

Final Evaluation Report

Resourcing Families Capacity Building Project

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I. Executive Summary

The success of the transition to the National Disability Insurance Scheme (NDIS) in Australia will largely be predicated on the ability of people with a disability and their families to drive the quality of services, and exercise individual choice. Ageing, Disability and Home Care (ADHC), Department of Family and Community Services, NSW has recognised the need to support families of people with a disability to embrace the current changes in the sector. This report is an evaluation of the Resourcing Families Capacity Building Project (RFCBP) which was funded by ADHC to help build the skills and knowledge of family members who support someone with a disability. RFCBP assigned Griffith University and Queensland University of Technology (QUT) to conduct an external evaluation of their project which assisted families in urban and regional areas in NSW to develop a positive vision, build support networks, create community connections and exercise more choice and control over self-directing supports in relation to their family member with a disability.

The evaluation research in this report was developed using a program logic model (Unrau 1993) and the use of multiple methods of inquiry, including surveys, direct observation of practice, and in-depth interviews with family members who attended RFCBP events. The aim of the research was:

To evaluate the extent to which RFCBP builds the knowledge, skills and confidence of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.

The findings of the research are important on several levels. Firstly, the research indicates that even within a short time-span of several months, families are capable of making significant changes in the lives of their loved one with a disability if they are given the skills, opportunities and resources to “dream big” and take action.

Secondly, the research demonstrates that the RFCBP was an economically viable and successful social investment on the part of ADHC to encourage and develop the confidence and abilities of families to build meaningful lives for people with a disability. Many families who used RFCBP resources were able to make small but important steps to enhance the community presence of their member with a disability. This included building on freely given natural supports in the community.

Third, the research indicates that projects such as RFCBP can provide important information for policymakers and practitioners about capacity building. This is particularly significant at this time when the National Disability Insurance Agency (NDIA) is developing its framework for Information, Linkages and Capacity Building (ILC). The ILC component of the NDIS has a crucial role to play in the scheme and for people with disability and their families. The RFCBP assisted families to meet the everyday needs of their family member with a disability and encourage their social and economic participation with less reliance on paid formal service provision. With the ongoing discussion of burgeoning costs of a disability insurance scheme model, initiatives such as RFCBP can improve the long-term sustainability of the NDIS.

The following recommendations were developed from evaluation findings:

Recommendation 1: Resourcing Families and/or Family Advocacy liaise with service providers, government departments in the areas they visit outlining the issues many families raise in their workshops in regards to needs for further emotional support and practical support;

Recommendation 2: The information and feedback about existing services which is shared in Resourcing Families workshops is passed onto the relevant agencies wherever possible, without compromising the privacy or well-being of families and their loved ones, in order to ensure existing services are more responsive to people with a disability and their families;

Recommendation 3: Resourcing Families invest further time and resources into recruiting participants to events who have had no previous contact with Family Advocacy or Resourcing Families;

Recommendation 4: Resourcing Families invest further time and resources to recruit more fathers and siblings to workshops to ensure the voice and involvement of all family members in capacity building;

Recommendation 5: Resourcing Families stay longer in particular regional areas to improve attendance rates at workshops; to cover content in more depth and to work around the caring commitments of families;

Recommendation 6: Resourcing Families gather the success stories of attendees from their workshops and use these with the families' permission as teaching examples for future events;

Recommendation 7: Further opportunities in workshops be given to families to anticipate and respond to potential barriers they encounter in building a meaningful life for their loved one with a disability;

Recommendation 8: The capacity building work of Resourcing Families continues to be funded under the NDIS;

Recommendation 9: The capacity building work of Resourcing Families is documented through longitudinal research projects to inform the sector of best practice in working with families and people with a disability.

II. Introduction

The RFCBP is a project which focuses on building knowledge and skills in people with a disability and their families. The aim is to build meaningful lives for people with a disability, so they can have authentic opportunities and be regarded as valued members in their communities. In particular, RFCBP acknowledges the integral role families can play in the rights and well-being of people with a disability and aims to strengthen the leadership skills in family members. RFCBP contracted Griffith University and QUT to undertake a systematic evaluation of their practices and processes used to empower people with a disability and their families. By documenting and disseminating the learning and insights gathered from the project through external evaluation, RFCBP aimed to build on the existing work done by Family Advocacy and Resourcing Families throughout NSW and extend its influence to practice in the sector both at a state and national level.

III. Project Description

Background Information on Resourcing Families and the Institute for Family Advocacy and Leadership Development

Resourcing Families, the overarching program that carried out the work of the RFCBP began as an idea of the Institute for Family Advocacy and Leadership Development (hereafter referred to as Family Advocacy). Resourcing Families provides information for families to create full and meaningful lives for their family member with disability as valued members of their community. Workshops and resources focus on developing a positive vision, building support networks, creating community connections and exercising more choice and control through self-directing supports.

Family Advocacy is a statewide advocacy organisation concerned with the needs, interests and rights of people who have developmental disability. Its aim is to achieve positive social roles for people with disability through the development of advocacy by families and by strengthening the knowledge, role and influence of the family. Family Advocacy began in 1991 and focuses on three levels:

- **The systemic level:** where it seeks to influence policy, legislation and practice.
- **The advisory level:** where it provides individual advocacy advice to families, together with information and resources to the wider community.
- **The educational level:** through the running of workshops and seminars concerned with promoting the rights and interests of people with disability.

Family Advocacy receives funding from both the NSW and Commonwealth Governments.

Resourcing Families was created in 2010 and was largely inspired by a study tour Family Advocacy made to Canada in 2009. Canada had been a pioneer in providing more opportunity for people with disability and their families to exercise more choice and control over their lives and supports through self-direction. At the time of the study tour self-directed support had been available in Canada for some decades but was not an option that many were choosing. There was concern that the self-directed option for support may be discontinued if government decided there was little demand. Canadian advocates for self-direction considered that one of the factors that may have resulted in low uptake was the absence of capacity building interventions and resources for people

with disability and their families. This possibly limited awareness of what might be possible for people beyond traditional support arrangements and how individualised lifestyle options could be created around a person's genuine interests. As a result of this learning, Canadian advocates focused more on the provision of capacity building initiatives. Family Advocacy took this learning and created Resourcing Families to assist people to imagine better for people's lives and have the resources, confidence and skills to action their goals and aspirations. It was clear from the study tour that unless there was an investment in capacity building then people were not equipped and resourced to maximise choice and control over their lives through self-direction.

RFCBP

RFCBP is an initiative of Resourcing Families and Family Advocacy. The project receives funding from Ageing, Disability and Home Care (ADHC), Department of Family and Community Services, NSW. Its overall aim is to ensure that people with a disability and their family, friends and allies have the knowledge, skills, confidence and networks to access and utilise individualised support as it becomes available in New South Wales. In essence, RFCBP assists in developing a positive vision for a person with disability; helps build networks of informal supports around a person; encourages people with a disability and their families to make informed decisions and have more control over available supports and services. In keeping with the changing disability service system under the NDIS, RFCBP seeks to help people develop the confidence to plan and implement ideas by providing various types of information. This includes stories from families, video clips, 'how to' documents, fact sheets, articles, webinars and policy documents available online. There is also a range of events people can attend, such as workshops, and guest speaker presentations. People with a disability and their families are also provided with mentoring possibilities and are given information via phone or email to assist in planning and implementation.

This current report focuses primarily on five workshops conducted by RFCBP. These workshops are *From Planning to Action*, *Involving Others and Building Networks*, *Developing Community Connections*, *A Practical Pathway to a Better Life*, and *Ideas for Self-Directing Supports*. These workshops were given over an extended period from March 2014 to May 2015 in Lismore, Armidale, Broken Hill, Orange, Wagga Wagga, Sydney, and Nowra. Details of the content of these workshops are provided in Table 1 below:

Table One: Workshop Content

<i>Workshop 1: From Planning to Action</i>
A workshop about thinking big and raising expectations for what might be possible for the life of a person with disability through imagining better, developing a vision, goal setting and making a plan to achieve goals to bring the vision to reality.
<i>Workshop 2: Involving Others and Building Networks</i>
A workshop about strategies for involving others in the life of a person with disability, building personal support networks and starting circles of support.
<i>Workshop 3: Developing Community Connections</i>
A workshop providing practical principles and ideas for supporting a person with disability into genuine involvement and connection within their community. Ideas focus on honouring a person's genuine interests and aspirations, considering contexts where connections are more likely to happen and creating opportunities for meaningful connection.
<i>Workshop 4: A Practical Pathway for a Better Life</i>
A workshop presented by Jane Sherwin (Accredited Teacher of SRV) that practically explores the importance of valued roles and how they can be crafted for a person with disability to enhance their image with others, develop their skills, connections and contribution within community.
<i>Workshop 5: Ideas for Self-Directing Supports</i>
A workshop presented by Meg Sweeney from her lived experience about practical ideas for using individualised arrangements and funding to craft a meaningful week for a person with disability. Information explores the different ways of self-managing, including direct payments and employing your own staff.

IV. Research Methodology

This research has been funded by Family Advocacy who auspice the Resourcing Families Capacity Building Project. It was approved by the QUT and Griffith University Human Research Ethics Committees.

The evaluation research conducted by Griffith University and QUT adopted a reflective and participatory approach to evaluation (Patton, 2008). A program logic model was formulated with the RFCBP team to provide a common road map for all stakeholders on the nature of the capacity building project, its purpose and assumptions (Unrau, 1993). This model was integrated with concepts associated with the model coherency model used in Social Role Valorisation (SRV) theory (Wolfensberger, 1998).

The key aim of this evaluation research was:

To evaluate the extent to which RFCBP builds the knowledge, skills and confidence of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.

The research has been designed to measure the following factors:

1. **Intentions:** The extent to which there is a change in the **intentions** of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.
2. **Actions:** The extent to which there is a change in the **actions** of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.
3. **Perceived change:** The extent to which families of people with a disability **perceive a change** in the life of their family member with a disability to have a better life, to exercise more choice and control over his or her supports, and to have a stronger networks and community engagement.
4. **Barriers:** To identify any **barriers** that may be making it difficult or undesirable for people with a disability and their families to embrace the above changes and to discover ideas from RFCBP to assist in overcoming these barriers.

Data Collection

Multiple methods were utilised to gather information on RFCBP. These included:

Background Information from RFCBP Staff

Informal discussions were held frequently throughout the course of the research with RFCBP staff regarding the work. These discussions included sharing of insights about the particular areas where workshops were conducted, as well as documentation of some of the tasks involved in the outreach work in these areas.

Workshop Observations

Six workshops were attended by a member of the research team and field notes were taken and later shared with the RFCBP team. The workshops attended were in Armidale, Lismore, Wagga Wagga, Orange, West Ryde (Sydney), and Nowra. The particular workshop topics were *From Planning to Action*, *Involving Others and Building Networks*, *Developing Community Connections*, and *A Practical Pathway to a Better Life*. These notes were shared with RFCBP shortly after each workshop to provide them with ongoing feedback from the team. The themes which emerged from these observations are included in the *Findings* section below. In addition, a breakdown of the types of participants in all of the workshops in the areas of the study is provided in the *Survey Findings* section.

Evaluation Surveys

A short survey was administered after each workshop for participants to complete. The findings from these surveys are included in the *Findings* section below. An example of the survey tool is provided in *Appendix A* of this report.

Interviews with Family Members

Family members who attended workshops were invited to also participate in individual in-depth interviews either in person, over the telephone or through Skype. Those who were interviewed were also invited to be interviewed at a later date to ascertain if there were any long-term changes in their lives and what influence RFCBP may have had in this process. Twenty-six family members were interviewed overall, and of these twelve families agreed to be interviewed a second time. Responses from interviews were transcribed, de-identified and analysed thematically using NVivo 10 software. Themes were organised into broad categories of *perceived change in the life of the person with a disability*; *change in intentions of family member participants*; *change in actions of family member participants*; and *perceived barriers to change of family member participants*. Details of the findings from these interviews are included in the next *Findings* section. *Appendix B* outlines the schedule used for these interviews.

V. Literature Review

The key focus of the RFCBP is to increase the knowledge and skills of people with a disability and their families in order for them to plan and implement ideas for a good life. Central to RFCBP is the integral and crucial role that families play in the support and promotion of rights and wellbeing of people with a disability. The project also aimed to strengthen the leadership skills in family members.

This literature review presents a summary of some of the published research available in areas relevant to the RFCBP. For the purposes of this evaluation, the focus included main areas of:

- Planning for family members with a disability
- Community connection and participation
- Funding and support

While this is not an exhaustive review of all available research, it does cover the current state of knowledge in these areas.

Planning for Family Members with a Disability

Since the shift from institutions to community living, the disability sector has adopted different approaches to planning for the future for a person with a disability. These have evolved over time from the initial focus on individualised program planning to more person and family centred approaches. This reflected the shift from planning from a service perspective – i.e. make the person fit the service or program – to an emphasis on thinking about the person within the family and the community.

Person-centred planning (PCP) is now widely accepted as the key approach in planning for a good life and organising for people with a disability. Developed almost 30 years ago in the USA, PCP is now widely adopted in the UK, Canada, New Zealand and Australia. Like individualised planning, the key element of PCP is that it is individualised but, as Mansell and Beadle-Brown (2004) argued, there are some distinct differences. First, PCP considers aspirations and capacities expressed by the individual. Second, it attempts to include and mobilise the family and wider network i.e. it acknowledges that families know the person best and have a stake in sharing power and decisions. Third, PCP emphasises providing the support required to achieve goals. This is different from merely limiting goals to what the service can offer but rather being creative about how goals might be met (Mansell & Beadle-Brown, 2004). PCP is fundamentally different from traditional planning, in that it is about sharing power and community inclusion (Sanderson, 2000).

In Australia, person centred approaches have been implemented across a range of jurisdictions in disability service provision. Largely this has been under State government policies and programs some of which have been evaluated. Many disability service providers and organisations have also adopted these approaches and evaluated them. These reports contribute to the 'grey' literature in this area – that is publications that are commissioned and usually not subjected to peer review.

Outcomes of PCP

There are few large scale studies of the effectiveness of PCP and much of the research is from the US or UK. However, there are a number of studies that demonstrate the positive benefits associated with PCP for persons with intellectual disability (for example, Glendinning et al., 2009). These benefits include community involvement, contact with friends, contact with family and choice. Sanderson, Thompson and Kilbane (2006) in a UK study found that introducing PCP led to positive changes such as a 52% increase in social networks, 140% increase in contact with family members and significant increases in contact with friends (40%), the number of community activities (30%) and the hours per week in day activities (33%). Interestingly, people in this study experienced 180% more choice. These results are reflective of many other international studies in which similar positive benefits of PCP have been reported (Glendinning et al., 2009; Lord & Hutchison, 2003). Overall, PCP has been found to be largely cost neutral (Sanderson et al., 2006).

Barriers / Shortcomings

The underlying values and objectives of PCP appear to be universally supported and positive benefits are well documented. There are some barriers to the implementation of PCP that are important to explore.

There is some evidence that PCP works better for some people than others. In reviewing several studies, it appears that people with mental health issues, emotional or behavioural problems or complex health needs are less likely to get a plan (Robertson, Emerson, et al., 2007) and/or have it implemented. However, as a barrier this was ranked low in other studies (Robertson, Hatton, et al., 2007).

The overwhelming barriers however seem to reside within organisations. A key factor here is the vital importance of committed facilitators in the success of PCP. Robertson, Hatton and others (2007) found that the commitment of facilitators to PCP was the most powerful predictor of whether people would receive a plan, and was also related to increased chances of benefiting in the areas of: choice; contact with friends; hours per week of scheduled activity and size of social networks. The most common reason for the failure of PCP to be implemented was problems related to facilitators (64%) – e.g. leaving their position or not being available.

Other barriers to PCP included time, the availability of services and appropriate skilled staff. This points to an implementation gap (Mansell & Beadle –Brown, 2004) wherein plans are not carried out due to a lack of resources and fiscal restraints in the support allocation.

Other Considerations

A crucial consideration is the real need to **focus on the person's** goals and outcomes not the plan itself. 'The plan in and of itself does not produce change' (Taylor & Taylor, 2013) and planning can become an 'activity trap', replacing action and utilising effort and resources that could otherwise be directed at creating real change for the person. The focus on the person and the family therefore must remain front and centre and be safeguarded throughout what are often complex organisational procedures.

Readiness for PCP and self-direction is another consideration relevant to this evaluation. There is little attention in the literature to the readiness of families and persons with disability although it is widely discussed in policy documents. A recent study of family members in NSW has highlighted that families in the disability sector had heard of PCP and individualised funding and understood what these meant. Over half (57%) were ready to manage their own funding (Broady, 2014). A further finding from this study and very relevant to this project, was that there was no significant differences in responses across different geographical regions. In contrast, much Australian policy research has highlighted the disparity of service delivery and access to rural areas (for example, Dew et al., 2014). This warrants further exploration for this project in that there is a purposeful focus on rural and regional areas as well as metropolitan centres.

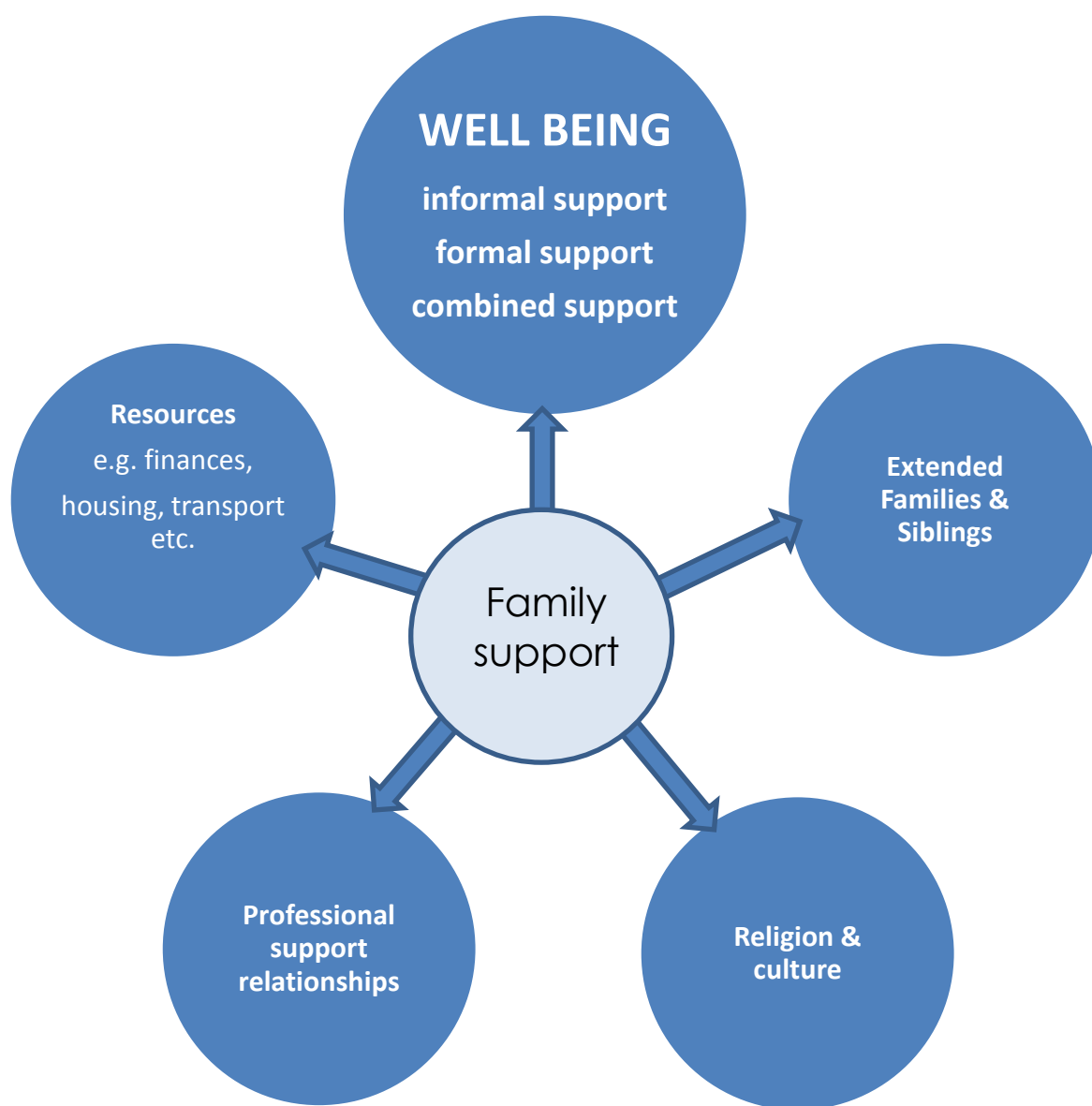
Community Connection and Participation

It is well established in the disability research literature that connections to community and participation in ordinary activities are central to the inclusion project yielding positive outcomes for people with disability and families. Over several decades, community integration, as it was previously termed, emerged as a key goal of community-based service provision for people with intellectual disability (Pretty, Rapley, & Bramston, 2002). This was regarded as a crucial response to isolation, loneliness, and poor quality of life that so many people with disability experienced. Pioneering work in this arena focused on the importance of going beyond what John O'Brien called "mere community presence" to real community participation. However, there are still ongoing debates within inclusion policy and research where less attention is paid to social connections and relationships (Hoskin 2010 cited in Robinson & Notara, 2015, p. 726) than physical presence.

One of the biggest challenges facing families of children with disabilities is how best to support their family member to connect with and participate in their local community (Vargas et al., 2012). Belonging and connection of families and their children to community may be a fragile and difficult process (Robinson & Notara, 2015) and, when considered alongside other family challenges such as dealing with the shock of initial diagnosis, navigating complex health and disability support systems as well as the ordinary tasks of family life, may stretch family capacity beyond its limits (Vargas et al., 2012). In early research of mothers of children with intellectual disability, Emerson (2003) noted that social and economic disadvantage had a large impact on family functioning and social connectedness.

There is little research available that specifically provides information about how to best provide families with resources and supports for increasing connections and participation in community. A review of available research on creating supportive connections summarised several broad themes that are relevant to this project (Canary, 2008). These are summarised in Figure 1 below.

Figure One: Creating Supportive Connections for Families



The links between support and well-being are well established in the research. Both formal and informal supports are important in promoting family well-being. Informal support networks have been found to be important in increasing resilience and the family's capacity to manage (Moore, Kennedy, & McLoughlin, 2011). Families are more likely to trust information and recommendations from peers and friends. Formal supports are found to be more valued when provided in strong family centred models and relationships. Often it is the combined overall support that is most significant.

The role of extended family members and siblings in support and community participation really depends on the quality of those relationships and the family member's knowledge of disability and specifically the needs of the family member with a disability. Canary's (2008)

review suggests that training focussing on creating quality connections and relationships with extended family members could be productive.

It is apparent from Canary's (2008) review and from Emerson's (2003) work, that socioeconomic factors and availability of resources are significant factors in the creation of supportive connections. This can range from having no suitable transport to community activities through to severe financial hardship being a real barrier to community participation.

In facilitating community connection it is important to consider the cultural context for the family. Families from different cultural and linguistic backgrounds (CALD) often face deeper challenges and may not access supports because of cultural norms, language issues or discrimination (Canary, 2008; Vargas et al., 2012). Different cultural norms may also influence attitudes to disability generally, and place much more emphasis on family support within the home rather than connecting the person to the wider community.

For the RFCBP, consideration of place and location, e.g. small town, large metropolitan centre, rural community, is also important in facilitating community connection and participation. Opportunities for community presence and building relationships do differ across different contexts. For example, people with disability living in regional or rural communities have been found to have patterns of community usage and lifestyle similar to those without a disability (see Pretty et al., 2002).

In summary, community connections and participation are integral to wellbeing and inclusion – to having an ordinary life. A number of factors influence the extent to which families facilitate these connections though little is known about the ways this connection happens (Carpenter & McConkey, 2012). There is very little attention paid in research as to how communities can become more inclusive and welcoming. Thus the responsibility seems to be left with families to facilitate the connecting. More exploration of this as a two way process is certainly needed.

Funding and Support

As disability services and support have shifted to person centred approaches, funding models have similarly shifted to more individualised and self-directed approaches. Included in this shift, in the 1980s and 1990s, there was an active campaign by the disability movement for the right for people with a disability to be given the cash to purchase their own support (D. Leece & Leece, 2006). Individualised funding (IF) of disability supports is viewed by many in the field as a mechanism for ensuring that the paradigm shift is grounded in genuine options and increased control for individuals and families (J. Leece & Peace, 2010).

The alternative to traditional modes of funding and service provision for people with disabilities – to support people to make choices and to be included – goes under many different names, including person-centred services; self-directed support; person-directed service; independent living; consumer control; self-determination; self-directed services; consumer-directed services; Individualised Funding (IF). All these models are based on the same principle: if people with disabilities are to participate and contribute as equal citizens they must have choice and control over the funding and support they need to go about their daily lives (Netten et al., 2012). According to Chenoweth and Clements (2009) the key concepts inherent in these approaches are:

Self-determination/consumer-direction/self-direction: a belief based on the understanding that people have both the right and responsibility to exercise control over the services they receive;

Individualised Funding: is a style of funding community services where funds needed to purchase required community services and supports go directly to the individual, based on a plan that is negotiated with government. Financial resources and a greater degree of decision-making power will thus be placed in the hands of people with disabilities and their personal networks;

Independent living in the community: definitions vary; however common themes relating to this value include consumer sovereignty, self-reliance, inclusiveness, and integration.

Much of the available literature in this area is based on international studies of the impact of IF with little published about families' understanding and experiences of IF and self-directed funding. In the Australian context, literature is largely looking at IF from a policy standpoint (for example, Dew et al., 2014; Purcal, Fisher, & Laragy, 2014). Evidence and first person accounts of consumer experiences with self-direction in supporting people with disabilities in the Australian context are extremely limited (Ottmann, Laragy, & Haddon, 2009).

For the purposes of this evaluation, a summary of available literature specifically addressing issues for consumers and families is presented. Crozier and others (2013) in their review of the benefits and challenges of self-direction have included some insights into experiences for individuals and families. They have summarised the benefits as:

- higher levels of satisfaction with self-directed services and increased satisfaction with support
- greater satisfaction with the availability and type of services they received
- progress towards their personal goals
- feel that their needs were being met
- increased flexibility and choice and control over support worker recruitment etc. (Crozier et al., 2013).

Additionally, family members have reported that receiving support and information is important when they are making decisions on behalf of a family member (Putnam, Pickard, Rodriguez, & Shear, 2010). However, there is also some evidence that family members involved in self-directed support programs may feel increasingly isolated as time progresses if adequate supports are not implemented (Ottmann et al., 2009).

Being prepared to take up the task of organising support services may be emotionally and practically daunting for many families but feeling prepared has predicted higher levels of satisfaction with caregiving work (Kietzman, Benjamin, & Matthias, 2008). Broady's (2014) study in New South Wales also indicated that parents (carers) were certainly willing to take on these funding models.

What this limited research seems to indicate however is that families need adequate preparation and support for caregivers over a longer period of time. The challenges in self-directed support can include practical tasks of finding and hiring workers and financial

management as well as the higher order issues of ensuring safeguards, sustainability over long periods of time (i.e. a life course) and dealing with changing needs and transitions.

No single model stands out as ideal according to the literature, so a range of options are needed, based on a change of focus from the service perspective to a person perspective (Parmenter & Arnold, 2008). Powers, Sowers, & Singer (2006) state that models are being developed that avoid the oversimplified notion that service users are either autonomous or non-autonomous, permitting both collaborative direction of services by individual and trusted others, and delegate autonomy by surrogates.

This project is therefore timely and important in extending our knowledge base about informing, preparing and supporting families' in the shift to the NDIS.

VI. Findings

Background Information from RFCBP staff

The following information has been gathered through discussion with the RFCBP staff regarding the processes used in the outreach work in Armidale, Lismore, Wagga Wagga, Orange, West Ryde (Sydney), Broken Hill and Nowra.

As part of her role, the RFCBP Coordinator liaised with many stakeholders in each community, in order to share resources and encourage participation in the workshops. Meetings and information sessions were conducted in the regional areas with Early Childhood Services; regional councils; health and community centres; government and non-government disability services; services catering for particular cultural groups; Medicare Local; and advocacy groups. RFCBP has also connected to neighbouring towns when presenting workshops in particular areas. These strategies indicate a hard working team of staff who utilise their existing funding and time carefully and strategically.

Common issues were reported with regards to rural and regional areas. These include issues of limited resources and information and social isolation – for example, in Broken Hill, participants talked about lack of affordable housing, lack of therapy and service choice. Given these challenges, RFCBP team felt the opportunities for workshops in the area were well received by both families and service providers.

It was noted by staff that some family participants were already implementing strategies for community connection and meaningful lives and that they felt encouraged to continue at the workshops. The workshops drew partly on existing connections with families already involved with Family Advocacy or Resourcing Families and the Coordinator also arranged meetings with individual family members to assist them further with implementing ideas and strategies.

Workshop Observations

Field notes were taken by the research team at six workshops run by RFCBP. These were gathered at the following workshops and locations:

18th June 2014 – Ex-Service League, Armidale – *From Planning to Action, Involving Others and Building Networks*

27th August 2014 – Lismore Workers Club, Lismore – *Developing Community Connections*

- 23rd October 2014 – Mantra Pavilion Hotel, Wagga Wagga – *A Practical Pathway to a Better Life*
- 11th November 2014 – Quality Inn Ambassador Hotel, Orange – *A Practical Pathway to a Better Life*
- 13th November 2014 – Ryde Eastwood Leagues Club, West Ryde, Sydney – *A Practical Pathway to a Better Life*
- 14th November 2014 – Shoalhaven Entertainment Centre, Nowra - *A Practical Pathway to a Better Life*

The workshops were conducted in a central location in the respective areas. The venues provided space for attendees to have refreshments and socialise between breaks in workshop content. Participants were encouraged from the beginning of each workshop to ask questions, and were provided with further contact information for RFCBP, and often information about new service initiatives, such as the Ability Links Program and the RUN Project. Family members were encouraged to make appointments with the RFCBP Coordinator to further develop their ideas and strategies of developing a meaningful life for their family member with a disability. Exercises at workshops generally catered for a variety of learning styles, and involved individual and group activities. Attendees were equipped with written workshop materials, including worksheets which they could take home and do at a later date.

Facilitating educational events for families of people with a disability can be a challenging task. RFCBP had the additional undertaking to deliver these workshops in rural and remote communities where families may live far away from the workshop venue. Attendance from families was relatively high at the workshops the research team observed. It was noted in some venues that families had travelled significant distances to attend the workshop. For example, at the Orange workshop, the geographical spread of attendees included people from Orange, Lithgow, Parkes, Dubbo and Blayney.

Another challenge involved letting families know of the impending workshops. Reliance on organisations to spread the information was not always reliable, as attested by one workshop attendee in Wagga Wagga, who reported that the local schools and doctors didn't always forward information to parents.

The caring commitments of families sometimes interrupted their attendance at workshops. One mother from Wagga Wagga explained to service providers who were also present at the workshops that she had to take time off paid work to attend the workshop, where they were being paid to be there. She made the comment that some parents wanted to rest when their child is at school or a day program. RFCBP was mindful of the responsibilities of families, and often tried to schedule the workshops during school hours and break down the workshop material into short time periods, so that families had the opportunity to leave if they had to during breaks.

Workshops were open to family members, people with a disability and service providers – although the content was primarily targeted for family members. The inclusion of paid staff in workshops presented an opportunity to extend the message to a broader audience, but there were mixed outcomes in doing so. Sometimes paid workers appeared resistant to certain ideas being discussed, but the same could also be said of family members. The research team wondered if family participation was more guarded at times due to service providers being present, yet in a few workshops it was difficult to determine who were family members and who were paid workers among attendees. As in any other group setting, the diversity of group members can make group dynamics unpredictable, and

workshop presenters would often establish at the beginning of the event what roles participants had.

Social Role Valorisation (SRV) was the underpinning theoretical framework behind the series of RFCBP workshops. Sometimes this was made explicit, such as in the *Practical Pathway to a Better Life* workshops, and the degree of understanding about more sophisticated concepts was mixed in the audience. Other times SRV concepts were explained only in everyday language. From workshop observations, the overall intent was to make the material as practical and accessible as possible, so that participants could apply the ideas easily to their situation.

An overarching theme for all workshops was “finding the ordinary” for people with a disability. Participants were encouraged to develop a vision and goals that were not led by disability service agendas, but started with identifying what the person with a disability truly wanted in life. The content was often delivered through stories of lived experience, where attendees would hear how parents had developed creative ideas and strategies to enable an authentic life for their loved one with a disability.

In delivering the content, workshop presenters would often have to respond to complex problems presented by family members. The research team heard families discuss difficulties in planning an ordinary life for someone with a profound disability; or express worries about what would happen to the person with a disability when the parent was no longer living. RFCBP staff generally seemed undeterred by these discussions, and encouraged families to be open with their concerns. However, the short timeframe of events and the public forum in which matters were discussed meant there was less opportunity to really begin to address these issues. The RFCBP Coordinator was very aware of these tensions and provided support to individual family members during workshop breaks. She also made herself available for individual conversations with family members in person and over the telephone. It was clear that every effort had been made to provide meaningful support to family members, but as the findings from the qualitative interviews presented in this report will attest, there is a pressing need for ongoing support for families if they are to be instrumental in building authentic lives for their loved one with a disability.

The observations made here by the research team demonstrate how much skill and energy is required to support families to dream big and to build an ordinary life for their loved one with a disability. A quote from a parent (Margaret Ward) which was shared in one workshop captures the nature of this work: “Working for an ordinary life is a harder path but a better path.” The RFCBP is an ambitious endeavour, but the outcomes of such work are likely to be rewarding and beneficial to people with a disability and their families.

Survey Responses

The use of a written survey was another means employed by the research team to evaluate RFCBP. All participants were invited to complete an evaluation survey at the end of every workshop. These surveys were distributed via participants’ handouts for the workshops and every effort was made to ensure that participants were able to answer questions voluntarily and anonymously. A total of 242 attendees completed the survey. Details of the location and workshop attendance numbers are presented in Table Two. This indicates 28% of total attendees completed the survey which is a fair response rate. It is important to note here too that a number of people attended more than one workshop in each location. Hence the overall “reach” numbers – i.e. individuals are somewhat fewer.

Table Two: Number of Participants

Site	From Planning to Action	Involving others & Building networks	Developing Community Connections	A Practical Pathway to a Better Life	Ideas for Self-Directing Supports	Total
Lismore	33	25	29	25	30	142
Armidale	27	26	9	21	13	96
Nowra/Shoalhaven	30	27	33	36	45	171
Orange	18	19	6	16	25	84
Wagga Wagga	30	23	16	22	31	122
Broken Hill	10	10	8	8	9	45
Sydney	21	21	57	36	68	203
TOTAL	169	151	158	164	221	863

A range of participants attended the workshops with the majority being family members (47.8%), as well as people with a disability (.04%) and professionals (41%). Several people identified in more than one role. Table Three outlines the different participant roles.

Table Three: Participant Roles

Participant role	No
Family member	420
PWD	36
Professional	359
Other	63
TOTAL	878

Prior Knowledge

Analysis of survey responses indicates that the workshops attracted a fairly informed audience with approximately 37% respondents reporting that they had a “good understanding” of the topic. This confident group included family members and professionals. The vast majority, some 51% overall across all workshops and sites, reported that they had some knowledge. Within this group approximately 25% indicated that they had some knowledge but needed more information about how to implement ideas into action. While overall approximately 20% reported having only a “vague” idea of knowing very little, there was some variation across the workshop topics. For example, only 14% reported knowing little or nothing about *From Planning to Action*, while 27% indicated such lack of knowledge in the *Involving Others and Building Networks* workshop.

Change in Understanding

Approximately 68% of all participants reported that their understanding had changed through attending the workshop. Two themes were apparent in these answers: changes in feelings and affect and increases in knowledge, information and practical strategies. Many participants reported changes in their confidence, for example, feeling “motivated” or “galvanised” into taking action or “revamping my vision for my son”. Other responses focused on having increased clarity about strategies to implement or simply having more

information. Others reported feeling more confident to try new things and realising that they needed to bring in others to help.

Key Ideas Gained

Participants took away several key ideas from the workshops. Most significantly people referred to the need to develop a vision (or revisit an old one) for their family member. These responses referred to the need to “aim high”, to “think outside the box” and to “freshen up ideas”. Following from the vision idea, many participants then outlined the need to develop goals and plans and to involve others in developing these with the person with a disability. There were many references to the need for networking and importantly, new ideas about how to extend networks in the community, for example:

“to stay connected, be more part of the community so to increase opportunities for my son to make friends”

A large number also reported they learned about “practical tools” such as circles of support, the “art of asking” or how to write up plans. Many participants said the workshops helped them recognise the importance of planning, aiming higher and thinking outside the square. The *Practical Pathway to a Better Life* workshop seemed to bring about a clear idea of implementation such as how the theory of valued social roles might be “operationalised” in their family member’s life. This workshop had a smaller number of attendees which may have facilitated deeper learning opportunities.

In summary, the participants gained many key ideas from the workshops. These included theoretical, practical and motivational ideas and information.

Workshop Feedback

Overwhelmingly, the majority of participants reported positively about the workshops. They found them clear, well organised and provided useful information. Many people really appreciated the personal stories and examples while others found the workshops to be an “eye opening experience”. Several comments indicated that for some the workshops were too short to cover the material and allow people to explore the issues in more depth. For example a handful of people wanted more time for questions and discussion. A couple of people reported feeling overwhelmed by the content – e.g. “a circle is pointless for someone with no family”. Many family members appreciated the hospitality – good food and welcoming hosts. This was especially appreciated given many in country areas drove a long way to attend. It was apparent too that some participants were very familiar with Family Advocacy as an organisation and the support it offers.

Summary

The survey findings provided a broad snapshot of views about the workshops from the majority of participants who attended. As mentioned above, RFCBP received very positive responses overall from attendees.

The surveys were intentionally brief to ensure a good completion rate and to take into account that participants may have had other pressing commitments to attend to at the end of the workshop. In essence, they measure the degree of satisfaction participants had

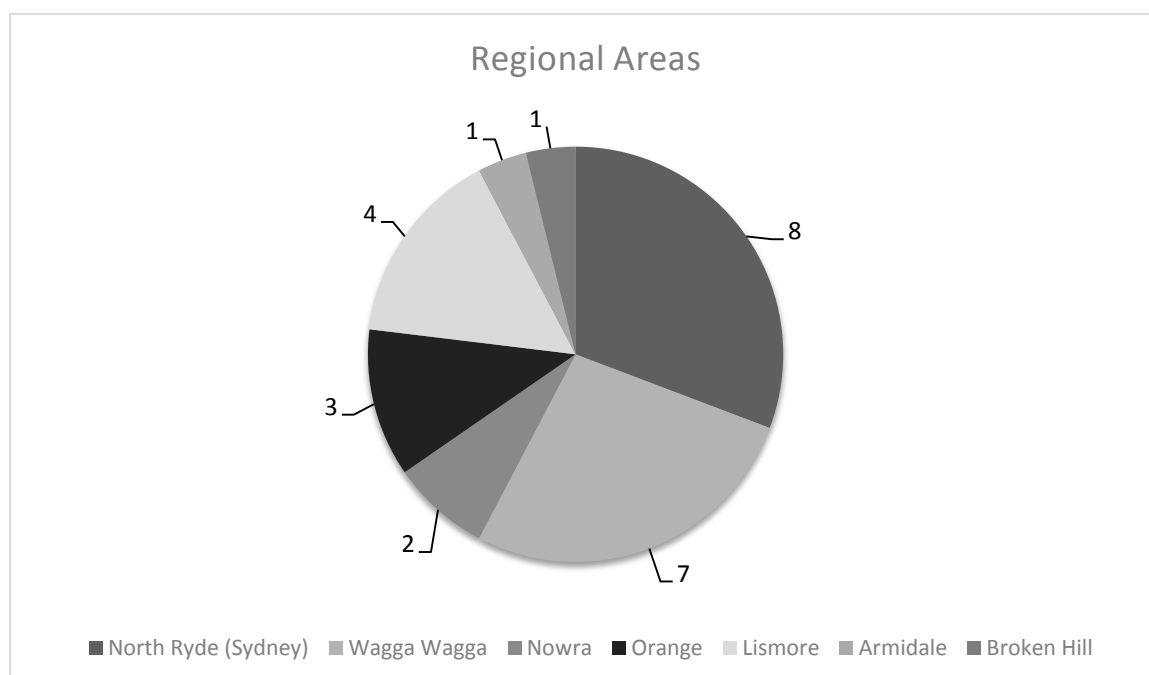
at the time of the workshop, but do not provide enough detail as to how ideas were utilised by family members, the group who was the key focus of the project. It was for this reason the research team also interviewed some family members individually to gather more in-depth information on their experiences.

Interviews with Family Members

A summary of the findings from interviews with twenty-six family members is presented below. These family members had nominated their interest to be interviewed at the workshops and were contacted by someone from the research team to arrange a convenient time and location. Participants' interviews were recorded and transcribed with their permission and identifying factors in people's responses were removed to ensure anonymity. Confidentiality appeared to be a significant concern for some interview participants, who were concerned that ADHC who commissioned the research would use the information to deny them funding on the basis they were doing "too well". The research team took great care in de-identification and therefore the report on these findings below does not always disclose the area in which people attended workshops for these reasons. Some demographic information about the research sample is provided in *Figures 2, 3 and Table 4*.

As *Figure 2* demonstrates, 16 family members (62%) had previous association with either Family Advocacy or Resourcing Families. The proportion of families who agreed to be interviewed in each area are as follows: North Ryde (Sydney), 8 family members (31%); Wagga Wagga, 7 family members (27%); Nowra, 2 family members (8%); Orange, 3 family members (12%); Lismore, 4 family members (15%); Armidale, 1 family member (4%); and Broken Hill, 1 family member (4%).

Figure Two: Regional Areas



The majority of participants were mothers, with the exception of one father and one sibling. Sixteen participants (62%) supported a person with an intellectual disability; but there were also family members who supported a person with autism, cerebral palsy, brain

tumour, and learning disabilities. These categories also do not take into account those people with more than one condition. The family members with a disability were at different life stages (see Figure 3), and therefore the concerns and priorities of participants were diverse depending on their current life experiences.

Figure Three: Life Stage of Person with a Disability

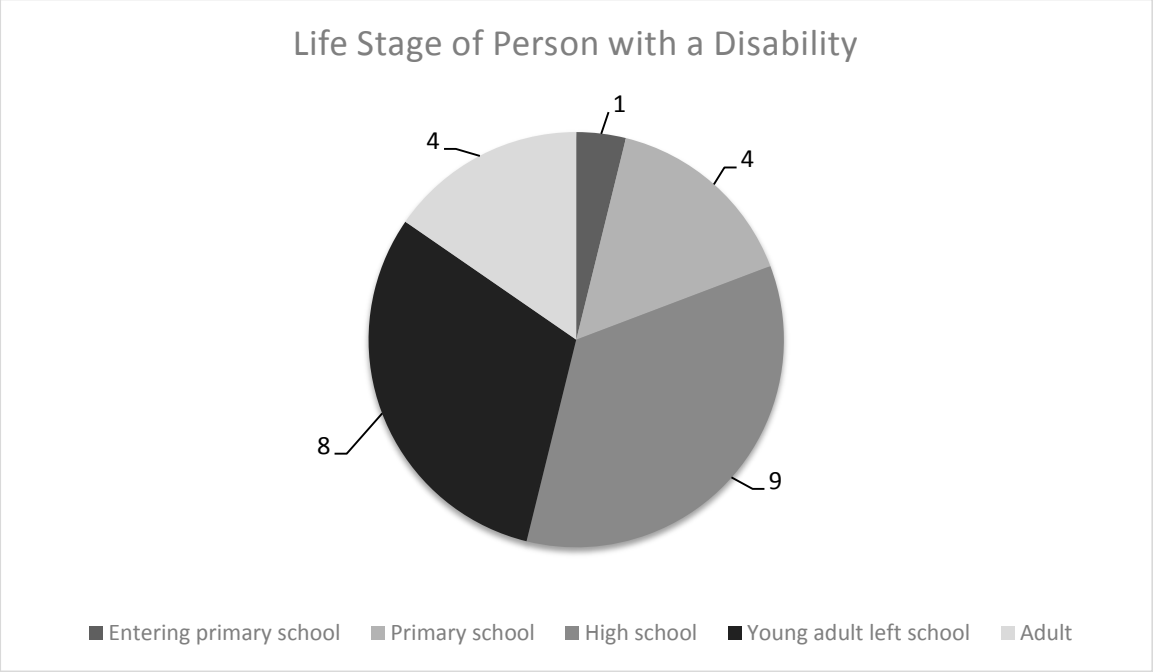


Table Four: Demographics of Interview Participants

Place where attended workshops	Gender	Relationship to family member with a disability	Previous association with RF/FA	Workshops attended ¹	Second interview undertaken	Nature of Family Member's Disability	Life stage of family member with a disability
North Ryde	Male	Father	Yes	1, 2, 3, 4	No	Intellectual disability	Young adult left school
North Ryde	Female	Mother	Yes	3,4	Yes	Intellectual disability	High school age
North Ryde	Female	Mother	Yes	4	Yes	Cerebral Palsy	Young adult left school
North Ryde	Female	Mother	No	2,4	Yes	Intellectual disability	Adult
North Ryde	Female	Mother	No	4	No	Intellectual disability	Primary school
North Ryde	Female	Mother	Yes	3	No	Intellectual disability	High school age
North Ryde	Female	Mother	No	4	No	Intellectual disability	Young adult left school
North Ryde	Female	Mother	Yes	4	Yes	Intellectual disability	Primary school
Wagga Wagga	Female	Mother	Yes	1	Yes	Cerebral Palsy	Adult
Wagga Wagga	Female	Mother	No	5	No	Cerebral Palsy	Primary school
Wagga Wagga	Female	Mother	Yes	3,4	Yes	Autism	Young adult left school
Wagga Wagga	Female	Mother	No	1, 2	Yes	Intellectual disability	High school age
Wagga Wagga	Female	Mother	No	3	Yes	Autism	High school age
Wagga Wagga	Female	Mother	No	1,2,3	Yes	Intellectual disability	Primary school
Wagga Wagga	Female	Mother	Yes	5	No	Intellectual disability	Young adult left

¹ Workshop numbers are the following: 1 – From Planning to Action; 2 – Involving others and building networks; 3 – Developing community connections; 4- A practical pathway to a better life; 5- Ideas for self-directing supports

							school
Nowra	Female	Sister	Yes	1, 2, 3, 4, 5	Yes	Intellectual disability	Adult
Nowra	Female	Mother	Yes	4	Yes	Intellectual disability	Entering primary school
Orange	Female	Mother	Yes	3,4	Yes	Cerebral Palsy	High school age
Orange	Female	Mother	No	5	No	Neurofibromatosis and learning disability	Young adult left school
Orange	Female	Mother	Yes	5	No	Brain tumour	High school age
Lismore	Female	Mother	No	5	No	Intellectual disability	High school age
Lismore	Female	Mother	No	5	No	Intellectual disability	High school age
Lismore	Female	Mother	Yes	5	No	Autism (2 children)	High school age
Lismore	Female	Mother	Yes	1,2,5	No	Intellectual disability	Young adult left school
Armidale	Female	Mother	Yes	1,2,5	No	Intellectual disability	Adult
Broken Hill	Female	Mother	Yes	3	No	Autism	Young adult left school

Interview Findings

Having a Vision

Formulating and refining a vision is a key step in building a meaningful, ordinary life for a person with a disability. The idea of having a vision was first introduced to families in the *From Planning to Action* workshop. A vision could be described as having a clear idea and positive dreams for a person with a disability. The idea is to provide clarity and direction and move beyond the often limiting societal beliefs and ideas about people with a disability. Developing and sustaining a vision needs to be given frequent attention and can require significant energy and work to keep the ideas and dreams alive.

Two participants who had already formulated a vision with their loved one spoke about taking steps towards the vision and the skill, insight and determination needed. For one of these participants, moving towards the vision meant a continual adjustment of expectations regarding her son who was about to enter primary school:

I don't know what the answer to this is, the balance between having high expectations and realistic expectations and dealing with the fall out in between those. Because I think early on I was like yeah, yeah we'll have this thing sorted, I'm a teacher, we're really positive about this, it will be fine, he's part of our family. And then we just had thing after thing after thing that has happened for him and so I've had to keep adjusting those expectations because they have to be realistic as well so just dealing with that in myself.

She felt it was important to step back regularly and review decisions and actions taken to see if they were in alignment with the dreams she and her family had for her son. The other participant described the Resourcing Families workshops as venues for providing information on having a vision, but felt that many families would need ongoing support to sustain these ideas:

A lot of families have their family member in a group home, they're over it. Can't condemn families, they are not being supported in a vision. Going to a workshop can give them information, but some people need their hand held.

There were a total of eleven participants who spoke of a clear vision they had for their family member prior to contact with Resourcing Families. The goals and intentions discussed by these participants were not unlike other family members who were interviewed, but there was a sense that there was a deliberate overarching statement about how life could be for their family member. For example, one father read out a vision statement:

The vision is "I will live by myself and make my own choices without being limited. I will lead a meaningful inclusive life making a valuable contribution to work and other activities. I will live in a stable relationship being close to my family and friends. And

finally, I will pursue my interest in animals, travel, friends, sports, cooking and learning new skills."

Of the eleven participants who had a defined vision statement, nine had previous association with either Family Advocacy or Resourcing Families. One mother described having a vision as "something that Family Advocacy has always drilled into me" and had done a vision statement for her daughter from the time she was three years old. Participants discussed concepts such as having their family member live an independent and inclusive life in their local community, pursue valued roles (e.g. having their own business, seeking further education), develop and sustain stable and supportive relationships, and pursue their own interests and passions. Three participants in this group of family members who already had a clear vision stated that the vision for their loved one had remained the same but they had been further encouraged to continue to pursue these ideals by attending the workshops. One family member mentioned the need to set little goals with her daughter to move her towards fulfilment of the vision.

One participant in this group brought up some of the barriers she felt were getting in the way of implementing her vision:

I've been encouraged, but for my son my goals and vision have been to maintain physical, emotional and mental health by having him active every day. Any more than that, I can't see it... For him to be living independently he'd need 24/7 support, he'd be lonely. We get \$40,000 funding now, he'd need \$200,000 to be independent. My goal is having a good day every day; waking up well, going to bed happy. These ideas about a "grand vision and goals", the NDIS framework is based on this. But when I show the service provider photos of [my son] surfing, at the café, with the dog they're not interested. I'm in a big black hole about goals. I want to know how to make the NDIS waffle people happy with a program that's realistic for our day to day. [My son's] only on Youth Allowance. They say he needs to fund his activities himself, they'll fund the worker. Normal people on a pension don't go to movies, to concerts, to cafes. He can't afford that. I want to know how to create goals for someone like him. His goal would be to in a small circle of people laughing. They say that's meaningless. I don't know that I have a vision beyond doing good things for him, for as long as they allow him. I want him to be out in the community. I know there are lots of people with disability around here but I barely see anyone out. They're not having a good life.

This family member summarised what she got out of attending the *From Planning to Action* workshop as:

That there are parents like me out there pushing the boundaries and testing the guidelines to get what they need. All I'm getting are the gestapo black flags, "no, no". In July I'm going to try a new provider. Hopefully we'll get what we had. With guidelines, it's all up to the interpretation. Resourcing Families is encouraging this, this, this, but ADHC is saying no, no, no.

This participant's account highlighted the challenges families face in other contexts, and points to the need for ongoing support and encouragement outside forums such as those run by Resourcing Families.

Three family members spoke of developing a vision after attending Resourcing Families workshops. All three had previous association with Resourcing Families or Family Advocacy. One mother spoke of developing a vision with the NDIS in mind:

It's given me more fodder for future planning and what sort of things we've got to think about for the NDIS as well.

For another mother it was linking her daughter's vision with what her peers were doing and what she could be accessing. The other parent commented on how formulating a vision with her son reminded her of a concept imparted in the workshops – that of how a person's identity is often wrapped up in what they do in their life.

One mother of a young adult woman encapsulates some of the feelings family members may experience when choosing to hold a positive vision for their family member:

A *Well, I'm optimistic about it, yeah. I probably sound a bit tired but...*

Q *Are you feeling tired?*

A *Yeah. Always been tired. No. It is tiring. It is tiring and it does take its toll on relationships and things like that. Matthew and I try and do everything ourselves without imposing on people but by doing that you wear yourself out. But trying something new excites us and we feel that Lisa should be happier and better within herself when she's doing things that are relevant to her. So we're looking forward to it. I'm a little bit scared, of course. A little bit apprehensive. But that's in what's anything new. Stepping outside the square.*

Key learnings: The majority of families who spoke of holding a vision for their loved one had previous association with either Resourcing Families or Family Advocacy. This may suggest that the concept of “dreaming big” does not come overnight for families, and that people need to be exposed to the ideas over an extended period of time to truly take in their relevance. Even when families do formulate a vision with their loved one, they must also be prepared to face others in their local community who may not share in that vision. This can be exhausting and discouraging and families need regular opportunities to re-energise and revisit dreams and aspirations.

The content provided in *From Planning to Action* workshops is developmental in its approach. Families are given opportunities to reflect on the importance of a vision in their own lives, before applying the concept to their loved one with a disability. They are provided with thought-provoking questions about the person with a disability and what he or she may want in life and they are encouraged to write down their discoveries, and ultimately the vision statement.

The workshops by RFCBP are a beginning step to a cultural shift for many family members, but there is a need for other opportunities to sustain these important ideas. The findings from the literature review indicate that disability service organisations can play an important part in supporting planning efforts by families (Robertson, Hatton, et al., 2007), and therefore concurrent efforts are needed beyond this project to influence the practices of disability agencies and broader community attitudes toward people with a disability.

Planning with the Person with a Disability

And that was what shocked me about one of the quotes that was in the workshop that Jane did. Like one of the quotes they put up was from one of the parents... and she said something about I dreamt of a life for him in which he would know this, this and this, and I thought well she dreamt of a life for him, not with him. I think that's a really tricky thing, particularly for a child with a disability, you know, the dreams they have for themselves, how can they articulate that or even develop that, versus the dream that the family might have for them and then kind of marrying that with what is feasible in practice.

- Mother of a school-aged child who attended *A Practical Pathway to a Better Life*

One of the key messages that family members received about planning for the good things in life for their loved one was to be mindful of the person's real interests and aspirations. The above quote from a parent was an exception to this, but perhaps speaks more to the challenge for families to distinguish their own needs from their family members and to find the means and mechanisms to really understand what is important to the person with a disability. This challenge is also there for service providers working with people, but family members are often best positioned, given their long-term and vested interests in the lives of the person to discover what the person's aspirations are. If a family member has a heightened awareness of this, they can also act as an advocate for their loved one to ensure these are incorporated into any planning around the person.

Six participants reported they felt encouraged to plan with their family member as a result of attending the workshops. One mother with a son still in primary school described her change in perception:

Just taking the blinkers off a little bit and widening my vision on how Jack's quality of life can still be supported but in ways that Jack might like to see that happen, and I've got to think of it as in Jack's age and his head and his brain.

Two participants really liked the idea of having a plan for each week and involving their family member in that plan, by incorporating activities that they knew their child was interested in, and by involving their child in the writing and reading of the plan.

For another two participants, their understanding of the planning process also involved challenging what they thought their family member was capable of. As one mother stated:

I suppose it's opening up my eyes to opportunities that I hadn't thought about and not to just keep the shutters on and think "He has Down Syndrome, this is all he can do".

This mother appreciated the activity sheets given at the workshops which got people to think about the interests and loves of their family member:

He can't tell me what he wants to do, and he doesn't necessarily even know what he wants to do, but I know the things that he loves doing, so something as simple as this can help.

Understanding how a person with a disability communicates their passions in life can be an acquired skill and there may be barriers to be overcome. A person with a disability can also be limited in their understanding of choices, partly due to a lack of exposure to similar life opportunities as other people without a disability. One parent spoke of "doing research" and "presenting different avenues" to her daughter to help her to express her desires. This appeared to be a real tension for the mother who said she didn't want to impose her own agenda onto her daughter, but was conscious her daughter could be devoid of new ideas. There was also the added challenge of working around her daughter's motivation and energy levels:

...Sometimes she can't probably really understand maybe what that might all involve and then we'll go, let's go have a look or let's go and try it or something, and sometimes it's a bit hard to get her out the door sometimes but she's good once you get there.

People may express desires which may need to be modified to fit reality, as attested by one sibling participant who described conversations her brother had with job network providers:

But it's tricky because when he was being interviewed what did he want to do as a job, he said oh I want to be a physiotherapist. They went okay and then he said but really I'd rather be a faith healer and they couldn't get him a job as a faith healer. So when they're trying to do planning with him, it gets a bit in the way, because he's not realistic.

Key Learnings: It is apparent from these examples and reports from other family participant experiences of ascertaining what their loved one wants in his or her life, that multiple strategies are needed on an ongoing basis, which may include processes of negotiation, experimentation and exploration. The RFCBP workshops provided important material to engage in such activities, including strategies for exploration of the possible interests and passions of the person with a disability. However, as with formulating a vision, there is a need for constant review and adaptation to fit with changing life circumstances.

Families play an important part in planning, and events such as these workshops can facilitate such processes but there is also a need for service providers to listen to the wisdom of families and to develop their own expertise in really listening to the person with a disability. Perhaps further work could also be done with families on points of influence with service providers to make them more individualised and responsive. Certainly the more families are exposed to workshops on planning such as these; they are likely to become more confident in advocating for their family member with a disability.

Building and Nurturing Freely Given Relationships

A good support network of people who give their time freely to a person with a disability and his or her family is often considered vital to the person having a good life. The RFCBP workshops espoused these values and provided tools for participants to assess the current relationships in their loved one's life and explore the potential of new relationships. Information was also provided on how to create a circle of support around a person with a disability.

Many participants yearned for more relationships in their loved ones' lives. One young mother eloquently expressed this need:

People are happy to spectate, they're happy to stand on the sidelines and go you're doing a great job but they don't actually get in the car with you, they kind of stand on the side. And you actually need people to get in the car with you. And not people who are going to sit in the car and go oh you poor thing this is so hard I don't know how you do it. You need people that are actually going hang on I'll hold onto the steering wheel for a second while you deal with that; that kind of well I'll do him up while you steer. It's getting people more involved in a natural way.

For a few family members, some types of freely given relationships were considered easier than others. Three participants spoke of the potential of intimate relationships for their son or daughter, which one of these mothers described as unknown:

I don't know whether he's ever going to get married or have any children. Like you hope your kids will, but I just don't know whether that's ever going to happen for him. Fortunately he's not interested in girls at the moment.

Two parents reported that their daughters often spoke of getting married. One of these mothers said she hoped this could happen and was quite emotional about the topic. The other mother felt she didn't know how to address the issue:

I mean there was a lot of talk about where they're going to live and supported living and all that sort of stuff which was great but then that also brings home, you know, I suppose having an intimate relationship and where do they go from there? That's a little bit of a part of her life that I would like to learn more about how to help her there.

Considerations about freely given relationships in the lives of people with a disability inevitably involve some examination of the person's private world, including the

private world of family members. The interviews conducted with participants were often a forum where people intimated some of the challenges experienced in building meaningful relationships. These were often sensitive issues and out of respect to participants were not explored in-depth with families. For one family member, the sometimes aggressive behaviour of her son meant she did not feel comfortable visiting other people's homes, and there had also been some tension with neighbours due to their lack of understanding of her son's disability. For another participant, gathering family together to engage in planning and support for her loved one was not considered possible because of strained relationships:

Well just that the dysfunctional nature of - it's just the strangers in your own family, it's the people who live close to him are strangers to him. They don't understand him, well they don't know him therefore they don't love him, therefore they don't - aren't committed to him. So that's the problem.

This participant had not brought up these concerns in the context of the workshops because of the personal and emotional nature of the issues. Another participant felt that her family was not really connected with other people to begin with:

It's probably easier if you've got a lot of connections which we don't really have so I guess we've found it's a bit hard, just that pushing yourself out there and making those connections... maybe not as natural as it might be for some people.

For some families, particularly those who had previous association with Resourcing Families or Family Advocacy this concept of intentionally building networks around the person with a disability was something they had been practicing for a significant time. One parent of an adult man had been running a circle of support for three years. The parent described this as gathering of people at a barbeque that happened every three months. People invited included those who had been involved in her son's life previously as well as new people he had come across:

From that you get people who will volunteer to spend some time with Craig. It could become more formalised, but I don't want to make it too formal because I don't want to frighten people off.

At the last circle of support the group went out to a local resort. Her son stayed there overnight along with some family members from interstate. This was seen as another way of strengthening networks by having a more extended time together. The process was described by the parent as ongoing and needing to include new people regularly for it to be sustainable. She also regarded the act of asking others to be a "huge task", which was often made easier by providing a limited timeframe for people's involvement:

When I went overseas I asked people to be involved for a limited period - "I'm going overseas for eight weeks, I'm really concerned about Craig. Could you drop in, have a meal, phone or email, or respond in an emergency? Everyone said "Absolutely yes". People have become involved and been ongoing, but can't ask for ongoing involvement, it needs to have a cut-off point.

Three participants also reported that social supports can dwindle as the person with a disability gets older. One of these mothers reported that her child with a disability no longer gets party invitations from school friends. Another mother felt the opportunities for her son to connect with other young people were more difficult now that the majority of able-bodied youth went to university. The other mother talked about circles of support changing over time:

A lot of people are really helpful when they're younger. They're cute and that. But as they get older they drop off. She's harder to handle now and I suppose it takes a lot more effort.

Another parent who had been intentionally seeking social support for her daughter for a significant time described the process of building networks as time consuming and “hard to do” but nevertheless important. She discussed her experience of attending the workshops below as re-energising her, a comment that was common across many interviews with family members:

It reinforces that I need to keep doing it because like I said in the last four years I've really slackened off because I just felt we were in a rut I couldn't do anything, she couldn't leave school, there was nowhere for her to go. Yeah felt really in a rut. But now she's just out of school I'm just starting to get my legs back and this has prompted me and told me what to do... My husband is away at the moment so I'll read through it with him. And yeah like I say I go to everything I can because even if you get one thing out of it's better than getting none.

A father of a young man who had recently left school also reiterated that the process of making meaningful connection with others takes time. This father had begun a circle of support for his son as a result of attending the workshops. He reported approaching people to become involved as challenging at times:

When we contact some other people they sort of are very politely trying to say they'll think about it, they will see in the future if they can do it, blah, blah, all this sort of wishy-washy type of thing.

A mother of a younger child also reported receiving “no’s” on several occasions in setting up a circle. She used the upcoming workshop as an opportunity to gather social support:

And so I Facebooked and text messaged heaps of people, heaps and heaps of people and said we'd love you to come to this workshop in helping us dream big for Sam and just left it at that. And then I had a week of just great conversations with people about what was the workshop about, never heard of social role valorisation before, what's it about. And people saying look I really can't come but I'd love to have coffee with you and talk about it. And not necessarily the people that I expected.

She summarised her learning as a result of attending workshops and actively engaging with the concepts as the following:

And there are some people that I feel like you're beating your head against a brick wall and to some degree it's like okay that's not going to work just find someone else. And I'm starting to see if you get a little in with someone but not pursue it like don't run them down kind of thing but go with it and keep pulling those people that are supporting you to you and keep them in the loop as well and keep celebrating his stuff with them because that keeps feeding you as well.

For two participants exposure to the concepts of intentionally building networks was a new idea and something that seemed easy to do. For one of these parents, who had a son in high school, and something she said she had made a “mental note” on:

And that was the one good thing about a couple of those seminars, the networking seminars, just thinking of people who can help you if you are away for a weekend or a week. People who can either check in on them or ring them up and see that they're going okay... I found that really useful. And just to sort of give a dozen people one tiny little job each. You know, which makes it really easy... I found it really useful to have those ideas of how to break it up and spread the burden as thinly as you can and have as many people as you can, sort of, doing little things.

Three participants felt the content regarding intentional relationship building was not that relevant to their situation. For two of these parents, this was because they felt their family member already had an active social life. For one parent, the discussion about circles of support was “a bit disillusioning”:

For families of a person who is really disabled, 99% of the time you would only have a circle if people were paid. People won't be in a circle if they are not paid. In society people don't want to know those who are the most broken. We have friends through the football club who also have family members with additional needs. No-one ever says we'll take him for a couple of hours while you go and do something.

This mother nevertheless had been very active in ensuring her son made lots of social connections and had been arranging social gatherings with other people in her son's network at a local coffee shop.

Key Learnings: The discussions on relationship in these interviews highlight the complexity of Resourcing Families work in helping families to facilitate and foster meaningful social connections. Given the often personal challenges that each family faced, it would appear that workshops introducing these ideas and strategies are only a starting point, and perhaps only one mechanism in which to improve the lived experience for people with a disability and their loved ones. There may also be more pressing matters which families need to attend to before they are ready to actively seek support from informal networks in the community – for example, there may be urgent needs to address certain behavioural issues with the person with a disability before a family can have the confidence to engage with others outside their immediate network. These findings are consistent with the literature on the challenges of community connection work with families, where there are many complex personal and social issues which can create added challenges (Vargas et al., 2012).

The gathering of like-minded people with a common purpose of building intentional and inclusive communities can be encouraging and re-energising for participants, but the work is ongoing and connections need to be made at an individual level with families. Each family's level of readiness to do the work of building relationships needs to be accounted for. Resourcing Families have spent considerable time and resources to work with families on an individual basis given their funding, the broad geographical area they cover and their small amount of staffing. Many families are contacted after workshops and considerable time is spent with them helping them consolidate ideas and make change. However, further initiatives are needed which help family members build the faith, courage, energy and resilience to continue their efforts in building personal networks. Counselling services may be helpful for individual family members in some instances, to help them process the emotional challenges they face. One mother speaks of this need for further support:

I sort of came away thinking, they were saying build the team around you and do this and that and I thought I already know all this. And I know you do have to do that but you run out of puff sometimes, it's hard to build a team around you because you're always the entertainer and you're always the instigator and just sometimes you want to hop in your box and hide.

Community Participation and Connection

Closely related to the fostering and nurturing of freely given relationships is the notion of community participation and connection. When situations are created for a person with a disability to become an active member of the community, there is a greater possibility for them to connect to other people. By discovering and extending upon the interests and passions of the person with a disability there becomes an opportunity to connect to others who share similar interests.

Many of the families who attended the Resourcing Families workshops had already been active in pursuing activities that were meaningful for their family member and could list a diverse array of experiences people were involved in. Families also reported extending the range of community activities after attending the workshop which was mostly activities for people with and without disabilities. Some of these activities are listed below:

Church groups
Horse riding
Photography
Basketball
Girl Guides
Gymnastics
Dance classes
Drumming

One of the key learnings which participants spoke about from the workshops involved developing a sense of purpose in the pursuit of such activities. Some participants spoke

about grasping opportunities as they arose for social interaction and connection. One mother used her friend's parent's backyard for swimming lessons for her son. The lessons were conducted by a "local mum" who had been trained to be a school teacher but who was keen to have a go at teaching swimming. Another participant found opportunities in everyday routine:

It's only even things like if I'm at work and she's at home well then she can walk up to the local supermarket and get the bread for the day... because I stop every day and get some bread on the way home and I think well that could be her job it's so easy just to walk up, it's about three blocks away and she just goes into the shop.

One participant also demonstrated that there are creative ways of supporting interaction with others in community activities. Her daughter attended a Pet for Therapy course where she brought her own dog.

So she's got a whole new group of people there, she's very confident with them because you've got the dog there as an icebreaker to interact with people...

This mother also made the effort to personally thank one of the coordinators of the course for naturally including her daughter.

Another mother of a primary school age child spoke of the importance of taking action now. When asked about what ideas she developed from the workshop, she said she had always thought she would need to be more active in developing networks for her child when he left school:

... but now I realise well actually we can start doing it now and that it's beneficial at any time.

She appreciated the activity sheets handed out by Resourcing Families which helped her think further about possibilities to build on her son's community connections. The same parent also began to question the disability recreation program her son currently attended:

I think the aim is more to give me respite than to give him something worthwhile to do... They do all different things, but it's a group based thing with other kids with disabilities. They're different people each time and he might not necessarily know the other kids or have anything in common with them, but they're all together doing something... and if you don't like the staff you can't do anything about that, and next time there will probably be a different one. You don't know who the staff are going to be in advance, all those sorts of things.

Two other parents also spoke about the need to veer away from formal disability supports at times and find mainstream activities for their loved one to engage in:

Like not everything has to be in like a disability club, like how Suzanne said her daughter's in the mainstream horse riding club, not the RDA club.

Families also began to think more about the age appropriateness of activities. One mother of a son with autism acted on this idea by facilitating regular events with other families:

I know that was a big concept that came out, that you treat your child as any other 14 year old as best as you can... that was probably our biggest thing was that 14 year olds get on their bike and ride to the shop or they walk to the shop and they go to their friend's and things like that, and that they go to the movies together or they go to the pool together. So even though the mums still had to organise it, we were getting them to do that and once a fortnight between every two, three or four weeks we started a social group so the parents were organising so we asked the kids what they wanted to do and then we'd go and drop them off and then we'd go and have coffee or something. So they were doing lots of different, like, laser tag and mini golf and bowling and just different activities so they were meeting kids like themselves and doing activities that every other kids do with the idea that eventually that they would organise it themselves. We'd still have to drop them off, you know, every parent does so trying to, I guess, work them along their way of becoming like every other teenager.

Challenges for participants in community connection work included factoring in the energy levels of their loved one, barriers in the physical environment, work demands for parents, and negative community attitudes. Facilitating community connections for a person with a disability can also involve overcoming fear. Fears can include fear of failure, rejection and possible harm to the person because of their vulnerability. Two participants spoke of moving through some of these fears as the result of the workshop. For one parent, it involved helping her daughter with a disability overcome fear going on Girl Guides camp:

She wasn't too keen to go, but we prepped her and we spoke about it and made sure that she knew she wasn't going to be left alone. She was going to be in the cabin with the leader and blah, blah, blah. So it was really making sure she had a good understanding of exactly what was going on. Keeping her involved in choices as well.

The daughter was able to have an enjoyable time after this preparation had been made. For the other participant, community connection meant developing trust in others. She came away from the workshops with a sense of “the power of a community”:

It's taught me that I need to let go of my own fears because it's not about me. It's about her life. It doesn't mean that everyone, sure, you know, you have to keep an eye on them. While I'm around I will always protect her but you can protect too much and then that does become isolated. So that's what I got out of it.

A mother of a son who was about to enter school also talked about the need to prepare ahead when it came to including people in activities. She was able to include her son in gymnastics classes, partly through her previous involvement with Resourcing Families. This occurred even though her son's skill level was well behind other children his age. She managed this through pre-empting what some of the difficulties might be and having a range of responses to assist him. This mother

mentioned however, that at times it was very hard to include her son in certain contexts, such as preschool when her knowledge of her son was not always recognised by others.

Key learnings: It is clear that the RFCBP workshops helped many families to recognise the everyday opportunities for community connection. This is encouraging for families because they can begin to see that even small actions such as going to the local shop hold the potential for relationship. The activities provided in the workshops helped participants to break down what may have seemed insurmountable tasks to real, practical steps. Families reported many successes in this area and were able to prepare ahead to assist their family member in the new context. Participants also were able to step outside their comfort zones at times and overcome fears.

Perhaps on one level connecting to people and places in the community is easier than targeted activities as asking people to become involved in a circle of support. The successes made in connecting to the community need to be celebrated and ongoing work encouraging families in this regard would be valuable.

Creating Valued Roles

The concept of valued roles for a person with a disability was the topic of *A Practical Pathway to a Better Life* workshop. Valued roles were often mentioned in other workshops too to get participants to think beyond programs and activities and to think about a person's presence in community and the skills he or she can learn. One family member mentioned that she had heard of this concept previously through Resourcing Families workshops:

So through that and then also I've read quite a bit on their website about different articles, some of which I think have been written by Jane Sherwin and others as well.

Another participant also attended the workshop but had missed what the concept was – possibly due to the fact that English was not her first language:

Q Sorry had you heard about having roles for people before?

A No I can't sorry, I just missed that, can you explain it more?

When reminded of the meaning, the participant articulated that she wanted her son to take on a volunteering role after he left school:

I just want him to be involved in the society, because he don't have much family here, I don't want him to be at home all the time, I just want him to be able to go and for me it's important he learn, participate and also learn new tasks, new environment, hospital, new role as a volunteer.

Three other participants mentioned that at the workshops it had been the first time they had come across the concept of valued roles. One parent expressed:

Yes, I thought that was really good, it was a good way of putting it, like, to think of your child that way and understand it that way.

Eight participants shared their intentions to pursue valued roles for their family member after attending Resourcing Families workshops. The sister of an older man with a disability wanted her brother to get some assistance to reconnect with his grandson:

I think that would be the most valued role, linking to his daughter that links him to his grandson and there are some different roles there. For them to develop a relationship. Because when they get to know him he is lovely, but they don't see him with the same lens that I see.

Another participant planned to keep a lookout for opportunities for her daughter:

Yes, I'm basically keeping my eye out more on the things that would be suitable for her within our community, at school, or with Guides, or things that are in the local paper. If I see there's an arts competition or something like that.... Just being aware actually.

One parent spoke of an interest her daughter had in babies and whether this could be built upon into some sort of role:

Well, how she could perhaps incorporate that interest into her future role and maybe when they do work experience, I don't know gives you the opportunity to baby cuddling somehow as her work experience maybe visiting a day care centre or a hospital nursery, I don't know.

Another parent had the idea of her daughter becoming involved with therapy dogs or studying animal studies at TAFE to encourage her daughter's interests with dogs (this family is also mentioned under Community Participation and Connection):

And what sort of roles she can take on, I'm imagining a lot of them probably volunteer type roles whether it's sharing her dog with kids in hospitals or that sort of stuff, I think that would bring her joy and I think a lot of other people too, really could form relationships.

The concept of roles also helped one mother prepare her son for first time at school. She thought of the role of a student and unpacked the skills and steps needed for her son to carry his own bag to school.

Learning about valued roles also helped one mother to acknowledge the part her daughter played in the day-to-day running of their household:

I do the please and thank you and all that sort of stuff but I never really thought of it as it's her role to do specific things. It definitely opens up your mind in terms of that she has to feel good about herself... Just roles in terms of at night instead of just saying "Kerry can you set the table" when she does do something then I'll acknowledge her and say you know Kerry's now in charge of setting the table. That's her thing.

The daughter was able to extend her role as a household contributor by helping her grandparents in their home when the grandmother lost her vision.

Two participants spoke of specific actions they had taken since attending a *Practical Pathway to a Better Life* workshop. One mother reported that her adult son was now doing more work at home, as well as paid work at McDonalds, and had become involved in a choir. She felt that her son had become more confident and “grown up” as a result of these new roles. Another mother, whose son was in primary school spoke about how her son had now become a member of a football club and would attend a few matches in the following year.

Two particular barriers in developing valued roles were discussed in interviews – these were around the competencies and skill level of the person with a disability, as well as their motivation to extend the number of roles in their lives. One parent believed that her daughter’s intellectual ability would be a challenge in developing meaningful roles as an adult. Her daughter was still in primary school and therefore adult roles and competencies were issues further ahead. She was however buoyed by stories of adults with an intellectual disability achieving great things:

She will certainly struggle, I believe, I mean I don't know--there are adults with this that hold down jobs and pay mortgages and do all of that. Whether Clara is able to do that, I'm not sure.

Another parent spoke of returning home from a Resourcing Families workshop with many different ideas for expanding her son’s roles, including getting into music, martial arts and socialising more. These ideas were “knocked back” by her son with his “usual no”. She felt that he didn’t want to try something new because it would interrupt the time he had at home playing on his computer games.

Key learnings: The concepts of valued roles seemed to be easily understood by families and the Resourcing Families workshops provide concrete examples of the many roles people with a disability can play in the community. Some families in the interviews also demonstrated they were considering the degree of participation in tasks and socialisation for their family member.

Perhaps for those participants who were concerned about the skill levels of their loved ones to engage in roles, it is a matter of helping these participants to revisit the nature of participation in roles and breaking these down into more achievable activities. The process of really listening to the person with a disability and exploring their passions and desires is an ongoing one and could assist in situations where the person with a disability seems to lack motivation to try something new. More forums in which family members can problem solve issues as they arise would be beneficial. Resourcing Families have the experience and knowledge base to run such forums, because of their connections to many families who are successfully supporting the inclusion of people with a disability. The stories and strategies of other parents and siblings are powerful teaching tools in this regard.

Developing Independence

Although not all participants were explicit in their vision, many families articulated what their hopes and dreams were prior to coming to a Resourcing Families event. An overarching theme for many of these families was the concept of their loved one developing independence. “Independence” came in many different forms including employment, education, developing life skills, and having a productive retirement.

Work

Eleven participants mentioned finding work for their family member as something they had considered prior to attending Resourcing Families events and a further three participants spoke of their intentions to assist their family member find work as a result of attending Resourcing Families workshops. Comments were often expressed by participants about how attending the events acted as a source of encouragement. One mother stated she didn’t think her son could be fully independent but nevertheless he needed to make a contribution to society:

I don't want him to sit here and get money.

Another mother also talked of the importance of work:

So the biggest thing I probably found is because I've looked after Alice all my life and I've done everything for her that I can, and my family and my husband, I've had to sacrifice working. I only work a couple of hours a day a couple of times a week so that I've at least got an interest and earn a bit of income. But it's a big sacrifice; I've had to sacrifice earning a decent income for the last ten years or whatever. And that's why I'd like her to be able to look after herself so that she can feel like a participating person in the community, a taxpayer, and I can go back to work and start earning some money and having an interest and all that sort of thing because it's no good for anyone. I just think paid work is probably the best thing you can ever do for yourself. And it will be for her, once she starts earning she'll be a workaholic because she loves the dough.

Overall the expectations for paid employment were quite modest. What was touched on by some participants was finding work that could accommodate the person’s level of ability and also be something that was meaningful to the person.

There were accounts from families about the barriers to finding work for people with a disability. Some of these barriers were anticipated by families but not yet experienced, and for others the challenges in finding work were ongoing. One participant relayed the experiences of her brother with a disability accessing an employment agency and volunteer work. The agency had failed to accurately assess the supports needed by her brother, did not understand his need to appear more competent than he was in some areas, and had not helped her brother to set realistic goals:

So people judge my brother a lot, thinking, not seeing his disability but they judge him. I don't because I understand how the disability impacts upon him. I also understand he

covers his disability up, but he covers it up out of dignity. Therefore he's not able to do a lot of things. He can talk you into a lot of things, but there's no substance of his being able to carry a lot of things through. That in turn annoys people, but it's because he doesn't want to recognise his disability really.

Similarly, the brother had also experienced difficulties in doing volunteer work – where the organisations he worked for had unrealistic expectations of him, as well as having one incident where he was “sacked” from being a volunteer. Supporting her brother to find work was a significant task for this participant, who was often involved in mediation and advocacy to get a better deal for her brother.

Anticipated barriers mentioned by participants included difficulties accessing transport, particularly in regional areas, and negative attitudes towards people with a disability in the workplace:

So again that's a matter of choosing the right places, finding the right places. That's when you've got to do the hard yards, you've got to pound the pavement, you've got to suss everything out, you've got to go visit it, is this okay are they okay and I can see this working or I can't. So again that comes back to the parent or the carer again to get out there and put the groundwork in. Everything I've always done for Alice, always gone in taken photos, shown her before she has to go there so that everything is calm. I've got an office full of social stories and stuff that I've done for her over the years, and that's why she's like she is today.

Volunteer work was often considered by families as a way their loved one could make a contribution, with two families already supporting their loved one prior to attending the workshops. Both people were volunteering in childcare and/or retail in roles which the mother had arranged through their own work and social networks. Ideas for volunteer work included work in areas such as hospital settings, retail stores, libraries, schools and op shops, with one mother enlisting her son in a bush care volunteering group after attending the workshops.

Paid employment was discussed by one participant as arising from the existing volunteer work and by another in the form of setting up a walking dog business. One participant felt that any regular paid work would be essential for her son when he left high school:

So if he can't get any kind of employment in a normal workplace, then I'll let him go and work in the shelter place here... And I don't really want him to work there. I've never wanted him to work there, but he's got to work somewhere and if he has to work there he'll work there. Because he's not one to sit at home. He'd get bored and depressed.

This participant stated that plans for employment were not likely to start for her son until another eighteen months as he was getting closer to leaving school. On further discussion, she spoke of the challenges of finding paid employment in her regional location, and accurately assessing her son's capabilities. She had not ruled out volunteer work as an alternative:

The trouble is, and I know that this is a problem especially in small businesses, but when you've got a person whose abilities are limited, it's hard to employ them because, in small businesses, you often need someone who can do every job in the business. And if you've got an employee who you can't send out to take an order because somebody's off sick today and you just need somebody who can go out and take the orders or something. I mean, he might cope with that. I mean, he probably would with a bit of practical training. He wouldn't be able to work in a busy restaurant and he mightn't be able to do a busy lunch time order, but if it was slow at morning tea time he could probably manage.

This mother also had plans of approaching her childcare centre employer to see if he or she would give her son a traineeship when he left school. Her son had been attending work experience in the childcare centre:

I haven't broached it with the boss because I'm a bit scared to probably, and I'm a bit scared of the answer, and I'm a bit scared that they'd say no he couldn't, and I'm a bit scared to say yes he can. And the thing that might be unsaid is but only because you're his mother and you work here... I'm thinking like if we did do a traineeship, like a normal traineeship would be 12 months, but I'm thinking you can do it over two years.

Two parents spoke of their young adult children setting up their own business. As one of these parents explained, it was important to find work that was individually meaningful for her daughter who had recently left school and was attending a transition to work program for two days of her week:

The transition to work program picks her up today and takes her back there, and then she has Thursday, Friday there but she doesn't like it much and is finding it difficult. I'd rather be directing her into activities that she'd prefer to be doing rather than just grouping her with people that probably aren't of similar interests to her.

This parent applied for the Direct Payment Self-Managed System as a result of attending Resourcing Families workshops and had ideas to find work for her daughter in the hospitality industry.

Another parent had attended both *A Practical Pathway to a Better Life* and *Ideas for Self-Directing Supports*. She relayed that the latter workshop had inspired her to approach her son's day service and request to self-manage his funding. She listed several potential places for her son to volunteer and stated that workers from the day service were now going to approach these places for her son. She also shared her ideas for setting up a business for her son:

And we thought maybe with his money that if they're able to use, because I'm not sure what you can spend the money on, we may be going back to the farm so he wants to do a dog breeding program. Because he loves dogs, he really likes Dachshunds and it's a way he could make money too because if he buys the breeding pair and then he could sell them, make quite a bit of money that way. So whether you can use the funding to buy the dogs or whatever, set up his little business there that's something he can do that will be quite easy for him. So not just using money but making money out of that.

Key Learnings: Many of the ideas regarding future work discussed by families in interviews were still at the infancy stage. This is not to say that these ideas will not eventuate into action, but it is more indicative of the time period of the research and the time needed for families to make the appropriate connections and help their family member to become work-ready. Finding work for a person with a disability is a significant task, and the multitude of stakeholders involved in the process makes it all the more complex. A workshop or forum which focused specifically on developing skills in advocacy and community connections in this area would be helpful, as there appears to be a strong interest in the area from those interviewed for this research.

Education

Six participants who had attended the Resourcing Families workshops already had specific intentions regarding education for their family member. One mother was actively involved in preparing her son to attend primary school, which involved frequent communication with the intended school, as well as strategies for behaviour management and skill development with her young son. Another mother mentioned the hopes for tertiary study for her daughter who was currently in primary school. Another mother wanted her child who was in a regular primary school to transition successfully into a mainstream high school. Attending the Resourcing Families workshop had encouraged her to continue to pursue these goals:

It reinforced to me what I had been wanting but didn't really know if I could achieve it so I suppose it gave me more courage to think "I can actually achieve this for him"... There's so many barriers that people put up and say "You should be going to special school" or things like that, so it was quite nice to hear an organisation that's really passionate about mainstream and knowing that there's help when you need it from people to help you access mainstream things and give you information and advice...

For this mother there were still significant concerns about the transition and about the commitment of the intended high school to both welcome and educate her son:

I'm really hopeful that he can stay there for the next six years and have a meaningful learning experience and not just be there as an observer but that he can be embraced and that his learning needs - he can learn. I just don't want them to be teaching him to cook.

She was about to invest in speech pathology for her son to improve his communication skills for the new environment.

Similarly, a parent whose daughter with a disability was in Grade Four in primary school was motivated to think about the transition to high school as a result of attending the workshops. This was even though the transition would not happen for several years:

I guess I have just been thinking about the things that were raised in the workshop and we are starting to look at the next transition for Mary and the high school... so we made the political decision to all go along to the high school Year 7 family barbeque...

they made it very clear that it was a family affair and I said to my husband shall we all go, they've said that everyone's welcome, it's making a bit of a statement by turning up, it's not exactly subtle, when you front up with a kid in a bright pink power wheelchair.

The high school intended for her daughter was out of the catchment area in which the family lived, but it was where an older daughter was attending and was seen as providing more opportunities for inclusion because of the absence of a support unit for students with a disability.

There were also two participants who spoke of their existing experiences in mainstream schooling. For one mother, there was an ongoing struggle with the school to keep her daughter enrolled and included in a regular classroom. For the other mother, there was continuing dialogue with the school to recognise her son's brain injury and the impact it had on his learning and behaviour. The workshops held by Resourcing Families had the potential to reinforce the vision and goals of these parents to build a good life and education for their children.

Several participants discussed the possibility of their family attending mainstream TAFE education/traineeships, stressing the need for adequate accommodations for their family member if they were to attend - either through having a support person there with the person, or extending the study period so the person could work at their own pace:

Well there is a TAFE course, I just wonder if she could do some broken down sort of TAFE thing. She would have to be assisted up there because our TAFE is really big and it would be quite daunting for her. And having bad experience at all previous educational settings I'd really want someone to sit alongside her for the first bit anyway.

The ideas regarding attendance at TAFE were often strengthened by attending Resourcing Families workshops. This was particularly the case for those families with young adults who had recently left high school. The majority discussed enrolment in regular mainstream classrooms in fields such as childcare, signwriting, gaming technology, or retail:

We want that time to count towards a qualification. And attend a course like that she would need someone to assist her. So that's how we intend on using the funding. So assistance to gain a qualification

One parent had moved her son out of supported employment which her son did not like to a variety of different activities during the week including a TAFE course on computing after attending the workshops. Only one participant mentioned classes specifically designed for people with a disability. This parent had researched the courses available for people with a disability in her local area, but seemed to question whether these courses really catered for her daughter's interests.

Two participants had ideas about obtaining individual tuition for their family member. One family member intended to apply for funding through the RUN project to enable

her daughter to have art lessons, and the other participant was considering approaching the local university to see if a student there could help her son with computing tasks.

Key Learnings: It is clear from participant accounts that families want the same opportunities for education for their loved ones with a disability as others without a disability. Discriminatory practices in the schooling system were significant stressors for several participants. The focus of workshops was not primarily on these matters, but several parents reported that discussions and stories of life beyond school gave them much food for thought for the future. For those families considering post-school education, the options appeared limited to TAFE and individual tuition. This speaks to a large degree of the failure of universities to include all people with disabilities in higher education. It may also be indicative of the available educational facilities in participants' locations throughout New South Wales.

The type of education wanted by families was often centred on the interests of the person with a disability, included accommodations for the person's learning style, and produced outcomes which would assist the person to find work. Once again, this is an area of interest expressed by many participants in the sample, which may warrant its own forum for families to develop specific strategies. Resourcing Families' connection with Family Advocacy would be beneficial here, as another source of information and advice in navigating education systems.

Developing Living Skills

Several participants indicated that they wanted their family member to further develop their day-to-day living skills, either prior to attending the workshops or as a result of workshop attendance. These skills included housework, budgeting and managing money, learning to drive a car, improving communication and listening skills, shopping skills, and using public transport. Developing independent living skills was also considered important for one older mother who was actively taking steps in succession planning for her son so that his needs would be met when she was no longer around.

Time and patience can be important considerations in helping a person with a disability to develop independent living skills, as one mother attested:

Well I suppose things have gotten in the way in the past. It just all gets too hard. I've got to go to work and so then I just think I'll just do it. That's probably the biggest hurdle when things because things with her just take so long. Between the barrier of I don't want to do or I can't do it and you've always helped me before so why won't you help me now? Getting out of that will be quite difficult.

For a few participants it was felt that their loved one did not want be taught by their parents and were seeking other sources in which the skills could be learnt. One of these parents reported:

We need to train Aaron more in doing housework, cooking, washing. I would like someone to teach me how to teach Aaron. He does not want to learn from me. I can send him to TAFE to learn cooking and living skills, but it is very expensive. It was free previously, but now it costs \$680 to go ½ day per week for six weeks. We didn't continue.

One parent was particularly inspired by the story of a mother who had a daughter with Down Syndrome:

I just liked the way they really wanted someone who was just an ordinary person who could teach their child life skills because that's often what it's about...After that, I actually really thought about, because I live in a university town, like maybe getting a university student like in teacher education or something who would spend a couple of hours a week with Keith...

This parent could see the multiple benefits in developing skills in this way – as it also provided an opportunity to build on the social networks for her son. One father acted on this idea and employed a retired teacher to provide individual tuition to his son in his home once a week as a result of attending the Resourcing Families workshop. The teacher was a friend of the family and was teaching mathematics, English, communication and living skills to the son.

Even with these kinds of arrangements, it was apparent that the parents were still actively involved in teaching their children living skills. Sometimes getting others in the person's immediate network to have the same priorities can require a degree of vigilance and diplomacy on the part of the parent:

I want Gabby to do new things, but I don't want to scare workers off. I want her to learn to catch the bus. I rang the bus company to see if I could get a concession for Gabby and carer. The bus company said they can get on for nothing whenever they like. The younger worker was looking up the bus timetable. I said get Gabby to do that. I'm not happy when workers do things for her. But I don't want to lose them, so I can't use my nasty voice. The older worker tried to teach Gabby to read the timetable. Gabby said no. I will get her to try again. Baby steps.

One parent who found out about an opportunity to apply for individualised funding at a Resourcing Families workshop had followed up about getting support through the project for her son to obtain driving lessons:

We weren't successful in that and they contacted me more or less saying that apply again for round four but think of something different...Apparently they'd had lots of other people applying for the same thing or doing the same thing and they wanted different things. And I have to say I was a little bit peeved because I thought, you know, is this funding for the individual or is it for their statistics to say we've got a diverse range of things.

This parent was not prepared to let the idea go, as she felt the suggestion of funding another activity was not in her son's best interests. She stated she would reapply for the same support:

I'm still determined for him to get his Ls and, you know, what that probably means is that we'll mostly be teaching him to drive. I would pay for some lessons for him myself because I do think there's value in that but, you know, if I'm paying out of my own pocket, he's not going to get a lot. You know because with the... project he probably could've got one to two lessons every week for, you know, a few months. Whereas if I am still unsuccessful in getting that funding then he'll probably just get half a dozen lessons, you know, before he's ready to go for his licence.

Key Learnings: The Resourcing Families workshops helped many families to think about developing living skills in a different way from what is traditionally offered in formal services. Enhancing competencies in daily living can also involve opportunities to connect with others and extend personal networks, such as the example of the father employing a family friend to teach his son. Acting on these ideas may also mean that families can encounter setbacks. These setbacks can include resistance to change on the part of the person with a disability, inflexibility in funded supports, and direct care workers not taking the opportunity for incidental learning of skills. It may be useful in the workshops run by Resourcing Families to actively explore with participants what some of these setbacks might be and help develop effective strategies to overcome these.

Moving into a Home of One's Own

Closely related to independent living skills is the goal of living in one's own home. Some families had already successfully achieved this goal. One parent of a 35 year old son had begun planning when her son was in his 20s and a Department of Housing unit had become available when her son was 25. Another participant had secured community housing for her brother interstate to ensure there were protective measures around him to prevent him being exploited by landlords in the private market. Three participants had seen this as an important future goal prior to attending a Resourcing Families event. One mother spoke about having a unit in the backyard of her home for her son, but was unsure how she would achieve this as her family were only renting. Only one of these participants spoke of the steps she had taken towards this goal, which involved applying for the Disability Support Pension for her son and putting this income aside for future housing needs.

Two participants relayed they had ideas about future living arrangements for their children after attending Resourcing Families workshops. Both participants had school-aged children and therefore the planning regarding such a transition was not likely to happen for a significant time. One of these mothers referred to a group home arrangement:

I mean ideally I would love for it to include some kind of group living if it was supported enough, but in country New South Wales... we don't have supported group housing to

that extent. Like there is some disability housing, but people don't leave there, you know...If there could be 24 seven care there in some kind of group housing situation I would love for Justin to have that independence and live with mates, and yes somebody might need to come in and shower him and cook for him, but he's more than able to then feed himself and sit in front of the telly and watch a suitable programme. So he has the ability to do some things. So I would love to see something like that. Justin's very social.

The other parent had differing thoughts on what independent living would look like, which was based on a story of a parent who presented at a workshop:

I don't want him living in a group home. I suppose, I think now, I want him to be able to live in a flat like a two bedroom flat and to be able to have a flatmate and when we spoke to the... the parent,... she was talking about her daughter living in a two bedroom place and then advertising for a flatmate and getting a flatmate, I just realised that that had been what I wanted but I sort of didn't know if we would be able to do that but I realise now that there are lots of people doing it so I feel we would be able to do it more now.

Key Learnings: There are many considerations for families when they are looking for their loved one to move out of the family home. The interview participants who discussed this issue were considering this option for a much later date in their family member's life. Stories from other parents helped one participant to see what was possible in terms of a person having a home of their own, but another participant appeared attached to more traditional models of supported accommodation. The broad focus of the Resourcing Families workshops meant that the choices about moving out of home could not be covered in detail. This topic is presented frequently in workshops run by Family Advocacy and participants could be made aware of these opportunities.

Exploring Paid Supports

Resourcing Families uses particular terminology around support in their education material. This terminology is important to clarify in this report as it can differ from terminology used by government bodies in NSW and elsewhere in Australia. The following definitions apply to the following section of findings:

- **Unpaid support**
 - Freely given by those closest to the person
 - Not time bound
 - Tasks and duties are ongoing
 - May involve personal care
 - Part of the role and responsibility of the primary caregiver
- **Paid support**
 - Provided for a fee
 - Time bound
 - Tasks and duties are assigned

- May involve personal care
- Part of the role and responsibility of an employee
- **Natural support**
 - Freely given by typical people in the community
 - Time given is more flexible and spontaneous
 - Tasks and duties are volunteered or asked for without obligation
 - Is not likely to involve personal care
 - Aim is to help someone participate in community
- **Individualised or self-directed funding**
 - Funding that can be used to meet the unique needs of an individual in a way that is determined by the individual and his or her supporters
 - Generally a service provider would be involved as the holder of the funds
 - Also includes direct payments, where the individual and his or her supporters are the holder of the funds

Existing Funded Supports

Of the sample of family members interviewed, 13 were receiving some form of funded disability support, either through an individualised package or services from a block-funded program. An additional 5 families reported they were self-managing individualised support packages funded through ADHC. Two participants said their family member received supports only through a disability employment provider and six families whose family member was of school age stated they did not receive any funded disability support other than the support provided through the education system.

Some families relayed the problems they had with existing services for their loved one. Issues included waiting exorbitant times for important equipment such as wheelchairs; excessive paperwork to complete to apply for services; getting to crisis points such as breakdown in the parent's mental health before support could be provided; lack of information and contact from government departments; and fragmentation of formal supports, so that the family is required to attend numerous agencies which only deal with one small aspect of their support needs. Exhaustion was a common experience for families in dealing with these issues:

It's hard work then going off to have to chase all that. Like it's hard enough what we do, you know. Like I'm sure a lot of carers probably aren't as proactive as me. So I think what I'm doing is good, but there's even further more stuff but the fact that you live on three hours, five hours sleep a night and then you're running the family. Like this morning I've trialled equipment. I've been on the phone to doctors. I've had a lot of stuff going on. Like where do I fit in, let alone know who to call and then you've got to follow up with that and then you've got to follow up with that, and then so often you hit dead ends and it saps your energy. It's exhausting.

One mother felt that she had been treated with respect by Resourcing Families staff and that this was in sharp contrast to what supports she had received from ADHC and other services:

The most help I get is from Resourcing Families since I moved here. But from other you don't see this sort of help. They never say is there anything we can do for you?

Attendance at the workshop also highlighted to this mother that other families were receiving formal supports when she wasn't. She questioned the equity in the service system because of this.

Applying for Paid Supports

Eight family members who currently did not receive any disability support funding outside support at school or through employment services discussed their intentions to apply for funding after attending Resourcing Families workshops. The workshops often represented an opportunity for participants to find out about new sources of formal support for their loved one, in particular information about Ability Links and the Run Project. For five of these families, interest had been sparked about self-directed supports, but the degree to which they were ready to apply for such supports was very much dependent on the life stage of the person with a disability (many in this group were still attending school) and the degree to which participants felt their family member would be eligible for such support. Hearing stories from other parents who either attended the workshop or were presenters were often positive influences in this regard:

But when Suzanne was talking yesterday I went, "oh, that stuff is interesting. I need to look at that again"

For one parent of a high school aged child with a brain tumour, the workshops provided new information about ADHC:

The funding usually comes from me and my ex-partner... But what it did do is made me see.... I mean, I learned about ADHC who I had heard about, but really didn't know who they were. And I can actually see that I could go onto the Resourcing Families website and just see whether there was funding potentially available for George and how to go about accessing that. And I might be able to because just recently when he actually had his last MRI scan, the neurosurgeon linked us up with a fellow who deals with epilepsy who then linked us up with another team of people who support families of kids with brain injuries and through that we may be able to access some funding. I'm hopeful that we can. I keep all this information in folders at home and hopefully I'll be able to use it to access services and things.

This mother was conscious that her son did not currently fit into a disability service category for funding. She was hopeful this would change with the introduction of the NDIS. She reported that one of the workshop examples given regarding self-directing funding was with a family who had significant funding, and therefore a very different

situation from her own. She explained she was always looking for more work to pay for her son's supports, including professional reports and occupational therapy services.

For another participant, whose brother with a disability lived interstate and was in his sixties, the chances of obtaining funding seemed remote. She stated that it was more important to apply the principles of self-direction to her brother's current life and ensure that supports were tailored to his individual needs and wants:

It keeps me real, it keeps me on my toes, keeps me thinking of ways to be out of the box. Because the service provider I was talking to, he was thinking of my brother going down the lines with them cleaning, and I just said, "No, he's cleaning to the point where he's injured himself, wouldn't it be better to think about a small business where he could be entrepreneurial?"

Self-Directing Paid Supports

Seven families who had existing disability support funding also discussed the possibilities of self-direction, with four family members actively taking steps toward self-management during the time of the workshops. Three family members who took action had not attended the *Ideas for Self-Directing Supports* workshop, but had gleaned enough information at the workshops they did attend to take action. One of these parents had applied for an individualised funding package with ADHC and had come up against barriers for her son's existing service. The service had apparently stalled on providing a cost to ADHC for the services they provided her son because they did not know how to break up the costings from a block funded service model. The parent had found the number of phone calls she needed to make all too difficult but found encouragement from attending the Resourcing Families workshop:

Talking to [RFCBP staff member] you feel, no, it's not too hard, I can get on and face this battle. I think it's a really common thing for families to just be worn down with the barriers that are always put in front of them. So as well as giving you the information here they buoy you up to get you back in the action again.

By the time a second interview was arranged five months later, the parent had received approval for funding, a small amount which had originally been used for respite support. The parent saw this as an opportunity to "start practicing for the NDIS" and was to attend a further information session with ADHC around self-direction and planning.

The other parent participation who had taken decisive action about self-direction, said she had not known she could find out how much funding her daughter received until she attended a Resourcing Families workshop. At her first interview she expressed a desire for more information from Resourcing Families:

I'd love for them to say how you go to these government departments and what you say because I don't know the correct wording for it all. And that's where having Susan there yesterday I couldn't stop looking at her and thinking oh God quick bring her on. And the way she just put her sentences together and said the right words, because I

don't know what things are called, community participation programs I don't know what that is.

The input from the parent presenter at the workshops had been an inspiration to this participant. Five months after the research team's first contact with this mother, she was applying for the Direct Payment Self-Managed System, and planned to employ a university student to work with her daughter, gather support for her daughter to earn a qualification at TAFE and further her recreational and social interests. This was seen as a better alternative to the existing Transition to Work program her daughter attended (this family is also mentioned under the heading of Work in this report):

Whereas when you're locked into going to a group like Transition to Work you've just got to do what everyone else is doing, and it's usually something that's got nothing to do with getting a job.

Although this mother was very positive about shifting to self-direction, she also acknowledged the limited funding she would manage – equating to eight hours a week:

So that's why you don't see a lot of people doing these self-managed programs because it's easier to group them all together and use the money that way. Because, like I said, it's going to be a lot of work on our part organising everything and tweaking it and getting it right. Unless you've got the time and the brainpower to do it.

Another parent who had attended the *From Planning to Action* workshop amalgamated the community participation, supported living and homecare funding for her son as a result of her learning. This was largely to avoid what she believed were exorbitant administration fees. A local building society was approached to act as a financial intermediary to pay accounts and to provide an acquittal to ADHC each year. Her adult son who has a physical disability was willing to manage a majority of the funding for his support. This parent felt she was more equipped to handle the upcoming changes with the NDIS than other family members she was in contact with in her area. Her biggest concern at the time of her last interview as an ageing parent was who would manage the funding when she was no longer able to. She was applying for funding for a case manager for her son and hoped she would be involved in recruiting the person.

Three family members who had existing disability service funding were less certain about the applicability of self-directed supports to their situation. These family members had school-aged children with a disability and perhaps the need to become involved was less pressing. One of these parents whose child was entering primary school had attended other forums outside of Resourcing Families on self-direction where there had been some criticism of the NDIS working from a deficit model. She did not attend the *Ideas for Self-Directing Support* workshop but reported difficulties in working out what “the big picture” would be for her son:

I don't know what I'm going to need in two years' time... And so some of that stuff I find really difficult. And I think I'm a parent who can read and think about stuff and

engage with stuff, what happens to the parents who don't, how do they manage all this stuff, they just let somebody else do it.

Another of these parents had been encouraged by other parents to attend the *Ideas for Self-Directing Support* workshop. She described the workshop as being:

...more about the ones that can do stuff for themselves. We want to know more about the ones that can't do anything; that need help. What do we do for them?

When asked about what she learnt about self-directed funding, she responded:

It seems like you have to write down every little bit. My problem was, if we took it out to the movies or something, I think you had to write down specifically the benefits of taking her to the movies and things like that. Which I found was really hard for me. That's another - because I'm someone that I can't spell, so I can't write things down. So I found that hard. That's why I couldn't self-manage, because I can't do all the paperwork. My husband works, so he couldn't do it. So that's why I thought I'd have to go to a service to help me with all that.

This parent explained that she was still trying to work out what to do when the NDIS arrived. She had been informed by a support worker that she would have to fight for funding and be very clear on what she wanted for her daughter.

The other parent who appeared undecided about self-direction had attended the associated workshop and developed ideas about recruiting and employing support staff for her ten year old son and bringing in professional therapists. Self-direction was seen as an opportunity to purchase specialist mobility equipment without having to wait lengthy periods. This parent reported that she didn't know self-managed funding existed prior to attending the workshop and she was surprised that one could do so prior to the NDIS officially being implemented. At the time of the interview she was uncertain whether she needed to apply to self-manage.

Five participants were already involved in self-managing their supports at the time of attending Resourcing Families workshops. All of these families had previous association with Family Advocacy or Resourcing Families. The positives of self-direction were seen by these families as having control over the supports for their family member and the opportunity to be flexible with those supports.

There were also challenges about taking this approach. Two parents found it challenging recruiting suitable people to work with their family member. For one mother it was difficult finding someone age appropriate for her daughter in a town with a small population and she had been dissatisfied with the choices of her support staff to take her daughter to the hall where other people with a disability congregated at TAFE. The other mother explained that when a support person was unwell or could not come in to work, it meant that the care needs at that point of time became "her problem". For another mother, not all services could be amalgamated into a self-managed approach and she had to make do with an in-home respite service which she found unreliable and inflexible. Another parent reported that the disability service system was becoming more restrictive in how funds could be spent, including

restrictions on the purchase of concert tickets, food on outings and fuel costs. She reported:

Since that workshop things have gone downhill. ADHC want the CPP to be in line with NDIS. People in programs have signed their money over. It's money in, money out for wages. The self-managed people who have done wonderful, flexible things, they're having fun squashing us. It's tragic. I have another couple of providers I'm going to try.

One of the five participants was particularly concerned about the administration costs in her son's funding package and attended the *Ideas for Self-Directing Supports* workshop to work out the process of managing direct payments. She was able to recall a significant amount of information at the time of being interviewed about the process but still expressed concerns about the accountability requirements:

The main barrier with... taking government funding ... you just need to be able to make sure that you have a transparent process and you acquit well... Having it sit with an agency, you've got... third party eyes on something, you know, because I would be extremely anxious to make sure I did absolutely the right thing.

This family member decided that she would negotiate the administration fees with her service provider now that the system was "up and running".

Five participants felt they wanted more specific information on self-direction from Resourcing Families. Four of these participants had attended the *Ideas for Self-Directing Support* workshop and the other had attended the first three workshops in the series. The information needed was regarding accountability and insurance requirements; and how to manage the changing needs of the person with a disability within the context of self-directed funding. One participant described the *Ideas for Self-Directing Support* workshop as below:

It was really, just giving me ideas I suppose, but not so much what to do with the money, what costs are involved, all the sort of hidden costs within things that you don't know about... So if I was at home sitting at the computer, having a spread sheet in front of me, I guess how to budget costs, how to use it the best to get the most out of the money. That's what I had in my head I was going to. It was nothing like that, but it was still good.

The participant who had not attended the specific workshop on self-direction said she would like written information about the topic as well as individualised tuition and advice.

Preparing for the NDIS

Many families discussed their concerns about the implementation of the NDIS. While Resourcing Families workshops were not designed to focus specifically on this issue, the thoughts of families regarding the impending changes clearly influenced their intentions and actions, and therefore these ideas are shared in this report.

A key concern for families was the lack of information and uncertainty about what level and kind of support they could expect for their loved one with a disability. This included worries as to what level of control consumers would have in their supports. One mother recognised that a lot was unknown even by government bodies at this point in time. She commented on the cultural shift required for families and services as significant and wondered if stakeholders were ready for such changes. She was concerned that there would be too much expectation to rely on the community and freely given relationships for people:

They're saying about relying on support in the community, there's a limit to how much support the community can give. You can't ask people to do things for free. Craig has a friend he used to ask to come and help with his computer. If he's spending hours there you can't asking him to do that for free all the time when he does that as a paid role. Craig needs to have dignity in his life and if you're asking for things to be done free all the time that's not dignified.

Another mother was hopeful that with the advent of the NDIS, there would be more structures in place to gather information about the various services in her local area. For other participants there were concerns that the NDIS would not account for their particular needs. One mother was worried that her family would be “punished” by the NDIS because they had worked hard to make their son independent, and therefore may not get the level of support needed. Another mother wondered if assessors would have the expertise and knowledge regarding her son who had a brain tumour, and the consequences of this.

The content of the Resourcing Families workshops was helpful to one family member in relation to the NDIS:

I haven't tried to fill my head with it [NDIS] too much now because I think, right, well I'll fix little things I can do now about expanding roles and stuff and worry about the rest next year when it might get a bit closer.

For another participant, the workshops were a source of inspiration, but felt there was a need for specific information about how to write a plan in language that would be meaningful to bureaucracies:

“Goals” is a massive disease in bureaucracies. When we started with our funding it was just five sentences. It's not just thinking up goals, I need a template. It's like I'm learning Japanese, like I'm in kindergarten. I want something I can cut and paste from. A list of goals so I can decide “this is what I want to choose”. That's how empty and vacant I feel about goals.

Key Learnings: Participants spoke a great deal about existing services, funding mechanisms and future service changes under the NDIS. Many participants had previous experiences of poor service delivery and were aware of the need to remain vigilant to the standards of what was on offer. For some participants, the future seemed uncertain and they were eager to find out new information.

The new service arrangements becoming available through the NDIS roll out present lots of opportunities for people with a disability and families to be actively involved in the nature and types of support available. At the same time, service users need to develop sophisticated skills and knowledge if they are truly to embrace new self-directing funding models, and some participants at the time of interview were not prepared to put in the extra work needed to self-direct their supports. Those that were already self-managing their supports wanted further information on how to refine their skills and effectively communicate their needs to funding bodies. Those in this category felt that RFCBP was the ideal resource to help them further their skills. Certainly any forums which assist in the development of skills and knowledge in the new service environment will need to be ongoing as more information comes to light.

Many who took the steps towards self-direction found that the existing services were not always ready for such changes. The interviews highlighted examples where family members were more informed than service providers as to how such models would work. Support from the Resourcing Families staff enabled some families to push through the resistance from service providers to individualise their funding.

Given the rapidly changing service environment, the content of the RFCBP workshops is all the more pertinent for families. The emphasis on vision, roles, and relationships will help families to prioritise what is important, in a context where there are many stakeholders with many different interests and agendas. Families can play an important role in ensuring the integrity of new service systems, because they often have a vested interest in ensuring a good life for their loved one with a disability. Resourcing Families has a key part in assisting family members to have a voice in the changing context and thereby safeguarding a positive vision for people with a disability overall.

Overall Comments About RFCBP

As a conclusion to the findings from interviews, there were many general comments made about RFCBP workshops which are worth mentioning. These comments convey an overall experience for families which was supportive and inspiring.

Sixteen interview participants said they found the information provided in workshops valuable. The content was described as factual, practical and interesting. Two participants described the experience as opening up new ways of thinking and giving families the courage to challenge the entrenched attitudes of others and their own limiting beliefs. One of these participants described this as:

It's just that power of families pushing for things but also combined with the facts to know how systems work and how to get what you want or what you're trying for.

Several participants expressed a desire for more information or workshops in particular areas. A lot of this information is provided in various formats in other workshops by Resourcing Families and Family Advocacy, but also speak to a need for

various service systems to provide more information to service users. The areas in which participants wanted more information included the following:

- Administrative and legal issues in regards to self-directed supports
- Guardianship of people with a disability
- Supporting a person with a disability in a rural area
- Supporting school-aged children with a disability
- Available services in the area a person lived
- Support for siblings in regards to planning and day-to-day challenges
- Planning a good life for people with severe disabilities, where communication and mobility are major concerns
- Stories of the “good life” from parents with children on the autism spectrum
- Supporting a person with a disability to achieve intimate relationships

Although some families desired more specific information relevant to their current situation, there was an acknowledgement from six participants that they had the ability to pick and choose in workshops what was relevant from the broad focus on different family experiences. One mother of a child in primary school elaborated on this:

I always get something out of it, even if it's something that I file away for later and not necessarily use straight away. Just to kind of plant those seeds of this is one way you can address that challenge, or this is something that could be achievable because others have done it before, and not to kind of give up on that vision or dream of the full inclusive independent living... whatever it might be.

Participants particularly valued hearing about new ideas as to what they could use funding for; information about resources available in their community; real life examples of other families doing creative and meaningful things; the opportunity to have worksheets and slides supporting the workshop content; and email contact after the workshops. Four participants reported their intentions to pass on information from the workshops to other parents.

Eleven participants said they felt encouraged and inspired by attending the workshops. This was important to these families, as they often used descriptors such as “plodding away”, “getting bogged down in the drudgery”, “doing something that is impossible” and “a battle to do everything”. The idea of thinking “big” was often mentioned as a positive outcome from attendance. One mother reported that she wanted to go to all the workshops because she always came home “with so much more knowledge and power”. Another said she needed these kinds of workshops every few months to help “get back on the wagon”. The workshops were considered an opportunity to connect

with other families who had similar aspirations and for three participants attendance confirmed to them that they were “doing okay” supporting their loved ones. These participants found the workshops motivating and one mother felt comforted that there were other people out there to support her and her family member in pursuing their dreams. This same parent also commented that the real challenge in the ideas discussed was putting them into place.

Very positive comments were made about the parent presenters in the workshops, for example:

She was fantastic because not only did she have the information, she had that connection. I guess that emotional connection to actually be living it. So therefore she knew how to work the resources and the information, and how to make it make sense to people in situations that are similar or even with a little bit of something to take away for somebody else.

- Mother of a child in primary school

Participants valued the opportunity to ask parent presenters further questions in the breaks, and also some families contacted the presenters after workshops were over. There were two participants who reported initially that they did not develop any new ideas after attending the Resourcing Families workshop, although both felt they had enjoyed attending the forums. Both participants had already attended a significant number of events run by Family Advocacy and Resourcing Families and were already actively engaged in building an active and full life for their family member with a disability. After further discussion, one of these participants had reported she had received a lot of useful information from the Resourcing Families website around creating valued roles and recruiting workers. She also felt that as a result of the workshop she was thinking more broadly about who she might get to work with her son, now recognising the advantage of having someone who does not have any previous experience or preconceived ideas of working in the disability sector. She was now considering employing one of the personal trainers at her son’s gym.

The timing and location of the workshops were commented on by three participants. Two of these participants came from Albury and felt that it was a long way to travel to get to the workshop at Wagga Wagga. The other participant explained that generally she is not able to attend some workshops because of “too much on her plate”, and not because the workshops were not relevant.

Four participants commented that Resourcing Families needed to find other means of advertising their workshops to families. These mothers were disappointed that other family members in their respective areas did not attend the workshops. One participant had attended a workshop which had a large number of service providers in attendance (a rare occurrence throughout the workshop series), and she felt that she needed a space for just family members to get together and discuss ideas.

VII. Conclusions and Recommendations

This research has found that there is consistent positive feedback from family members who have attended the RFCBP. This feedback has come from the survey material, the interviews with families and the observation notes of the research team.

The content delivered in workshops and online is founded upon on SRV theory, yet it is presented in a clear and accessible way for both family members and paid staff. The workshops are generally very interactive, and encourage lots of comments and questions. The structure of workshops is designed to cater for different learning styles, and is interspersed with stories from and about family members, video presentations, group tasks and time for question and answers. Families have reported feeling re-energised and this is apparent in their level of participation in the exercises and tasks set within the workshop environment. In these events conversation about the material often continues throughout the breaks, and the RFCBP team is committed to staying within the particular area in which the workshop is conducted for a few days in order to follow up and support particular families.

As previously outlined, the research was designed to measure the following factors:

1. **Intentions:** The extent to which there is a change in the **intentions** of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.
2. **Actions:** The extent to which there is a change in the **actions** of families of people with a disability to imagine a better life, to exercise more choice and control over supports and over their lives, and to strengthen their networks and community engagement.
3. **Perceived change:** The extent to which families of people with a disability **perceive a change** in the life of their family member with a disability to have a better life, to exercise more choice and control over his or her supports, and to have a stronger networks and community engagement.
4. **Barriers:** To identify any **barriers** that may be making it difficult or undesirable for people with a disability and their families to embrace the above changes and to discover ideas for RFCBP to assist in overcoming these barriers.

Intentions

With regards to family intentions, the participants who filled out the surveys or engaged in the interviews were largely receptive and enthusiastic about the ideas and

strategies behind the RFCBP. As previously mentioned, there were incidences where families had travelled significant distances to attend RFCBP workshops, which would indicate a high level of motivation. The survey findings and overall feedback from interviews also reported positive changes in the level of confidence in family members to try new things for the person with a disability after workshop attendance.

The concept of developing a vision for the person with a disability was embraced by many workshop participants – in terms of revisiting existing ideas or formulating dreams for the first time. By encouraging participants to aim high, RFCBP sent a strong message to family members that they could make an important contribution to their loved one, to other families, to service providers and to the broader community.

The RFCBP workshops also provided important material for families to engage in planning activities which centred on the interests and passions of the person with a disability. A key assumption made by RFCBP was that families held a significant amount of knowledge about their loved one with a disability which could be tapped into to build a better life. This belief in the expertise of families strengthened existing plans and expectations and buoyed many participants to make positive changes in their family member's life. The RFCBP employed multiple strategies to tap into the wisdom of families, including worksheets, the use of parent narrative, and individual consultation. The inclusivity and creativity of their approach catered to many different learning styles and was likely to be a further motivating factor for many families.

There were some core messages to families from the RFCBP workshops:

- Families can start imagining and building a meaningful life for their loved ones **now**, regardless of the person's age or circumstances
- Small, purposeful steps toward change are significant and worth doing
- Families have existing community resources they can access if they are encouraged to think differently
- What is needed for a good life is not necessarily what is currently on offer in paid services
- Any supports for a good life can be examined in terms of the valued role it gives to the person with a disability and in terms of building supportive ongoing relationships with others.

Actions Taken and Perceived Change

The interviews with family members uncovered many examples of actions taken as a result of attending RFCBP workshops. The findings in this regard are particularly encouraging given the short timespan over which the interviews were conducted. There were several examples of families starting a circle of support or arranging social gatherings with other people as a result of the workshops. Many families extended the range of community activities their loved one was involved in, identifying opportunities for connection and social interaction in everyday experiences, and acknowledging and affirming the actions of members in the community who welcomed the person with a disability. These acts of community connection were

purposive and thoughtful and included considerations of what was typical for someone the same age as the person with a disability. There were also examples of participants planning ahead for community events and addressing any potential challenges or barriers to the person being fully included.

Similarly, some participants spoke of raising their expectations of their loved one with a disability. This was often discussed in terms of valued roles and how consideration of these concepts led to more opportunities for the person to make a contribution to the household, to other family members and to the community.

There were also many examples of family members beginning to think critically about existing service arrangements around their loved one with a disability. Many steps were taken to address unsatisfactory service arrangements and to become further informed as to what was available. There were reports of advocacy efforts in relation to improving the response of employment agencies; in tracking and monitoring workers to ensure they are actively encouraging the person to develop their independence; and in contacting ADHC to find out the exact level of funding the person with a disability received. Some families applied for self-directed funding packages as a result of attending the RFCBP workshops. There were also changes made in terms of existing service arrangements, with some families withdrawing their family member from services they deemed unsatisfactory. Some families also developed new ideas as to who would be appropriate to provide paid support to their loved one, with examples of families employing people outside the disability service system to provide support and tuition to the family member.

It was clear that attendance at RFCBP workshops resulted in many positive changes in the lives of people with a disability. There were clear indications of either a change in mindset and actions of family members, or further encouragement and reinforcement of existing efforts and ideas to build a meaningful life for the person with a disability. What is intimated in the accounts of families is that the workshops had a flow on effect to disability service providers and to people in the broader community. Certainly the steps taken above would involve raised awareness of including people with a disability in everyday life and for service providers to re-examine existing practices in light of family members' requests.

Barriers

The findings from this study indicate that there are several challenges faced by families in supporting a good life for a person with a disability. Similar to the findings in this report's literature review, there is some indication that the ideas and concepts presented at the workshops were easier to take on board for some families than others. There is a myriad of reasons for this, and this section summarises the challenges mentioned by families in the surveys and interviews.

For some families whose family member had particularly complex needs and/or where there were existing tensions in family and community relationships, ideas such as a

“circle of support” were confronting or overwhelming. Resolving personal issues, such as family conflict and lack of understanding in the community require long-term efforts. The group setting in RFCBP workshops was not the ideal forum for families to raise such sensitive issues, and this would not have been the overall intention of RFCBP to uncover such concerns. However, it is inevitable that such work can trigger strong emotions at times, as it can tap into previous traumatic experiences of discrimination and rejection.

Other issues of a personal nature included feelings of apprehension in trying something new; fears about asking for support from friends, family and work colleagues; and concerns that the person with a disability may come to some harm in the community. These attitudes were understandable since many families spoke about previous experiences of rejection and exploitation from others in the community – something that was a particularly sensitive issue for participants who cared for a person with a severe disability.

Some families also reported that understanding what the person with a disability really wants, and what they are capable of doing was difficult at times. There were concerns from participants about imposing their own agenda on the person with a disability; and conversely, how to motivate their loved one to try new things. These dilemmas require ongoing assessment of the particular situation by families, but also show the level of care and concern family members had to act in the best interest of their loved one.

This research also confirms what other studies have found regarding the lack of appropriate skillset and fiscal resources in disability services (Mansell & Beadle-Brown, 2004). While the strategies and ideas recommended by RFCBP did not rely on the involvement of service providers, families did report of difficulties in implementing their vision due to resistance and lack of understanding from funding bodies and paid service providers. Difficulties cited included inflexible funding arrangements; ineligibility for and expense of services; excessive bureaucratic processes and paperwork in organisations; failure of services to cater for the interests and relationship needs of the person with a disability; lack of recognition of the knowledge and expertise of families; exorbitant waiting times for equipment; fragmentation of services so that the family is required to attend numerous agencies which each deal with only one small aspect of support needs; and families having to follow up on promises made by services.

Finally and perhaps an obvious outcome of all of the above challenges, were reports from family members about tiredness getting in the way of planning a good life for their loved one. Certainly, attending workshops were seen as re-energising by many family members and the continued work of Resourcing Families could be seen as a way of providing ongoing support for family efforts.

Limitations of the Research

It is important to note the limitations of this research. A key consideration is sampling bias which can occur in many research studies. The positive results could partly be contributed to the high degree of motivation among the family members interviewed to build a meaningful life for their loved one with a disability. Given the voluntary nature of research participation, the research may have attracted more participants who felt positive about their efforts to support their family member with a disability and were therefore already receptive to RFCBP ideas and processes. In addition, sixty-two per cent of the interview sample had previous association with either Family Advocacy or Resourcing Families, and therefore many of the concepts discussed in workshops were likely to be familiar to them. These participants with previous association may have greater confidence and knowledge to engage in planning for a good life than other families. However, this could also indicate the ability of Family Advocacy and Resourcing Families to support families over an extended period of time. Many of these family members saw themselves as taking important leadership roles with other families and were keen to pass on their insight and wisdom to help others.

Another important consideration in the findings is the length of time needed to implement change in the lives of people with a disability. Whether the research timeframes fully captured these changes in the limited time period allocated is open to speculation. Certainly, there were many examples of positive changes being made in the lives of people with a disability due to the actions of family members who attended RFCBP workshops, but the degree to which the change would continue over a longer period of time is beyond the scope of this particular evaluation.

The study was conducted over several geographical locations throughout New South Wales. Certainly there were some issues discussed by participants that were particular to the regional context, but the overall small sample size did not allow for definitive comparison between different regions.

Despite these limitations, the study provides important insights into a very skilled and seldom documented practice of supporting families to dream “big” around their loved one with a disability. The findings are rich in information about the potential for families to really influence the lives of people with a disability in positive ways. There is also ample discussion about the barriers in formal service systems and the general community which impede family efforts. This is valuable information which comes at a critical time when the NDIS is being rolled out across Australia.

Recommendations

The following list of recommendations has been derived from the research team’s observations and the overall findings:

Recommendation 1: Resourcing Families and/or Family Advocacy liaise with service providers, government departments in the areas they visit outlining the issues many families raise in their workshops in regards to needs for further emotional support and practical support;

Recommendation 2: The information and feedback about existing services which is shared in Resourcing Families workshops is passed onto the relevant agencies wherever possible, without compromising the privacy or well-being of families and their loved ones, in order to ensure existing services are more responsive to people with a disability and their families;

Recommendation 3: Resourcing Families invest further time and resources into recruiting participants to events who have had no previous contact with Family Advocacy or Resourcing Families;

Recommendation 4: Resourcing Families invest further time and resources to recruit more fathers and siblings to workshops to ensure the voice and involvement of all family members in capacity building;

Recommendation 5: Resourcing Families stay longer in particular regional areas to improve attendance rates at workshops; to cover content in more depth and to work around the caring commitments of families;

Recommendation 6: Resourcing Families gather the success stories of attendees from their workshops and use these with the families' permission as teaching examples for future events;

Recommendation 7: Further opportunities in workshops be given to families to anticipate and respond to potential barriers they encounter in building a meaningful life for their loved one with a disability;

Recommendation 8: The capacity building work of Resourcing Families continues to be funded under the NDIS;

Recommendation 9: The capacity building work of Resourcing Families is documented through longitudinal research projects to inform the sector of best practice in working with families and people with a disability

Conclusion

Resourcing Families are to be commended for the many positive aspects of their work. The RFCBP encouraged families to “dream big” and assisted them in refining and developing their visions and plans for their loved one with a disability. This evaluation report has highlighted the skills, resources and expertise required to assist families to build an authentic and meaningful life for people with a disability. In many respects, Resourcing Families has developed an exemplary series of educational and capacity building workshops and materials for families across NSW with a limited amount of

financial resources. It would be valuable to estimate the social and economic benefits of their approach in the context of the changing service delivery system under the NDIS.

The overarching message behind this evaluation research is the need to safeguard initiatives which build on the capacity of families of people with a disability, such as Resourcing Families. The RFCBP workshops built the capacity and courage for many family members to have a vision for their loved one, build connections and prepare for the impending changes under the NDIS. They instilled hope for many families often through the stories of other parents who had overcome significant challenges. The facilitators in the workshops had the hard task of addressing the diversity of life views, personalities and experiences of participants, who included families at different life stages, and paid staff with various levels of understanding and acceptance of the concepts and values introduced. The nature of this work is ongoing and will continue to be needed in the changing service context. It is therefore imperative for government bodies responsible for the provision of services and supports to people with a disability throughout Australia to factor in the important role families play in ensuring a good life for their loved ones. The NDIS, particularly under its Information, Linkages and Capacity (ILC) framework will need to skill and resource families to continue in these roles, as families are often best positioned within our society to see how service and community responses impact on their loved one with a disability.

VIII. Appendix A



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Workshop/Webinar Questionnaire

1. Please indicate which best describes you:

- ☐ A person with a disability
- ☐ A family member of a person with a disability
- ☐ A friend of a person with a disability
- ☐ A professional who works in disability services
- ☐ Other:

2. How did you find out about the Resourcing Families event?

3. What were your expectations of this event and have they been adequately met?

4. What has been your experience, if any of *[workshop/webinar content – e.g. using circles of support, individualized funding]*?

5. What have you learnt from the webinar/workshop?

6. What would you have liked to learn but didn't?

7. What key actions, if any, will you take after today?

8. How easy was it to access the webinar/workshop and listen to/read the material?

9. How can the webinar/workshop be improved for others in the future?

10. Do you have any other comments?

Thank you for your participation in this survey.

IX. Appendix B

Interview Schedule for Family Members

These questions are intended as a guide only to facilitate discussion.

Talk to family member about aims of the evaluation, where researcher is from, etc. Go through information sheet and consent form. Explain that interview is just like a conversation – no need to answer any question that makes them feel uncomfortable.

Guidelines for first interview

Background information about the family

If it is okay with you, can we start talking a bit about you and your family so I can get an idea about what is important to you.

Tell me a little about your immediate family – ages of children, relationship status, where children are living, etc

Tell me a little about your child/family member (K) who has a disability – how would you describe K? What are his or her likes and dislikes? How does K get on with other family members? May ask if family have any photos of the person they would like to share.

Interaction with Resourcing Families

How did you find out about Resourcing Families and what interested you about becoming involved?

What types of information/resources have you accessed from Resourcing Families?

What, if anything, did you learn about from accessing information and events run by Resourcing Families?

Is there anything that you intend to act on?

What would you have liked to learn about but didn't?

Specific questions about different themes (ask only the sections which are relevant to family – either 1,2,3,4,5)

1. From Planning to Action

Have you thought about what your (family's) vision is for your family member's life? (interviewee may have written vision to share).

Had you developed a vision before you attended the Resourcing Families event or was the idea new to you?

Has your understanding about developing a vision changed at all since attending the Resourcing Families event?

What was it like for you developing a vision for your family member? Were there any challenges about thinking in this way?

Are there things you want to change in your family member's life since you have taken the time to imagine better for them?

How do you think your vision will help direct your decision making now and in the future?

What do you see as your role in the planning process for your family member's life?

Have you been able to formulate some goals about making some new things happen for your family member?

How did attending the Resourcing Families event help in making plans with your family member?

Have there been any barriers in moving from your vision to action?

If there have been barriers, is there any additional assistance that could be useful in diminishing or removing those barriers?

2. Involving others and building networks

Can you tell me a little about the current supports you and your family member have in your life?

What ideas do you have to expand your family member's networks? Have any of these ideas come from attending a Resourcing Families event?

Have you considered starting a circle of support? What steps have you taken so far?

Is there any additional assistance or information that would be useful for you to take action?

3. Developing Community Connections

How do you feel about the community connections your family member now has?

What did you learn about building community connections from the Resourcing Families event?

How useful was this information to you and your family member?

Do you have any ideas now on how to establish more community connections for your family member?

What do you think are barriers to your family member making more connections in their community?

What could help you to overcome those barriers?

4. A Practical Pathway to a Better Life

Can you tell me what a typical week looks like for your family member – e.g. what do they do during the day etc? Do you think any of this will change now that you have attended the Resourcing Families event?

Have you heard about roles – or valued social roles before? If yes, what was your understanding of this? Have you taken any steps to support K to have more valued roles in the past? If so, can you tell me a bit about this?

Do you think that your family member could be assisted by having more valued roles in the future?

Have you thought about what the roles could be or in what area of life? What would need to happen for K to have these roles? Would anything get in the way of K achieving these roles?

Is there any additional assistance or information that would be useful to you in supporting K to develop a valued social role or roles?

5. Ideas for self-directing supports

Do you currently self-manage or self-direct any funding?

If yes, what type of funding?

If no, then straight to...

What prompted you to go to the Resourcing Families event? *Possible prompt* - Were you after inspiration, ideas or experiencing difficulties?

What, if anything, did you learn about at the event that you intend to act on?

Is there anything - big or small - that you have already acted on?

Is there any extra information that could be helpful in supporting K to use their funding most effectively?

Finishing up:

Is there anything else you would like to share with me today about your experience of Resourcing Families, etc?

Thank family member for their time, present gift voucher, discuss possibilities for recontacting family member at a later date, make arrangements to give family summary of interview, answer any questions

Guidelines for Follow Up Interview

Provide family with a summary of what was discussed previously.

From this summary the following questions could be asked if relevant:

How have things changed for you and your family since last we spoke?

Things to consider – day to day life; thoughts/feelings about the future; relationships with services; current opportunities/challenges for having a good, ordinary life; changes in roles

Interaction with Resourcing Families

Have you had any further contact with Resourcing Families since we last spoke? What did that involve?

What other types of information/resources have you accessed for your family member since we last spoke?

If there were an opportunity to attend another workshop/event for supporting your family member, what ideally would you want to know about?

Specific questions about different themes (ask only the sections which are relevant to family – either 1,2,3,4,5)

1. From Planning to Action

What may have changed for you and your family member since last we met – particularly in regards to your vision and any actions arising from that vision?

Have you been able to formulate any more goals about making some new things happen for your family member?

Have there been any barriers in moving from your vision to action?

If there have been barriers, is there any additional assistance that could be useful in diminishing or removing those barriers?

2. Involving others and building networks

Since we last spoke, has anything changed about the social networks in your family member's life?

If so, what?

Have you considered starting a circle of support (*if relevant*)? What steps have you taken so far? How do you feel now about encouraging other people to become involved in your family member's life?

If someone has taken action – Has anything happened as a result of working on expanding networks?

Or – What has happened with the circle so far?

What changes, if any, have resulted for K?

Have you experienced any barriers to taking up ideas?

3. Developing Community Connections

Have you been able to develop some ideas or establish more community connections for your family member since the workshop?

If yes, what has that meant for K? What has that meant for you?

What do you think are barriers to your family member making more connections in their community?

What could help you to overcome those barriers? How might Resourcing Families assist?

4. A Practical Pathway to a Better Life

Have you or anyone else taken any steps since we last spoke to supporting K to have more roles? Could you tell me about that?

Have there been any changes for K as a result? (eg image in own eyes, image in the eyes of others, opportunities etc)

5. Ideas for Self-Directed Supports

Has the information you have received from Resourcing Families about self-directed supports helped you use the funding differently? If so, in what way?

If not, why not? (Eg. Found ideas unhelpful, too hard to implement, already familiar with info)

*Depending on response...*Is there anything that has stopped you acting on information received?

Has K's life – such as what K does during the day or who provides support – changed since you engaged with Resourcing Families?

Has your understanding of how funding support can be used changed since engaging with Resourcing Families?

Has your understanding of available supports changed since engaging with Resourcing Families?

Finishing up:

Is there anything else you would like to share with me today about your experience of Resourcing Families, etc?

Thank family member for their time, make arrangements to give family summary of interview, answer any questions

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