Although all participants consented to the taking of field notes

that included their contributions to the workshop sessions, it was not a condition of inclusion

that they participate in the larger research with the administration of the pre- and post-

intervention interviews. This was a joint decision of Children's Health Queensland and this author that reflects the genuine, pragmatic intent of the project.

Thirty-three families completed the surveys in the pre-intervention interview. Demographics collected included the age of the child/ren with disability in the family. Categories of age align with systemic transition points – for example, the NDIS has an Early Childhood Early Intervention (ECEI) Access pathway that differs considerably from its full-Scheme counterpart in terms of eligibility and processes (National Disability Insurance Agency, 2017a; O'Tarpey, 2016). This ECEI pathway is available to children under six years old, in this dataset referred to as 'pre-school' aged. In addition to this, Education Queensland requires all children be enrolled in primary education (including the full-time preparatory program) by the age of seven. Queensland's children move from primary to secondary education following grade six – aged approximately twelve years. This age is referred to in this dataset as 'child'. The term 'adolescent' hereafter refers to children between 13 and 17 years of age. The second piece of demographic information collected relates to the disability type. Rather than attempt to categorise disability generally, for the purposes of this program the categories are acquired – those resulting from a childhood illness or injury - and genetic disabilities. An overview of the thirty-three research participant families is presented in Table 6.1 below:

Table 6.1 *An overview of the participants of the capacity building program in Study 4.*

Family Attendees	Age of Child (Pre-School / Child / Adolescent)	Disability Type (Acquired / Genetic)	Location (Logan / QCH / North West)
Mother	Adolescent	Genetic	QCH
Mother	Adolescent	Acquired	QCH
Mother and Father	Child	Acquired	QCH
Mother	Pre-School	Genetic	QCH
Foster Mother	Child	Genetic	QCH
Father	Child	Genetic	QCH
Foster Mother	Child	Acquired	QCH
Mother	Pre-School	Acquired	QCH
Mother and Father	Pre-School	Genetic	QCH
Mother and Father	Child	Genetic	North West
Mother	Pre-School	Genetic	QCH
Mother	Child	Genetic	Logan
Mother	Child	Acquired	Logan
Mother	Pre-School	Genetic	North West
Mother	Pre-School	Genetic	QCH
Mother	Child	Genetic	Logan
Mother	Pre-School	Genetic	QCH
Mother	Child	Genetic	Logan

Mother and Father	Child	Genetic	North West
Mother	Child	Genetic	Logan
Mother	Adolescent	Genetic	QCH
Mother and Father	Child	Genetic	QCH
Father	Child	Genetic	QCH
Mother and Grandmother	Adolescent	Genetic	Logan
Mother	Adolescent	Acquired	QCH
Mother	Pre-School	Genetic	Logan
Mother	Child	Genetic	North West
Mother	Adolescent	Genetic	North West
Mother	Child	Acquired	North West
Mother and Aunt	Child	Acquired	North West
Carer	Child	Genetic	North West
Mother and Grandmother	Child	Acquired	North West
Father	Child	Genetic	North West

6.3.1. Logan Central Community Health Centre.

The Logan Central Community Health centre is located approximately 25km southeast of the Brisbane Central Business District in the local government area of Logan City. It is home to a variety of community outreach health services including Children's Health Queensland's Child Development Program and Paediatric Rehabilitation Clinics. Nine participants signed up for the Logan Central program, delivered on Wednesday mornings at 9.30am over four weeks in May 2018.

The Logan City local government area has a population of 326,615 (Australian Bureau of Statistics, 2018b). Whilst specific data about childhood disability is not available, the number of residents requiring assistance with core activities is approximately 18,291 or 5.6% of the population, 0.5 percentage points higher than the national figure (Australian Bureau of Statistics, 2016). The median equivalised weekly household income is $808, approximately 8% lower than the national median and just over 50% of the national full time adult average wage. The Logan population experiences unemployment at 8.9%, a full 2 percentage points higher than the national average, and only 46.8% of the population aged fifteen and over have completed year 12 or equivalent education, although 53% have completed a post school qualification including trade and certificate-level study. Anecdotal information received from the staff of the Health Centre indicated that the Centre experienced appointment no-shows and lack of follow-up at a higher rate than other hubs. The shared feeling among staff was that a lack of education and health literacy coupled with limited access to transport and other resources were primary causes of this observed behaviour.

Attendance at the Logan program mirrored these experiences, with weekly attendance fluctuating between three and seven attendees. Four of the nine attendees were in the part time or casual workforce and the remaining five were not employed outside the family home. Only two participants attended every session over the four weeks, although all nine attended

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at least once. All nine participants received a workbook containing an overview of the program and of each module, including useful links, information, and activities. None of the Logan Central Community Health Centre cohort responded to appointment requests for post-intervention interviews. This patchy attendance did create some challenges in the delivery of the modules when participants showed a preference for their specific questions to be addressed during workshops regardless of the planned program. However, the flexible nature of the program and the small attendance at each session did reasonably allow for this, and the Logan cohort were offered personalised, individual supports and information wherever possible.

The pre-existing baseline understanding of the NDIS policy and engagement process was lowest among this cohort as evidenced by the nature of the questions and issues raised, and most families required referral to appropriate planning assistance following completion of the program. They were provided with a list of organisations offering no-cost NDIS planning services without recommendation and with the caveat that these services would likely expect to be employed as Plan Managers under the child's NDIS Plan when it was completed. All participants were informed that they were under no such obligation. This decision was taken with the aim to meet the program's ethical obligation to provide advice that did not leave families without support nor vulnerable to increasingly predatory practices observed in the market.

6.3.2. Queensland Children's Hospital.

Queensland Children's Hospital (QCH) is Queensland Health's only dedicated paediatric hospital and the home of Children's Health Queensland. It is co-located with the Queensland Centre for Children's Health Research in South Brisbane, approximately 3km from the Brisbane Central Business District. Twenty-three parents signed up to the QCH

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program offering, which took place over four Tuesday evenings in June 2018. Most parents in the QCH cohort were in the full- or part-time workforce.

Brisbane City is the capital of Queensland, and has a population of 1,231,605 (Australian Bureau of Statistics, 2018a). The number of persons requiring assistance with core activities is approximately 49,264 or 4% of the population (Australian Bureau of Statistics, 2016). The median equivalised weekly household income of $1,065 represents 121% of the same figure nationwide but is still only 66% of the national full-time adult average wage. Unemployment is 6.8%, very close to the national average of 6.9%. 66.7% of residents aged over fifteen have completed year 12 or equivalent education and 65% have completed a post school qualification. A total 32.6% of Brisbane residents report achieving qualification at Bachelor level or above.

Although data on parent education and employment was not explicitly collected, conversation and sharing throughout the program revealed that the Brisbane group was more likely to be in the full-time workforce and to have tertiary qualifications than the other cohorts. Commitment to the QCH group was very high with a minimum eighteen attending each workshop.

6.3.3. North West Community Health Centre.

The North West Community Health Centre is situated in Keperra, an outer suburb of Brisbane approximately 13km north west of the Central Business District of Brisbane City. It is similar in mission to the Logan Centre in that it is home to many health services including the Child Development Program and the Paediatric Rehabilitation Service. The North West region is more difficult to describe in terms of population data because it includes an area of Brisbane and an area of Moreton West local government areas. The Moreton West population statistics generally lie between the Logan and Brisbane numbers but are more closely aligned

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with Logan data. Therefore, the North West cohort contained a mixture of demographics. This was supported by the Centre staff, who indicated that they experienced a wide variety of family demographics in their practice. The North West Community Health Centre group comprised twelve parents reflecting a similar mix of demographics. Commitment to the program was high with the lowest workshop attendance being nine participants.

6.4. Program development

During the early stages of the PhD design, it was the intent of the research to develop a tool for use by GPs and other frontline health professionals to 'screen' and identify families most likely to require additional supports in advocating for their children and accessing required services and equipment. In order to meet the aim to provide genuine outcomes for families, this initial design made some assumptions that these additional supports existed on a scale that could meet the level of need, a notion quickly dispelled by the early review of existing research and the experiences offered by the parents and service providers.

The powerful elements of resilience, peer support, advocacy skills training, and prior advocacy experience identified in the parent interviews and provider focus groups led the broader program of research to consider these factors more fully. For example, if parent advocacy training could be designed and developed by or in collaboration with parents, it could be delivered in the context of a supportive peer-driven environment. In this context, all four major elements could be addressed. The more experienced and confident parental advocates would be the most likely collaborators and facilitators, responsible for ensuring that the information provided comes from a credible expert source. The parent attendees would each bring their own wealth of knowledge, experience, understanding, and empathy that makes peer support so vitally important in reducing isolation and developing family resilience.

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The final study was therefore reframed in the context of developing some of the supports that Studies 1-3 identified were lacking within the system as it currently stands. The redesign moved toward the provision of a direct intervention that would support self-nominating families to develop and exercise advocacy skills within the context of all systemic interactions, but particularly the NDIS, which was identified through the studies 1-3 as the area most timely and topical among the parent cohort. This is also observable in the planned NDIS rollout, which began in Queensland on 1 July 2016 but did not reach the South East corner of the State until mid-2017. Many areas of Brisbane including North Brisbane and the Moreton Shire did not enter the Scheme until mid- 2019 (National Disability Insurance Agency, 2016).

6.4.1. Thematic Elements.

The results of the literature reviews, the parent interviews, and the service provider focus groups presented consistent messages that informed the design of the program. These included:

6.4.1.1.   Peer Support.

Peer support was a recurring theme across the studies conducted throughout this program of research. Parents, researchers, and providers consistently articulated the importance of supportive peer relationships in developing parents' capacity to champion their children in complex systems. Conversely, parent isolation was reported to be a significant barrier to service access, advocacy development, and system knowledge. This suggested that establishing peer support networks early would advantage families in developing resilience and advocacy skills.

6.4.1.2. Family Resilience.

Positive family functioning was a key success indicator identified by studies 1-3 around parent capacity for advocacy and constructive outcomes for children. Further to this, parents themselves generally demonstrated a more positive mindset and willingness to engage with the system where their family relationships were encouraging and functional. The Australian Institute of Family Studies (AIFS) report (Edwards & Edwards, 2008) highlighted the influence of positive family functioning in the development of family resilience.

6.4.1.3. Existing Professional Supports.

In the context of the NDIS, the systematic literature review clearly demonstrated a relationship between the experience of positive professional relationships and parent satisfaction upon engagement with the NDIS. These existing supports were identified as a contributing factor to successful planning and positive outcomes from the NDIS. The parents and service providers further supported these findings when both groups recognised an expectation that providers should be a source of support and assistance for families throughout the NDIS rollout.

6.4.1.4. Access to Information in Complex Systems.

The NDIS and its associated Act represents the most significant Australian social policy reform since the introduction of universal healthcare in 1975 (Bonyhady, 2014; Palmer & Short, 2000), and will effectively replace all existing State and National disability service policies. In conjunction with other government leviathans such as education, social services, and the health systems, the NDIS aims to provide holistic, life-long services that afford Australians with disabilities the rights and responsibilities of full citizenship and community engagement. However, these large systems do not work in true partnership with one another

and navigating among them as an individual is complex and time consuming. All studies found that access to timely, tailored, accurate information was a contributor to successful advocacy across all contexts.

6.4.2. Program Delivery.

Previous programs aimed in part to develop a professional workforce of parent advocates, and the courses under development – such as the SEAT and the VAP (Burke, 2013) – require a considerable commitment in terms of time and resources on the part of the parents and families as well as the systems that deliver them. Informal consultation with consumers outside the parameters of the research project indicated that parents would not be likely to enrol in long-term interventions but were looking for practical, short-term strategies to strengthen their positions in the context of the NDIS rollout. In light of these considerations, this intervention would be delivered as a short and targeted pilot intervention.

6.4.2.1.   *Program Participation.*

The capacity building program – titled Parent Empowerment and the NDIS – was attended by 44 parents representing 37 families. The program was delivered in three separate cohorts – in May 2018 at the Logan Central Community Health Centre, in June 2018 at the Queensland Children's Hospital (formerly Lady Cilento Children's Hospital), and in August 2018 at the North West Community Health Centre at Keperra, all in the South East corner of Queensland. Each group was facilitated by the researcher with the support of Children's Health Queensland who supplied the above gratis venues and free hospital parking to participants. Aside from light refreshments during workshop breaks, no further incentives were supplied to respondents. The Community Centre offerings took place in the mornings from 9.30am to 12.30pm to accommodate school drop off and pickup times. The North West Community Health Centre offering included supervised play for young siblings. The

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Queensland Children's Hospital cohort met on Tuesday evenings from 5.30 to 9.30pm to better accommodate parents in the workforce. This variety in delivery options aimed to maximise the response rate but also – and more importantly - to accommodate a diverse range of family needs.

The workshop sessions were not audio or video recorded but field notes were kept throughout each program. These notes are drawn from to provide description of the program participation and flow. This chapter will generally discuss the program in its entirety – across all three iterations – but some cohort-specific context is necessary to paint a fuller picture.

6.5. Program Content

Content was divided into four modules delivered over a total 12 hours across four weeks. The design incorporated workshop-style facilitated sessions. A workshop is defined as a brief intensive educational program for a small group of people that focuses on techniques and skills in a particular field (Merriam-Webster, 1996), which fits the intent of this program well as it aims to provide specific skills and techniques around parental advocacy within a small cohort of parents. Steinert, Boillat, Meterissian, Liben, and McLeod (2008) discuss the advantages of workshops over lecture sessions in terms of collaborative discussion and problem-solving. It was critical in the design of this program that the recurring theme of peer support and engagement prevalent in the literature and in studies 2 and 3 be addressed. Workshop sessions provide an ideal opportunity for open discourse as well as for questions and sharing of experience.

The program covered the key areas identified by the preliminary studies and was loosely broken into two sections – advocacy skills development (modules 1 and 2) and NDIS engagement (modules 3 and 4). A brief overview of the content to be presented was supplied to all participants as they signed up to the program. It was anticipated that parents in this

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study may experience challenges in attending all four workshops due to the unpredictable nature of their child/ren's health. All participants were provided with a workbook at the beginning of the program that provided activities, information, and resources (Appendix 9.4) to ensure that every family received equitable access to the information. The workbook was also provided electronically as live weblinks were included in the content. Participants were asked during pre-intervention interviews whether they would require assistance or translation to access the course. Although seven participants indicated that English was a subsequent language, all reported a high level of proficiency. Three other participants reported that they themselves identified as having a disability – two naming autism spectrum disorder and one generalised anxiety disorder - but all indicated that they did not require any special assistance.

Although the general topics to be covered were programmed and communicated, the sessions themselves were loosely planned to encourage questions and tangential discussion. Although this may appear antithetical to the traditional educational approach, it fitted very well with the intent to provide tailored, practical content where possible. This design also offered an opportunity for participants to share their family stories and experiences, and trade information with their peers. For many of the participants, this program was their first opportunity to speak with a group exclusively comprised of families experiencing similar trajectories and challenges.

6.5.1. Module One.

Module one began with an introductory round table wherein participants were encouraged to introduce themselves and share as much or as little of their family stories as made them comfortable. One of the common themes among the literature, interviews, and focus groups alike was a broad and varied understanding of the concept, role, and activities of advocacy. This was the first scheduled subject and was delivered in the form of a small-group

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brainstorming activity to further encourage sharing and open discussion. Participants discussed advocating for themselves and advocating for others as well as exploring the three levels of advocacy as described by Wright and Jaffe (2013) – micro, mezzo, and macro - in the context of their own activities. Participants would then discuss their small-group conclusions with the larger cohort, stimulating an exchange of ideas. This activity was designed to reach a collective agreement about the definition/s of advocacy, but equally to illustrate the likelihood that all participants were already engaged in some form of advocacy on behalf of their child/ren.

From the definition of advocacy and its inherent activities, participants were introduced to the Personal Bill of Rights (Bourne, 2011) and encouraged to examine these rights from the position of their child/ren, their families, and themselves. This was designed to incite discussion about the importance of their role as advocate, as participants were able to draw direct links from the activities they were involved in and the rights they were aiming to protect. It also stimulated discussion around areas that had been neglected, especially as concerns their own health and wellbeing. This low prioritising of self was a recurring theme in the literature and was reflected in the interviews and focus groups is studies 3 and 4.

Module one continued with a mixture of information and small group brainstorming sessions around advocacy in the Australian systemic environment with a focus on the largest interactions such as health, education, social services, and the NDIS. Participants were encouraged to share their experiences – successful and otherwise – within these systemic interactions. Trainor's (2010) four strategic approaches to advocacy were introduced and explored in the context of participant activities and experience. The final subject involved an exploration of the participant understanding of negative advocacy – a 'what advocacy is not' conversation. It was important in the design of the program to develop the modules in a natural, logical format so that the flow of conversation and sharing was not often interrupted

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by an abrupt change of subject. Module 1 was designed to provide an overview of advocacy in the Queensland context – what it is, why we do it, where we do it, how we do it, and what not to do. This mirrored the natural flow of the interviews in Study 3 and built on the subjects to include open sharing and discussion.

6.5.2. Module Two.

The second of the four modules involved the workshopping in small groups of four fictional advocacy scenarios. Each group would choose one of the four scenarios and apply Wright and Jaffe's (2013) six steps to successful child advocacy to its resolution. Participants would be encouraged to replace the provided scenarios with one of their own if they had a live issue they wished to discuss. This scenario planning was designed to encourage participants to start thinking about the ways that they applied advocacy in context. Through this activity, participants would be able to prioritise and plan advocacy strategies to the benefit of their families and children. It was important to recognise that advocacy comes at a cost in terms of parental and family resources - physical, emotional, social, and financial. Planning a strategy is likely to highlight some of these costs to participants, and this would naturally lead to a discussion about recognising parents' own limits. Participants would discuss the confronting issues of carer burnout, and how to manage when resources are depleted. The next logical step was to supply information regarding external supports available to parents and families. Participants were given the name and contact details for local advocacy support agencies offering services as part of the National Disability Advocacy Plan.

6.5.3. Module Three.

Module three moved parents toward discussion of the National Disability Insurance Scheme. Key focus areas of module three included accessing the NDIS, tracking and

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reporting a child's daily activities, the concept of being 'no worse off' under the NDIS (National Disability Insurance Agency, 2016), and acknowledging the worst day while aiming for the best life for your child. Specific information would be provided about supports available under the NDIS in the context of funding guidelines such as the 'reasonable and necessary test'(Australian Federal Government, 2013) and intended mainstream interfaces and support delineations (National Disability Insurance Agency, 2014).

Although module three was very information-intensive, again the schedule was kept deliberately loose to encourage families to bring their own issues forward for discussion. A significant portion of module three was dedicated to discussing the planning of NDIS engagement from setting goals and procuring reports and quotes to managing the planning relationship and the funding itself. Given that the majority of parents in the program had yet to roll into the NDIS, a small provision was offered at the end of module three around implementing a participant plan including use of the MyGov online portal, sourcing and managing service agreements, and understanding funding categories. Other topics to be covered included annual or unscheduled review processes and the NDIA complaints resolution processes.

6.5.4. Module Four.

The final module was designed as a peer plenary session. The focus was on peer stories of engagement in the NDIS and other successful advocacy, and a robust discussion of issues, plans, and questions raised by participants for consideration by the group rounded out the program. Potential topics anticipated during this discussion included the use of social media and other digital platforms to engage with, engagement from a systemic perspective, and moving from advocacy towards activism.

The four modules were designed to address the primary intent of the study - to increase skills in parental advocacy - but equally aimed to meet the needs identified by the studies 1-4 for peer support, increased family resilience, exploiting existing professional supports, and access to timely and relevant information. Each activity contained elements of all four themes in an unobtrusive, intuitive manner.

6.6. Program delivery

The program was delivered with the support of Children's Health Queensland (CHQ) in assisting with review of documents, recruitment of participants, supply of venues, and gratis parking. Critical to the success of the program was the commitment of parent participants to attend and contribute to all four modules comprising the program design. Each module contained approximately three hours' worth of content. Options considered for delivery of the program included module-per-week, two-day intensive, and condensed single-day formats. Factors such as venue and parking availability as well as the needs of participants in terms of childcare and school hours were considered. The final format of weekly modules was chosen to best accommodate these considerations as well as allowing adequate time for peer relationships and trust to build amongst participants, a central tenet of the study.

6.6.1. Notable discussions.

It is important to relay information about the nature, content, and flow of the program in order to provide robust knowledge and understanding about the delivery of the project. Some of the notable discussions and incidents are outlined here and provide evidence of pragmatic outcomes and developments related to the thematic elements described in Studies 2 and 3.

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During Module 2 of the program, parents were introduced to the six steps described by Wright and Jaffe (2013) and asked to apply them in practical terms to a relevant scenario. Four scenarios were provided but groups were encouraged to substitute with a live example if they were comfortable doing so. One parent requested that her group work on an issue her family was planning to approach with her child's medical team. She wanted to consider a real food blended diet for her young tube-fed child and knew from previous discussions as well as advice from peers that this was not likely to be supported by the clinicians. However reluctant she felt to 'challenge the system' [sic], she was a qualified dietician and her husband was a chef so she felt they had the skills and knowledge to explore the option safely. She was preparing for what she anticipated may be a difficult negotiation. Her small group worked on strategising for the appointment and when the larger group reconvened, they presented the case.

This triggered a passionate discussion amongst the larger group, some of whom also had tube-fed children at home and had been faced with the same resistance by the Australian medical establishment. The group discussed the prevalence of blended diets in the United States and offered advice about where to find compelling evidence to present to the Australian medical team. They posed the question of whether it was 'better to apologise than ask permission' (proceed without informing the medical team), a controversial idea that participants expressed relief at being able to table in a safe and supportive space. Some parents further expressed interest in seeking this parent's advice regarding adequate nutrition and food preparation to enable them to do the same with their own children. During the fourth workshop, this parent announced that her family had decided to make the shift to a real food diet prior to the next round of medical appointments so that she would have some results to share. She also informed the group that her child had gained two kilograms and ceased to experience vomiting and diarrhea since the new diet began. He had also started to show an

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interest in the taste and smell of food. She thanked the group for their positive feedback and credited them with giving her the confidence to proceed and to advocate for her child with the medical team going forward.

Another stand-out incident took place within the group during the third workshop. Participants were discussing adaptive equipment needs and how to ensure that the NDIS had all the information required to include assistive technologies in their child's Plan. One parent spoke about the need for a standing frame for her child, and about the requirement to trial, prescribe, and quote equipment prior to the NDIS planning meeting. She shared with the group that she had approached suppliers but was on a long waitlist for trial equipment. She shared a concern that she would not have everything ready in time for the planning meeting. Another parent approached her during a break and they spoke about the type of frame she was waiting to trial. This parent had the same piece of equipment at home that could not be used by her child during a period of recovery from surgery. She offered to lend it to the first parent to complete the requisite trial period. The exchange took place between workshops and a successful trial was completed over two weeks. During the post-intervention interviews, both parents spoke about this as a direct benefit of the program and the equipment has since been approved for purchase by the NDIS. The above examples are two of many such that illustrate the practical outcomes of peer support; these ones stand out because aside from the benefit to the parent/s, there was a reported and measurable positive wellbeing outcome for the children.

On another occasion, a (single) parent experienced visible distress (with physical collapse) on receiving a phone call towards the end of a workshop from her young son's school. She told the group that her son's wheelchair brake had failed and that his chair had rolled down an embankment and tipped over, her son striking his head on the ground. The school assured her that he appeared well but they had called an ambulance per the policy on

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potential head injuries. This parent explained to the group that she had been suffering from post-traumatic stress disorder related to the myriad medical emergencies she had experienced while caring for her son. She expressed embarrassment at what she perceived to be an overreaction but the group was empathetic and could see that she was shaky and struggling and needed support. One parent drove her in her own car to the school while another followed to drive him back to his own vehicle afterwards. At a later workshop, the parent reported that her son was doing well and expressed her gratitude for the support of the group. She spoke about the many times she had experienced emergencies in the past without support and about what a positive difference it made to have a community of peers around her at such a time. She said that this had been hugely impactful for both her and her son as she had been able to get to the school quickly and safely and travel with her son to the hospital in the ambulance.

The above is not the only example of a group coming together to provide emotional and practical support to a peer. At the end of the first workshop, a member of one cohort was noticed quietly crying whilst packing up her belongings. She was approached by the facilitator and a peer and became increasingly upset but was struggling to articulate what was wrong. Also present at the time was a clinician from the Child Development Program, who had come to sign out of the room's computer system. The four sat together after everyone else had gone and shared a cup of tea while the participant explained that this program was the first time she had been in a room with other parents like herself, living with similar challenges in their lives. She expressed gratitude and positive feelings about the experience but had also found it very confronting – as though she had 'just realised that (child)'s issues are permanent; that this is the life we're going to have; that he's not going to magically grow out of this' [sic]. The QCH clinician suggested that a conversation with a hospital social worker might lead to some extra supports for the family and offered to arrange for a

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telephone call the next day, to which the parent agreed. At the following workshop, the participants were solicitous and universally expressed care and concern for the parent, who assured the group that she was feeling more positive. She was able to openly discuss for the first time some of the feelings she had been experiencing and this sparked a very honest, open discussion about the difficulty of the early post-diagnosis period and the importance of self-care and building positive coping mechanisms. The discussion, while difficult and emotive, was later remarked upon as being positive and even 'cathartic' by participants in their post-intervention interviews, including but not limited to the initial parent.

Throughout each program, participants shared their stories – building from basic information about their families and their reason for attendance during the first workshop to full and frank discussions with significant depth and impact as trust and camaraderie grew over the weeks. With the exception of the Logan participants (likely due to unstable group attendance), each program's participants developed behaviours and norms that align well with Tuckman and Jensens's (1977) five stages of group formation: forming, storming, norming, performing, and – added at review (Tuckman & Jensen, 2010) - adjourning. As the groups became more cohesive, the hesitance and uncertainty of their first hours together gave way to genuine collaboration in the form of information and experience sharing, advice and support. Questions were raised and answered not just by the facilitator but from within the group itself. Personal and family stories moved beyond the challenges of raising a child with a disability or preparing for the NDIS and into more personal anecdotes. There was an increasing air of positivity in these exchanges as participants shared laughter and talked about family hopes and goals. The sense of community was shown in more practical ways as well, such as group members preparing and sharing food with their peers during the break times. During the QCH workshops, participants spoke openly about this, discussing the relief they

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felt at being in a space where their families were 'not objects of pity' [sic] but felt 'ordinary' [sic] and free to speak about their experience of family life in normative terms.

6.7. Measures

The first of the surveys is the Parent Empowerment and Efficacy Measure (PEEM), which was initially designed for use by organisations providing supports to families of youthful offenders in Queensland (Freiberg et al., 2014). It is intended as a tool for program evaluation. For the purposes of this study and following consultation with Dr Freiburg, the PEEM was adapted for use by replacing mention of police and other community services with professionals relevant to the parent cohort such as doctors, nurses, and educators. The PEEM is a strengths-based management tool that measures the capacity of parents to manage the challenges of their roles and to provide a safe and supportive home environment for their children. Improved PEEM scores would indicate increased parental efficacy and empowerment following participation in the capacity building program. The PEEM validation study resulted an overall alpha score of 0.92 (Freiberg et al., 2014). Further details can be found in Appendix 9.2.1.

The second survey measure is the Beach Centre Family Quality of Life Survey (FQoL) (Summers, 2006), designed to measure family quality of life in the context of having a family member with disability. The FQoL measures quality of life across five domains:

1. family interaction – alpha 0.89;

2. parenting – alpha 0.89;

3. emotional wellbeing – alpha 0.79;

4. physical/material wellbeing – alpha 0.81; and

5. disability supports – alpha 0.86.

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It was administered without amendment or adaptation. It is anticipated that confident, effective advocacy is more likely to result in successful engagement with the NDIS. If families can secure funding and put in place adequate supports and services for their child/ren, it stands to reason that the FQoL score should show improvement, particularly in the domains of physical/material wellbeing and disability supports. Further tool validation details can be found in Appendix 9.2.2.

The final measure is the Paediatric Inventory for Parents (PIP) (Streisand et al., 2001), which measures parental stress across four domains:

1. communication;

2. emotional functioning;

3. medical care; and

4. role function (Streisand et al., 2001).

Improvements across domains 1 and 4 in particular would support a finding of value in the intervention when associated with positive commentary in the short feedback supplied by the participant. Initially designed for use in families of children with type 1 diabetes and later adapted for parents of children undergoing oncology treatment, the PIP has been used here without alteration or amendment to take inventory of parental resources including financial, emotional, and physical to measure levels of stress related to childhood disability. The overall alpha score for the PIP across two validation studies is 0.97 (Streisand, Swift, Wickmark, Chen, & Holmes, 2005) and 0.95 (Lewin et al., 2005) respectively. Further validation details can be found in Appendix 9.2.3.

6.8. Program Evaluation

The capacity building program was intended as a pilot to demonstrate the effectiveness of early intervention in the development of an advocacy skill set and mindset in

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the parents of children with disabilities. It was evaluated by way of a pre- and post-intervention application of three survey instruments, administered approximately one month prior to program participation and then approximately six months post-program. A short structured interview was included as an addendum to the post-program surveys to provide richer, qualitative data and to add depth and understanding to the individual trajectories of parents in the program.

6.8.1. Pre-intervention results.

Validation information for all survey measures is detailed in Appendix 9.2. Thirty-three sets of surveys were completed by 37 parents (four were jointly completed by both parents from the same family). This sample is too small to ascertain robust statistical conclusion but the results do offer descriptive insight into the participant families that has added depth to the evaluation of the program.

The Parent Empowerment and Efficacy Measure (PEEM) (Freiberg et al., 2014) looks at parenting efficacy from a strengths-based perspective. The total empowerment score exists in a range from 10 to 200, where a higher score indicates increased parenting efficacy and overall empowerment. Freiberg et al. (2014) report that the average score across the typical parent population is approximately 154. Within the parent participants of this program, the average score was 140, suggesting that parents in this cohort are reporting a slightly lower sense of empowerment and efficacy in parenting and support seeking, with scores falling in the 70th percentile compared to the 77th percentile control average.

If these results are examined in terms of the subscales of *efficacy to parent* (scale 11-110, participant average 74) and *efficacy to connect* (scale 9-90, participant average 66), participants scored in the 67th and the 73rd percentile respectively. It is evident that these families report generally higher levels of confidence in their ability to connect than to parent

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their children. This may be intuitively explained by the level of complexity involved in learning to parent a child who doesn't present in the expected or typical way. This may naturally result in a reduced level of confidence in parenting but equally presents an increased need to connect with and access supports and services outside the family unit and requires that parents develop the skills to do so effectively. Further supporting this hypothesis, the efficacy scores overall were slightly higher among the parent cohort whose children acquired their disabilities as opposed to those with genetic disorders, perhaps because this group had the opportunity to develop robust parenting skills and resources while parenting their typical child that they were able to draw on following the event that resulted in the acquisition of disability. These trends are illustrated in Figure 6.1 below:
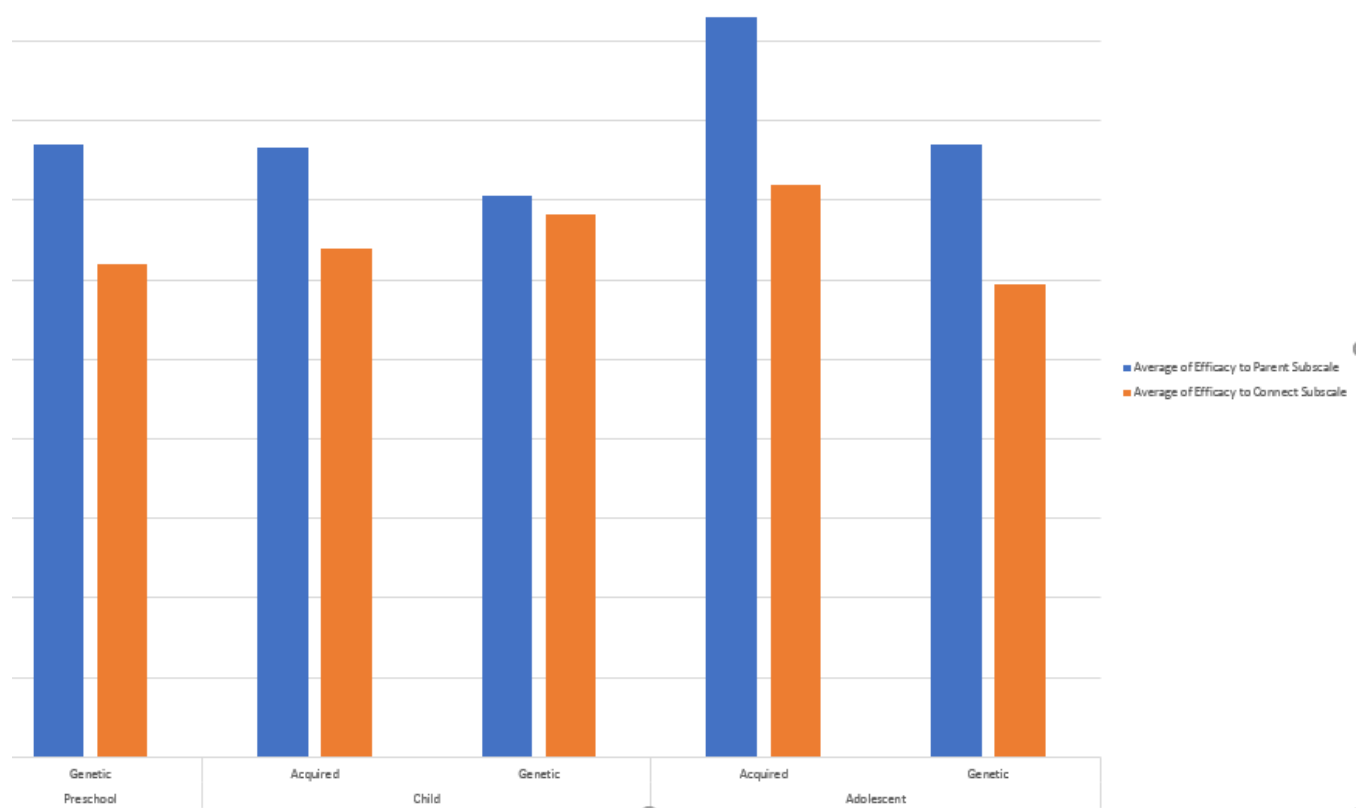

Figure 6.1: PEEM (Freiberg et al., 2014) illustration by subscale, disability type, and child age. Scores demonstrate levels of perceived empowerment and efficacy.

The FQoL (Summers, 2006) measures overall quality of life within a family where disability is present in one or more family member/s. Again, the sample is too small to yield any statistically significant data but general trends are noted. For example, in the illustration Figure 6.2 below it is possible to observe a downward trend in the subscales for emotional wellbeing and disability supports as children age. This may suggest a relationship between the level of supports available to a family and their emotional wellbeing, a finding supported by the interviews and focus groups alike. It is also notable that the emotional wellbeing result is generally lower than the other subscales, suggesting that this is a common 'cost' of childhood disability.
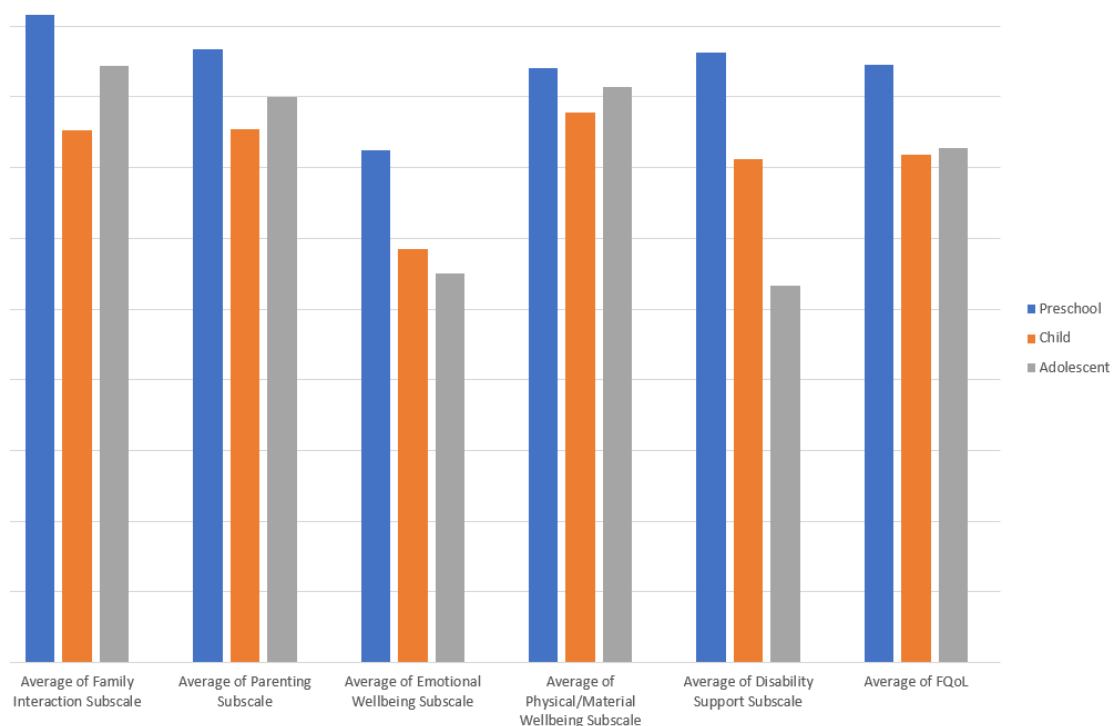

Figure 6.2: FQoL (Summers, 2006) trends by subscale and child age. Higher scores indicate higher perceived family quality of life related to the subscale.

The Paediatric Inventory for Parents (Streisand et al., 2001) expands on the findings of the FQoL in that it examines the available resources and associated stress of parents in coping with and responding to childhood illness. Streisand et al. (2001) tested the PIP in a

cohort of parents whose children were undergoing oncology treatments and found that parents of younger children reported a higher frequency of stressors. A subsequent use of the PIP by Streisand et al. (2005) found a similar trend in parents of children with Type 1 diabetes. In this study looking at a population of parents whose children live with disability, the results differed in that the parents of adolescent children reported higher frequency and difficulty of stressors than their peers whose children were under 12 years. This trend is illustrated in Figure 6.3 below:
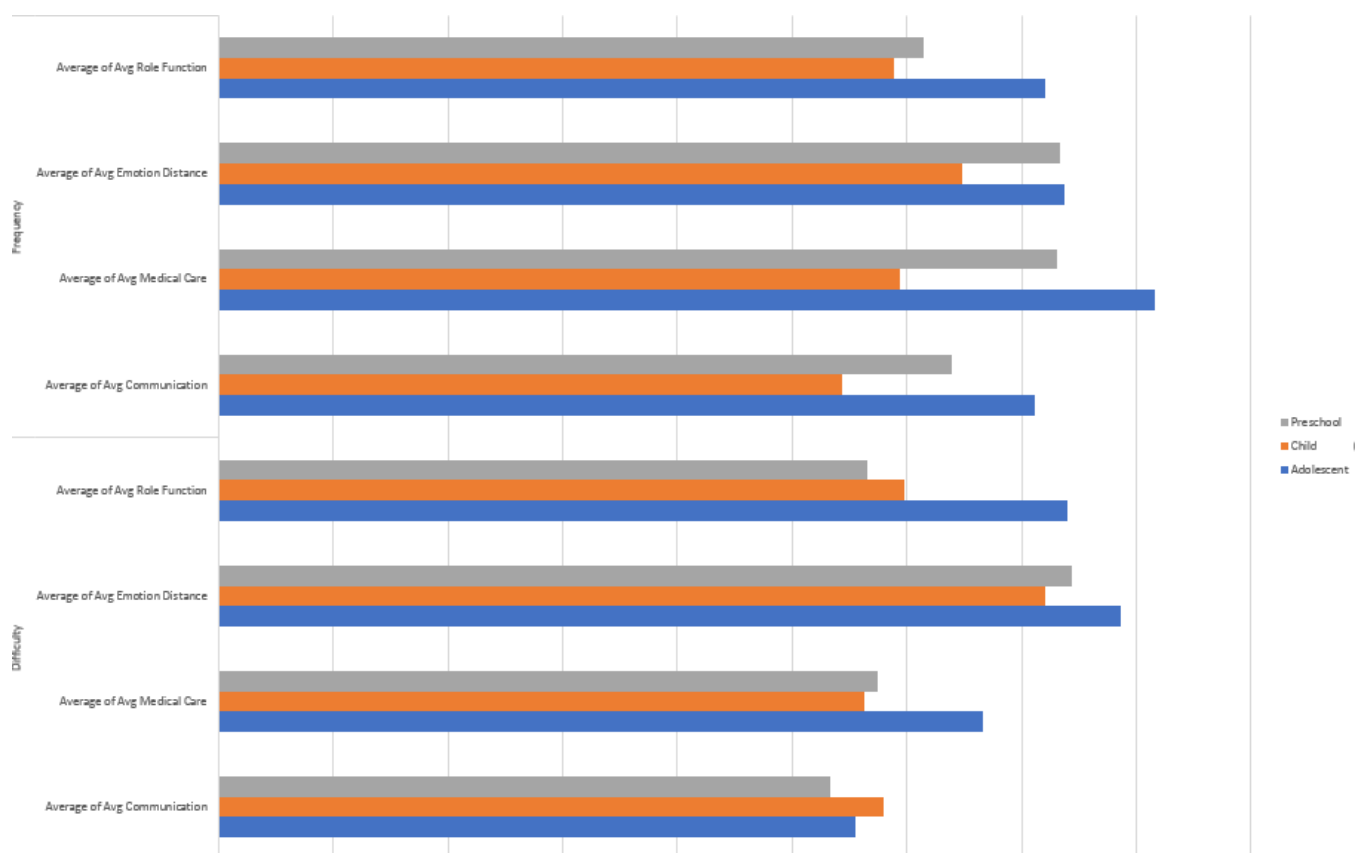

Figure 6.3: Participant trends across the PIP (Streisand et al., 2001) subscales by age of child. Higher scores indicate increased stressor impact and depleted parental resources.

One possible explanation – further supported by the insights offered by the FQoL trends – is the availability of supports for children and families. It is reasonable to assume that the parents of younger children in these cohorts have less experience and understanding of their child's special needs and may therefore find themselves more affected by the inherent

challenges, particularly as resilience and coping mechanisms develop over time. It is equally intuitive that children in both the oncology and the diabetes cohorts are likely to be receiving intensive health-related supports regardless of age.

In the case of lifelong disability, however, the Australian systemic landscape and the parents in this study both suggest that the supports available to families lessen as the child/ren grow. Intensive, family-centred health services available at a children's hospital are not mirrored in adult facilities; educational supports available in primary school are much reduced in the high school setting; and at the same time the physical demands (and adaptive equipment needs) of a child with disability are likely to increase in line with the child's own growth and development. With these things in mind, it is perhaps less surprising to find that parent stressors in this population increase as their children grow.

6.8.2. Post-intervention evaluation.

Post-intervention interviews including repeat measures took place approximately six months after the workshop was completed. It was the intention of the study to conduct these interviews following meaningful participant engagement with the NDIS. This aligned with the planned Queensland rollout of the Scheme. It was anticipated that the surveys would support an exploration of the confidence with which parents engaged with the NDIS, the efficacy of their advocacy skills in securing appropriate supports for their child/ren, and the positive influence these supports have on family quality of life and parental resources. However, the NDIS did not meet its intended targets and many participants had not engaged with the Scheme at six months post-intervention. Eleven participants in various stages of the NDIS planning process made themselves available for post intervention interviews and completed the same three survey instruments. Four of these parents had received their child's first Plan, four more had commenced Planning conversations with the NDIA, and the remaining three reported that they were actively pre-planning.

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The post-intervention individual interviews were conducted approximately six months after participation in the capacity building program. These interviews included the repeat completion of the three measures referred to above as well as a short structured interview, and were conducted during face to face meetings (two regional respondents participated via videoconference). The questions posed during the structured interview are included in Appendix 9.3.

The small sample size limits the statistical relevance of the instrument scoring. However, scores can be used to identify general trends, individual changes, and make observations in addition to the structured interview responses provided by participants of the program. Overall trends considered the averages of individual differences between the pre- and post-intervention measures and are well aligned with the findings of the structured interviews. The below trends provide a summary overview of the outcomes measured by the post-intervention instruments. Whilst there were a few notable outliers whose individual cases warrant a little more scrutiny (and are presented in section 6.9.1.1.), whole group data is presented here.

Individual pre- versus post-intervention scoring across the Parent Empowerment and Efficacy Scale (PEEM) (Freiberg et al., 2014) showed an average improvement of 10% across each of the two subscales – improved efficacy to connect and improved efficacy to parent. This suggests that families who engaged with the capacity building program have seen an increase in their abilities to effect positive change for their children, and improvement in their capacity to connect with other families and appropriate services in order to do so.

The Paediatric Inventory for Parents (PIP) (Streisand et al., 2001) returned similarly positive trends, demonstrating an average 7.3% reduction in the frequency of stressors and an

associated 3.8% reduction in the perceived difficulty of the stressors. If the most significant outlier is removed from the scoring (case below: 'Sara'), the remaining participants reduced the frequency of stressors by an average of 13% and their associated difficulty by 11%. The most notable PIP subscale improvement was that of emotional distress, where the average reduction in frequency of stressors was 7.5% and difficulty associated with those stressors reduced by 7%. This suggests that the participants in the program have improved their own resilience through an increase in parental resources related to their child's disability and associated needs and experiences.

The Family Quality of Life (FQoL) (Summers, 2006) scores showed the least amount of change over the six-month period between pre- and post-intervention measures with an average nominal positive shift of approximately 3.5% across all domains and respondents. It is reasonable to suggest that this may be a reflection of the limits of a capacity building program such as this to enact the sort of practical change that would substantially impact FQoL. The program itself offers tools that can help parents exploit systemic resources for their child/ren and work towards improving FQoL overall. These systemic resources must be available and actualised before positive FQoL results will be observed. In the case of the NDIS particularly, the supports provided – whilst for the direct benefit of the Scheme participant – should have a positive impact on family relationships and alleviate barriers to in-home / in-community family functioning (Bonyhady, 2014), which should in turn have a positive impact on FQoL. However, most of the program participants have not yet received their child's NDIS Plans or enacted any supports, and even then there would likely be a period of adjustment before the full FQoL benefit is realised.

During the structured questionnaire portion of the post-intervention interviews, participants were asked a short series of questions about their experience of the capacity building program and its impact over the subsequent six months. Every participant indicated

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that the program had delivered the type of content they had expected, and that the content was a well-balanced mix of advocacy skills building, NDIS-related information and support, and peer support and discussion. Although the questionnaire didn't prompt it, all participants spoke about the significant benefit of peer interaction and support. Some of the comments are transcribed below:

> [The most useful aspect of this program for my family was]:
>
> …the reassurance of knowing that we are not alone.
>
> …feeling less isolated and more empowered.
>
> …having the opportunity to meet others and talk freely about our experiences.
>
> …peer knowledge and experience.
>
> …being heard and hearing others.
>
> …the identification of common ground and service needs.

Given the prevalence of positive peer interaction in these responses, it is perhaps unsurprising that more than half of the respondents indicated that they had maintained a relationship with parents they met during the program. Further responses to the same question included an improved understanding of what advocacy could and should be, how to hone and develop skills over time, adapting communication styles to suit different contexts, useful information and advice around the incoming NDIS, and an improved understanding of when and where to seek support. All participants indicated that they believed the program had been of benefit to them and to their children and families and would recommend it to others in their networks. Some indicated that they had specific families in mind who would benefit from a program such as this and asked to be kept informed of any plans to repeat the program in the future.

Participants were asked whether their involvement in the program had influenced any decision made since, and ten of the eleven replied in the affirmative. The remaining parent

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stated that it was 'too early to tell'. Participants spoke about planning for the NDIS, advocating more strongly within their existing service provider relationships, making educational decisions, directing their child's care, and asking for help –that is, advocating for themselves. Some of the comments are transcribed below:

[Has your participation in this program influenced any decision you have made since?]:

…I am more open to thinking about the future and making plans for schooling et cetera. I also felt more empowered to advocate during a recent hospital stay.

…I have changed a provider I wasn't happy with, and been more inclined to advocate for things that I might have let slide in the past.

…I feel I planned for our NDIS meeting much better than I might have.

…I was so well-prepared for our NDIS Planning session, it all went so quickly and so well that I actually thought, 'was that it?' After all the angst and worry! I was all over it.

…we had such good follow-up support from people we met here that I think our daughter's outcomes have been better all round.

6.8.2.1.   Cases.

In presenting the pre- and post-intervention survey results, it is important to acknowledge some individual cases whose scores represent significant outliers when compared with the larger group. In this section, three such outliers will be presented and discussed. The first of these will be designated Jane (pseudonym). Jane attended the capacity building program at Queensland Children's Hospital. Jane is a partnered parent of two pre-school aged children, one of whom has been medically complex for most of his life and had a recent diagnosis of genetic disability. Jane's experience is briefly discussed in section 6.6.1 above – she was the participant who was visibly distressed following the first session of the program. At that time she expressed feeling confronted by the realisation that her young son's disability was lifelong, and quite suddenly felt the loss of the life she had imagined for her family. At the same time, she felt buoyed by the sense of support and

positivity from the rest of the group, especially those with older children. This mix of strong emotions had overwhelmed her and she began to recognise that she and her husband had been 'barely keeping our heads above water' [sic] in managing her son's immediate medical needs and hadn't yet faced the longer term reality. She felt they were both 'close to complete burnout' [sic]. Following the provision of some supports and her participation in the program, Jane's post-intervention PIP (Streisand et al., 2001) showed a reduction of close to 10% in the frequency of stressors as well as a 7.6% reduction in the difficulty associated with them. Most significant was a 15% reduction in the frequency and 27.5% reduction in the difficulty associated with the Medical Care subscale. This is notable because it was the area in which Jane had expressed the most confidence and had been placing most of her energy. This may appear counterintuitive but is an excellent illustration of the unexpected benefits of balancing the proverbial load. Jane also showed remarkable improvement in the PEEM (Freiberg et al., 2014), with a 17% improvement in overall empowerment scoring. This aligns with Jane's post-intervention interview, during which she reported that her participation in the program left her feeling better prepared for meeting the longer term needs of her son and her family. She shared that she had since put into place some self-care routines suggested by the group and was developing coping mechanisms to help her avoid the 'burnout' she felt at the beginning of the program. She further shared that her participation in the program had directly influenced many decisions her family had made since, including medical and allied health service providers, NDIS planning and goalsetting, and schooling for her son. She has also continued some of the relationships forged over the duration of the program and said that the social benefit was an unexpected but highly valued positive outcome for her.

On the other end of the change spectrum, Sara (pseudonym) is the single parent of a child with a genetic disability and attended the Logan City program. Sara's results showed a

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significant decrease in parental resources and higher stress indicators in the PIP, with a 20% increase in the frequency of stressors associated with a 26.7% increase in difficulty. At the time of the post-intervention measure, Sara was moving house and was making plans to transition her pre-teen daughter from special schooling into a mainstream high school in a new city. This process was presenting considerable barriers and stressors that were new to Sara and her daughter. This was also reflected in Sara's feedback regarding the program delivery. When asked about areas for improvement in the delivery of the program, Sara suggested that future programs be tailored to the needs of a more focussed cohort such as disability type, child's age, transition point etc. She confided that there were things she felt she needed to learn that weren't covered by the program but also acknowledged that she didn't have a good understanding at that time about what those things would be. Despite this, Sara stated that she had received benefit from the peer knowledge and experience as well as the skills gained in positive advocacy, which she was putting to use in her subsequent search for the right educational setting for her daughter. It is important to note that Sara's empowerment and efficacy scores evidenced by the PEEM (Freiberg et al., 2014) actually improved by 5% over the same period. This result indicates that parents' situational stressors change over time, and even a confident, empowered, experienced, resilient parent is not immune to the impact of these new stressors. This is important because although the original intent of the capacity building program was to target newly diagnosed families, this result along with the uptake of participation by parents transitioning into the NDIS shows that any point of transition – especially into areas previously unknown to the family – requires systemic support as well as new skills and knowledge on the part of the parents.

The last outlier will be designated Michelle (pseudonym). Michelle is a single parent to a pre-school aged child with a lifelong genetic disability and a diagnosis of cancer that had recently been stabilised. She attended the Queensland Children's Hospital program.

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Michelle found herself in a similar position to that described by Jane in that she had been directing most of her energy towards her daughter's intensive medical needs. However, unlike Jane, Michelle had been aware and accepting of her daughter's genetic disability before the health crisis. In the six months between the two measures, Michelle had transitioned successfully into the NDIS and had begun to choose and engage supports. Michelle recorded a 19.5% improvement in her overall empowerment score (PEEM) following the program as well as a 12% decrease in the frequency of stressors with an associated drop of 8% in the difficulty score (PIP). Most notably, Michelle's result across the subscale for emotional distress improved by 26.6% (frequency) and 16% (difficulty). This aligned with Michelle's post-intervention interview where she stated that the program had helped her to 'be more proactive and stand up for my child. I am advocating more on things I might have let slide in the past' [sic]. The improvement in Michelle's improved sense of empowerment as a parent appears to have had a direct influence on her resilience as measured by the frequency and impact of stressors in the PIP. She also discussed the benefit of peer interaction and information sharing, noting that even when topics went a 'bit off track' [sic], they were still helping someone answer a critical question or share a relatable experience. She has continued a number of relationships with parents she met during the program and shared that she has made more of an effort since to reach out to other parents around her who are struggling. When asked whether she would recommend a program like this to other families, Michelle stated 'absolutely 100%. I can think of a few families that need it right now' [sic]. Michelle's results strongly advocate the need for a platform by which newly diagnosed families can start to engage in peer support. They further suggest that there is a snowballing effect attached to a positive peer experience – Michelle herself now actively supporting other families and capably identifying areas of unmet need.

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6.9. Discussion

The collected data suggests that the participants' experience of advocacy has improved following the capacity building program. Whilst this cannot be causally linked to the completion of the program, this finding is supported by the qualitative responses given at the post-intervention interview. The formalised post-intervention meetings were not the only form of feedback received from the program participants. Informal feedback was also encouraged and provided during the delivery of the program. Participants indicated that they felt they had developed an improved understanding of the role of the parent advocate and clearer expectations of the service providers with whom they regularly communicate. They reported feeling that they had been given timely and topical information to support their activity and to help them make choices with regard to their children's care. Most significantly, they indicated that they felt heard and supported by a community of capable peers, resulting in a lessened sense of isolation. Taking this one step further, many participants noted that they felt empowered to pass along information and actively support other parents outside this research program, suggesting that the benefits of participation reach beyond the families themselves.

It is important to note that while the trends are positive in terms of a pilot program outcome, the results show that individual experiences of advocacy are influenced by a combination of compounding factors. Some of those discussed include family structure, resilience and coping mechanisms, age of child, type of disability and health needs, social and financial circumstances, and adverse life events. Parental advocacy is a nuanced and complex activity that needs perpetual revision as children and families - and their environments - grow and change.

Chapter Seven: Discussion

The value of effective advocacy in the context of childhood disability has been demonstrated in terms of improved family functioning, efficient use of resources, and effective outcomes for children. This program of research took a structured, linear approach to explore the experience and understanding of advocacy through a sequential mixed-methods program. The literature review provided a robust backdrop regarding the development of family-focussed services and the shift towards the principles of family centred care across the globe. It also explored the lived experience of parents advocating for their children in a diverse range of contexts including education, health, and community. In-depth interviews with Queensland parents caring for children with disability provided rich experiential data about the reality of their lives, from developing resilience and learning how to navigate the systems that support their children to finding the confidence to share their skills and knowledge with other families and influence change. This study also clearly identified the newly legislated National Disability Insurance Scheme (NDIS) as a shared and particularly anxiety-inducing topic among parents and families. The Systematic Literature Review (SLR) filled a knowledge gap by examining the factors that contributed to a positive NDIS engagement experience among the parents of young Scheme participants, finding that these strongly echoed many of the positive influencers of advocacy identified in the parent interviews: existing supportive relationships (professional and peer), simplified and streamlined systemic processes, and access to information that was timely, tailored, and accurate.

These initial studies provided a wealth of information about the consumer and family experience of health, education, and community engagement in the context of advocacy and childhood disability. However, this provided only one half of the advocacy experience – and revealed a missing link in the experience of the service providers. The value of supportive

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partnerships between families and professionals was a common theme in the literature review, the SLR, and the parent interviews. The act of advocacy itself requires three parties: a subject (child), an advocate (parent), and a recipient (likely a service provider). The next study therefore examined the experiences of these professionals to whom families advocate. Two focus groups included professionals from education, health, social services, NDIS delivery partners, and community-based support providers. These professionals gave of their time to improve the understanding of advocacy because each saw the value in aligning the approach of families and professionals to enable true partnership in the provision and improvement of services and supports. A key finding of this study was that these professionals perceived themselves as advocates as well – advocating for the children and families they provided services to as well as for their professional interests, colleagues, and their organisations. It is interesting to note that every professional identified their advocacy on behalf of the child client to be of the highest priority. This is important because it further illustrates the complex nature of the advocacy relationship – that it is not a simple one-way transaction but a nuanced, multi-layered activity with collaboration and partnership at its core. Other common themes among the service providers reflected the principles that underpin family-centred care – integrity in information sharing, joint decision-making with families, collaborating and cooperating with other professionals in the child's life, providing opportunities for families to offer feedback, and connecting families to other services or educational opportunities. Another theme that tied closely to the parent experience was the acknowledgement of the power of peer support – not just among families but also for themselves as professionals.

Through Studies 1, 2, and 3, an improved understanding of the factors and conditions that contribute to success in advocacy has been achieved. There are many consistently appearing factors across all studies that provide insight into the factors for advocacy success.

These include supportive professional relationships based on reciprocal trust and respect, access to peer supports and social connectedness, streamlined and user-friendly systems and processes in service delivery, and access to information or education sessions especially around times of significant change or transition such as the national implementation of the NDIS.

These studies also identified significant barriers to the development and exercise of advocacy in this context. These directly reflect the success factors described above and include non-supportive or combative family-professional contact, social or geographic isolation, complex and unnecessarily bureaucratic systems and processes, and a lack of information or educational opportunities for families especially around periods of significant change or transition. These findings were used in the development and delivery of a short capacity building intervention for the parents and carers of Queensland children with disability as they prepared for the introduction of the NDIS, which makes up the final study in this program of research.

7.1. Where policy meets practice – piloting a program

It is important that policy and practice evolve as understanding grows and changes. Disability supports in Australia have historically taken the form of ad hoc programs and services delivered by NGOs using multi-level government and charitable block funds or were privately sourced by those with the means to buy them. Block funding arrangements might mean that a service provider has 150 spaces in its program despite a local need in the hundreds or thousands, meaning that services were often triaged or waitlisted and many Australians went unsupported. Some regions – particularly metro areas – may have a variety of services whereas regional or remote communities remained underfunded and underserviced. Services and funding tended to be concentrated on an identified group of 'disability types', which left those with complex or rare disabilities without assistance. Many

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services targeted preschool aged or adult populations, leaving a dearth of support for school aged and young people, effectively anything in between. The introduction of the Federally-delivered NDIS, whilst taking steps in the direction of closing some of these identified service gaps (as far as equipment, therapies, domestic and in-community supports) does not address the provision of education and medical supports which remain the responsibility of State-based education and health systems. Although both education and health systems in Queensland are making moves toward collaborative engagement with families and enacting family- and person-centred care principles, they remain largely professional-led in their structures and processes. In contrast, the structure and intent of the NDIS is to offer persons with disability genuine choice and control in the functional supports it provides.

This move away from professional-led supports and services under the NDIS has many positive implications, but it does shift the burden of responsibility for coordination and planning to families and to persons with disability themselves. This role requires a high level of system and health literacy as well as advocacy skills and confidence, especially during the annual Planning sessions, where families must articulate goals and present a case for supports and funding directly related to those goals in a meaningful, cost-effective way. There is also a significant investment of emotional resources and level of mental resilience required of families during these intensive planning periods, which will occur annually throughout the participant's lifetime. Without effective planning, funding is not likely to meet the needs of the individual over the course of the year. Putting aside for a moment the moral and ethical concerns, this is also likely to lead to negative health outcomes and a subsequent increased (and preventable) fiscal burden on health systems. This creates an obligation – both moral and fiscal – to provide adequate supports for persons with disability and their families as they engage in a lifelong relationship with the National Disability Insurance Agency (NDIA).

The NDIA provided considerable funding for preparatory sessions delivered via a variety of existing non-government organisations (NGOs) in the six months leading up to Scheme commencement in each region. These sessions provided information to persons with disability and their families about the Scheme and the supports it could offer as well as practical tips and strategies for goalsetting and planning, although they stopped short of offering direct advocacy education or supports. These sessions will not be provided on an ongoing basis, meaning that the families of newly diagnosed children and those with newly acquired disability are likely to be disadvantaged. This presents a clear gap in the operationalisation of the Scheme as these families are likely to receive inadequate support packages as a result of ineffective Scheme engagement, which will in turn have a negative effect on quality of life and family functioning. This is likely to result in negative health, educational, employment, and community outcomes for persons with disability, leading to increased systemic costs over a lifetime.

Children with disability require an effective champion to engage with the NDIS and other services as they grow. This program of research was focussed on the development of the advocacy skillset and mindset required of the parents of these children. The pilot program aimed to provide the parents of children eligible for the NDIS with information and support to enable them to effectively advocate for their children, with a focus on engaging productively with the Scheme. Delivered in three South East Queensland regions, 44 parent carers from 37 families engaged with the four-week program led by a parent peer. The design of the program incorporated all of the major findings from the previous studies including the provision of tools and techniques to assist in creating and maintaining positive relationships with service providers; provision of timely, accurate, and topical information tailored to the audience regarding NDIS processes and engagement; and real opportunities for informal contact and open discussion with a group of supportive peers. The program was delivered

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with the support of Queensland Health and intended as a pilot to be considered by the health system for rollout with newly diagnosed families going forward.

Williams, Perrigo, Banda, Matic, and Goldfarb (2013) favour the 'no wrong door' approach to supporting families in accessing services for children with complex needs. First articulated by the US Dept of Health and Human Services' Center for Substance Abuse Treatment (Clark, 2002), this concept applies well to any system that requires co-ordination of service access to ensure an adequate level of care. Where young children are involved, there is often a co-occurrence of behavioural, medical, and developmental issues that result in parents presenting at any one of a large range of agencies such as general practitioners, mental health specialists, child development clinics, paediatricians, or educators. The 'no wrong door' concept would see every family given information and referrals to the most appropriate agency for their child's needs. A capacity building program offered to every parent at or near the identification of disability could provide this avenue of support and referral as well as offering tools and strategies that build towards the mindset and skillset that will be required of these parents as their children grow.

The health system – as the logical 'first responders' when disability is identified – is a common thread among the parents in this study. All of the respondents' children had existing relationships with GPs, tertiary medical specialists and other health professionals regarding their child/ren's long term health needs. The intervention proposed by this program of research aimed to tap into that first line of support and provide an evidence base for consideration by the health department that interventions provided at or near the time of diagnosis would start families on the path of advocacy success – ultimately resulting in improved outcomes for children.

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7.2. Areas for future research

Common in research projects are tangential questions that emerge throughout the development and execution of a project. This program of research raised a number of issues and questions that deserve further scrutiny. One such questions is the issue of the limits of parental advocacy. For the parents of typically developing children, parental advocacy naturally includes a progression towards children becoming capable self-advocates as they reach adulthood. Where this capacity may be impacted by disability, how can parents and families negotiate this transition while ensuring protective factors are balanced with appropriate personal agency?

The aim of the disability rights movement is to enable full and equal citizenship for Australians with disability (Cooper, 1999), and part of this must include personal agency – an ideal personified by the call for 'nothing about us without us' that was introduced in the late 1990s (Charlton, 1998). In order to maximise the potential for the development of personal agency among those who experience childhood disability, the children must first be given every opportunity to develop their skills and capacity to its full potential. Research demonstrates clearly that this requires considerable advocacy on the part of parents and families (Crowe & Florez, 2006; Dempsey & Dunst, 2004; Ryan & Runswick Cole, 2009). However, it is important that as a child's capacity increases, they are empowered to develop their own voices and direct their own care. This – especially in cases where cognitive impairment is a factor – may be a confronting reality for parents and children as they transition into adult services and full adult participation in the community. This has been acknowledged by the highly successful Triple P parenting programs, which offer a series of short courses specifically for the parents of children with disability (Sanders, Mazzucchelli, & Studman, 2004). This framework may present a good starting point for the development of a further framework to consider the transition from parent-led to person-led advocacy.

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Another interesting theme emerged during the literature review and was briefly discussed a number of times throughout the research. This considers the impact of gender on advocacy styles and success factors. Many studies found that women are far more likely to be the primary caregivers and advocates for vulnerable family members. Equally, there are studies that suggest women are perceived differently when advocating, particularly when engaging in self-advocacy (Amanatullah & Tinsley, 2013). Given the high level of personal investment when advocating on behalf of one's child, it is conceivable that the activity is perceived by the advocee (target of the advocacy) as being closer to self-advocacy than traditional concepts of other-advocacy. The political and economic emancipation of women also occurred across a similar timeline with a change in the public discourse and disability reform. Exploring this co-existent activity through the lens of feminist theory would improve the understanding of advocacy development from the historical perspective.

This author acknowledges some limitations to this work which may assist to inform future areas for parental advocacy research. One of these is the small participant group in Study 4. A larger group would yield data that could provide statistically relevant results from the application of the survey measures. It would also allow for the experience of certain cohorts to be grouped and compared to enable a more targeted systemic response. These may include such focus areas as culturally and linguistically diverse families, groupings related to child's age or disability type, socio-demographics, geographic location and more. Another limitation was the regionality of this research, which was conducted exclusively within Queensland, Australia. As evidenced by the global literature regarding this phenomenon (advocacy in the context of parenting a child with disability), this is not an issue confined to the local community but a shared experience of parents all around Australia and the world. Replicating this body of work in other nations, cultures, and systemic environments would provide a more robust picture of this innately human experience.

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7.3. Reflexivity

As an insider researcher, myself the parent of a child with a profound and complex genetic condition, I was able to bring a personal understanding and experience of parenting a child with disability in Queensland to this program of research. This experiential knowledge enabled me to take a pragmatic and structured approach to improving the understanding of the phenomenon of raising a child with disability across different representative demographics. Each study built on the one before it to form a well-rounded and robust picture of advocacy in this context before the capacity building program was designed. This nuance also resulted in many other benefits that were evident throughout this program of research.

The parent-carer population is by nature of the role a difficult group to engage, partly due to their children's ever-changing, unpredictable (and always top priority) needs. Parents in this population are more likely to spend their limited resources pursuing research programs that offer treatments and cures for their children rather than those that might benefit themselves, reflecting the common priorities of parents across the family spectrum. As a peer, I was able to anticipate and empathise with this priority and clearly highlight the positive outcomes for children whose parents are strong and capable advocates. I believe this had in turn a positive impact on the recruitment process and participant retention.

I have a personal appreciation for the drive to keep some things private when it comes to our children and our family lives. With so many systemic touchpoints throughout our children's lives, it can often feel as though nothing is sacred. However, I was and remain extremely grateful for the depth and breadth of personal experiences that parents shared freely and openly during the individual interviews, and their willingness to do so in the hope that it might help other families experiencing similar trajectories. Sentiments ranged from wishing to share their expertise and knowledge to helping others avoid the pitfalls they

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themselves fell into, but parents were universally altruistic in their intent. A number of parents expressed a feeling of trust in my motivations for engaging in this research, which is humbling on a personal note but was also critical to the depth of data I was able to collect in a very short time.

My position as a peer facilitator may also have assisted the capacity building group to reach a cohesive stage of development more quickly as there was an immediate sense of shared mission, critical to the formation of a cohesive group (Tuckman & Jensen, 2010). When facilitated by a perceived outsider, it is reasonable that trust may take longer to form, partly due to expectations on both sides. Where offered by a service organisation, for example, participants may expect that issues raised and suggestions offered be addressed and actioned by the organisation. Equally, facilitators may expect participants to support or purchase their services. The position of the peer leader limits the weight of these expectations and allows for the development of trust and collaboration to occur more quickly (Diefenbeck, Klemm, & Hayes, 2014).

It is equally important to be mindful of the challenges of insider research. I believe that the key to mitigating bias is in acknowledging its existence. Hewitt-Taylor (2002) and Greene (2014) discuss the benefits of insider qualitative research and suggest a number of mitigation strategies to both acknowledge and avoid potentially damaging (or skewing) researcher bias. In this program of research, I approached these issues by engaging with the mentorship offered by the student-supervisor relationship. At my request, my Principal and Associate Supervisors reviewed the ethics applications, interview guides and transcripts, program design and other documents with a critical eye for potential bias or leading content. Analytical interpretations of data were continuously discussed with my supervisory team to ensure that they faithfully reflected the perceptions and experiences of the participants.

7.4. Realising benefit – contributions to knowledge and practice

This research supports the finding that individual psychological states and life circumstances influence a family's experience of parenting and advocating for a child with disability. This very personal lens perhaps represents another layer of nuance in the depiction of the parent carer role in Figure 4.2. The child at the centre is the subject of the parent roles described, but the parent and family are in turn subject to the environment (intrinsic and extrinsic) they are in. It is this level of complexity coupled with the high personal investment that makes parental advocacy unique among its more professional (and therefore less subjective) counterparts. The family's social, physical, and psychological states cannot be separated from their capacity for and activities of advocacy. It is through recognising the existence of this layer and seeking to understand it that the systemic response can be optimised. It would be very easy to assume that an empowered, family-led systemic environment (such as Australia is developing through the NDIS) is the way forward, but the reality is that this approach must be tempered by the understanding that not all children have access to an invested, capable, willing advocate. A differentiated response in support and education for families is likely to be necessary so that every family is given the opportunity to partner in their child's care. At the same time, policies and systems must ensure that no children are disadvantaged by the varying levels of access, capacity, and willingness to engage in the parent population. This delicate balance requires the in-depth knowledge and understanding provided by this and other future programs of research around parental advocacy, personal agency for people with disabilities, and parent-professional partnerships.

The capacity building program was designed to draw on the knowledge offered by the preceding studies. The feedback provided throughout the program and at the six-month post-intervention interviews demonstrate benefits that align with the themes of positive advocacy identified by the early studies in this program of research. These included an increase in

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parental resources and improved sense of empowerment, timely access to information that was aligned with family needs and future planning, and the support of a capable community of peers. Further to this was the inclination of many parents to move beyond the confines of the program participation itself and engage with the wider community, passing along information and offering support and advice to those outside this program of research and actively lobbying for change.

This finding is significant not only because it further demonstrates the willingness of parents to move from advocacy into activism, but also because it suggests that the benefits of a program such as this reach beyond the participants themselves and into the wider community. Putting aside for a moment the moral and ethical obligation that society has to support its more vulnerable members, consider the benefits of a system that is well connected to its client base, shares information openly and with integrity, fosters trust, and is able to exploit the increased capacity of parents to be capable directors and empowered partners in the delivery of care for their children.

7.5. Conclusion

This program of research examined the experience of raising a child living with disability in Australia today. Each subsequent study built on the preceding one to produce a deep understanding of the challenges and opportunities facing parents and families as they secure the resources required for the children to achieve full community citizenship. This research has delivered on its central aims by building a robust understanding of the complexity of the parent carer role and exploring the advocacy activity common among this parent carer population. These studies improve the understanding of the challenges faced by parent carers in achieving recognition for their role as advocates for their children in systems where the processes and policies frequently exclude them. The design, development, and

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implementation of the capacity building intervention in Study 4 showed positive outcomes associated with peer networking, parent empowerment, and advocacy skills development.

Positioning the largest Australian paediatric systems within health, education, social services, and the NDIS to support knowledgeable, empowered parent partners will logically result in higher organisational efficiencies. Co-designed services will better meet the needs of children and families, processes can be streamlined as families learn to navigate within the system/s, and services will be able to reach more families, those families in turn reaching and supporting others and provide critical links to further services. Children do not exist in the silo of any one service or system, but one constant (for most) is the family unit, often including willing and capable primary caregivers and advocates. Given the right tools and systemic encouragement and support, these family advocates have the potential to contribute to meaningful systemic improvements and – most importantly - change the lives of Australia's children for the better.

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Appendices

9.1. Appendix A - Semi-structured interview guiding script

The interviews will be largely unscripted and flexible, but will focus on four key areas:

1. Impact of the child/ren's disabilities on day to day life (child, carer, and family);

2. Supports in place - formal and informal – and supports required;

3. Observations (including identification of advocacy activity) about current systemic interactions including the imminent NDIS; and

4. Perceived self-efficacy (including understanding of success) around parenting, caring, and advocacy activities.

Guiding Questions MAY include (only where necessary):

a. Tell me a little about your family;

b. Tell me about your child/ren with a disability;

c. How does your child/ren's disability impact your own life?;

d. How does your child/ren's disability impact your family?;

e. What does a normal day/week/month look like for you?;

f. What do you do for your child with disability that 'typical' parents don't have to do?

2.

a. How do you manage all the extra things you have to do?;

b. Do you have informal (family and friends) supports in place?;

c. Do you have any professional supports in place?;

d. Do you receive any funding or funded supports?;

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e. Do you feel you have all the support you/your child need/s?;

f. Are you waiting for access to any supports you've applied for?;

g. Are there other supports you wish were available?

3.

a. Tell me a little about your relationship with your child/ren's medical team/educators/allied health professionals/social services (service providers) etc?;

b. Do you feel that you have any say in decisions made about your child/ren?;

c. Do you feel that you manage/coordinate your child/ren's care or is it mostly managed by 'the system'?;

d. Do you feel well supported by service providers in general?;

e. Do you feel comfortable talking about the future (planning, goalsetting) with service providers?

4.

a. What does advocacy mean to you? (offer definition on a card);

b. What activities do you undertake that you would consider 'advocacy'?;

c. Do you feel you are a confident advocate for your child/ren?;

d. Do you understand your rights and responsibilities when speaking with professionals about your child/ren?;

e. Do you understand the processes around eligibility and assessment?;

f. Do you feel able to be assertive with service providers where necessary?;

g. What do you do when conflict arises?;

h. Do you know where to look for answers when you need them?;

i. Do you feel your advocacy skills have developed since diagnosis?;

j. Do you feel like a partner in your child/ren's care when speaking with service providers?;

k. Do service providers value your knowledge and expertise when it comes to your

child/ren?

l. Is it possible to advocate 'too much'?

m. How do you know when you've done a good job as an advocate?

9.2. Appendix B - Validation of instruments

9.2.1. The Parental Empowerment and Efficacy Measure (PEEM)

The Parental Empowerment and Efficacy Measure (Freiberg et al., 2014) is a 20-item measure of empowerment and efficacy among parents.

Validation of the PEEM (Freiberg et al., 2014)

Study of 886 Australian parents of primary school aged children including 174 parents accessing community-based family support services.

Method:

Confirmatory Factor Analysis

Concurrent Validity

Results:

Overall alpha 0.92

Two-factor analysis: empowerment and efficacy

Cronbach's alpha .88 and .85 respectively.

Discussion:

General population results were compared with those of families accessing community supports. These families were generally representative of disadvantaged communities and were more likely to be experiencing a sense of disempowerment and stress. A lower mean score was observed among families experiencing higher levels of adversity evidenced by community worker case notes. The PEEM reliably demonstrated the capacity to detect variation in the construct it was designed to measure.

9.2.2. The Family Quality of Life Scale

The Beach Center Family Quality of Life Scale (Beach Center on Disability, 2012) is a 25-item survey instrument designed to measure family quality of life in families that include a member with a disability.

Validation of the Beach Center FQoL (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006)

Study of 488 families of children with disabilities – family quality of life

Method:

Confirmatory Factor Analysis (CFA)

Results:

Five-factor analysis – family interaction; parenting; emotional wellbeing; physical/material wellbeing; and disability-related support.

Cronbach's alpha: family interaction .89, parenting .89, emotional wellbeing .79, physical/material wellbeing .81, and disability related support .86.

Satisfaction ratings .85, .81, .83, .64, and .70 respectively

Discussion:

Results imply excellent internal validity with regard to both importance and satisfaction for family interaction and emotional wellbeing. Parenting and disability-related supports show excellent internal validity for importance but somewhat less for satisfaction. Physical/material wellbeing showed excellent validity re importance but a significantly lower alpha for satisfaction, suggesting that families were not satisfied with each indicator in this subscale.

Each of the five subscales was unidimensional and internally consistent.

9.2.3. The Paediatric Inventory for Parents

The PIP (Streisand et al., 2005) is a 42-item instrument designed to measure parenting stress in the context of parenting a child with a chronic condition.

Validation of the PIP

1. Streisand et al. (2001)

   - Study of 126 parents of children with cancer diagnoses

2. Lewin et al. (2005)

   - Study of 28 mothers of children with Type 1 diabetes

Method:

1. Internal Validity, Confirmatory Factor Analysis (CFA)

2. Cronbach's internal consistency measure, convergent validity using other tools.

Results:

1. Cronbach's for domains of Frequency (.95) and Difficulty (.96). Alphas within each subscale ranged from .80 to .88 (Frequency) and .82 to .92 (Difficulty) (Streisand et al., 2005).

2. Cronbach's for the total measure .97. Frequency domain .94, Difficulty domain .94. Similarly high scores within the four subscales in each domain (Lewin et al., 2005).

   a. Convergent validity: PIP Frequency and Difficulty domains were highly related ($r = .93$, $p < .01$ using:

i. Child Behaviour Checklist (CBCL) for children ages 4 –18 (Achenbach, 1991), a widely used measure of childhood externalizing and internalizing problems.

ii. State-Trait Anxiety Inventory (STAI–S) (Spielberger, 2010) is a 20-item scale that measures current subjective reports of worry and anxiety.

Discussion:

Excellent internal validity across both studies, as well as "clinically significant positive relations of medium effect size between parental stress on the PIP and maternal ratings of state anxiety" (p.62). This study showed transferability of the scale from its original context with the parents of children with cancer diagnoses to other chronic conditions (in this case Type 1 diabetes).

9.3. Appendix C - Post-intervention structured interview

Parent Empowerment and the NDIS

Post-Intervention Short Structured Interview

1. Did the 'Parent Empowerment and the NDIS' program deliver the kind of content you expected?

2. Was there anything you had hoped to learn that wasn't' covered by the course?

3. What was the most useful aspect of this program for your family?

4. Is there something that could be improved in delivering this program in future?

5. Has your participation in this program influenced any decision you have made since?

6. Have you continued a relationship with anyone you met during this program?

7. Would you recommend a program like this to other families?

8. Is there any other feedback you'd like to give?

PARENT EMPOWERMENT AND THE NDIS

Program Guide - 2018

PROGRAM GUIDE

CAPACITY BUILDING FOR PARENTS OF QLD CHILDREN WITH DISABILITY

OVERVIEW

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KEY FOCUS AREAS

- What is advocacy?
  - Advocating for self
  - Advocating for others
  - Micro, Mezzo & Macro Advocacy
- Why advocate?
  - Personal Bill of Rights *(Bourne, 1990)*
- Systemic Interactions and Advocacy
  - Health
  - Education
  - NDIS
  - Social Services
- Common parental advocacy techniques *(Trainor, 2010)*
- What Advocacy is Not
  - Assertive vs Aggressive

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MODULE 2 – STRATEGIES FOR SUCCESS

KEY FOCUS AREAS

- The "Six Steps to Successful Child Advocacy" *(Wright & Jaffe, 2014)*
  1. Knowing your issue
  2. Research for background and impact
  3. Preparing effective materials
  4. Making meetings that work
  5. Conducting strategic follow up
  6. Reinforcing successful outcomes
- Recognising our own limits
- Seeking external support
  - How can I find the right support?
  - Managing external advocates – keeping your message clear.

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MODULE 3 – MAKING THE MOST OF THE NDIS

KEY FOCUS AREAS

- Accessing the NDIS
- Tracking my Child's Daily Activity
  - 'No Worse Off'?
  - Acknowledging the worst day while aiming for the best life
- NDIS Supports
  - The *'Reasonable and Necessary'* Test
  - What should we ask for?
- Planning
  - Reports, Assessments, and Quotes – oh, my!
  - Making the 'Six Steps' work for your child
  - The planning relationship
  - Choosing a management style
- Implementing your child's Plan
  - Using the MyGov NDIS Portal
  - Service Seeking
  - Service Agreements
  - Financial Management

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MODULE 4 – PEER PLENARY SESSION

KEY FOCUS AREAS

- Peer stories
- Q & A sessions
- Supporting each other
  - Using social media and other digital platforms
  - Consumer engagement
  - Activism
- Moving Forward

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Welcome to the Children's Health Research Centre (CCHR) and thank you for your interest in this program. Children's Health Queensland (CHQ) and the University of Southern Queensland (USQ) are grateful for your time and input. This program will be facilitated by Fiona Russo, a PhD candidate at USQ. More personally, I am a parent and a carer for a child with a complex disability. The program you are about to begin was drawn from my own family's experiences, existing research, and the collective wisdom of many parents, carers, and service providers who were willing to sit with me and tell their stories. I acknowledge their contribution here and thank them all.

This program is being delivered as part of a research project. Participants are required to sign consent forms and are advised that they can withdraw their participation at any time for any reason. Approximately three months after the program is completed, I will contact all families to conduct a brief follow up interview, which will provide valuable information about the impact the program has had on your child, yourself, and your family. Feedback about the delivery and content of the program is welcomed, and you can contact me at any time if you have any queries or concerns.

Upon completion of the modules, I hope that you will feel better prepared to advocate for your child/ren as the NDIS approaches. I look forward to speaking with you all over the coming weeks.

Kind regards,

Fiona Russo.
0404 246 223
fiona.russo@usq.edu.au

WHAT IS ADVOCACY ANYWAY?

The Oxford English Dictionary describes Advocacy as *public support for or recommendation of a particular cause or policy*. It also suggests that *to advocate* means to *plead for or speak on behalf of another*.

The Oxford English Dictionary notes the first mention of an advocate around 1340AD, then defined as *a person or agent believed to intercede between God and sinners*. Although the language is a little different and society perhaps more complex, the core meaning – to publicly support someone or something - hasn't changed much.

Perhaps it is simpler to see an advocate as someone who liaises with the powerful on behalf of the powerless.

There are two main types of advocacy:

➡ *Self Advocacy* – Standing up for your rights and representing your own best interests.

➡ *Other Advocacy* – Standing up for the rights of another and representing their best interests.

ACTIVITY
List the activities of advocacy in the context of being a parent caring for a child with complex health needs or disability. Do the definitions above cover it all or is there more to the story?

Which of these applies to a parent advocating for their child/ren?

THE VOICE OF THE CHILD

In advocating for someone, it is important to ensure that '*their own voice*' is heard as much as possible. This doesn't mean that a child needs to physically speak – young age, limited cognitive capacity, and functional communication challenges are some obvious barriers to this. Even the most capable child is likely to need the support of a champion when they are dealing with complex systems like education, health, and the NDIS.

The most powerful tool at our disposal as parents and carers is the ability to understand – on an intimate level – what daily life is like for our children. Many of us have developed techniques for communicating with our children despite the toughest of challenges. With this knowledge and ability, we can:

➡ Understand the situation – and identify any unmet needs.

➡ Ensure that our children are given the chance to exercise developmentally appropriate choice and control.

➡ Communicate which options would best suit the preferences of our child/ren.

➡ Protect our child's privacy and dignity.

RESOURCE
The Personal Bill of Rights *(Bourne, 1990 - Appendix 1)*
In small groups, identify aspects of our own lives we would hesitate to share. Discuss the application of the Personal Bill of Rights in our advocacy.

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What does it mean to *presume competence?*

What does this look like at home?

How can we as parents and carers ensure that we are practising this in our advocacy?

How can we encourage others to presume competence?

How can we encourage this in others when we are not with our child/ren?

pre·sume com·pe·tence
prɪˈzoom/ ˈkämpətəns/

To presume competence is to acknowledge that all individuals have the ability to learn, to communicate, to participate in their own way. It means that we provide opportunities by creating accessible & inclusive spaces.

To presume competence is to respect the value of human diversity.

Not presuming competence is to actively harm.

facebook.com/AutismWomensNetwork

WHY DO WE ADVOCATE?

> ### *ACTIVITY*
> *Brainstorm the reasons that parents advocate. Link the results with the activities of advocacy previously identified. Discuss the meaning of success – how do we know when it's working?*

Parents and carers advocate for a variety of reasons. Every child and every family has their own ideas about what constitutes a good life. The systems we interact with on a regular basis do not often cater for the preferences of the individual, but rather aim to meet the general needs of the majority. How do we bridge that gap?

MICRO, MEZZO, AND MACRO ADVOCACY (WRIGHT & JAFFE, 2014)

Micro (small scale) advocacy usually concerns a single child or family. It is focussed on achieving positive outcomes specific to that child and family, but it is important to note that it doesn't imply that the level of effort is small or the outcomes insignificant. Micro advocacy is the main focus of this program and is often described as the most isolating type as it tends to be largely undertaken by one primary caregiver.

Many parents of children with complex needs find themselves engaged in **mezzo** (medium scale) advocacy throughout their journey. Mezzo advocacy concerns a group or community-level activity. It may include things such as advocating for your child's school or class group, or joining forces with other families facing similar diagnoses/challenges and taking up common causes together. Once again, it does not reflect the amount of effort or the significance of the outcomes.

Macro (large scale) advocacy moves into the realm of **activism**. Activism is any activity that seeks to bring about political or social change. A good example of macro advocacy is the development of the National Disability Insurance Scheme (NDIS), first imagined and later progressed by a group of people with disabilities and their families and carers who lobbied and advocated on behalf of all Australians living with disability. This type of advocacy, while daunting, tends to be more collaborative in nature.

Many parents are active across all three advocacy types at different times throughout our children's lives. We wear many different hats in our parenting roles. **Where are you putting most of your effort right now?**
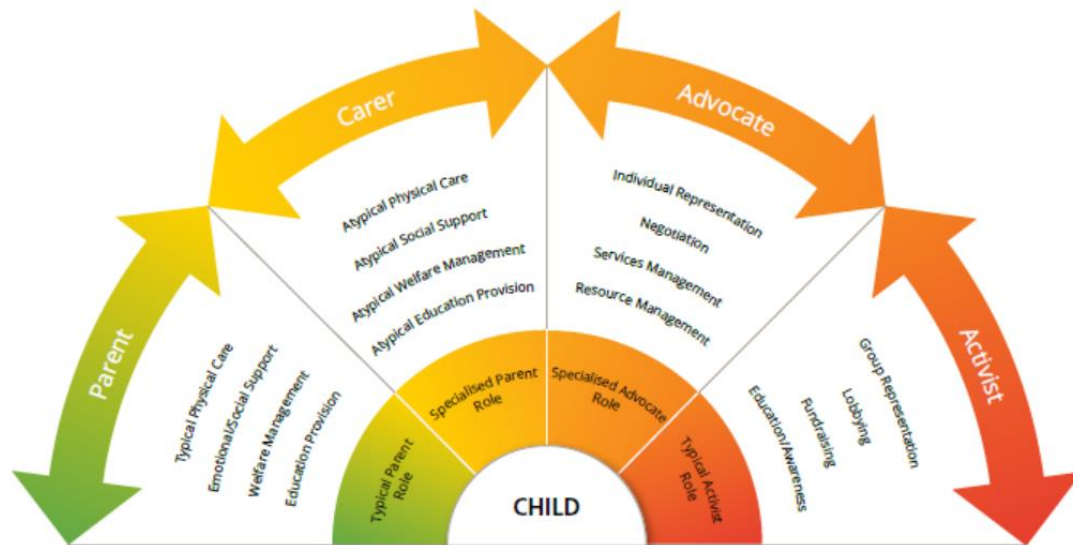
WORKING WITH THE SYSTEM(S)

Our children interact with many systems throughout their early lives, and as their champions, we are alongside them. From the initial appointment with the GP to choosing the right school to the implementation of the first NDIS plan, what does that journey typically look like? Here is one example:

ACTIVITY
Consider your own family's journey.
Complete a brief flowchart that illustrates your lived experience. Where are the system 'touch-points'?
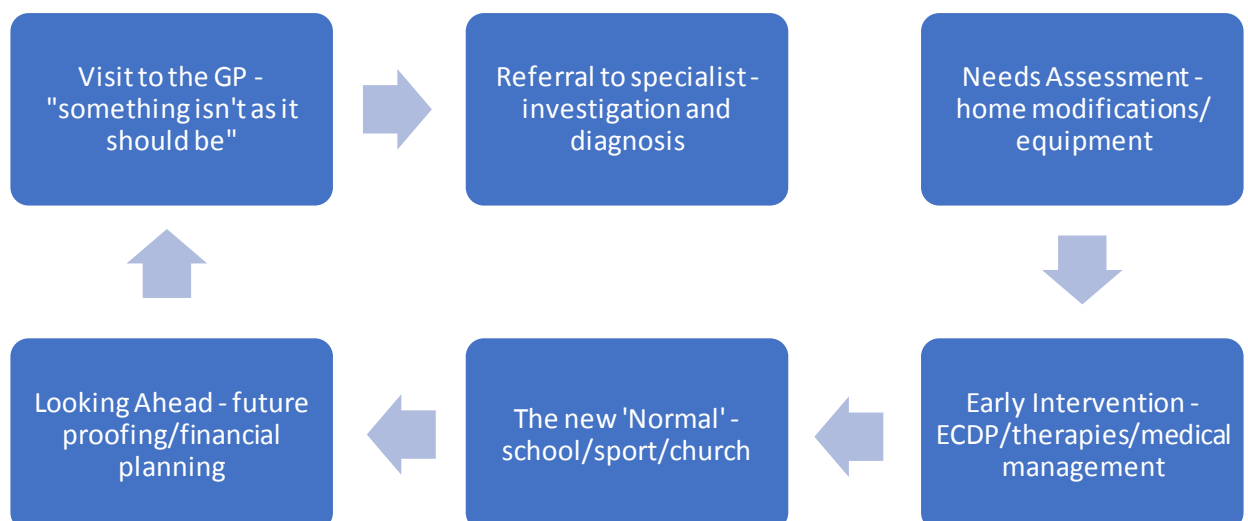
COMMON STRATEGIES (FROM TRAINOR, 2010)

Parents use a variety of strategies when advocating. An American researcher named Audrey Trainor studied the advocacy styles of parents in the education system in 2010. She found that there were four identifiable strategies in the parents' approaches:

Category	Characteristics	Limitations
Intuitive Advocate	Relies heavily on 'knowing their child' better than anyone else in order to exert more influence over decisions relating to support requirements, service access, and contingency planning.	Tends to be discounted by professionals.
Disability Expert	Seeks to impart knowledge of the child's disability and associated problems. It was noted that parents of children with Autism were most likely to identify with this approach.	Potential to create a 'defecit' view of the child by focussing on challenges rather than opportunities.
Strategist	Well-versed on systemic policy and legislation, their roles and rights, and their children's rights. Strategically prioritises their child's needs and set goals, manipulating the system to achieve them.	Parents reported gaining a 'troublemaker' reputation when asserting themselves in this way.
Agent of Change	Identifies a gap in the system or delivery processes, and advocates for change. Community-minded activism - improving the system not only for their own children, but for the families to follow.	There is potential for a negative effect on the individual child when parents are focussed on broader activism.

ACTIVITY
In pairs, identify and discuss your 'go to' advocacy style. Where has it worked well? Where have you had to change your approach? Are you a flexible advocate?

Most parents report that they use all of these approaches in combination, depending on the audience and the desired outcome. However, many parents also report that they have a natural style that leans toward one of these strategies.

Common to many researchers is the finding that parents feel their systemic interactions are often adversarial – that they feel they are always 'fighting' the system. Does this ring true for you?

WHAT ADVOCACY IS **NOT**

Now that we've spent time talking about what advocacy is and how and why we do it, it's time to give some thought to what advocacy is **not**. As food for thought, here are some answers offered by parents (although it may be argued that there are exceptions to these):

- Aggressive
- Telling your child what they want
- Getting your own way at any cost
- Fund-'raging'
- Rorting the system
- Complaining without offering solutions
- Making all the decisions

ACTIVITY
*Brainstorm examples of **bad advocacy**. Is there such a thing? Does negative advocacy depend on the outcome or are there a few common 'rules'?*

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MODULE 2: STRATEGIES FOR SUCCESS

1. Know Your Issue
- Identify the issue
- Analyse - issue, stakeholders, policy
- Framing the issue

2. Research
- Research for background and impact
- Primary and secondary research

3. Prepare Materials
- Communicating effectively
  - Persuasive
  - Succinct
- Crafting your message well

4. Meetings that Work
- Setting up meetings
- What and who to bring
- Keeping good notes

5. Strategic Follow-up
- Meeting actions
- Keeping stakeholders informed and engaged
- Using your networks

6. Reinforce Success
- The importance of reinforcing positive outcomes
- Monitoring and evaluation
- Learning from unsuccessful outcomes

Much of the information in this module is adapted from a book by Amy Conley Wright and Kenneth J Jaffe (2014) called '*Six Steps to Successful Child Advocacy: Changing the World for Children*'. The book offers examples that range from a parent advocating in a hospital setting for her child experiencing seizures (micro) to a kindergarten class lobbying for a new pedestrian crossing near their school (mezzo) to tackling the heartbreaking issue of the sanctioned killing of street children in Brazil (macro). In all cases and everything between, Wright and Jaffe apply a six-step framework for effective advocacy.

An example relevant to this group might be the procurement of a wheelchair. The level of advocacy required – particularly under the incoming NDIS – may be intense and multi-faceted over a short period of time. Let's follow this wheelchair example throughout the six steps.

The core issue is a child's limited capacity for mobility. Assessment, scripting, quoting, and funding will need to be undertaken. Consider the support you need (and from whom) and whether it is available.

Can you demonstrate that a wheelchair will help adress the issue? Can you identify any chairs that would suit more than others? How do you know? Even if your research is simply asking similar families for advice, this can provide valuable evidence.

What evidence do you need to gather? What does it need to say and who will be reading it? What is their level of influence – and what is most important to them (value for money/ clinical outcomes/quality of life)?

Schedule trials and assessments at times that suit your child (wakefulness, hunger, mood etc). Be sure to organise and present all of your supporting documents and take notes about anything anyone agrees to do.

Keep all of your stakeholders (wheelchair supplier, physio/OT, NDIA planner etc) informed of the progress. If someone agreed to do something, follow up with an email reminder and a polite but clear deadline.

If your application is approved, you can build on your relationships by simply thanking people for their support. Let them know how your child is going with the new equipment. If you were not successful, gather as much information as you can for a second attempt. Let all stakeholders know about the feedback.

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Example Scenarios for consideration: how would you apply the Six Steps to each of these?

Scenario 1	Scenario 2
My child's paediatrician wants to start a new medication, but I have read about some scary side effects. When I try to ask about them, I feel like the doctor dismisses my concerns.	I would like my child to be considered for the special education unit at school as I feel s/he is struggling too much in a mainstream classroom. I have a parent-teacher interview coming up.
Scenario 3	**Scenario 4** (*as outlined above*)
My child is seeing a physiotherapist who has some ideas about equipment that could support my child's physical needs in the classroom. My child is worried about 'standing out' among their peers at school.	My child has outgrown their wheelchair and needs a new one. I know the NDIS can help us to purchase this, and we have a planning meeting coming up. Our physio and OT have suggested a few models for us to trial.

RECOGNISING OUR LIMITS

What does carer burnout look like? What are the warning signs? Are you effectively self-assessing and regulating?

*Remember: **If you're not looking after yourself, you're no good to anyone else.***

If you are experiencing carer burnout – or if you just feel that a situation has you in over your head, what can you do? Where can parents and carers look for support?

SUPPORT IS AVAILABLE

There are many organisations offering support for Queenslanders with disability and their families. Here are just a few of them:

Carers Queensland
Various Locations across Qld
1800 242 636
info@carersqld.com.au
www.carersqld.com.au
Carers Queensland offers a large range of supports and services to Queensland carers (parents, siblings, children etc.).

Speaking Up For You (SUFY)
West End, Brisbane
07 3255 3638
sufy@sufy.org.au
www.sufy.org.au
SUFY offers specialised advocacy support in the disability space.

Queensland Advocacy Incorporated
South Brisbane
07 3844 4200
qai@qai.org.au
www.qai.org.au
QAI offers Systems Advocacy as well as specialised individual legal advocacy in the disability space.

ADA Australia
Geebung, Qld
1800 818 338
info@adaaustralia.com.au
www.adaaustralia.com.au
ADA Australia offers advocacy support in the fields of aged and disability care.

MODULE 3: MAKING THE MOST OF THE NDIS

RESIDENCY

To meet the residency requirements, you must live in Australia and:

- be an Australian citizen OR
- hold a Permanent Visa OR
- hold a Protected Special Category Visa, that is you:
  - were in Australia on a Special Category Visa on 26 February 2001 or
  - had been in Australia for at least 12 months in the 2 years immediately before 26 February 2001 and you returned to Australia after that day.

DISABILITY

You may meet the disability requirements if:

- you have an impairment or condition that is likely to be permanent (i.e. it is likely to be life-long) and
- your impairment substantially reduces your ability to participate effectively in activities, or perform tasks or actions unless you have:
- assistance from other people or
- you have assistive technology or equipment (other than common items such as glasses) or
- you can't participate effectively even with assistance or aides and equipment **and**
- your impairment affects your capacity for social and economic participation **and**
- you are likely to require support under the NDIS for your lifetime.

An impairment that varies in intensity e.g. because the impairment is of a chronic episodic nature may still be permanent, and you may require support under the NDIS for your lifetime, despite the variation.

To access the NDIS, you will need to complete an Access Request Form. You can find one at this online address (https://www.ndis.gov.au/people-with-disability/access-requirements/completing-your-access-request-form) or by entering 'NDIS Access Request Form' into your search engine.

AGE

You must be under 65 years of age when you apply to join the Scheme.

Participants under the age of seven (7) years will enter the scheme under the Early Childhood Early Intervention (ECEI) stream.

EARLY INTERVENTION REQUIREMENTS

You may meet the early intervention requirements:

if you have an impairment or condition that is likely to be permanent and there is evidence that getting supports now (early interventions) will help you by:

- reducing how much help you will need to do things because of your impairment in the future **and**
- improving or reducing deterioration of your functional capacity or
- helping your family and carers to keep helping you **and**
- those supports are most appropriately funded through the NDIS, and not through another service system.

OR

you are a child aged under 6 years of age with developmental delay which results in:

- substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development and
- results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; **and**
- those supports are most appropriately funded through the NDIS, and not through another service system.

Upon receiving a valid access request, the NDIA must respond within 21 days. You can find more information about this in the NDIA Operational Guidelines. This timeframe applies to a person who resides in an NDIS area, and who has made a valid request with all relevant information and evidence about their disability or impairment.

In some cases, the NDIA may need more documents, assessments or evidence, which means it might take longer for your request to be assessed.

For Early Childhood Early Intervention access (under 6 years old), the pathway for access is a little different. You will need to make contact with the ECEI partner in your area for assistance.

In QLD, the Partners delivering ECEI services are:

UnitingCare Community (external) in Townsville, Toowoomba and Mackay Service Areas.

EACH (external) in the Ipswich Service Area.

BUSHKids (external) in the Bundaberg, Rockhampton, Maryborough, and Maroochydore Service Areas.

The Benevolent Society (external) in the Beenleigh, Brisbane North/South, and Caboolture/Strathpine Service Areas.

Mission Australia (external) in the Cairns Service Area

Note: The NDIA is working to source a Partner to deliver ECEI services in the Robina Service Area. If you live in Robina and need support for your child aged 0-6, please contact the NDIA.

TRACKING MY CHILD'S DAILY ACTIVITY

What does your family schedule look like? What is your child involved in during any given week? Do you have strict rules and routines? Are there particular things your child would like to do (or you would like for them to do) that is currently not possible? What is it that makes these goals hard to achieve?

> **ACTIVITY**
> *Draw up a brief calendar of events for next week. Does it look like a typical week for your child/family? What do you wish it looked like? What makes your 'wish list' hard to achieve?*

NDIS SUPPORTS

'NO DISADVANTAGE'?

Governments made a commitment – through the Intergovernmental Agreement for the NDIS Launch (IGA) – that if you were receiving supports before becoming a participant in the NDIS you should not be disadvantaged by your transition to the NDIS.

The commitment is that people who become participants in the NDIS should be able to achieve at least the same outcomes under the NDIS.

This **does not mean** that you will always have the same level of funding or supports provided in the same way. You will have access to reasonable and necessary supports consistent with the *National Disability Insurance Scheme Act 2013*.

Where the NDIS does not fund a support you previously received under another program, the Agency will seek to identify alternative supports or refer you to other systems with a view to ensuring you are able to achieve substantially the same outcomes as a participant in the NDIS.

ACKNOWLEDGING THE WORST DAY WHILE AIMING FOR THE BEST LIFE

The NDIA makes decisions based on the [National Disability Insurance Scheme Act 2013](#) (NDIS Act) and the rules made under the NDIS Act. The [operational guidelines](#) also provide practical guidance for decision makers.

When the NDIA makes decisions about which supports would be reasonable and necessary for a particular participant, we refer to the particular operational guideline that relates to each specific support. In order to be considered reasonable and necessary, a support must:

- *be related to the participant's disability*
- *not include day-to-day living costs that are not related to a participant's disability support needs*
- *represent value for money*
- *be likely to be effective and beneficial to the participant, and*
- *take into account informal supports given to participants by families, carers, networks, and the community.*

➢

Reasonable and necessary supports are funded by the NDIS to help you reach your goals, objectives and aspirations in a range of areas.

These supports will help you to increase your independence, increase your social and economic participation, and develop your capacity to actively take part in the community.

THE TYPES OF SUPPORTS THAT THE NDIS MAY FUND FOR PARTICIPANTS INCLUDE:

➢ daily personal activities
➢ transport to enable participation in community, social, economic and daily life activities
➢ workplace help to allow a participant to successfully get or keep employment in the open or supported labour market
➢ therapeutic supports including behavioural support
➢ help with household tasks to allow the participant to maintain their home environment
➢ help to a participant by skilled personnel in aids or equipment assessment, setup and training
➢ home modification design and construction
➢ mobility equipment, and
➢ vehicle modifications

A SUPPORT WILL NOT BE FUNDED IF:

➢ is not related to the participant's disability
➢ duplicates other supports already funded by a different mechanism through the NDIS
➢ relates to day-to-day living costs that are not related to a participant's support needs, or
is likely to cause harm to the participant or pose a risk to others.

PLANNING

PREPARING FOR A PLANNING MEETING

The NDIA suggests that you get ready for your planning meeting by addressing six broad questions:

Your Personal Details

You will be asked your name, where you live, and about your primary disability. Make sure you have all your personal details and any reports or assessments in one place to assist with this.

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Your Community and Mainstream Supports

You will be asked about supports you currently receive and about the people in your life and in the community who help you. This may include things like health services, school, sporting clubs, or church groups as well as friends and family who help you.

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How You Manage Everyday Activities

You will be asked about how you manage your everyday activities. This will help the NDIA understand what you do and what help you may need to do it, including equipment, accommodation, or help at home and in the community.

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Your Safety

The NDIA aims to assist people to learn how to do things safely. They will ask about anything that makes you feel unsafe or areas where you may need extra help. Write down anything you wish to discuss.

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Starting Your Plan

You will be asked about your goals over the next 12 months, and about what assistance you will need to help you achieve them. First, focus on your immediate and essential needs. Other goals may include your health and wellbeing, social and community participation, learning or education, employment or housing. The planner will also ask about how you will develop longer term goals over the next 12 months. Write down anything you want to discuss.

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You will be asked about the way you wish to manage your plan. Your planner will include a statement about how your plan is to be managed, which could include a combination of agency (NDIA), plan manager, or self management funds. Write down your preferences.

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REPORTS, ASSESSMENTS, AND QUOTES – OH, MY!

Your plan can include funds for equipment and vehicle or home modification assessments. You will need to speak with your planner about your capital equipment needs, and they can explain the process to you.

CHOOSING A MANAGEMENT STYLE

There are three basic management styles you can request for your child's NDIS plan. These are:

Agency-Managed

Agency Managed plans are visible to you on the NDIS portal via MyGov, but all finances are handled directly between the agency (NDIA) and the service provider. You may still choose your providers and suppliers, but they must be Agency Registered and you will generally be required to sign service agreements with them.

Plan Manager

A plan manager acts as a 'broker' of sorts between yourself (as the child's nominee) and the NDIA. The NDIA will cover the cost of the Plan Manager and you can choose who it will be from a list of registered providers. The plan manager can assist you in finding supports and will pay the providers from your child's plan. You have the option to use unregistered service providers.

Benefits of Chosen Option	NDIS MGMT	Self MGMT	Plan MGMT
No cost to you	✓	✓	✓
Access to Registered Providers	✓	✓	✓
Access to Unregistered Providers	✗	✓	✓
Help to find or change providers	✗	✗	✓
Help to make sure all your service agreements are signed	✗	✗	✓
All your bills paid for you	✓	✗	✓
All your paperwork kept for you	✓	✗	✓

Self-Managed

This option offers the most flexibility but also the highest level of responsibility for the implementation and management of your child's plan. You may source unregistered providers and are responsible for paying support

providers directly and claiming the funds back from your child's NDIS plan via the online portal. You will also need to keep robust records including invoices and the NDIA may conduct audits.

ADVICE FROM THE NDIA:

Here are some questions that can help you work out if you are ready to self-manage:

- Do you pay your bills on time?
- Can you review a bank statement and see if there is anything that you have not authorised?
- Can you keep and organise receipts, bank statements and other paperwork?
- Can you be firm with someone if you don't like what they are doing to support you?
- Do you understand which skills you do and don't have when it comes to filling out forms or handling money, and do you know who to ask for help?
- If you want to hire your own staff directly, do you know what the laws are about hiring your own staff?

If you answered yes to all of these questions, then you are ready to consider self-managing part - or all - of your NDIS Budget.

SO YOU HAVE A PLAN... NOW WHAT?

IMPLEMENTING YOUR CHILD'S PLAN USING THE MYGOV NDIS PORTAL

If you haven't already set up your MyGov account, now is a good time to do it. This is where you will be able to view and manage your child's plan. Go to www.mygov.gov.au to set up your account. If you have already set up a MyGov account, you should see an active link to the NDIS (alongside links to the ATO, Centrelink, Medicare etc). Once your plan has been approved, you should receive an Access Code to activate the portal for the first time. You may need to first 'Unlink' the NDIS from your MyGov account and then relink it using the code you have been given.

There are tutorials available online that show you how to use the features of the NDIS portal, which is called 'MyPlace'. The NDIA's own guide can be found at https://www.ndis.gov.au/participant-portal-user-guide. You can also contact the NDIA on **1800 800 110** for advice and assistance.

REQUESTING REVIEWS OR AMENDMENTS

The NDIA offers the following information about the review process:

INTERNAL REVIEW OF A DECISION

If you think a decision made by the National Disability Insurance Agency (NDIA) about you is wrong, you can submit an application for internal review of a decision. Any person directly affected by a decision of the NDIA can request such a review.

There is a list of reviewable decisions in the NDIS legislation. Many decisions made by the NDIA are reviewable, including things like being accepted as a participant and the provision of reasonable and necessary supports.

When you are told about an NDIA decision, you will be told how to request an internal review. A request for internal review of a decision must be made **within three months** of receiving notice of the decision from the NDIA.

The staff member who works on the internal review will not have been involved in the earlier decision. They may want to talk to you directly as part of this process.

How to request an internal review of a decision

A request for internal review of a decision can be made by:

- submitting a written request to:
  Chief Executive Officer
  National Disability Insurance Agency
  GPO Box 700
  Canberra ACT 2601
- talking to someone at an NDIA office
- calling 1800 800 110
- sending an email to: enquiries@ndis.gov.au

When asking for a review, you should explain why you think the decision is incorrect.

See the Application for review of a reviewable decision page for the application form. You don't have to use this form, but it can help you to describe why you want an internal review of the decision.

What happens next?

The NDIA staff member responsible for the internal review will make a decision to confirm, vary or set aside and substitute the earlier decision. This decision will be made as soon as reasonably practicable.

What if you are still dissatisfied after the internal review of the decision?

If you are still not happy after the internal review of the decision, you can apply for a review by the Administrative Appeals Tribunal (AAT), a tribunal that exists outside the NDIA.

You cannot ask the AAT to review a decision by the NDIA until the decision has been internally reviewed by the NDIA.

For information about applying for a review by the AAT, see the AAT website or call 1800 228 333.

> *CONSIDER*
>
> *Is there anything you're particularly worried about in terms of your child's NDIS supports? Are you planning to request anything you believe may be problematic? Give some thought to how you could approach this request in a way that answers potential NDIA concerns ahead of time.*

Useful Electronic Resources

Resource *You can type these titles into your search engine if you cannot follow the links.*	Online Direct Link
NDIA Fact Sheets - Home Page	https://www.ndis.gov.au/people-disability/fact-sheets-and-publications
NDIS Glossary of Terms	https://www.ndis.gov.au/glossary.html
About the NDIS – Easy English Version	https://www.ndis.gov.au/medias/documents/h28/hef/8798374002718/Easy-English-About-the-NDIS-PDF-2.5MB-.pdf
Factsheet: Early Childhood Early Intervention	https://www.ndis.gov.au/medias/documents/hae/h72/8799577505822/ECEI-How-the-NDIS-can-help-your-child.pdf
Factsheet: Developing your First Plan	https://www.ndis.gov.au/medias/documents/hee/ha0/8798779113502/Fact-Sheet-Developing-your-NDIS-plan-21.10.16-accessible.pdf
Factsheet: Starting your Plan	https://ndis.gov.au/medias/documents/h3c/he0/8799397969950/Factsheet-Starting-Your-Plan-PDF-11KB-.pdf
Factsheet: Starting my Plan as a Self-Managed Participant	https://ndis.gov.au/medias/documents/ha7/h5d/8799398035486/Self-Managed-Participant-PDF-227KB-.pdf
Factsheet: Supporting Families and Carers	https://www.ndis.gov.au/html/sites/default/files/Supporting-families-carers.pdf
Factsheet: Accessing Supports for my Child	https://ndis.gov.au/medias/documents/hb4/h2c/8799429427230/Accessing-supports-for-my-child-PDF-203KB-.pdf
NDIA Operational Guidelines	https://www.ndis.gov.au/Operational-Guidelines
NDIS Price Guide 2017-18	https://www.ndis.gov.au/medias/documents/h4a/ha4/8805126078494/201718-VIC-NSW-QLD-TAS-Price-Guide.pdf

MODULE 4: PEER SESSION

During this session you will have the opportunity to hear from other parents and carers about their own experience with advocacy and the NDIS. Think about the things you would most like to know and jot down any questions you could ask. You can also make notes here during the session.

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PERSONAL BILL OF RIGHTS

1. I have the right to ask for what I want.
2. I have the right to say no to requests or demands I can't meet.
3. I have the right to change my mind.
4. I have the right to make mistakes and not have to be perfect.
5. I have the right to follow my own values and standards.
6. I have the right to express all of my feelings, both positive or negative, in a manner that will not harm others.
7. I have the right to say no to anything when I feel I am not ready, it is unsafe, or it violates my values.
8. I have the right to determine my own priorities.
9. I have the right not to be responsible for others' behavior, actions, feelings or problems.
10. I have the right to expect honesty from others.
11. I have the right to feel angry at someone I love and to express this in a responsible manner.
12. I have the right to be uniquely myself.
13. I have the right to feel scared and say "I'm afraid."
14. I have the right to say "I don't know."
15. I have the right to make decisions based on my feelings, beliefs and values.
16. I have the right to my own reality.
17. I have the right to my own needs for personal space and time.
18. I have the right to be playful and frivolous.
19. I have the right to be healthy.
20. I have the right to be in a non-abusive environment.
21. I have the right to make friends and be comfortable around people.
22. I have the right to change and grow.
23. I have the right to have my needs and wants respected by others.
24. I have the right to be treated with dignity and respect.
25. I have the right to grieve.
26. I have the right to a fulfilling sex life.
27. I have the right to be happy.

(Adapted by Mary Ellen Copeland from the *Anxiety and Phobia Workbook*, Edmund J. Bourne, Ph.D., 1990, New Harbinger Publications, Oakland, CA.)