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Mid Coast Communities is a non-government organisation with the overarching aim to build stronger communities. The Social Policy Research Centre (SPRC) at The University of New South Wales (UNSW) worked with Mid Coast Communities to build evaluation capacity in the organisation and conduct research on family agency in families with young children with disability, living in the mid north coast of NSW. The two organisations collaborated to design a methodology that was implemented by Mid Coast Communities. Families were interviewed in two waves, prior to involvement in the project, and again afterwards. The research was informed by a literature review.

Fourteen families participated in the research and all had at least one child with disability. In the first wave of interviews, they spoke of the difficulty for their families during the process of diagnosis. Finally arriving at a diagnosis was a great relief; partly because the difficult period of diagnosis was over, but also because having a diagnosis meant that children were eligible for services and support.

All the families described working hard to ensure the best for their children. Finding the right diagnosis, treatment, equipment, services and support involved a lot of work and perseverance. Most families said that they were overly busy, managing the care and treatment needs of their children. Financial pressure was an added difficulty.

Living in a regional location had great advantages for families, but a number said that they did not feel they had access to the range of services their children needed. When services were available, families reported very mixed experiences with them. Families also spoke of the difficulties they encountered when trying to find out what services might be available to them. Often they said that they only discovered a service after a long time or after another service or parent mentioned it to them. A number of parents said that supported parent groups were invaluable sources of information, both from other parents and from local services. Many of the families felt that being in a regional area had definite advantages when it came to maintaining these and other social networks.

Co-design project and research findings

The programs implemented as part of the co-design intervention ranged from community events that included a large number of participants to intensive work with individual families. Many families who participated in the research were involved in the Family Fun Day, which brought families, community services and local recreation services together in a park;
Action Learning, which gathered families into a small workshop to develop ideas together; and ACT NOW, which brought Aboriginal families, government and community organisations together to share ideas. Big Plan involved family, friends and professionals coming together to make plans for a particular person with disability. Some activities, like the Family Fun days and an Autism Awareness event held at a local club, were organised by a small group of parents determined to make a difference. Other activities involved one-on-one engagement with individual parents or families.

Generally, families found their engagement with the Co-design Project to be a motivating or empowering experience. While some of the parents who were interviewed were already highly motivated and strong-willed people and may well have seen their activities through without the Co-design Project, they nonetheless appreciated the support and guidance that the project offered. The parents who were central to the organisation of events or services also spoke positively about the connections they made with other people, both in the organisation of the events and during the events.

Most families spoke very positively about their involvement in the Co-design Project. They made important social connections with other families in their communities, especially at the big community events. They found that these connections offered important emotional and practical support through shared experiences, ideas and service contacts. While enthused at the time of the event, a couple of families spoke of a need for ongoing support to help them maintain that level of engagement or determination. Many others said that while the Co-design Project had been helpful or inspiring, they still needed particular types of support services or therapies for their children.

The Co-design Project was a flexible and responsive project that kept people with disability and their families at the centre, and worked with them to design and seek the support they wanted. The Project helped families access the services by aiding in the development of social networks which, in combination with the empowerment and motivation that the Project provided, grew the families’ sense of agency.
2. Introduction

Mid Coast Communities is a non-government organisation with the overarching aim to build stronger communities. This is a project report based on collaboration between Mid Coast Communities and the Social Policy Research Centre (SPRC) at The University of New South Wales (UNSW). SPRC worked with Mid Coast Communities to build evaluation capacity in the organisation by conducting research on family agency in families with young children with disability, living in the mid north coast of NSW.

The ‘Stronger Together 2 Mid North Coast Research and Family Agency Capacity Project’ (Co-design Project) was a 10-month project operating from March-December 2013 that had received funding from the NSW Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) in June 2012. The Co-design Project falls within ADHC’s larger ‘Children, Family and Therapy Project’ and funding was sourced from the skill development stream of Children, Family and Therapy, Stronger Together 2, which aims to “assist individuals, their families and carers to identify needs and goals, plan their service requirements, access specialist disability services and to assist with access to mainstream services” (NSW Government, 2011, p. 21).

The research project consisted of a short literature review and two phases of research with families.

The aim of the first phase of research was to assess families’ ability to plan, shape or initiate action in an effective and influential manner. It involved interviewing families with children with disability aged 0-12 years, to assess their capacity to make choices and shape their lives (i.e. their sense of agency). The findings from the interviews were used to develop options for frameworks to support families to co-design services.

The second phase of research was the co-design process (or ‘program implementation’). In this stage, Mid Coast Communities worked with families to co-design and co-produce formal (i.e. funded services) and informal supports, in collaboration with those supports and services.

An aim of the project was that involvement of families in the co-design of services and supports would build their skills around self-controlled funding, person-and family-centred planning and, ultimately, readiness for the National Disability Insurance Scheme (NDIS). It was intended that participating families in the research project would benefit by:
• Building skills around co-design

• Making or strengthening connections with supports and services

• Making or strengthening connections with other families participating in the project

• Understanding and building agency and resilience within their family and a range of settings, and

• Becoming ready for self-directed supports and the NDIS.
A literature review was conducted to (a) build knowledge by addressing a current gap in the literature on co-design and family agency; and (b) help families and service providers be more prepared for the implementation of the NDIS, which is built on an individualised funding model of service delivery.

A summary of the key findings is presented in this section, with the complete review in Appendix A.

### 3.1 Family agency

In the context of this project, agency is one of a number of distinct concepts with shared elements that are relevant to families where a child has a disability. These include empowerment, power, self-determination and a self-determined life, self-advocacy, participatory action research methods, emancipatory research, process and outcome, causal agency, self-directed support seeking, freedom in goal setting, decision making and problem solving, efficacy, competency, capability, control, confidence, family capacity, family and individual quality and life, and family and individual resilience. All of these terms capture the various notions of family agency.

Family agency refers to a sense of empowerment and control among families with a child with a disability (i.e. feeling they are an agent of their own affairs). Family capacity refers either to a family’s sense of capability to choose and make decisions about their own care, or the resources they have that facilitate that sense of capability, such as strong community supports (i.e. feeling capable of being an agent of their own affairs). For example, Neely-Barnes, Marcenko, and Weber (2008) found that people with mild intellectual disabilities reported greater choice in services than those with severe disabilities, suggesting that the severity of disability may impact on the (perceived) effectiveness of consumer-directed services.

Increased personal agency on the part of parents is linked in research to parents becoming more connected to social support networks, and is understood to increase the likelihood of parents seeking appropriate support when needed, advocating for their children, being involved in their schooling, and protecting them from harm (Sanders, 1999). This suggests that empowered and self-directed seeking of support and connections yields positive outcomes for parents and children with a disability (and is a way of organising consumer-directed care).

In summary, the literature on family agency, empowerment and self-determination describes the principles and circumstances under which people with
disability are free to make choices about the services and supports they wish to use, and therefore the choices they make over their own life. Empowerment and self-determination are both a process and outcome that aim to give people with disability power in their relationships with others (especially service providers) but also in meaningful everyday relationships, so that they can be causal agents in their self-determined lives.

Family agency (or sense of empowerment) over the services and supports that families with a disability choose to use or access occurs when they also show signs of quality of life and resilience. That is, family quality of life and family resilience are considered to be two of the most important and desired outcomes of the process of family agency.

3.2 Co-design

Minimal literature was found directly concerned with co-design activities and processes involved in the support and strengthening of family agency. During the search for relevant literature, it became apparent that the body of research on co-design (and co-production) is both small and recent, mostly written since 2005. The literature on co-production is however notably greater than the literature on co-design, suggesting a greater trend in this area. Nevertheless, the role of co-design in improving family agency can be explored from the nascent literature.

The literature review also indicated that there are a number of characteristics of families and service providers that affect family agency, both positively and negatively. This was also covered to ensure relevant information on families, service providers, and the relationship between them, informs the development of co-designed support.

3.2.1 Terminology

This project was informed by the co-design methodology used and taught by the Australian Centre for Social Innovation.

The terms ‘co-design’, ‘co-production’ and ‘co-creation’ are often used synonymously in the literature. However, Freire and Sangiorgi (2010) argue that there has been a shift in emphasis from ‘co-design’ and ‘co-production’ to ‘co-creation’, even in a short space of time. More importantly, these terms are not in effect synonymous. Co-design in healthcare services is defined as a partnership between patients, professionals and the community in the development process of a final solution, which is then implemented and led by professionals (Boyle & Harris, 2009). Co-production on the other hand involves asking for people’s help and using their capacities to deliver public services in an equal and reciprocal relationship between professionals and the core economy (family, neighbourhood and community), in effect, shifting the balance of power, responsibility and resources from professionals to individuals (Sanders & Stappers, 2008). Finally, co-creation is seen to occur when users are central not only to the design of services, but also to their production and continuous development, therefore based on ordinary people generating the content of services and shaping their nature (Cottam & Leadbeater, 2004; Murray et al., 2006).

These definitions are consistent with other authors in the field (Ryan, 2012; Kettunen, 2010; Ottmann, Laragy, Allen & Feldman, 2011; Coen & Kearns, 2013; Roberts, Greenhill & Talbot, 2012; Bradwell & Marr, 2008). However, Needham and Carr (2009) add the following to the motives to study and embrace co-production in particular (as cited in Fledderus, 2012):

• A decline in support of target-based and process driven models of service delivery
• A wish for higher service efficiency because of fiscal pressure
• An increase in the awareness of ‘user-generated’ knowledge
• A desire to strengthen local democracy, and
• A tendency to personalise social service through the effective participation of the people who use them.


3.3 Support needs of families with children with disability

The impact on families of having a child with a disability is usually profound, in both positive and negative ways. The research on the effect of having a child with a disability on siblings indicates that (a) their experiences and needs are unique, (b) they benefit from both support groups that are family-centred and early intervention services, and (c) how they adjust to having a brother or sister with a disability is substantially affected by their parents’ behaviours and family factors.

Given that the whole family is affected by the diagnosis of a disability in a child, services that are family-centred are crucial for effective intervention. Family-centred practice and collaborative relationships between families and service providers are therefore important elements for stimulating family agency. Family-centred practice sees the family as the unit of attention, emphasises their strengths, promotes family choice and control over desired resources, delivers individualised family services, and relies on the development of a collaborative relationship between parents and professionals. Good collaborative partnerships are marked by communication, commitment, equality, skills, trust, and respect (Blue-Banning, Summers & Frankland, 2004).

In addition to collaboration, a range of factors can compromise a family’s satisfaction in their partnership with a service provider, including the type and severity of disability, the age of the child, professionals failing to willingly share power with their client family, reliance on a few key staff to deliver family-centred practice, lack of symbiosis between families and professionals, and conflict at the inter-organisational, intra-organisational, inter-professional, inter-personal, and intra-personal levels.

Other features of the services sector that are also important for enhancing family agency include the quality of professionals and services, whether service expectations were met, the provision of easy read information, and sensitivity to cultural diversity in service delivery.
4. Methodology

The project design, methodology and research instruments were designed by SPRC in collaboration with Mid Coast Communities.

4.1 Recruiting participants

Recruitment of participants included:

- Invitations sent to a range of children’s services, including child care centres, preschools, early intervention services, and disability services such as Northcott
- Advertising via Facebook pages, including ‘Coffs for Kids’ and a page specifically set up for the project, ‘A Better Life for Kids Research’
- Information included in the Mid Coast Communities Newsletter (distributed to 700 people)
- Visits by the Project Officer within the target area to network meetings for Aboriginal services, disability services and support groups (such as the Coffs Regional Autism Association), neighbourhood network meetings, and child care services with few participants
- Presentations delivered to a regional forum for Home and Community Services
- Distribution by ADHC of flyers to families receiving case management support.

In total, 25 people contacted the researcher.

4.2 Interviews

Before the commencement of the Co-design Project, interviews were conducted with families to develop an understanding of their circumstances and the needs and interests of families with children with disability in the area. In particular, the interviews included questions about:

- Family structure and number of children in the family unit
- When the family first had concerns about the child and the journey toward diagnosis
- If the child has contact with therapeutic services
- Family relationships and economic impact of disability
- Relationship with services and the community
- Plans for the future
4.3 Methodological benefits and limitations

The qualitative research presented here offers a detailed and nuanced insight into families’ experience of raising children with disability, and of participating in the Co-design Project. While the particular experiences of this small group cannot be generalised (as the projects they were involved in were tailored to their needs), they do give an indication of the kinds of Co-design Projects that are well received and useful for families.

The research benefited from the involvement of the Co-design Project Officer as the primary researcher. The Project Officer worked with SPRC to design the research and the interview questions, conducted the interviews, transcribed the interviews and participated in the analysis. This provided a unique understanding about co-design intervention. However, as the Project Officer had highly detailed knowledge of all the co-design projects and knew each of the research participants, it is possible that some research participants might not have felt comfortable criticising the Co-design Project with the person responsible for its implementation.

After the Co-design Project had been implemented, families who had been involved in the programs were invited to be interviewed. Families who were in the first interview series and had a child within the target age group were also contacted and invited to participate in interviews. These second wave interviews were designed to allow families to reflect on their involvement in the Co-design Project, the benefits it offered, any changes they would suggest, and to provide the research team with an ability to assess the impact of the Co-design Project on participating families.

Interviews occurred mostly in the family home. Four families had their interviews in pairs and two interviews were held over the phone. All families who completed a final interview received a voucher for $30, unless they chose not to receive the voucher if there was potential to have conflict of interest with paid employment.

All but three of the interviews were recorded by a voice recorder and transcribed. The transcriptions were imported into NVivo for coding. Initial interviews were coded to investigate families’ experiences of diagnosis, engagement with formal services, finding information, informal social support, self-advocacy or empowerment, and wellbeing. The second wave interviews were also analysed using these codes and supplemented with an analysis of each type of co-design intervention.

The project methodology was approved by UNSW Human Research Ethics Committee.
5. Demographic Summary of Sample

Fourteen families participated in the research and all had at least one child with disability. In seven families there were two children with disability, and in one family there were three.

Autism was the most common form of disability, experienced by more than half of the children. Other disabilities included Down syndrome and other congenital disabilities, severe allergies and Cerebral Palsy.

All but one of the families had children aged less than 18 years at the time of the study. Most families had one or two children aged less than 18.

Most were couple parent families, with sole parents in two families. Most of the parents who participated in the study were mothers (11 out of 14). The age range of participating parents was from 26 to 56 years, with mean age of 44 years. There was one Aboriginal parent and one parent from a non-English speaking background.

Three parents of those participating in the study worked full-time, six part-time, and six were not in paid employment. Nine of the parents’ partners worked full-time, one worked part-time and two partners were not employed.

Table 1: Number of children in family aged less than 18 years

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<tr>
<td>One</td>
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<td>Two</td>
<td>6</td>
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<td>Three</td>
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6. Results: Initial Interviews Before Co-Design Intervention

The main purpose of the initial interviews was to determine, prior to commencement of the co-design intervention, the participant families’ history and experiences with diagnoses, services, available information, informal supports, family agency and wellbeing. The initial interviews also captured feedback on where the families would like to be by the time the program was implemented.

6.1 History and experiences of families going into the program

6.1.1 Diagnosis

Most people said that the process of diagnosis was complicated and took a long time. Often it was years after the family was first concerned that their child might have a disability that they received a diagnosis. Parents spoke of repeatedly going to many different specialists. One mother said “I went round and round in circles”, while another added “You have to get six reports, 2 or 3 appointments to confirm their suspicion”.

This was a difficult time for many families; “That period between concern and diagnosis was horrendous”, said one mother. Some felt their parenting was being judged as the cause of their child’s condition; “Finally diagnosed at 6 years. In the mean time you are being told that you are a bad parent”. Many families felt isolated and lost and this made the period before diagnosis even more difficult; “It was pretty horrible; we were really on our own”.

By contrast, for a few families the path to diagnosis was relatively straightforward. This was partly due to the type of disability and partly due to their connections with local services and how those services responded. This mother’s account shows how insightful and well-coordinated local services facilitated her daughter’s diagnosis:

The early childhood nurse put us onto early intervention. I thought you needed a diagnosis, but we had an assessment with early intervention and the speech therapist and the occupational therapist before we went to the paediatrician. This meant that we could get the diagnosis from the paediatrician without travelling. We are so thankful that we could get it done locally…It was a relief to get a diagnosis.

As this quote details, finally arriving at a diagnosis was a great relief, partly because the difficult period of diagnosis was over, but also because having a diagnosis meant that the child was eligible for services and support. One mother explained, for example,
“We were trying to get a diagnosis so he could get assistance at school…He needs one-to-one support”.

It is important in this context that almost no-one talked about the diagnosis process as empowering them or involving them in the shape or design of the support they would receive. Only one mother, who had previously worked with people with disabilities, spoke about the diagnosis process with a sense of purpose and strength; “It is only because of my work and connections and that I knew what to do and advocated strongly”.

6.1.2 Engagement with formal services

Living in a regional location had great advantages for families, but a number said they did not feel they had access to the range of services their children needed, and often travelled to major cities to see specialists and therapists. As one mother explained “I realised that as much as I love this area, we did not have access to the expertise that we needed”. These limitations included:

- Playgrounds – “There is one swing in this whole town. There is nothing”

- Equipment – “In Sydney, you could just go to a room and see all these wheelchairs, but here you have to wait for a supplier to visit and they only have one wheelchair”

- Medical and disability professionals – “There is no one here who has a great understanding of [his condition]. I have to get a referral from the GP to see the specialist who is [interstate]”

When services were available, families reported very mixed experiences with them. Sometimes they found dealing with services difficult. Poor communication was a common source of frustration; families described their annoyance with services that did not listen to their child or their articulation of their needs. As one example, a mother said that her daughter is “touch and sound sensitive but the therapist poked her on the back even when asked not to do this”.

Parents also noticed a lack of communication between services. One parent said “nothing was very forthcoming, nothing connected. [The first service] did not talk to [the second service] who did not talk to [the third service]”. This led to difficulties finding information about the types of services which might be available for their children in the local area.

Other complaints were that waiting times were excessively long, or that services were too busy to properly meet a family’s needs. It was also difficult if they had problems with a local service because there were few other options available.

Nevertheless, most families also detailed positive experiences with services. It helped when families were quickly put in contact with the right service for their needs at that time. One mother, whose daughter was a young baby at the time, said “We were quite lucky here because [they] did a clinic on feeding, getting from tubes to eating. This made all the difference”.

Often they spoke of one key person who really helped. This might be one staff member at a school or organisation that understood the family’s circumstances and helped them negotiate for the support they needed, or the right professional to work with their child:

> A clinic nurse knew that we needed to get to the right people, [so] I came in through the back door.

> The first 12 months of occupational therapy we just followed [our son] around the room and it did not help at all. What’s changed? An occupational therapist who uses music. She ended up getting a CD and put it on in the room and it was amazing.

> I don’t know what I would have done if not for [this one therapist].

The daily importance of schools in the lives of children and their families meant they were frequently mentioned. It was difficult when poor communication and a lack of experience impeded the school’s capacity to best educate and care for all their students. Where the school was prepared to work with a student’s family, and especially when the school had previous experience to draw upon, families spoke very warmly about their association. The difference this can make to students was explained by one mother:
In [her last school] she was put in a classroom for behaviour issues for years 3 to 6 - sixteen children in the class with a teacher and an aide teacher. It was not about dedicated learning. Then she hit the lowest point in her life and was on the verge of depression. At [her new school] she is in a regular class, she has aides and helpers, special programs and helpers. She does everything the class does. Now she can do things even if she is a bit slower to do things. She has come a long way.

6.1.3 Information

Most families spoke of the difficulties they encountered when trying to find what services might be available to them. They often said that they only discovered a service after a long time or after another service or parent mentioned it to them. Some felt they needed to specifically ask in order to be directed to a service they needed, but felt it might take time before they knew the right question to ask. For example, one parent said “The trouble is accessing services and finding out what is available because no one tells you. If you don’t ask you don’t get. We did not know about the respite services”. Another parent spoke of the importance of having a service visit her in her home and detail the support which they could access.

A number of parents said that supported parent groups were invaluable sources of information, both from other parents and from local services:

It was a wonderful group for information. This is a support group if you have Carers Allowance. It’s run by a co-ordinator and helper. You have a cup of coffee, it is partially supervised. It was wonderful. The coordinator gives information out. You talk to other Mums and get information that way.

Another said they found it difficult to maintain information networks; “We don’t know how to access help. Sometimes when you are sailing smoothly you lose all the contacts you had”.

Specific workshops were another important source of information for parents and their extended family to learn more about, and develop an understanding of, their child’s disability.

Many families searched for information about their children’s disability through the internet and a number were members of internet forums or groups that provided informal support as well as information:

Most of my information is through a forum on the internet…It’s just really good because all the parents write in, and I just read and I think, ‘Wow that’s him.’ So we are all on the same page, it’s great….Physically you are alone, but through technology you are not alone.

One mother reported having trouble finding time to look for web-based information.

6.1.4 Informal social support

Parents talked about having different types of social support. Some had good support networks, while others said that they were very isolated and had few opportunities to receive support from friends or family. One mother said “I don’t have a social life…I can’t take her many places on my own, we just stay home”.

Some families’ social networks were impacted because families found it difficult to be in public places because of their children’s challenging behaviour:

We don’t socialise whatsoever, we don’t go anywhere. If we go out and have lunch and my husband or I say something, just one word, and our daughter takes offence, she will play up, embarrass us and play up.

Others found that they were too busy, had too little money or that there was a lack of understanding from old friends:

We don’t have any family here. I feel like we can’t rely on anyone else, they have their own problems. I am really lucky to have a great group of friends and work. I can’t just leave my son with anyone. Sometimes the effort to settle him means that it is not worth leaving him with anyone.

Families that did keep regular contact with others said that informal support was a really important source of information about their children’s disability or about local services. One parent said that it as another parent who directed her to the most important therapist her daughter works with; “It was only that I ran into a
mum who suggested [this therapist]”. Another said “From talking to people we found out more than [the service] staff”.

At times it was agencies and support groups that helped families make social connections:

I met people through that [agency] support group who I have stayed in contact with. I’ve had contact with service providers who I stay in contact with. There was a mentoring program… who connected me up as a mentee. There are other people who I have met a various events. It’s fairly small circuit [around here], you run into the same people over and over again so I have met a few people that way.

I am friends with other mothers. I met them through an early intervention service. My son did early intervention getting ready for school. We met as a group before he started for school but everyone is busy now and no-one has time to get together.

Social networks helped families get their strength back when they were feeling overwhelmed or exhausted. As one mother said “We spoke to other families who told us that we have to be ballsy and keep asking for things”.

Many of the families felt that being in a regional area and/or at a small school had definite advantages when it came to maintaining their social networks:

I think it’s pretty good, I think [this area] is pretty good. [The school] is a fairly small school. It’s religious and has a bit of a community feel… The school fosters relationships. Generally I find [this area] pretty accepting. I find we can go out anywhere and people are, we are just like everybody else.

Some parents spoke of the importance of their children maintaining social contact, even when it was difficult or felt like hard work:

I take him everywhere. I am not going to isolate him. I know that it will make it worse if I isolate him.

Time on the bus is such a good time for friends. So what I have done is pick up a number of kids which means that [my daughter] can have the travel time as bonding time with friends. It just means I have to go a few extra streets.

6.1.5 Advocacy, empowerment and family agency

All the families described working hard to ensure the best for their children. Finding the right diagnosis, treatment, equipment, services and support involved a lot of work and perseverance. Often parents said that their tenacity had meant that they finally secured what their children needed:

My daughter could have been diagnosed at 18 months or earlier but we went on waiting lists for 6 months. In hindsight I would have done things differently. I am very persistent or it would have taken a lot longer.

Finding funding and services was hard and repetitive work. One parent said “I’m convinced that if you keep jumping up and down you will get it”.

At times parents felt forced into being an advocate for their children because they knew that if they did not speak up, no-one else would. One said “I had to take a real advocacy role. There was nobody to help me”. Another found, with experience, that her own knowledge of her child’s needs was far greater than that of many workers:

I would now say to respite workers: please don’t come and give me advice. Just come in and listen to me, don’t give me advice...Don’t tell me what I need to do, I’m living with him.

However families rarely spoke of the advocacy that they undertook for their children with a sense of agency or empowerment. More often, they seemed to find dealing with services exhausting rather than empowering. Only a few mothers spoke with energy and enthusiasm of the work they do for their children with services, schools and communities. One mother said if she needed to create employment for her daughter in the future, then she would:

She sees a future for herself and I don’t want to take that away from her. If we have to make a job for her, that’s what we will do.
Some mothers described their advocacy work as a routine and straightforward part of parenting a child with disability. For example, in preparing her daughter for secondary school, one mother said:

Next year she goes to high school. I have talked to the deputy principal and the principal. I want to know what is involved for my daughter. I talked to the special teacher.

6.1.6 Wellbeing

Most families said that they were overly busy managing the care and treatment needs of their children. As one parent explained “We are trying to juggle seven balls when we are only able to juggle three. We can’t do anything else, they just have to wait”. Most managed this intense time pressure by stopping all but the most essential activities and tasks, and/or by becoming highly efficient. Some also decided to simply try to not worry about it, saying “I go with the flow, I go with whatever they are doing” and “We’ll muddle through”.

Added to time pressure was financial pressure. A number of mothers said that they had stopped work because they could not find a way to combine employment with all their children’s appointments. The loss of income, combined with the additional costs of equipment and treatment, placed a number of families under considerable financial strain:

Financial stress is high. The hardest part is that I have dropped my 3 days of work per week and hubbie only works 2 days a week.

Another parent said “The pressure of having a child with a disability, emotionally, financially, it is really hard”.

A few parents said that they rarely managed to have a good night’s sleep because their children woke so much at night. This added to the strain they were feeling.

The combination of time pressure, financial pressure and worry about their children caused a lot of tension for families, parents especially. One mother describes the large number of sole mothers parenting children with disabilities because families have broken down under the pressure:

I went to a mothers weekend there were 32 mothers on this weekend, 30 of them were single mothers. I have seen them [fathers] drop like flies.

A few parents said they had come close to separating; “The stress when we went through that period when our daughter was diagnosed, that nearly broke us”. Another mother said she felt that her relationship with her partner has strengthened as well as suffered; “The disability has both pulled us together and forced us apart”.

One mother said that her friends had helped her through the most difficult time:

My relationship with my husband was terrible in that because we went through a time where he blamed me. We basically closed up shop, we had friends who were local and we spoke to by phone who just kept me going by phone. They just kept believing in me. Sometimes every day I was on the phone to those people.

Another parent told the story of finally finding a bike her son could ride and the pleasure that this gave the whole family. She had been too busy to prioritise the bike, but did so after persistent reminders from her son’s physiotherapist:

It’s amazing the first time he went for a big ride, we filmed him afterward and he was sitting in a chair going, ‘Ahhhh’ [happy contented sigh]. He was talking heaps saying, ‘We went around there and we went over there’. But it did take two and half years or more before we got onto it. And it was the physio prompting us. At times I would think ‘I just can’t deal with that right now’. So having the same person over a period of time was really useful.

6.2 Families’ expectations of where they would like to be after the program

6.2.1 Engagement with formal services

When speaking about what they hoped for in the future, either generally for their children and their families, or specifically in terms of the Co-design Project, families mentioned formal services most often. Services
desired by most families were local respite appropriate for children, a central information and referral service, and advocates:

All we need is for someone to help us navigate the system but there is nobody who can do it! If there was someone who could help us work it out, how to get into the system. This is where the real gap is. There are too many different things going on and nobody knows where to go.

The frequency with which families said they struggled to find information and to know what services were available suggests that this could be an important type of intervention through the Co-design Project.

Some families said they wanted training from local organisations in how to support their children. One mother explained that her son wanted to go on a camp with a local youth organisation, but they needed her to organise support for him:

We probably need a little support for organisations that are doing a good job. For example the camp required that no mums could come. It had to be a respite worker. Those organisations that take these kids in, they are all volunteers, it would be great to give them a bit of help so they can take these kids in.

A few families were organising a satellite class for children with autism:

I am working on a project to get a satellite class. They have 6 kids with a teacher and an aide. They have teachers who are specially trained in autism and an aide. The aim is to give the support that is needed and then transition into a mainstream class.

Another added “If this satellite class gets off the ground it would be like winning lotto”.

There appeared to be opportunity for the Co-design Project to support these families in this endeavour.

Other parents spoke of a need for very specific services that their child needed, including:

- Local autism services (behaviour and social skills training, craft, walks, cooking)

- Early intervention services
- Local resource office with printing and laminating services
- Resource library
- Speech therapy
- Playgroup
- Park equipment
- Social skills and behaviour training
- Peer-to-peer connections between teachers.

While the Co-design Project could not develop all these services for particular needs, it could support families in finding creative ways to access these types of services.

In addition, families’ descriptions of their experience of the diagnosis process and accessing formal services suggests a need for easily accessible information, well-coordinated local services, and having their concerns and understanding of their child’s need listened to and taken seriously. Ideally, instead of leaving families exhausted from a circular and confusing system, formal services could empower families, giving them the strength to continue finding the appropriate treatment and services for their children.

6.2.2 Informal social support

A few parents said that they would like more avenues through which to join social support networks, either for themselves or for their children:

We really need the emotional support, the relationship with other families. We just want to socialise with others.

One family who had heard of the plans for Family Fun Day, had hopes that by attending they would have an opportunity to socialise with other families; “Social connection difficulty is extreme – Family Fun Day may be helpful for this”.

Despite not being raised often by families when discussing the future, the clear importance of social support for family wellbeing, information sharing, inspiring agency, and supporting the social relations
of children, suggests that the Co-design Project could help families develop networks of social support. A number of families spoke warmly of informal connections made through particular agencies, suggesting possibilities for creating more spaces for families to connect with each other.

6.2.3 Family agency and wellbeing

No families directly mentioned wanting to develop their sense of agency. Only one family said that support was needed for the family in general, not just their child with disability. Nonetheless, the few families that demonstrated strong agency and clear plans for their children were resourceful and appeared to have better family wellbeing. By contrast, families that were struggling to manage from day to day seemed to find it hard to summon the necessary strength to advocate for their children, or the time or energy to connect with other families. The research reviewed above suggests that helping families with advocacy or developing a sense of agency might help improve their wellbeing.
7. Results: Families Experience of Co-design

The Project Officer engaged in lengthy discussions with the reference group and met with 25 families to develop an understanding of the challenges they faced and what types of interventions worked best. A number of ideas were initiated, some by the project team, some by families, and others by services or a combination of all of the above.

The programs implemented as part of the co-design intervention ranged from community events that included a large number of participants, to intensive work with an individual family. The activities that involved the most families who were interviewed in the second wave of the research were the Family Fun Day, Action Learning and Big Plan.

The following analysis examines each co-design activity in turn, first describing the activity, and then presenting the finding from interviews with families who participated in that activity. Further detailed descriptions of the activities can be found in Appendix D.

7.1 Family Fun Day

Two local parents organised a number of activities (‘Family Fun Days’) to bring families of children with disability together. Family Fun Days were free events held in a local park and funded through in-kind donations of food, equipment and activities. On the day, local community service and recreational organisations helped to run the event. The two local parents had organised three events every few months during 2013 and planned to make Family Fun Days a regular part of the local calendar.

Four interview participants mentioned the Family Fun Days. Families appreciated the chance to meet other families, and the support that families could offer each other. One parent gave an example of the level of shared understanding between parents at the Family Fun Day.

Fabulous! Everyone seems to understand. If your child is doing something, someone will come up and say, ‘It’s alright’. The last time I went, someone took my daughter by the hand when I was about to burst into tears. They took her by the hand and said, ‘Come on, my dear, you are coming with me.’ It was just what I needed.

Another said they “felt normal that day” because it was a social environment of families who understood life with children with disability.

One of the two parents responsible for organising the Family Fun Days described her involvement as “A
parent who has seen a need and made a difference. It has been great. Not stressful, very rewarding”. The other said he had plans for more Family Fun Days and wanted to extend the idea:

I’d like to go away for a family camp and bring all the dads together…The important thing is that Dads get to support Dads, and siblings get to get together.

The most satisfying part of the gatherings for the organisers was “just to stand back and see those families networking and building friendships and sharing stories”.

Plans for another event (‘Autism Awareness’) began at one of the Family Fun Days with two parents who “bumped into [another] at the Family Fun Day. We said let’s do something”.

### 7.2 Action Learning

The Co-design Project Officer used the technique of ‘Action Learning’ to work with a small number of families who had ideas that they wanted to develop. In the Action Learning sessions, parents tried to develop solutions to some of the challenges they faced. In two sessions, two parents came together with a community services worker and a facilitator to talk through their difficulties and hopes, and to create plans for the future.

All four of the Action Learning participants were interviewed. They spoke very positively about the process:

The Action Learning was really good. To get someone else’s perspective and realise that you are not the only person fighting your own battle was fantastic. It was really good for finding your own community supports.

It gave me other people. [Sometimes trying to organise something] you wonder if you are being too pushy or if you are being a nuisance. The action learning helped to come up with strategies which all went into the plan, and it was like, ‘Yes, this is happening.’

One parent described what Action Learning involved:

At a lot of levels we all know a pathway, how to achieve a goal or work through a problem. The Action Learning allowed us to work through problems, pull it apart. For you to be able to move on to a different level. It was useful on the day that we did it. It was like a ‘wow moment’. It is allowing a progression of thoughts to work around some of the issues and have some ideas for action at the end of it.

One mother provided an example of how it was possible to move from her personal experience to a broader understanding of the needs of the local community. Through the Action Learning process, she began planning a ‘family hub’ that would act as a central point for families raising children with disability to gather, mentor each other, and share information.

These parents described the process of sharing of their problems and receiving support when thinking through how to develop a plan of action, as helpful. They felt supported as they approached schools and services with a request for tailored programs for their children. While not all their plans came to fruition, making the plans as they did was in itself, a positive experience. Those plans that did translate into new approaches for their children were very rewarding:

The school could see that I wasn’t going to go away and forget about this issue…This was our number one aim…It is so nice, him going off to school and it’s going smoothly. He is going full days and coping compared to half days all last year. This affects my life.

In the above example, the mother’s sense of agency was strengthened by her involvement in the project. She felt she could persist in her advocacy at her son’s school and it had direct consequences for the family’s wellbeing, with her son now able to attend school for full days.

The strength of the Action Learning process for families was the ability to spend time, supported by professionals, undertaking focused work on their particular needs. They found this inspiring and useful.
7.3 Big Plan

The ‘Big Plan’ was a different mechanism implemented by the Co-design Project to develop ideas for the particular interests and needs of children with disability. Based on the work of Stephen Coulson and Heather Simmons in Edinburgh (2006), the Big Plan involved family members coming together with friends and support workers to work through a series of activities to plan for the future. Each group focused on one child and worked with a facilitator to create a ‘Big Plan’.

Four families that took part in the Big Plan shared their experience in the interviews, including two young people who made plans with their families.

All the interviewees spoke warmly and positively about their involvement with the Big Plan. Both the young people who made plans said that the process was challenging at times, but enjoyable. One said “It helped with lots of things. It gave me ideas for my business that we got up and running”. This young person is now producing products at home and is involved in all stages of the process, from creating the product, to designing the packaging and then selling his wares at local markets.

The parents also found the Big Plan process to be useful. Parents liked being supported to see the future from their child’s perspective:

I thought I would look after her for the rest of my life but that’s not what my daughter wants, she wants her independence, she wants a relationship. She does not want to be looked after, she wants to have her own place. It’s good.

They appreciated the opportunity to look at their child’s support needs in a different way, with one mother feeling that she was more able to take advantage of services, activities and events that were already in the local community:

The Big Plan represented a whole lot of opportunities. It helped you to look around and link in with what was happening in the community.

Another said “We have thought more ‘out of the square’ and got a bit more happening”.

Overall, the Big Plan intervention strengthened child and parent agency through the creative use of available community and other services, and helped families and support workers find employment opportunities for children with disabilities.

7.4 Autism Awareness

A plan to raise awareness about Autism was hatched by two parents at a Family Fun Day. They decided to run an event for all local families to share information about Autism. They chose to run the event at a local bistro that was popular among families and particularly popular for families with children with Autism Spectrum Disorder. The organisers wanted to increase understanding about Autism so that all families could feel comfortable when visiting the bistro. The day included activities and entertainment for children, free food, and support from local community service organisations. The Co-design Project Officer attended and reported “on the night it certainly felt like there was a shift in the understanding of the community and [that] children with Autism will be better included in general community settings”.

The two mothers who organised ‘Autism Awareness’ participated in a joint interview after the event. When asked why they organised the day, they explained:

We have been talking about the attitudes of people and, as mothers, trying to explain to people why our children are the way they are. We were getting bad vibes and attitudes from people and we were thinking, ‘How can we change this?’ We had been talking about it for months.

There is also a lack of awareness in preschools and day care centres, educators having absolutely no idea about how to care for children with autism.

Unless you are living with a child with autism you just can’t get it.

Their ideas turned into something specific at a Family Fun Day. Talking with other parents, they developed a plan:

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Basically we were excited that there is something called world autism awareness day. So we thought, ‘Let’s dress up in blue. Let’s invite everyone to the tavern. Let’s just find a way to raise awareness and celebrate autism.
They were amazed by the level of community support for the event. They said that just through word of mouth they received many offers of assistance. One of the organisers said “I feel a little overwhelmed, positively overwhelmed at the support. My heart has been warmed”. The other mother, although happy with the day, said she found organising the event stressful; “I felt a little stressed, I must admit I have post-traumatic stress disorder. I feel like it’s okay now, everyone is helping”. Overall, they reported:

It is a bit empowering actually, knowing that we are the people who have come up with the idea. But then having the support of you guys [the Co-design Project] has helped. There is no way that we could have done things to the same degree [without the Co-design Project], there is no way!

While aspects of the organisation might have been difficult, the parents felt that the event was a great success and had potential to be expanded. They are hoping to hold another Autism Awareness event and include local services and educators, such as preschool and school teachers. Participation in the Autism Awareness event supported family agency and the development of informal networks. It is also notable that the very first discussions towards holding this activity occurred at another Co-design Project event.

7.5 ACT NOW gathering

ACT NOW was a gathering of more than 200 Aboriginal community members, with representatives from relevant government and non-government organisations. Over a period of three days, they worked together to share experiences, inspiration, knowledge and ideas. Specific co-design activities were run as part of ACT NOW, including the facilitated exploration of the information, support, and direction that people would want to prepare for the NDIS.

Two parents who attended ACT NOW participated in interviews after the event. Both found the event rewarding. They liked the format and the opportunity to talk openly about their experiences. One said “Sharing stories, yarning about what is important to us, creating solutions together was excellent”, but also felt that the gathering could have been more culturally appropriate. The other interviewed parent said:

It was excellent, going to go there and being told, ‘Say whatever you want.’ It is a bit daunting, with all these service providers there who you do work with. I thought, ‘If I’m going to go I am just going to speak the honest truth.’

The first parent said that she felt that many of the representatives from service providers who attended listened carefully to her story and told her that they would make changes as a result:

Another lady came up to me and said, ‘Can I give you a hug? I am a service provider and I just want to thank you. What you were saying has really resonated with me. Going back, how can I change [how our staff work]?’ You feel disempowered so much of the time, it was really great.

She also said “When I left ACT NOW I felt more empowered than I have felt for a long time”.

Both interviewed parents found out about services they had not previously encountered. This information came from the organisations that were represented at the event, and also from other families:

The gathering was fantastic to reconnect and know what is going on. It was fantastic for finding out what other service providers are doing and to pick their brains.

Despite the importance of this event and the helpfulness of finding out about new services, it did not affect the uncertainty that one mother felt about the future. She said “I don’t know what is going to happen to us” and explained that she could not see how to meet her family’s need for some basic services and equipment, such as out of school hours or respite care, and a wheelchair.

ACT NOW provided important connections, both formal and informal, between families and workers. While there was clearly an unmet need for some quite basic services, the event was nevertheless a valuable source of information about support services.
7.6 Co-design project one-on-one engagement

Four parents worked with the Co-design Project in a way that was tailored to meet their specific needs and interests.

One parent was working towards changing the attitudes of her local community towards people with disability. Her work included working with local services, local government and the local community through wide ranging activities designed to ensure her son could be active and involved, just like other children. The Co-design Project Officer worked with her as needed. The Project Officer described her involvement as “listening to the ideas …reflecting back and discussing the ideas and placing these ideas into a priority list and timeline”.

Thinking about the Co-design Project, the mother reported:

Self-determination is the most effective. You are designing services [for your child]. You have come up with how things should be done differently.

You might identify what needs to happen, you then look at what your strengths are, then you go ahead and work using those strengths. You work out then what are the actions that you want to do. Or you may need some training.

That is where families need support. We need to be facilitated through a process of who we are, what we value.

Another parent worked with the Co-design Project to create a workshop to “plan the best” for her daughter. The parent and Project Officer planned on gathering together all the people who knew her daughter best; family, friends, neighbours, school staff, therapists and other service providers. The aim of the evening was to

- Celebrate who her daughter is and what people enjoy about her
- Acknowledge the challenges that her daughter has and ways to reduce the impact of her condition

- Investigate opportunities for her daughter in her community
- Discover the team that supports her daughter and reflect on who is missing and how this team can be stronger
- Devise a plan to make more good days for her daughter.

Unfortunately, due to her daughter’s condition deteriorating, the evening never occurred and priorities changed for the family.

A third parent worked closely with the Co-design Project Officer to create a plan for improved school inclusion for her child. They shared the strategies they developed with other families. A number of other families included school inclusion in their Big Plans and Action Learning activities. This particular parent found that support from the Project Officer was invaluable when negotiating with the school:

It was actually really beneficial having you there that one time. I found that after I had a professional there, I got a lot more notice… Even since I have thought about ringing you and getting you to come along as my professional.

The support of the Project Officer helped this parent feel that she deserved respectful attention from the school about her son’s needs. She felt the school was more willing to listen and work with her once she had the backing of the Co-design Project and this research:

When I explained that I was involved in a research project it actually got me a lot more respect. That was a huge benefit. Before that I was getting to know them, they were getting to know me and I thought at times that they thought I was a neurotic mother. That is how it is, that was a huge benefit.

Once this respectful groundwork was laid, she reported that “We have progressed on from there” and is making and implementing plans for her son’s school inclusion.

A fourth parent has worked with the Co-design Project Officer to advocate for the introduction of a ‘satellite class’ following the ASPECT (Autism Spectrum Australia) model to be situated in a local school. The
role of the Project Officer was to advertise information nights, and advocate for the satellite class at a meeting with a group of services. This mother has devoted 18 months to the project, working hard to build support from schools, local services and families. It has been a difficult and busy process; negotiating the politics of developing a new service was more complicated than she expected. Simply managing the time to spend on the many tasks involved was difficult; “It has been a difficult process…everyone is doing everything on top of their busy lives”.

It was also demanding because the mother has devoted so much time to the satellite class that she has had less time for her family. She found this difficult and so did her family. She said “I feel like my family wasn't getting the best out of me because I was too busy with the ASPECT stuff”. She is unsure how long she can sustain this kind of involvement, reporting “I don’t want to sacrifice my marriage, my child and my sanity for all of this”.

This mother also found it difficult dealing with other families’ worries:

Families would ring and say ‘My child has been expelled, we are at crisis point.’ I had to come to a point where I could say, ‘You know what, I can’t control the outcome of this, everyone is responsible for their own child.’ It was really starting to get to me.

Overall, though, she feels that it has been a positive experience:

Even if it does not work out I have formed some really close relationships with some people. I feel like I have used my skills for a good purpose. I meet a lot of mums who haven’t had the same chances that I have had - I had parents that supported me.

Despite the positive experience, the mother says she would have appreciated more assistance when trying to establish the satellite class, saying “In a perfect world [a community service] would have a community relationship person who would drive this stuff”. The mother was extremely organised and active and she would almost certainly have achieved as much if the Co-design Project Officer wasn’t supporting her. However, the Project Officer’s support was useful, and the mother’s work has been recorded here as an instance of proactively creating the support that she felt was required for her son and others in the same community.

The one-on-one work conducted as part of the Co-design Project highlights the importance and value of a flexible approach to working with families. This is so that families’ needs might be met whether they are advocating for an individual child, advocating for people with disability in general, or developing specific tailored activities to meet particular service and therapy needs. Some of the parents were highly motivated and focused, and successfully navigated complex systems in order to enact their plans. These parents may have achieved their ends without the Co-design Project, but they nonetheless found the Project to be helpful in giving them support and assisting with planning and shaping their plans.
8. Discussion and Conclusion

The findings of this project resonate with the literature on family agency and how best to meet the support needs of families of children with disability. This was a family-centred project that worked with families to establish or secure supports for their children. In general, families spoke very positively about their involvement in the Co-design Project. They made important social connection with other families in their communities, especially at the big events that brought families together, such as the Family Fun Day and Autism Awareness. They found that these connections offered important emotional and practical support, through sharing experiences, ideas and service contacts. The parents commented about the importance of the informal support and networks that they encountered with phrases such as:

- “heart-warming”
- “she gave me another idea”
- “building friendships and sharing stories”
- “good to meet other families”
- “good to bounce a few ideas with other families”
- “everyone seemed to understand”
- “met some awesome people and families”.

The parents who were central to the organisation of events or services also spoke positively about the connections they made with other people, both in the organisation of the events and during the events. At the same time however, co-ordinating activities placed additional pressure on some of the parents. One parent explained that, as she became an important source of informal support for other families, she felt that “at times I had everyone else’s worries” and that this could be difficult to manage. Another parent struggled with the “politics associated with volunteer movements”.

Generally families found their engagement with the Co-design Project to be a motivating or empowering experience, strengthening their sense of agency. A number of families initiated new activities following their involvement with the Project, either for their children and themselves, or for other families of children with disability. The Big Plan and the Action Learning projects were notable in helping families develop new ideas. Some of the comments from families involved in these two projects included:

- “it gave me ideas for my business that we got up and running”
- “it was really good for finding your own community supports”
• “once you start and you see the difference”
• “by the time we had finished it we were ready to do it with or without funding”
• “we thought we would raise awareness here”
• “it is a bit empowering actually, knowing that we are the people who have come up with the idea but then having the support of you guys has helped”
• “we put goals in place”
• “work around some of the issues and have some ideas for action”.

Some of the parents who were interviewed were already highly motivated and strong-willed people. These parents may well have seen their activities through without the Co-design Project, yet nonetheless they appreciated the support and guidance that the project offered.

While inspired at the time of the event, a few families spoke of a need for ongoing support, and others found the need to coordinate everything themselves difficult. For example, one mother said “Although I think you have to make it happen. We have to make it happen. It would be nice to have things organised for you”. Another said “It would have been good to have a bit of a follow-up even a month afterwards to help keep things moving”.

Finding appropriate services also continued to be difficult for families after the Co-design Project. Many said that while the Project had been helpful or inspiring, they still needed particular types of support services or therapies for their children. These parents refer to the perennial challenge for families of children with disability; securing enough support from community services. Their experiences show that, while participation in the Co-design Project was helpful for their families, for some it was difficult to find sufficient energy to initiate and maintain activities. In addition, for other families, participation in the Project did not remove the need for access to other important community and therapeutic services.

Parents spoke about the services of the Co-design Project Officer and the importance of the support she offered:

• “I found that after I had a professional there, I got a lot more notice. When I explained that I was involved in a research project it actually got me a lot more respect”
• “if you did it without the support of services it would be a lot harder”
• “having the support of you guys has helped”.

Maintaining the wellbeing of their families was difficult for the parent in this study. The parents were busy managing their day-to-day lives and often worried about their children and were stressed by trying to secure the support that they needed. Some found involvement in the Project itself caused some difficulties:

• “I felt a little stressed…I feel like it’s okay now, everyone is helping”
• “initially any change is stressful”
• “I feel like my family wasn’t getting the best out of me because I was too busy”.

Generally, however, parents found their participation in co-design activities gave them some relief:

• “it was very worthwhile and we really enjoyed it”
• “it gave our daughter a chance to express herself”
• “it was a good thing to be a bit emotional. You keep things bottled up, when you are really busy there is no time to grieve. I need time to breathe a little”.

Other parents said the planning they undertook as part of the Co-design Project had ongoing benefits:

• “he has started basketball and loves it, loves the social interaction”
• “it is so nice, her going off to school and it’s going smoothly…this affects my life”
• “being part of the project has helped to enhance our resilience…the more tools that you have in your toolbox the better. The more tools people with disabilities have the better”.

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Finding appropriate services also continued to be difficult for families after the Co-design Project. Many said that while the Project had been helpful or inspiring, they still needed particular types of support services or therapies for their children. These parents refer to the perennial challenge for families of children with disability; securing enough support from community services. Their experiences show that, while participation in the Co-design Project was helpful for their families, for some it was difficult to find sufficient energy to initiate and maintain activities. In addition, for other families, participation in the Project did not remove the need for access to other important community and therapeutic services.

Parents spoke about the services of the Co-design Project Officer and the importance of the support she offered:
The Co-design Project was a flexible and responsive project that kept people with disability and their families at the centre of support, and worked with them to design and seek the support they wanted. The Project helped families access services by aiding in the development of social networks which, in combination with the empowerment and motivation that the Project provided, grew the families’ sense of agency.
Appendix A: Detailed descriptions of co-design projects

1. Family Fun Day

In September 2012, a group of parents came jointly to an understanding about what was needed to create a better life for people with disabilities in their local area:

- “it’s up to us as a community to do it locally, create examples and show what can be done”
- “we should use groups that already exist and come together (where there is already people and energy), link these people with ideas”
- “we need to think about participation using open invitations for services, families and people with disabilities to come together”

By February 2013, one mother thought something should happen with Easter approaching. A family ‘Easter egg hunt’ seemed like a good theme to start getting families of children with a disability together.

Organising the first Family Fun Day involved:

- Choosing a location that had a community space, was fenced, had safe waterways, shelter, bbqs, toilets and was wheelchair friendly
- Contacting organisations that supply recreational activities who might offer their services
- Contacting disability services who might provide sponsorship or volunteer assistance
- Creating and distributing a flyer inviting families to come.

In April 2013 the first Family Fun Day was held.

This was a completely free event for families with children with a disability. About 40 children took part in the day (including children with disability and their siblings). Northcott and R&R Disability Services paid for Easter eggs, food, and volunteered their time to assist on the day. Early Intervention, Ageing and Disability Services and other people involved in disability services mingled with families and provided assistance with running the day. A local business loaned its paddle boards and assisted people to learn how to use them. Another business provided actors in theme costume to mingle with the kids.

Having generated much enthusiasm and energy a July Family Fun Day was organised. For this event, additional activities were volunteered by community recreational organisations. Activities on the day included beach buggies, jumping castles, kayak and boat rides. This time, about 80 people joined in the day. It was estimated that about 95% of these families included a child with a disability.

In October 2013, a third event was coordinated with over 120 people in attendance. More disability service organisations provided funds for drinks (ADHC), food (Northcott Disability Services), organisational support (R&R Disability Services) and a local organisation supplied a jumping castle. Small business owners supported the event by freely supplying their kayaks, paddle boards and ice creams. Dorothy the Dinosaur also volunteered her time! R&R Disability Services hired a magician to perform.

It is anticipated that Family Fun Days will continue through collaboration between leading families and service providers.

2. Action Learning

What is Action Learning?

The basic philosophy underpinning Action Learning is that the most effective learning takes place when we are faced with a real problem, which we are obliged to solve. Action Learning occurs in a small, closed group, called an ‘Action Learning Set’.

Key Principles of Action Learning:

1. Learning starts with not knowing. We become open to learning when we first admit what we don’t know and begin taking action in order to learn.

2. There are no experts in complex challenges where there are no right answers.
3. People who choose to take responsibility in a challenging situation have the best chance of positively impacting and resolving the challenge.

4. Learning involves both programmed knowledge (theoretical knowledge that is taught) and questioning insight (learning gained through testing the adequacy of programmed knowledge for use on our current challenges). This involves exploring what is unknown and unfamiliar and developing new action plans that might not work.

5. Learning should be greater than the rate of change. An individual or organisation that continues to express only the ideas of the past is not learning. Action Learning is particularly useful for providing a reflective space to explore new ways of working, dealing with complex challenges or when major change is occurring. An Action Learning Set can be formed from within a team, organisation, within a sector, or across sectors. Set members should have some common ground to bind the group.

**What happens in an Action Learning Set?**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Presenter describes their challenge to the group</td>
<td>Presenters worksheet</td>
</tr>
<tr>
<td>5</td>
<td>Members ask clarifying questions about the challenge</td>
<td>Questions handout</td>
</tr>
<tr>
<td>30</td>
<td>Members ask open, curious questions to assist the presenter to see their challenge in new ways</td>
<td>Questions handout</td>
</tr>
<tr>
<td>5</td>
<td>Members ask questions to review options and help the presenter to decide on an action plan</td>
<td>Questions handout</td>
</tr>
<tr>
<td>10</td>
<td>Facilitator leads a reflective discussion about the process and content of the presentation</td>
<td>Questions handout</td>
</tr>
<tr>
<td>10</td>
<td>All members complete a personal reflection relating to the learning to themselves</td>
<td>Reflection worksheet</td>
</tr>
</tbody>
</table>

**Action Learning and the Co-design Project**

The technique of Action Learning was used in the Co-design Project in response to families feeling ‘out-of-control’ and indicating that they were not being heard. Action Learning was used as a technique to assist families to design responses to their challenges in a supportive, respectful and deep-listening environment.

The first Action Learning Set was completed by two participating parents and a person from the community service industry, together with a facilitator. The second Action Learning Set was completed by two participating parents and a disability support trainee, together with a facilitator. Eight parents were invited to participate; six responded positively to the invitation, four were able to make it to the actual days.

**3. Big Plan**

The Big Plan took a group of 6-12 individuals through a series of activities that lead to the development of an action plan. Each individual has a facilitator and group of supporters, who may include family members and other people important to them. The process goes through a sequence of activities that encourage each individual to explore the following themes:

- Labels
- Gifts
- Family
- Community
- Dreams
- People and activities that bring energy and joy
- Positive and possible action

At the heart of the Big Plan is the following question: What would it take for this young man or this young woman to have an interesting, fulfilling life where they can make a contribution to the community and meet people who might become friends?

Within the co-design research interviews, families indicated that services tend to be very goal-orientated and appeared to work in isolation. Several parents indicated an interest in exploring how The Big Plan
could be used to assist them to facilitate a community-orientated, strengths-based approach to coordination and design of support.

In the situation of a family with a young child, the following question would be asked: What would it take for this child to have an interesting, fulfilling life where they can make a contribution to the community and meet children and adults who might become friends?

One of the authors of the original Big Plan (Heather Simmons) had been contracted to provide training to community members and disability support workers to facilitate The Big Plan in the Coffs Harbour area. Two parents from the co-design research project committed to completion of The Big Plan facilitation training and to complete a Big Plan session with their child.

On 11, 12 and 13 September 2013, 30 people completed The Big Plan facilitation training with Heather Simmons. One of the facilitators trained is a parent in the co-design research project. The second parent withdrew at the last minute due to the declining health of their child necessitating travel interstate.

On 16 and 17 September 2013, the first Big Plan events were held in Taree and Coffs Harbour. One co-design research family participated in the planning process. Further Big Plan sessions were held on 9, 10, 22 and 23 October 2013.

In addition to the group facilitation training, Rachel Gillin, Aboriginal Family Support Coordinator for the project area, received a full day intensive training session to facilitate Big Plan strategies and to provide guidance and advice regarding the use of the Big Plan activities for Aboriginal Families. The response of the Family Support Coordinator was that:

• The Big Plan activities are a comfortable fit with community members

• Families should be encouraged to consider their totem as part of the description of themselves; the idea of a totem may replace or work alongside the idea of a family crest

• The flow of activities that view the individual within the context of family and community was a more appropriate model of planning for community members than more individualistic planning tools

• It may be difficult to get families, friends and neighbours to attend Big Plan events; good food and culturally secure venues and location would be vital for success.

Some Big Plan activities are scheduled to be incorporated in an upcoming camp for Aboriginal families with children with a disability.

Three families who participated in the Coffs Harbour Big Plan were interviewed six months later to check what long term impact had occurred.

A range of information is available on the Big Plan including: The Big Plan: A Good Life After School by Stephen Coulson and Heather Simmons, Inclusion Press ISBN 1-895418-70-4 2006

4. School Inclusion

School inclusion is a recurring dilemma for families whose children attend mainstream schools, and sometimes for families whose children attend specialist support classes.

In the Co-design Project, the Project Officer met with one parent and a welfare officer to design ways for the school to continue to improve what they were doing well, and create new ways to increase successful inclusion of children with disability, in particular children with Autism.

The parent designed strategies to build the capacity of her child to attend school by attending ‘Secret Agent Society’ training, where a myriad of techniques to identify emotion and manage rising anxiety levels are taught. During this class, the child befriended another child who also had Autism.

Additional strategies put in place by the parent included:

• Involvement of grandparents to ease the level of stress in the before-school routine

• Changing the family routine to ensure that the child was as well rested as possible at the end of the weekend and in the final week of school holidays

• Addition of a friend to walk to school with the family on days when tiredness leads to increasing levels of anxiety before school
• Incentives and records were kept at home to keep encouraging behaviour that enables school participation.

Together with the classroom teacher, welfare officer/chaplain, parent and Co-design Project Officer, a number of strategies were developed to enable classroom inclusion, including:

• The Welfare Officer meeting the child at the front office to have a tea party to settle before going to class

• Incorporation of heavy work activities within the class routine (for example pushing, pulling, lifting, weighted activities). These activities were incorporated for all children in the classroom.

• Encouraging use of oral actions and hand activities (squeezing, pinging or fidgeting) to assist the child to manage their anxiety levels.

• Adding relaxation sessions to the daily plan, particularly in afternoons later in the week when tiredness exacerbates levels of anxiety. These relaxation sessions are held for all students in the classroom.

• Use of equipment such as hot water-bottles to increase level of comfort in the classroom. This equipment was made available to all children.

Specific actions were taken as a school-wide program to better include children with disability, including:

<table>
<thead>
<tr>
<th>Action</th>
<th>Outcome experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Training</strong></td>
<td>Four day Autism Spectrum Disorder training for teacher</td>
</tr>
<tr>
<td><strong>Relationship building</strong></td>
<td>Meet with families well before the child starts in your class; use phone calls, emails and communication books throughout the year</td>
</tr>
<tr>
<td><strong>Start transition early</strong></td>
<td>Invite the child and a few peers to share activities around their new classroom</td>
</tr>
<tr>
<td><strong>Plan to reduce anxiety</strong></td>
<td>Listen to parents for ideas and have activities prepared that can lower anxiety</td>
</tr>
<tr>
<td><strong>Chaplain/welfare officer involvement</strong></td>
<td>Welfare staff can do follow-up calls to families and assist child to transition from home to the classroom whenever needed</td>
</tr>
<tr>
<td><strong>Friendship</strong></td>
<td>Encourage kids who understand each other, particularly if there are connections from specialist programs such as ‘Secret Agents Society’</td>
</tr>
<tr>
<td><strong>Boys club</strong></td>
<td>The teacher would like to start a club for kids with shared challenges to encourage relationships</td>
</tr>
<tr>
<td><strong>Space</strong></td>
<td>Areas have been allocated for anxious kids to go if they need to get away from other kids</td>
</tr>
</tbody>
</table>

When the child was refusing to come to class her friend expressed how worried she was, made a joke and brought the anxious child right out from her highly anxious state of mind.

It is anticipated that participating kids may feel less alone and have others to share strategies.

When children recognise that their level of anxiety has increased they go to their designated safe place to relax.
### Access to occupational and psychotherapy tools
The ‘Secret Agents Society’ program teaches children many tools to identify and manage emotion. The classroom has as many tools available as possible. Children have ready access to the tools they need to manage their emotions.

### ‘Bounce Back’ program
Programs for all class members to learn strategies to communicate and manage emotions. This is just starting.

### Availability of the ‘Secret Agents Society program’
This program could be offered due to a number of families grouping their Autism Spectrum Disorder funding. Children benefited by learning about tools to identify and manage their emotions. The peer support from this program was also highly beneficial.

### Open School Policy
Families are welcome to use the staff room and make flexible arrangements to visit teachers. Parents share what is going on in family life, giving the teacher a better understanding and opportunity to prepare appropriate strategies.

### Accepting variation in mood
Students are given permission to feel up’s and down’s. There is no ‘wrong’ or unacceptable feeling.

### Parent support groups
Creating an opportunity for parents to mix has been helpful for local families from the Aboriginal community. Perhaps setting aside a similar time for families of children with ASD could be helpful too. This idea is as yet untested but could be an opportunity for parents to get together, share ideas and offer support.

### Positive feedback
Teachers take every opportunity to provide positive feedback to parents about their child. Families feel better about their child and more comfortable when speaking to teachers.

### Acceptance
Teachers and support staff showing parents that they like the child and are glad to have them in their class. Strengthened relationships and opportunities to work together to ensure a good school experience.

### Time and staff availability for parents
Welfare officer time and support to follow up concerns at school and at home. Parents, teachers and students are better supported.

As part of the Co-design Project, ideas working at this school were provided to other families working through a period of transition or challenge at school.

## 5. Autism Awareness

At a Family Fun Day, two parents worked with the Co-design Project Officer to design a way to increase the awareness of Autism in their local community.

The families lived in a coastal village with beautiful beaches, but scarce community facilities. The most popular place for families to meet was at the local tavern.

The tavern is well-suited for all families and particularly children with Autism. Nowhere else in the local area is there a fully enclosed playground that allows parents to relax a little, without fear of their child running into a water course. A permanent jumping castle allows kids to do some ‘heavy work’ therapy. There are quiet enclosed play spaces where children can get away from the noise and hustle and bustle that can sometimes trigger behaviour that is socially unacceptable.

Despite this excellent community resource, parents have felt humiliated by disapproving looks and inappropriate remarks when their children are “doing their thing”. The parents wanted to start changing the attitudes of people in their community so that their children could mix with other children in the community and be accepted as they are.
A plan to create change was developed

A celebration of World Autism Day would be staged at the tavern. Members and friends of local Autism services and children's services were invited to celebrate World Autism Day with a meal at the tavern. A reptile show was an additional incentive for community members to come.

ASPECT provided some practical tips on being friends with kids with autism.

There would be short magic performances, with Autism experiences shared between magic acts. The magician would perform additional shows in quiet spaces for children who preferred to be away from the crowd.

Information for families to learn more (for example, about the ASPECT website or Northcott website) were available.

The outcomes anticipated in the planning of the evening

- Families with a child with Autism will feel more welcome at the tavern and enjoy the facilities and community that is available there
- Families in the area will be caused to think about what they say and do which may open opportunities for greater inclusion in the child care centre, school and tavern
- Children with autism will enjoy a special night where they can feel good about themselves, feel accepted and free to be themselves.

What actually happened

Arrangements for the Autism Awareness Celebration came together quickly, resulting in an event where families contacted the organisers and received a $10 voucher that gave them a substantial meal and drink. 140 vouchers were used by families on the evening. Children received a meal, ice cream, drink and unlimited slushies for $5 each. The tavern estimated that around 250 meals were prepared for families associated with the Autism Awareness event.

In preparation for the event, the manager of the tavern welcomed the event and provided assistance with preparation of the area, designating staff to play footy and other games with the children, ensuring the jumping castle was in good order and ready to go. The tavern provided the services of a graphic designer to create materials to promote the event. The tavern also provided the services of their marketing manager who managed to promote the event on the back of the TV guide that comes with the free weekly newspaper distributed throughout the local area. Facebook and other media channels were also utilised. Southern Cross Media freely promoted the event on TV in the community notice board. Flyers were dropped in letterboxes. Local school newsletters promoted the event, and flyers were provided to families in the local child care centres and surrounding primary schools. Advertisements were run on the local radio station. Local shops displayed posters promoting the event. Overall, awareness of Autism was raised in the homes of people living throughout the area through contact with Facebook, radio, TV, flyers, posters, newsletters or newspapers.

Some surprising offers were made. For example, a business offered a second jumping castle for free for the event (this castle offer was not accepted due to the need for space for ball games). A soft drink company offered to provide unlimited slushies for all children to support the event. A large brewery sent a family-sized BBQ as a raffle prize (although it arrived a few days late). The reptile show was provided at a greatly reduced rate and was a real draw card for families in the community. The show ensured that attention was given to the front where information about Autism was provided. The magician provided a show in a variety of formats, including a roving show that allowed kids who don’t like a crowd to enjoy the magic in very small groups. He also provided an onstage show, drawing the attention of the crowd to the Autism message on stage. The magic show was also offered at a discount rate.

Autism Spectrum Australia provided information about Autism in two sections. The first presentation used audio material to demonstrate the sensory experience of a child with Autism and stories about the lived experience of Autism. The second presentation provided information about how families can be assisted and children included in activities, places and events if they have Autism.
An assistance dog moved around the event with a handler from PAWS. Helium balloons were supplied by Northcott Disability Services.

A local woman performed the song Don’t Give up on Me. Written for the Canadian Autism Association, the song is from the perspective of a child who has Autism who struggles to connect with their loved ones.

Children played on the jumping castle, participated in games of footy and enjoyed being themselves. The children’s play was probably the most meaningful part of the evening; everyone witnessed “kids being kids”, and everyone having a good time in a community setting. Many families commented about the children and that everyone was fully included.

Families with children with Autism came with their extended families. When speaking to families, some indicated that they had brought their family members to help these key people in the lives of their child, and to have a better understanding about what it means to have Autism. Some families travelled great distances to attend.

Members of the local community came to enjoy the free meals or to watch the reptile and magic show. These families were also able to learn more about Autism.

A range of flyers and information sheets were taken home by families.

It is difficult to measure how attitudes have changed in the local and surrounding areas but on the night, it certainly felt like there was a shift in the understanding of the community and that children with Autism will be better included in general community settings.

6. ACT NOW gathering

ACT NOW 2 was a three day ‘gathering’ event where over 200 Aboriginal community members, ADHC representatives and non-government organisations from the Mid North Coast, Far North Coast and New England regions came together to yarn about better ways to support Aboriginal people with disability, and their networks of support. The gathering was an excellent opportunity to work with Aboriginal families to co-design support for their children. Two Co-design Project families participated in ACT Now 2, participating in co-design activities.

The Co-design Project Officer worked together with the ACT NOW 2 steering committee members who came from Aboriginal sections of ADHC, and a mixture of non-government support and development services. This group worked in an enthusiastic and passionate way to create a good life for Aboriginal people.

This gathering was a time for ADHC staff, non-government community service staff and Aboriginal people with disability and their families to come together to learn about new models of disability support, be inspired by others, and to yarn about how Aboriginal people can be best supported in the future.
Appendix B: Information Statement and Consent Form

THE UNIVERSITY OF NEW SOUTH WALES AND MID COAST COMMUNITIES
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Research and Family Agency Capacity Project

What is this study about?

This study is the Family Agency and Co-Design Project. This Project aims to work with families in mid north coast NSW who have a young child (0-12 years) with a disability, to enable them to participate in designing the best support for them.

What is the aim of the study?

The aim of the study is to assist families to have a say in the support they receive by participating in the design of that support. We also want to know if participating in the design of support helps families, and if so what is helpful about it.

Why have I been invited to take part in this study?

You have been asked to take part in this study because you are the parent of a child with a disability, a delay, or there is something about your child’s development that is concerning you.

If I agree to take part, what is involved?

If you decide to take part in this study, we will speak with you about your experiences of having a child with a disability, and what you think would be helpful for you in getting better support for you and your family. We will also speak with you about the rest of the project, which is about parents and Mid Coast Communities working together to design support. The interview will take about 1 hour. The interview will be conducted by the Project Officer from Mid Coast Communities. A few months later you will be asked if you would like to take part in a follow up interview or focus group (with 6 to 8 people). If you agree, this interview or focus group will cover similar topics, take about one hour and again you will be reimbursed for your time.

Will my responses be kept confidential and anonymous?

We would like to take notes during the interviews and will ask you to agree to let us record the interview to make our notes better. You will not be identified in any of the reports or papers that we write or publish. What you tell us will be completely confidential and will not be told to anyone other than the researchers involved in the study, except as required by law. We also ask that all participants in today’s focus group agree to keep confidential any information that is shared by others during the focus group discussion.

How will my responses be used?

We will be interviewing as many participants as we can from the Program across Coffs Harbour, Nambucca Valley and Bellingen. This will help ensure we have
views from different people living in different areas around mid north coast NSW. All interviews will be conducted in September 2013. All the findings will be reported in a Final Report in December 2013. We will also write journal articles based on the findings. If you would like a short summary of the main findings from this study, please indicate this on the last page of this Form. We will send this to you by email or post (as per your request).

Will I receive any reimbursement for my participation in this study?

We expect that the interview will last for approximately 1 hour. We acknowledge that this is a significant amount of your time, and as a sign of appreciation Mid Coast Communities will reimburse you $30.

Are there any benefits for taking part in this study?

The results of this study will be used to identify key themes and make recommendations for future strategic planning and development. As a participant in this study, you have the opportunity to express your needs and experiences (both positive and negative), and contribute to the improvement of projects like this one in the future. However, we cannot and do not guarantee or promise that you will receive these or any other benefits from this study.

Are there any risks for taking part in this study?

It is possible that as a result of the discussion in this focus group, you may experience some level of distress. If this is the case, please inform the research team immediately.

What if I don’t want to take part or what if I change my mind later and want to leave the study?

Taking part in this study is voluntary. You do not have to take part if you don’t want to. If you decide to take part and then change your mind, you can leave (withdraw from) the study at any time. After starting the interview, you can choose not to answer some questions and you are free to leave the interview at any time. Your decision whether or not you take part will not have any effect on your future relations with The University of New South Wales or Mid Coast Communities.

I want to take part in the study ... So what do I do now?

If you have read this Participant Information Statement and are happy to take part in the study, please now sign the Consent Form on the next page.

If you do not wish to sign the form but still want to take part in the study, a verbal consent is acceptable.

Who can I talk to if I have any problems with this study?

If you have any concerns or complaints at any time about your part in the study, you can contact the Ethics Secretariat, University of New South Wales, Sydney 2052, phone (02) 9385 4234, fax 02 9385 6648, email ethics.sec@unsw.edu.au, quoting this reference number: HREC HC13085. Any complaint you make will be investigated promptly and you will be informed of the outcome.

Any other questions?

If you have any questions during the interview please ask Anna Thompson (Project Officer from Mid Coast Communities). If you have any additional questions later, kylie valentine (Chief Investigator from the University of New South Wales, 02 9385 7825) will be happy to answer them.

This Participant Information Statement is for you to keep.

Staff from Mid Coast Communities are experienced in addressing psychological distress. They will be available during and after the interview if you would like to talk to someone about any problems you are experiencing. If you want to talk to a different counsellor you can call:

Lifeline (a free 24 hour counselling service) on 13 11 14
You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

<table>
<thead>
<tr>
<th>Signature of Research Participant</th>
<th>Signature of Witness</th>
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<tbody>
<tr>
<td>(Please PRINT name)</td>
<td>(Please PRINT name)</td>
</tr>
<tr>
<td>Date</td>
<td>Nature of Witness</td>
</tr>
</tbody>
</table>

If you would like a copy of the summary of research findings, please provide your preferred address.

- [ ] My email address:

  

  OR

- [ ] My postal address:
I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise my relationship with The University of New South Wales or Mid Coast Communities.

(Please PRINT name)

The section for Revocation of Consent should be forwarded to Dr Kylie Valentine, Chief Investigator, Social Policy Research Centre (SPRC), University of New South Wales (UNSW), Sydney NSW 2052, (02) 9385 7825, k.valentine@unsw.edu.au.
Appendix C: Demographic Survey

You do not have to answer any or all of these questions.
Please ask if you are unsure.

1. How old are you? (in years)

2. What is your gender? (Please circle)
   - FEMALE
   - MALE

3. What is your postcode?

4. What is your cultural background? (You may tick more than ONE box)
   - Aboriginal and/or Torres Strait Islander?
   - Anglo Saxon and/or Celtic?
   - Non-English speaking background (NESB)?

5. Are you in paid employment?
   - Yes, I work full time
   - Yes, I work part time
   - No, I am not in paid employment

6. Is your partner in paid employment?
   - Yes, my partner works full time
   - Yes, my partner works part time
   - No, my partner is not in paid employment
   - N/A, I do not have a partner

7. When did you start the Family Agency and Co-design Project? (DD/MM/YY)

8. When did you end the Family Agency and Co-design Project? (DD/MM/YY)

9. How many children under 18 years do you have significant caring responsibilities for?

10. For each of these children, please complete the following information:

   - Child, Date of Birth (DD/MM/YYYY) Does this child have a disability? Yes/No If yes, what type/s of disability?

<table>
<thead>
<tr>
<th>Child</th>
<th>D.O.B</th>
<th>Y / N</th>
<th>TYPE OF DISABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>6</td>
<td><strong>/</strong>/___</td>
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</tbody>
</table>

11. How would you rate your levels of stress before beginning the Family Agency and Co-design Project? (Please circle ONE number between 1 and 10. 1 = No stress at all; 5 = Moderate level of stress; 10 = Very stressed)

   1  2  3  4  5  6  7  8  9  10

12. How would you rate your levels of stress after completing the Family Agency and Co-design Project? (Please circle ONE number between 1 and 10. 1 = No stress at all; 5 = Moderate level of stress; 10 = Very stressed)

   1  2  3  4  5  6  7  8  9  10
13 Are there any issues related to mental health that you think significantly affect your life? (You may tick more than one box)

- Depression
- Anxiety disorders
- Bipolar disorder
- Substance use disorder
- Other

Please list up to three other issues (e.g. PND, OCD, PTSD)

1.
2.
3.

- N/A – I do not think any mental health issues affect my life

14 Did you attend the family gathering meetings held by Mid Coast Communities as part of this Project?

- No
- Yes

Please list these here (e.g. Coffs Harbour, Nambucca Valley, Bellinger)

1.
2.
3.

15 Which services events or programs related to family agency and/or support services for families with young children with a disability have you used in your local community and how long for? (E.g. Education, early childhood, health services etc.)

Number Name of service or program Start date (DD/MM/YY) End date (DD/MM/YY)

<table>
<thead>
<tr>
<th>No</th>
<th>Service</th>
<th>Start Date</th>
<th>End Date</th>
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<tr>
<td>1</td>
<td>Family Fun Days</td>
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<tr>
<td>2</td>
<td>Increasing school inclusion</td>
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<td>3</td>
<td>Action learning sets</td>
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<td>Big Plan events</td>
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<td>5</td>
<td>Bello Belonging</td>
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<td>6</td>
<td>Developing a family education hub</td>
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16 Since starting the program with Mid Coast Communities, do you access any information about issues related to family agency and/or support services for families with a child with a disability outside of the program? (e.g. from websites, organisations, etc.)

- No
- Yes

Please list these here

1.
2.
3.
4.
5.
6.
17 Do you have any other comments or suggestions that you would like to make? (E.g. You may have forgotten to mention something, did not feel comfortable to mention it, or did not have the opportunity to mention it during the interview).

Examples:

• Any positive or negative experiences with the way the program was implemented?

• Any feelings or thoughts about the current state of support services to families with young children with a disability?

• Any suggestions for Mid Coast Communities about what they can do to increase family agency?

• Or any comments about the research project/ interview itself?

THIS IS THE END OF THE DEMOGRAPHICS SURVEY.

THANK YOU VERY MUCH FOR YOUR TIME.
Appendix D: Interview Schedule

**Initial Interview Questions**

1. The first question is about your family’s history and experiences since diagnosis of your child’s disability. So … (20 mins)
   - Can you tell us a little bit about your family: who lives with you, how many children do you have?
   - Can you tell us about the child with a delay or disability? (how old, when first concerned, diagnosis or not, challenging behaviours or other social constraints)
   - (if not referred from disability service): Does your child attend any early intervention or therapy services?
   - Having a child with disability or concerns can be a big challenge for families. How has your experience been for you and your family (partner, child, siblings) since you first became concerned about your child? [Let them answer first (i.e. it needs to be open-ended question and response), and then prompt them with the following to fill in any gaps they may not have brought up themselves]
     - Strength of relationships within families
     - Empathy within families
     - Economic stress
   - (if connected with disability or EI services) Thinking about the services and organisations helping your child, how is your relationship with those services?
     - How often do you talk with them, and how useful are the conversations for you?
   - Who else do you talk to about your child and your plans for the future? (If you want to talk to someone, is there someone you can talk to about this?)
   - Where do you get most of your information about your child’s disability, and about other families in similar situations?

2. The second question is about your well-being and support for you. So … (20 mins)
   - How long have you lived in this area? Do you have extended family, close friends locally? Who do you call on in an emergency?
   - Are there people who know your child well, and can sometimes help out by looking after them?
   - Are you happy with how your child’s school/preschool communicates with you? Would you like more of a say in what happens?
   - Has there been a situation where you weren’t happy with your child’s school/preschool/service? What did you do?
   - Who do you feel is ‘in charge’ of your family’s plans? (prompt: is it you, is it a therapist, are there no plans.)
   - How connected would you say you were to your local community? Is this a good place to be for a family like yours?

3. Explain co-design and the aims of the program. The third question is about your expectations of the program. So … (15 mins)
   - Why have you signed up to be in this program?
   - What are you hoping to get out of this program?

4. Do you have any other comments you would like to add? (5 mins)
   - E.g. Perhaps you didn’t say all you wanted to, or the questions we’ve asked didn’t cover what you were hoping to talk about?

**Follow-up Interview Questions**

How did you find the co-design process/service development?

Was it stressful to be part of the study and co-designing? Has it been a good experience?

Do you feel more in control as a family?

Is there a change in confidence?

How do you feel about participating in the program?

Do you have any suggestions to build family resilience?
This literature is intended to (i) build knowledge by addressing a current gap in the literature on co-design and family agency, and (ii) help families and service providers be better ready for the implementation of the National Disability Insurance Scheme (NDIS), which is built on an individualised funding model of service delivery. These are described below.

While much is known about family agency (i.e. empowerment) among families with children with disabilities and factors that can affect it (e.g. the effectiveness of early intervention services and family-centred programs; the impact on families of having a child with a disability), much less is known about how family agency is affected by the co-design of services and supports. Even less is known about the effectiveness of co-design strategies for families with young children (0-8 years) with a disability, who are likely to be closer in experience of a recent diagnosis. This literature review therefore addresses an important gap in the knowledge base around family agency and co-design among families with young children with a disability.

**What is the NDIS?**

In 2014, the Australian Federal Government commenced implementing the NDIS. The design of the NDIS places emphasis on:

- Embedding person centred supports in all aspects of the service system
- A life span approach to early intervention and prevention which includes life-long planning and an expanded and more flexible range of supports
- Building the long term capacity of the system to respond to growing demand, and
- Whole of government collaboration in creating an effective support pathway and the creation of inclusive communities.

**What is individualised funding and how is it related to the NDIS?**

The NDIS is a response to research and a movement within the landscape of disability politics that has amassed over many recent decades, starting in the late 1980s (Bennett, 2009). The trend has increasingly moved towards empowerment and inclusion of people with disability in the choices they make regarding the services and supports they use and receive, and thus choice over their own life. One way in which this empowerment and inclusion are enacted is through the use of individualised funding, which has been defined as ‘funding allocated directly to an individual or in the case of a child, their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens’ (Stainton, 2008, as cited in Bennett, 2009). In other words, block funding is not provided to agencies (Lord & Hutchison, 2008; Bleasdale, 2001). Its rise in prevalence is in line with changes occurring in other comparable, developed countries such as New Zealand, Canada, the UK, and the USA (Bennett, 2009).

According to Ottmann, Laragy and Damonze (2009), consumer-directed care (CDC) is a term that emerged within the North American context, and elsewhere is known under names such as ‘flexible funding’, ‘individualised funding’, ‘self-management’, ‘cash for care’, and ‘independent living’. It is regarded by many as a means to empower consumers and is comprised of four components (Kosciulek, 2000, as cited in Ottmann, Laragy & Damonze, 2009):

1. Consumers control and direct services
2. Have access to a variety of service options
3. Have access to information and long-term supports that create personal, legal, and financial safeguards, and
4. Participate in policy making and have design and decision-making input.
Individualised funding is typically characterised by a defined package of funding allocated to the person with a disability or someone in their immediate network of friends or family, or a state allocated broker or representative for the purposes of purchasing support that reflects individual needs and preferences (Glendinning, 2008; Leece & Bornat, 2006). It aims to promote personal responsibility, independence, capability and resilience through the delivery of low-cost and innovative services chosen by the consumer or their appointed representative, including both being able to select the type of support rendered and who it is delivered by (Glendinning, 2008; Leece & Bornat, 2006). Additionally, this approach to funding for disability support promotes meaningful social inclusion by increasing the opportunity for people with disabilities to participate in their local communities.

Individualised funding is consistent with a person-centred philosophy, a social model of disability and a human rights perspective (Bennett, 2009; Lord & Hutchison, 2008). It has responded to growing demand for increased independence, choice, control, and empowerment for people who use disability services and over the lives they lead (Bennett, 2009), reflects a commitment to self-determination and community participation (Lord & Hutchison, 2003), and is also based on the assumption that “people must not be required to give up their right to acquire income and personal assets in order to access public funding for disability supports” (Seattle 2000 Declaration [Seattle Declaration on Self-Determination and Individualised Funding]). Importantly, Williams (2007) argues that genuine control over the funds by the person or nominated advocate is necessary, and that substitute decision-making, where a funder/provider consults with the person, and then makes the decisions about what to provide, is not necessarily individualised funding” (as cited in Bennett, 2009).

Self-directed individual funding for disability services can assist people with disabilities and their families to link with a variety of disability-specific and mainstream services in their local community. Examples of programs that include small individual funding packages for children with disabilities and their families that can be found in Australia, are the NSW Family Assistance Fund, the WA Level One Funding administered through Local Area Coordinators, and the Queensland self-directed support pilot. These programs share goals about participation, integration and resilience, through the flexible purchase of support outside the specialist service system (Leece & Bornat, 2006).

**What are the benefits of individualised funding?**

Individualised funding is seen as both an effective, and cost-effective, way of meeting the needs of people and families with a disability. It is considered effective because it allows for a flexible, tailored response to a family’s unique circumstance and offers them choice in the services and supports they wish to use, boost, access and/or receive to meet their needs and aspirations. The results of the extensive literature review conducted by Bennett (2009) shows more specifically that compared to non-users (i.e. users of traditional service approaches), users of individualised funding report:

- Higher satisfaction with degree of independence and control they have over services in the community they choose to use
- Increased control over a range of decisions such as choice of staff and the time that support is provided
- Improved quality of life as measured through a range of indicators including improved self-esteem, social, psychological wellbeing, community presence and participation, employment, and education
- Improved quality of support across a range of dimensions such as personal dignity, safety, meals and nutrition, social participation and involvement, occupation, accommodation cleanliness and comfort
- Positive effects on physical health and wellbeing attributed to long-term and trusting relationships with carers supported through IF initiatives, and
- Improved relationships with family and increased participation in the community.

Individualised funding is also considered cost-effective because it works off the premise that, since families are in control of their services and supports then they “avoid the (later) development of crises that may require more expensive intervention” (Bennett,
2009, p. 94). It is also seen as “less expensive than traditional models of health and social care, which are characterised as inherently structurally wasteful primarily because resources are directed to services rather than people” (Bennett, 2009, p. 94).

**What are the problems associated with individualised funding?**

Despite some evidence about the cost effectiveness of individualised funding, Bennett (2009) argues that some authors are cautious of this as “the scope and focus of evaluations of individualised funding are limited, the sample sizes are small, and concerns have been expressed about the generalisability of findings” (p. 94). For example, “little is known about those who do not choose to participate in individualised funding (IF) schemes, and what the barriers to access and engagement with IF are for specific population groups, in particular minority ethnic groups and mental health service users” (Bennett, 2009, p. 41).

In fact, the literature on individualised funding more generally has not been without its reservations, pointing to several issues that can compromise its effectiveness. For example, Bennett (2009) says that “while much of the literature about individualised funding demonstrates positive outcomes, it is important to note that it is primarily focused on the initial perceptions and preliminary impacts of accessing individualised funding (IF)” (p. 94).

This is consistent with the findings of the longitudinal qualitative study conducted by (Ottmann, Laragy & Haddon, 2009), which showed that gains in terms of empowerment at the beginning of a program are not necessarily sustained over its course. They found that:

The sensation of empowerment that surfaced early on in the project appeared to be based on a better understanding of the service system, the funding packages that underpin it and the service options available to them ... Also, the formation of informal support groups added to their sense of empowerment as it gave families additional encouragement and assistance, and that families no longer had to negotiate with case managers added to their sense of autonomy and independence ... Over time (after four years), this knowledge-based sense of empowerment translated into an experience that leading a more fulfilled life was indeed possible ... (However) by focusing on a longer time frame the study was able to bring into view risks associated with CDC. For example, as carers disengage from information sources and support networks, CDC may contribute to an increased sense of isolation and a lack of support during transition and/or crisis points (p. 475).

As a result of these findings, these authors argue for the development of mechanisms to help safeguard families who face crisis points. Importantly, these findings question the sustainability of CDC (or individualised funding) models.

In addition to issues of generalisability and sustainability, Bennett (2009) identifies a range of key barriers to the effective implementation of individualised funding, for both funders and service providers, and for people with a disability and their families. For funders and service providers, the main barriers include:

- Individualised funding arrangements not implemented at the local level
- Insufficient staff training and support sessions
- Organisational cultural resistance, and
- Efforts not sustainable in the longer term because of resource issues such as inadequate funding.

For people and families living with disability, barriers to effective individualised funding arrangements include:

- Poor access to or communication about information on services which compromises their capacity to make choices about their options
- Concern about the complexities of understanding the system and the burden of administration (Bigby, 2008), and
- Lack of availability of independent support services.

Other authors have also commented on problems associated with individualised funding (e.g. (Cortis et al., 2013; Wilberforce et al., 2011). For example, Bleasdale (2001) notes the following challenges to funding bodies:
• ‘Unbundling’ block-funded services
• Ensuring equity whilst determining resources according to need, and
• Maintaining standards within the purchased service sector because it is essentially now less regulated.

He also notes that “service providers too are nervous about a radical transition to a demand-led system, some with good reason” (Bleasdale, 2001, p. 12). The following challenges to service providers are identified:
• Ongoing service viability given the removal of the certainty of block grants
• Contractual complexity, i.e. the proliferation of contracts that individualised funding requires will affect service providers and funding bodies
• Delivering flexible supports which could be difficult for agencies who are not ‘in the habit’ of doing so anyway, and
• Improving quality within existing resource constraints, because the introduction of individualised funding does not necessarily mean that the funding base for agencies will be expanded.

Finally, challenges to individuals include managing the complex affairs and contracts that go with being a recipient of government funds, and in many instances, with being an employer, resulting in a need to understand how to hire, fire and manage staff well, with due regard to legal levels of wages and conditions (Bleasdale, 2001).

Lord and Hutchison (2008) also report various reasons for why caution is exercised among researchers on individualised funding:
• In reality it is very difficult to customise supports
• The market approach to disability supports is also leading to the commodification of community supports (because “individualised funding provides an opportunity for service users to take their funding elsewhere if they are not satisfied with the standard of service they receive, or if they believe that their concerns are not being addressed”
• The whole procedure of personal budgets has been found to be confusing and complex to study participants warning of the importance that they should be implemented incrementally and very carefully
• Not everyone wants full individualised funding
• Individuals and families may receive less funding than they requested, and
• Funding could come from multiple government sources.

**Summary: How this literature review has implications for policies on individualised funding**

It is important that practitioners and policy makers are aware of potential issues that can arise in the use of the ‘person-centred’ NDIS that makes use of individualised funding, particularly to aid improving it and, in turn, be more prepared for its implementation. In other words, if this literature review is able to find evidence of, and identify the conditions under which there is and is not, an effective relationship between co-design and family agency, then it will help the services sector and families involved with them to be better prepared for the implementation of the NDIS. It will also help answer the broader question ‘Is the provision of individualised funding the best way of meeting the needs of families with young children with a disability?’ Importantly, the discussion on individualised funding here is not to review the literature but to simply set the context; that co-design occurs within the ‘individualised funding’ framework or approach to service development and delivery.

The literature review will be used in this study in a number of ways. It will:
• Explore notions of family agency and identify enablers of and barriers to family agency (in conjunction with the initial and follow up interviews); that is, research the conditions that foster family empowerment and agency, and find out what families with children who have a disability require to co-create services and community connection
• Be used to develop a draft framework for developing family agency capacity in program families through co-design activities (this framework
will be used by Mid Coast Communities when they work with program families and will be refined throughout the life of the project)

- Be used to inform the questions and prompts in the interviews schedules to be used during the initial and follow up interviews, and
- Be used to identify resources that families can use to help build and maintain family agency.

To achieve these aims it will collect and analyse evidence on national and international programs and related evaluation methodology and findings for comparative purposes so that (a) lessons can be learnt from previous experience (b) informed adjustments can be made to the Project and (c) evaluation to improve its effectiveness can be conducted. In short, it will summarise current thinking about successful family agency and principles of the co-design of services.

1. Method

Search terms and databases

The search engine used was Google scholar. Search terms included disability, family agency, empowerment, family resilience, and co-design.

The following search terms were not used directly but were part of the inclusion criteria (that is, if articles focused on these topics they were included): participatory research, participatory action research (PAR), co-production, individualised funding, parental efficacy, parent empowerment, competence, early intervention, autism spectrum disorders (ASD), cerebral palsy, physical disabilities, intellectual disabilities, deafness, blindness, acquired injury/disability, strengths-based, self-reliance, self-determination, family quality of life, consumer directed participation/services, family-centred services, and service satisfaction.

Some literature was also provided by Mid Coast Communities and these works have been mostly used to help establish a policy framework.

Exclusion criteria on the year of publication were not strictly implemented so that seminal works were not excluded, however generally literature published 2000-2013 has been used so that the most recent literature has been reviewed here. Other exclusion criteria such as country of research were also not implemented.

Methodological limitations

There is an abundance of research on the impact on families with a child with a disability, early intervention responses to families with a young child with a disability, parental satisfaction with services, family centred programs, family resilience and quality of life, empowerment and consumer-directed services. There was, in comparison, far less on the co-design of supports and services. The current literature on co-design in the disability sector spans a diverse range of topics from the co-design of curricular in school teaching to the co-design of housing for people with disabilities to inclusive co-design on computer integrated technologies (ICTs), but the literature on the co-design of supports and services is scant. This compromises the capacity of the literature review to provide a definitive or empirically grounded response to the question ‘Do families build agency by being involved in the co-design of services and supports?’ which is the main aim of this study. Nevertheless, the nascent literature can provide a starting point for integrating knowledge on co-design with family agency.

Also, while the literature on relevant topics in this study such as the impact on families with a child with a disability, parental satisfaction with services, family resilience, quality of life and empowerment, are numerous, the extent to which diverse samples are affected by these things is notably small. Therefore, literature on how these issues affect Indigenous Australians, ethnic minorities of non-English speaking background, or fathers and single parents, for example, is comparatively small.

2. Findings

Family agency

In the context of this project, agency is one of a number of distinct concepts with shared elements that are relevant to families where a child has a disability. These elements include empowerment, power, self-determination and a self-determined life, self-advocacy, participatory action research methods, emancipatory research, process and outcome, causal agency, self-directed support seeking, freedom in goal setting, decision making and problem solving,
efficacy, competency, capability, control, confidence, family capacity, family and individual quality and life, and family and individual resilience. All of these terms capture the various notions of family agency.

Family agency refers to a sense of empowerment and control among families with a child with a disability (i.e. feeling they are an agent of their own affairs), and family capacity refers either to a family’s sense of capability to choose and make decisions about their own care or the resources they have such as strong community supports that facilitate that sense of capability (i.e. feeling capable of being an agent of their own affairs). For example, Neely and colleagues (2008) found that people with mild intellectual disabilities reported greater choice in services than those with severe disabilities, suggesting that the support needs of the person with disability may impact on the (perceived) effectiveness of consumer-directed services.

Increased personal agency on the part of parents is linked in research to parents becoming more connected to social support networks and is understood to increase the likelihood of parents seeking appropriate support when needed, advocating for their children, being involved in their schooling and protecting them from harm (M. R. Sanders, 1999). Therefore, the empowered and self-directed seeking of support and connections yields positive outcomes for parents and children with a disability (and is a way of organising consumer-directed care).

Indeed, there is no shortage of literature that shows that empowerment in parents is key to the family’s capacity to represent the needs of their child with a disability. In the literature on empowerment among families with a child with a disability, several other related terms and concepts are also spoken of, such as self-advocacy, person-centred, self-determination, causal agency and emancipatory research. A discussion of these terms follows.

Arguably, the most important self-advocate of empowerment is Charlton (1998) who coined the widely known phrase (and the title of his book) “nothing about us without us”. It was written in response to, and with the aim of representing the, oppression and indignity that people with disabilities live and experience in their daily lives. It marked the beginning of a serious movement towards participatory action and emancipatory research methods and policy making because these were seen to enhance the self-determination of people with disabilities (Barnes, 2003). This is consistent with the assertion of van Houten and Jacobs (2005) that empowerment strategies necessary to create a ‘varied society’ based on notions of diversity are above all bottom-up.

Wehmeyer (2004) says that “people with [intellectual disability] can become more causally or agentically capable by improving goal setting, decision making, problem solving, self-advocacy skills, or increasing their opportunities for exercising existing causal or agentic capacities by having more opportunities to exert control over resources that impact their lives” (p. 357). Models of consumer directed care (CDC) or individualised funding are in line with this view. However, he also presents an interesting discussion on the term ‘self-determination’ and argues instead for a language that stresses ‘causal agency’ because:

The term self-determination has become laden with multiple meanings and intents that have resulted in confusion and misunderstanding ... It has become a buzzword, implying different things to different people. It is also based on values and priorities that do not reflect the beliefs, values, and practices of cultural groups other than those of mostly Western communities, questioning the applicability of the construct to their lives ... (Thus) it may be time to move beyond self-determination, not in the sense of abandoning its intents, but toward promoting the outcome that people live “self-determined” lives ... (because) there is still uniformity and clarity about what one means when one refers to a self-determined person (with causal agency) (p. 338).

One of the most common points of confusion around the terms empowerment and self-determination are in regards to whether they are a process or outcome. For example, Starkey (2003) points out that:

Although empowerment might be seen as an outcome in terms of ‘feeling empowered’, this suggests that an end-point can be reached where empowerment has ‘occurred’. It is argued instead that empowerment is not a fixed concept, but a dynamic and fluid process operating at different levels and potentially open
to disempowering events or forces which ‘set back people’ in this process (p. 281).

Therefore, there are risks with falsely reducing empowerment to an outcome only. Interestingly, Sprague and Hayes (2000) see that “to empower someone is to facilitate their self-determination” (p. 681). Empowerment is therefore seen as the vehicle towards self-determination. However, these authors also note that:

When professionals talk about the self-determination of people with developmental disabilities, they tend to talk about the possession of attributes that lead to specific behaviour patterns or outcomes such as having a paying job and living in an apartment or group home for the disabled. This focus on specific outcomes is an example of objectification, denying the subjectivity of people who are “free to choose their own behaviours in accordance with one’s inner needs, feelings and thoughts” (Deci, 1980, p. 112) and thus which argues for the freedom to be a self-reflective person developing a positive self (p. 676).

Another issue with empowerment is in regards to its relationship with power. Starkey (2003) notes that “it is important to ensure that any definition of empowerment is underpinned by a theory of power, yet this link is often not made in the literature” (p. 281). She goes on to say that, “if service users so desire, professionals can work to support people to develop their own power both personally and collectively, which may then extend beyond their contact with services” (p. 281). Subsequently, the way families and service providers work together is important for understanding the relationship between empowerment and power, not just between families and service providers, but within families themselves. Indeed, Sprague and Hayes (2000) argue that empowerment is a characteristic of relationships and therefore the kinds of relationships that are empowering need to be identified. In particular, they see that “ongoing connections with others who share one’s struggles and need one’s support” (p. 681) are an important characteristic of such relationships, highlighting the role of community connections outside of the formal services sector. Overall however, the importance of collaborative and equitable relationships are seen as key.

In summary, the literature on family agency, empowerment and self-determination describes the principles that people with disabilities are free to make choices about the services and supports they wish use and therefore the choices they make over their own life, and the circumstances that enable this. Empowerment and self-determination are both a process and outcome that aims to give people with disabilities power in their relationships with others (especially service providers), but also in meaningful everyday relationships, so that they can be causal agents in their self-determined lives.

Family agency (or sense of empowerment) over the services and supports that families with a disability choose to use or access is seen to occur when families also shows signs of quality of life and resilience. That is, family quality of life and family resilience are considered to be two of the most important and desired outcomes of the process of family agency. These two concepts are described below.

**Family quality of life**

According to Samuel and colleagues (2012), the concept of family quality of life (FQOL) emerged during the early 90s out of the individual quality of life literature, but the move towards a holistic measure of it at the family level was championed by scholars and practitioners in the fields of intellectual and developmental disabilities. Importantly, these authors assert that the concept of FQOL challenges assumptions about whether family agency does in fact increase wellbeing and quality living because it explores the reality of family life in a range of different domains:

The success of an increased role for families relies on assumptions by policy makers that most families are both able and willing to act as the main caregivers and decision makers, and that family life will be enhanced as a result of their greater involvement ... Qualitative data from family support programmes suggests that a family-centred, strengths-based approach is effective in empowering families of children with disabilities (Samuel et al., 2012, p. 2).

The study by Jackson and colleagues (2010) on FQOL following the early (as opposed to late) identification of deafness in children under six years in 207 families is important for showing that families do generally show
satisfaction with various areas of family life, but that emotional wellbeing was most negatively affected (but also time demands, financial wellbeing and support for the child who is deaf). This suggests that service providers who engage with families with young children with a disability should be particularly watchful of parents’ emotional well-being.

There is quite extensive research on cross-cultural differences in FQOL. For example, these two common instruments have been translated into other languages and results generally support the comparability of the instruments across cultures; Hu et al. (2012) found that the five factor structure of the FQOL Scale (FQOL-2006) validated on US samples replicated in a sample of 442 families in China.

The research on FQOL has led to development of several quantitative scales that measure FQOL among families with a disability. Hu et al. (2011) found 16 quantitative measures of family quality of life, wellbeing and satisfaction in the literature. Two of the most common scales used to measure FQOL are:

1. Beach Centre FQOL Scale (Park et al., 2003) which is comprised of five domains; family interaction, parenting, emotional wellbeing, physical and material wellbeing (ii)

2. Family Quality of Life Scale (FQOLS-2000) (Brown et al., 2003) and FQOLS-2006 (Brown et al., 2006), which are comprised of nine similar domains; health of the family, financial wellbeing, family relationships, support from others, support from disability-related services, influence of values, careers and preparing for careers, leisure and recreation and community interaction.

Family resilience

There are several definitions of resilience and family resilience in the disability-related literature. Bandura describes (personal) resilience as the complex interaction between the person and environment and is seen as being related in part to self-agency (as cited in Bentley-Williams, 2006). Certainly resilience in individual family members affects resilience in the family group; for example, Bentley-Williams (2006) found in his in-depth case study of one family that “surprisingly, it was the youth with the intellectual disability himself who had a powerful influence on building the family members’ resilience” (p. 8). He also more broadly found that family resilience was enhanced as a result of facing a range of negative situations and challenges which contributed to the family members’ determination to achieve despite others’ low expectations, and that relationships and strong connections between all family members in which there was a genuine sense of care, concern and empathy united them through hardships and the hurdles of experiencing rejection and setbacks.

Similar themes have been reported by other authors. For example, Hall et al. (2012) found that parents who quantitatively experienced high stress or low stress used different behavioural themes to describe their experience qualitatively. Specifically, parents who experienced less stress reported positive appraisals, resources, and ability to engage in problem solving and coping, which in turn were associated with family resiliency.

Rolland and Walsh (2006) highlight that family resiliency is not a fixed attribute. The important implication of this is that resiliency can be improved by interventions:

Resilience can be defined as the ability to withstand and rebound from disruptive life challenges, becoming strengthened and more resourceful. Not simply general strengths, resilience involves dynamic processes that foster positive adaptation in the context of significant adversity. It is a misconception that resilience means innate hardness, invulnerability, or simply bouncing back. It rather involves struggling well, effectively working through and learning from adversity, and integrating the experience into the fabric of individual and shared lives (p. 527).

These authors also stress that the family response to illness is crucial and that a family resilience orientation to practice needs to identify and build on strengths and potential in the family network, including parental and couple relationships, sibling bonds, and extended kin support. They offer a comprehensive description of the characteristic features of family resiliency (summarised in Table 1).

Resilience has been empirically demonstrated in diverse families such as single parents (Levine, 2009), and in families with children with a wide range of disability types, such as children with a genetic
disorder/disability (Hall et al., 2012), children with autism (Bayat, 2007), intellectual disabilities (Gerstein et al., 2009) and children with physical disabilities (Greeff et al., 2012).

In short, the term ‘resilience’ in relation to families is used to refer to their ability to function effectively or positively in ‘adverse circumstances’ (Masten, as cited in Schoon, 2006). It is also used to refer to the ability to achieve developmental milestones, wellbeing and goals, despite vulnerability and disadvantage (Schoon, 2006). As such, resilience is an important outcome for the families of children with disabilities.

Importantly, childhood resilience is a result of the complex interaction between parenting factors, a stable and safe home environment and an influential adult outside of the home (Masten et al., 1999; Muir et al., 2008). Less is known about adult resilience, though two major factors considered to contribute to it are paid employment and a united family (Muir et al., 2008).

Some families where a child has a disability experience additional demands and are more likely to experience risk and vulnerability compared to other families (Muir et al., 2008). Young adults with acquired disabilities experience similar vulnerability as they transition into and experience adulthood. Without adequate supports and services these families and people with disabilities can experience significant stress (Muir et al., 2008). Self-directed support can assist in mitigating these stresses and improving outcomes for the person with a disability and their family by offering a tailored solution outside of the traditional service system (Powers et al., 2006).

### Table 1: Key processes in family resilience (Rolland & Walsh, 2006)

<table>
<thead>
<tr>
<th>Belief systems</th>
<th>Make meaning of adversity</th>
<th>Positive outlook</th>
<th>Transcendence and spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• View resilience as relationally based – versus ‘rugged individual’</td>
<td>• Hope, optimistic bias; confidence in overcoming odds</td>
<td>• Larger values, purpose</td>
</tr>
<tr>
<td></td>
<td>• Normalize, contextualize adversity and distress</td>
<td>• Courage and encouragement; affirm strengths and build on potential</td>
<td>• Spirituality: faith, healing rituals, congregational support</td>
</tr>
<tr>
<td></td>
<td>• Sense of coherence: view crisis as challenge; meaningful, comprehensible, manageable</td>
<td>• Seize opportunities: active initiative and perseverance (can-do spirit)</td>
<td>• Inspiration: envision new possibilities; creative expression; social action</td>
</tr>
<tr>
<td></td>
<td>• Causal/explanatory attributions: How could this happen? What can be done?</td>
<td>• Master the possible; accept what cannot be changed</td>
<td>• Transformation: learning, change, and growth from adversity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organizational patterns</th>
<th>Flexibility</th>
<th>Connectedness</th>
<th>Social and economic resources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Open to change: rebound, reorganize, adapt to fit new challenges</td>
<td>• Mutual support, collaboration, and commitment</td>
<td>• Mobilize kin, social and community networks; models and mentors</td>
</tr>
<tr>
<td></td>
<td>• Stability through disruption: continuity, dependability, follow-through</td>
<td>• Respect individual needs, differences, and boundaries</td>
<td>• Build financial security; balance work/family strains</td>
</tr>
<tr>
<td></td>
<td>• Strong authoritative leadership: nurturance, protection, guidance</td>
<td>• Seek reconnection, reconciliation of wounded relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Varied family forms: cooperative parenting/caregiving teams</td>
<td>• Couple/co-parent relationship: equal partners</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication/ problem-solving</th>
<th>Clarity</th>
<th>Open emotional expression</th>
<th>Collaborative problem-solving</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Clear, consistent messages (words and actions)</td>
<td>• Share range of feelings (joy and pain; hopes and fears)</td>
<td>• Creative brainstorming; resourcefulness</td>
</tr>
<tr>
<td></td>
<td>• Clarify ambiguous information; truth seeking/truth speaking</td>
<td>• Mutual empathy; tolerance for differences</td>
<td>• Shared decision-making; conflict resolution: negotiation, fairness, reciprocity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Take responsibility for own feelings, behaviour; avoid blaming</td>
<td>• Focus on goals; take concrete steps; build on success; learn from failure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pleasurable interactions, respite; humour</td>
<td>• Proactive stance: prevent problems; avert crises; prepare for future challenges</td>
</tr>
</tbody>
</table>
3. Co-design of support services: key characteristics of families, services, and relationships

There is very little literature directly concerned with if (and when) co-design activities and processes are involved in the support and strengthening of family agency. During the search for relevant literature it became apparent that the body of research on co-design (and co-production) is quite recent, mostly since 2005, and quite small. Indeed, the literature on co-production is notably greater than the literature on co-design which only uses co-design to differentiate itself. Therefore, co-production seems to be the greater trend. Nevertheless, the role of co-design in improving family agency can be explored from the nascent literature.

The literature review also indicated however that there are a number of characteristics of the family and the services sector (i.e. providers and agencies) that affect family agency, both positively and negatively. Therefore, it is important to also cover these areas so that relevant information on families, agencies, and the relationship between them informs the development of co-designed support for families.

Co-design

The terms ‘co-design’, ‘co-production’ and ‘co-creation’ are often used synonymously in the literature. However, Freire and Sangiorgi (2010) argue that there are different processes and that there has been a shift in emphasis from ‘co-design’ and ‘co-production’ to ‘co-creation’, even in a short space of time. These authors define co-design in healthcare services as a partnership in the design development process between patients, professionals and community working together, and the resulting service is implemented by professionals (Boyle & Harris, 2009). Co-production on the other hand asks people’s help, using their capacities, to deliver public services in an equal and reciprocal relationship between professionals and the core economy (family, neighbourhood and community), shifting the balance of power, responsibility and resources from professionals to individuals (Sanders & Stappers, 2008). Finally, co-creation is seen to occur when users are central not only to the design of services, but also to their production and continuous development, so it is based on ordinary people generating the content of services and shaping their nature (Cottam & Leadbeater, 2004; Murray et al., 2006).

These definitions are consistent with other authors in the field (Ryan, 2012; Kettunen, 2010; Ottmann et al., 2011; Coen & Kearns, 2013; Roberts et al., 2012; Bradwell et al., 2008). However, Needham and Carr (2009) add the following motives to study and embrace co-production (as cited in Fledderus, 2012):

- A decline in support of target-based and process driven models of service delivery
- A wish for higher service efficiency because of fiscal pressure
- An increase in the awareness of ‘user-generated’ knowledge
- A desire to strengthen local democracy, and
- A tendency to personalise social service through the effective participation of the people who use them.

As a summary, Bovaird (2007) co-production framework is summarised in Table 2.
Table 2: Bovaird’s (2007) co-production framework

<table>
<thead>
<tr>
<th>Delivery of services</th>
<th>Design and planning of services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals as sole</td>
<td>Service user and/or community as co-planners</td>
</tr>
<tr>
<td>service deliverer</td>
<td>No professional input into service planning</td>
</tr>
<tr>
<td>1. Traditional professional service provision</td>
<td></td>
</tr>
<tr>
<td>Professionals and users/communities as co-deliverers</td>
<td>2. Traditional professional service provision with users and communities involved in planning and design</td>
</tr>
<tr>
<td>3. User co-delivery of professionally designed services</td>
<td></td>
</tr>
<tr>
<td>User/communities as sole</td>
<td>4. Full user-professional co-production</td>
</tr>
<tr>
<td>deliverers</td>
<td>5. User/community co-delivery of services with professionals, with little formal planning or design</td>
</tr>
<tr>
<td>6. User/community delivery of professionally planned services</td>
<td></td>
</tr>
<tr>
<td>7. User/community delivery of co-planned or co-designed services</td>
<td></td>
</tr>
<tr>
<td>8. Traditional self-organised community provision</td>
<td></td>
</tr>
</tbody>
</table>

According to Carr (2012), the term ‘co-production’ first appeared in the 2007 ‘Putting People First’ strategy in England, in line with principles of participation and reflecting a value for social capital (Cahn, 2001; Cummins & Miller, 2007) and a ‘deep’ personalisation through participation and independent living (Leadbeater, 2004; Chetty et al., 2012). It is a term that has become synonymous with innovative approaches (Ottmann et al., 2011). However, Carr argues that “the difficulties of the exercise of power and influence by service users in spaces created and controlled by professionals and their services” still remain (p. 46). Therefore, despite gaining recent currency, movements in favour of ‘co-production’ have not gone uncriticised.

As another example, Pestoff (2009) is sceptical of co-production given that there is no empirical evidence that ‘social value’ is actually the result of co-production (as cited in Fledderus, 2012). Similarly, there is no evidence that there are gains in social trust among citizens after being given more power in the design and implementation of their service choices and use. Fledderus (2012) notes however that several other variables might condition the creation of trust, such as the willingness and abilities of clients, intensity of service contact, individual or collective forms of co-production, and organisational features. However, these reservations of co-production are less relevant in this study, which aims to use co-design instead.

Irrespective, as families in this program will be feeding back their progress on family agency throughout the life of the Project, this study may in fact be exploring the role of co-creation rather than, or in addition to, co-design. That is, because families will be continuously developing the design of their service use, it seems there is an element of co-creation in this Project.

In short, this literature review discusses co-production over co-design but this is an artefact of the greater literature available on co-production. Moreover, given that the three terms – co-design, co-production and co-creation – are often used synonymously when they are in fact different things, it is worthwhile exploring their constituent features and what makes them each different. Finally, as participating families will be involved with Mid Coast Communities beyond the initial development of their own service supports, it seems reasonable to expand slightly on the project’s initial aim and explore whether co-production and co-creation also contribute to family agency.

Characteristics of the family

Greeff et al. (2012) note that when parents are confronted with the birth of a child with a disability, they may face many conflicting emotions such as sorrow, disappointment, guilt, anxiety, anger, bitterness and denial, and they may also feel uncertain or incompetent. Similarly, Rolland and Walsh (2006) write:

serious illness and disability in a child or adolescent pose daunting challenges for families. The profound sense of loss and unfairness of a child’s suffering make it
especially painful for loved ones. The impact reverberates throughout the family system, affecting all members and their relationship (p. 527).

The impact on families of having a child with a disability is usually profound, and can be in both positive and negative ways. Indeed as Rolland and Walsh (2006) note, “the quality of life deteriorates for some families, whereas others are able to rally, weather the challenges, and even thrive” (p. 527).

To examine what impacts the diagnosis of a disability has on the family unit and various family members, it is first important to define what ‘family’ is. For example, grandparents may play a critical role in the caring of a child with a disability and this may be especially important among culturally diverse families (DIA, 2003). Although there are multiple family types and forms, the literature still mostly focuses on nuclear families, examining in particular mothers, fathers and siblings.

In a recent study by Tsao, Davenport and Schmiege (2012), the majority of siblings of children with Autism were found to function well. However, in line with previous (but the relatively small body of) research, they also found that the relationships between siblings when one child has a disability are not identical to the relationships that exist between typically developing siblings. They also found that siblings of children with disabilities engage in a rich and complex set of roles such as that of teacher, caregiver, modeller, and confidant, which may promote developmental benefits for them. However, they argue that, in line with family-centred practice, early intervention services for siblings of children with a disability can also assist them to not only cope with a stressor, but also to adapt and thrive with their unique challenge. The need for support of siblings of children with Autism is enhanced by the behavioural problems frequently associated with an Autism Spectrum Disorder (ASD), such as aggression or temper issues which can cause a variety of negative emotions for typically developing siblings. They point out that the characteristics and support needs of the child with disabilities also need to be taken into account when making decisions about how to support siblings and what kinds of interventions are appropriate for individual families.

Interestingly, the study by Giallo and Gavidia-Payne (2006) on siblings (7-16 years) of children with a range of disabilities (including Down syndrome, intellectual disability, Autism, and Asperger’s syndrome) found that of all the socio-demographic variables examined only socio-economic status was significantly correlated with difficulties in sibling adjustment to a child with a disability. Therefore, the sibling’s gender and age, the gender of the child with disability, the parent’s age, marital status, and number of children in the family do not affect their adjustment. They also found that siblings’ perceptions of daily hassles and uplifts and their coping styles had little to do with their adjustment, but that their attendance at a sibling support group did make a positive difference. Finally, and most importantly, this study found that characteristics of siblings had less to do with adjustment than characteristics of parents and families. Specifically, as parents’ perceived stress decreased, and family problem solving communication, family hardiness and family time and routines increased, sibling adjustment increased.

Overall, the research on the effect of having a child with a disability on siblings indicates that (a) their experiences and needs are unique, (b) they benefit from support groups that are family-centred and early intervention services, and (c) how they adjust to having a brother or sister with a disability is substantially affected by their parent’s behaviours and family factors. Given the importance of parent’s experiences and reactions to the impact of having a child with a disability, this review now explores the effect on mothers and fathers.

Heightened psychological distress is repeatedly reported in the literature among parents and especially mothers (Barlow et al., 2006). For example, Gerstein and colleagues (2009) found that decreases in mothers’ daily parenting stress were associated with a mother’s and father’s wellbeing, perceived marital adjustment, and a positive father–child relationship. However, decreases in fathers’ daily parenting stress were only affected by a mother’s wellbeing and both parents’ perceived marital adjustment, indicating that individual parent characteristics and high-quality dyadic relationships contribute to resilience in parents of children with intellectual disabilities, but that parents also affect each others’ more resilient adaptations. Similarly, Lightsey and Sweeney (2008) found that mothers with lower stress exhibited higher meaning in life, used less emotion-oriented coping and had higher
family cohesion, and that mothers with higher family cohesion had higher family satisfaction. DIA (2003) note that since mothers of children with disabilities exhibit increased symptoms of depression, caregiver burden and stress compared to fathers, these differences are important for practitioners in the way they intervene with mothers versus fathers.

In addition, the economic burden of raising a child with developmental disabilities has a particular impact on mothers who work fewer hours and have lower earnings and greater work absenteeism than mothers of typically developing children, because of the increased time spent caring for the child than fathers (DIA, 2003).

DIA (2003) note that parents of children with Down syndrome have been found to experience less stress, and pessimism than parents of children with other diagnoses, particularly Autism. However they also note that it may not be the diagnosis, but rather the behavioural characteristics, support and communication needs associated with the diagnosis, that are the key predictors of negative family impact. This is due to their increased associated burden and stress, which in turn affects parenting efficacy and cognitive appraisals (e.g. the parent’s belief that they can manage the care giving tasks), mental health, and marital adjustment. This is consistent with research on problem behaviour in children with intellectual disabilities (Nachshen et al., 2005) and children with developmental delays (Baker et al., 2005). Similarly, Moore and Larkin (2005) report that “the most important predictors of parental wellbeing are the presence or otherwise of behaviour management issues in their children (and the level of general social support networks that all families need)” (p. 54).

Negative family impact has been noted in families with a child diagnosed with a range of disabilities including Autism (Nealy et al., 2012), cerebral palsy (Pousada et al., 2013), and children with unclassified developmental delays (Hsieh et al., 2013). Importantly, the work of Green (2007) shows that some mothers of a child with a disability may not be sad, but simply tired and it is important that practitioners are mindful of this so as not to incorrectly assume a level of parenting competence or family satisfaction.

Informal social supports and community connectedness

Repeatedly, the role and importance of social support and community connectedness emerges in the literature. In the words of Lord and Hutchison (2003) “individualised support and funding, in and of themselves, provide no guarantee that people’s lives will be better. Their potential lies in their individual nature, combined with a focus on building community capacity, network building, and unencumbered planning” (p. 85). Therefore the role, development and sustainability of community and networks to support people living with disability is fundamental to families’ wellbeing and agency. Indeed, Bennett (2009) points out that the necessity of supporting friends and family, and the impossibility of replacing this support with government funded formalised services, is key to building resilient, sustainable, inclusive and diverse communities and support systems for people with a disability.

In her review of the literature, Canary (2008) reports that many studies have found that higher levels of received (rather than perceived) informal social support (from friends and family), and perceptions of helpfulness of this type of support, associate with lower parental stress, greater feelings of parental empowerment, and higher levels of marital satisfaction. Informal support is also related to parental wellbeing across disability types and severity levels. The work of Banach and colleagues (2010) on the effectiveness of a support group for parents with a recent diagnosis of Autism in their child found that family support and empowerment are affected even in the early days after diagnosis, highlighting even further the importance of social support.

Importantly, Canary (2008) also states that:

The two most prominent theories on social support are systems theory and the ecological framework. Researchers using systems theory recognise that support outcomes for individual members are influenced by the entire family system. The ecological framework moves beyond family systems theory by taking into account other systems with which families interact, such as educational, community, and government microsystems. Future investigations can take advantage of the richness of this
approach with in-depth analyses of how interactions are interrelated and how support processes are influenced across multiple systems (p. 420).

It is evident that the role of social support fits into a much larger context, which practitioners and policy makers should keep in mind.

**Characteristics of service agencies**

Given that the whole family is affected by the diagnosis of a disability in a child and that the wider community with whom that child interacts is crucial to the child’s and family’s wellbeing, services that are family-centred are crucial for effective intervention. Family-centred practice and collaborative relationships between families and service providers are therefore important elements for stimulating family agency.

**Service expectations and satisfaction with family-centred practice and collaborative relationships**

According to James and Chard (2010), family-centred practice encompasses a philosophy and method of service delivery that underpins early intervention services and is considered ‘best practice’ in fields concerned with optimal child development. According to Espe-Sherwindt (2008), family-centred practice includes three key elements: (1) an emphasis on strengths, not deficits; (2) promoting family choice and control over desired resources; and (3) the development of a collaborative relationship between parents and professionals.

However, according to Moore and Larkin (2005), broadening of the concept of family-centred practice and its application has led to a lack of a common approach or understanding with regard to its principles and practices. In their review of the literature, Epley and colleagues (2010) found that though the key elements of family centeredness (i.e. family as the unit of attention, family choice, family strengths, family–professional relationship, and individualised family services) have remained consistent over the past decade, the emphasis in family-centred practice has shifted from the family as the unit of attention to family–professional relationship and family choice.

The comprehensive literature review conducted by Moore and Larkin (2005) identifies a number of key features of family centred practice, as summarised below:

- Families prefer family-centred services and supports to professionally-centred services
- Family-centred practice is not a service or an outcome in itself but a vehicle through which services and supports are delivered to children and families
- Family-centred approaches can contribute to greater parental satisfaction with services, lower stress and enhanced well-being
- The benefits of family-centred practice are over and above those produced by factors such as the form and frequency of services and contextual factors such as employment levels, housing quality and availability of health care
- The need for parents to be actively involved in setting the goals and determining the form of the home program is a key to developing their skills in meeting their child’s needs
- The importance of practitioners recognising the needs of the whole family and not just those of the child with a disability. However, it is possible to be family-centred but primarily child-focussed if that is the priority of the particular family
- When families feel they are part of a collaborative partnership with practitioners, it is easier for them to share information and to take control of the services and supports that they receive. In many instances, it takes families some time to get to this point. The challenge for agencies is to determine how this delay can be reduced so that the empowerment of families happens early on in their journey, ideally even before a family enters the early childhood intervention service
- Families are the experts with respect to their child and they bring to a collaborative relationship with practitioners, a great deal of information and knowledge about their child. However families are an under utilised resource and this further reinforces a need for a greater emphasis on the centrality of families in the development of systems, policy and practice
• It is important to build family collaboration into systems, processes and practices in a very real way, rather than as an afterthought. Otherwise, it runs the risk of being tokenistic at best.

• Strong links and partnerships with key specialist and universal child and family services need to be in place.

• The role of practitioners is to assist families to navigate their way through what is often a complex and overwhelming maze of people, services, supports and funding streams, and

• Flexible delivery of services at times that are suitable to families, for example, outside the usual nine-to-five day, five days per week are required.

All these themes and characteristics regarding family-centred practice are reported on extensively in the literature (Dodd et al., 2009; Summers et al., 2007; Epley et al., 2011; Fereday et al., 2010; Hiebert-Murphy et al., 2011; Law et al., 2003; Dempsey and Keen, 2008; Alam & Lawrence, 2009; Walter & Petr, 2000; Rodger et al., 2012; Kasahara & Turnbull, 2005; Basu et al., 2010; Murray et al., 2007). While most of the literature is explored from the perspective of families, some service providers’ perspective has also been researched (Mandell & Murray, 2009). Also, the experience of family-centred practice in regards to a variety of disabilities has been reported, including developmental disabilities (Nachshen & Minnes, 2005; Gardiner & Iarocci, 2012), deafness (Ingber & Dromi, 2010; Jackson et al., 2008), learning disabilities (Truesdale-Kennedy et al., 2006), and physical or cognitive disabilities (Kirsbaumba, 2000; Ziviani et al., 2011).

Canary (2008) says that parents express a desire for, and rely on, formal support by professional support services but studies are inconsistent in terms of the association between formal support and wellbeing. She says that some studies have found that services that are family-centred (e.g., provide needed information, treat parents with respect, include parental control of decision making) and specific to family needs are related to lower stress, greater wellbeing, and empowerment. However others indicate that parents do not receive the level and type of formal services that they need. Overall, Canary concludes that how formal support is provided is crucial to both family outcomes and its assessment by parents. This may help address any lack of match between caregiver needs and services, resources, or support available in the community to meet those needs (Resch et al., 2010).

Interestingly, King et al. (1999) found that parents of children with mild neurodevelopmental disorders rated professional caregiving as more family-centred than did parents of children with more severe levels of disorders. This may indicate that satisfaction with family-centred practice may be influenced by disability type and complexity of needs (as cited in Canary, 2008).

Knox (2000) reports that in addition to sensitivity from service providers to the way families feel, another aspect of service provision considered conducive to shared decision-making was being considered an equal partner, not a consumer. Indeed, Moore and Larkin (2005) also found that when providers are not sensitive to the realities of daily family life, they can inadvertently add to the stress of parents. They explain how “an essential element of family control over their lifestyles was to have all relevant options explored with them, and then to be allowed, indeed encouraged, to make decisions that they regarded as appropriate for their family” (p. 23). However, their study found that, although 56 participants (or 82%) considered that their interactions were characterised as a partnership, 41 of these participants (or 73%) considered that this control or partnership status resulted from their assertiveness rather than from professional encouragement, i.e. control had to be fought for, rather than being willingly shared. This finding highlights that service providers’ interactions may not be empowering after all.

Bennett (2009) warns that the success of individualised funding is often heavily reliant on specific key individuals and their understandings, attitudes to, and practice of, person-centeredness, which is a key risk to its success. She also points to the need for ongoing training and monitoring. However, Moore and Larkin (2005) highlight that “training on its own cannot be relied upon to result in changed behaviours. Management structures and processes also need to support the expected behaviours” (p. 55).

One threat to effective collaboration is given by the results of a study by Hurtubise and Carpenter (2011). They found that parents recognised and defined the roles they assumed in their child’s care and had distinct
expectations of the roles attributed to rehabilitation professionals, but that no formalised role-negotiation process was identified. Instead, the evolution of a symbiotic parent-professional relationship was described, in which dependency on professionals to meet parent specific needs subsequently fostered their assumption of primary responsibility. This relationship appeared to be the precursor to the development of effective parent-professional collaboration and key to parent satisfaction with rehabilitation services.

More broadly, Scott (2005) says that inter-organisational collaboration in the human services is challenging because of the multiple and complex nature of the inherent potential sources of conflict and that assessment of conflict at five possible sources or levels of analysis: inter-organisational, intra-organisational, inter-professional, inter-personal, and intra-personal. Therefore, potential conflict in the development and enhancement of collaborative partnerships at various levels need to be checked.

Interestingly, Summers et al. (2005) found differences in satisfaction with family-professional partnerships between parents of children with a disability aged 0 to 3 years, 3 to 5 years, and 6 to 12 years, with parents of older children reporting lower satisfaction. This suggests that the age of the child may impact on satisfaction with partnerships with professionals.

Quality of professionals

Moore and Larkin (2005) note that professionals should listen more than they talk, and focus on the strengths and capabilities of families. They also highlight that listening to the stories of families is an integral part of ‘therapy’, that the interpersonal skills of practitioners has an influence on therapy, and that it takes a considerable investment in time to develop the appropriate type of relationship. Importantly they note that "closing the gap between the rhetoric and reality of family-centred practice can be achieved through appropriate reflection, supervision, and parental feedback" (p. 58). In addition, they note that high quality specialist skills such as technical knowledge and expertise have positive effects on a child’s health and development but may have negative effects on the family if they are not delivered appropriately, an effort which requires good interpersonal and basic counselling skills. Such skills strengthen family competence and collaborative relationships.

Provision of and access to easy-read information

The importance of accessible and up-to-date information was emphasised by participants in a qualitative study conducted by Knox (2000) as an essential element of family control as information was seen as the principal basis on which appropriate decisions could best be made. She found that of the 68 participants interviewed in her study that “more than a third said they felt so overwhelmed by their family situation that they simply did not know what questions to ask, nor what services or resources should be available. They simply did not know what to ask. Participants felt they had no other option but to rely on their own resourcefulness and that of other families to access pertinent information” (p. 24). In light of such findings, information that is accessible and free of jargon (Moore & Larkin, 2005) is key to successful intervention with families. This is consistent with their observation that:

There is often a gap between the information they (families) seek and the information they are given. This raises many questions about the type of information in question, the manner in which it is shared, by whom and to whom it is provided, in what sort of format, and when it is provided ... All too often families are given information that is without hope, or is misinformed. The literature shows that families want accurate information that is shared in a complete and unbiased manner but leaves them with some sense of hope for the future (Moore & Larkin, 2005)

According to Gendera et al. (2011), who were involved in the evaluation of the Self Directed Support Pilot for Children and Young Adults with a Physical Disability in Queensland, it is important to avoid terminology such as ‘disability’ in communication materials, as families may not identify with the category, or may not yet have a diagnosed disability, making the term exclusionary. Gendera et al. also note that promotional material about a program should explain the program in a way that is attractive and understandable for young adults with disabilities and families of young children with disabilities. Finally, Ottmann and Laragy (2010) note that “effective user participation hinges on participants’ ability to make informed decisions and to articulate these in a variety of forums … (Thus) a mix of experiential learning styles framed by plenty of contextual information, and open-ended workshops,
seminars, and web-based resources providing more abstract information may be required” (p. 392).

In addition to inclusive language that is easy to read and disseminated in a variety of ways, and accessible and up to date, it is important that communications and promotional material be translated to access people and cultural groups where English proficiency and comprehension may be limited. This includes the website of service agencies (Friedmeyer-Trainor et al., 2012; McKee & Paasche-Orlow, 2012).

The importance of the provision of, and access to, easy read information is given by studies that find lack of information can have negative effects on parents’ sense of agency. For example, Uccelli and colleagues (2013) found that lack of information about multiple sclerosis (MS) impacted family functioning, anxiety and parents’ sense of competency and inferred that parents require support in becoming more knowledgeable about MS in order to feel competent and satisfied in their role and to cope successfully.

**Sensitivity to cultural diversity in service delivery**

Lindsay and colleagues (2012) conducted a qualitative study with 13 service providers in two multiracial areas in Canada to explore emergent themes when working with immigrant families with a child with a disability. They reported the five following areas of challenge: (1) lack of training in providing culturally sensitive care, (2) language and communication issues, (3) discrepancies in conceptualisations of disability between healthcare providers and immigrant parents, (4) building rapport, and (5) helping parents to advocate for themselves and their children. Based on these findings, they recommend that:

- Paediatric rehabilitation providers working with immigrant families raising a child with a disability should engage in training and education around culturally sensitive care to better meet the needs of these clients
- More time is needed when working with immigrant families to build trust and rapport
- Clinicians need to be sensitive around gender issues and try to involve both parents in the decision making around the care for their child, and
- Healthcare providers should help clients to become more aware of the resources available to them in the hospital and in the community.

Similar themes have been reported elsewhere. For example, Harry (2008) reports that barriers to the implementation of ideal practices in collaborative partnerships between families and service providers include (a) deficit views of culturally and linguistically diverse families, (b) cross-cultural misunderstandings related to the meanings of disability, (c) differential values in setting goals for individuals with disabilities, and (d) culturally based differences in caregivers’ views of their roles. In short, it is important to be responsive to the racial, cultural, ethnic and socioeconomic diversity of families (Moore & Larkin, 2005).

**Summary**

Family-centred early intervention service is crucial for the wellbeing and agency of families with a disability. Family-centred practice sees the family as the unit of attention, emphasises their strengths, promotes family choice and control over desired resources, delivers individualised family services, and relies on the development of a collaborative relationship between parents and professionals. Good collaborative partnerships are marked by communication, commitment, equality, skills, trust, and respect (Blue-Banning et al., 2004).

However, a range of factors can compromise parents’ satisfaction with partnership with professionals, including the type of disability and support needs they have, the age of the child, professionals failing to willingly share power with the family, reliance on a few key staff to deliver family centred practice, lack of symbiosis between families and professionals, and conflict at the inter-organisational, intra-organisational, inter-professional, inter-personal, and intra-personal levels.

In addition to family-centred practice, there are other features of the service sector that are also important for enhancing family agency. These include the quality of professionals and services, whether service expectations were met, the use of collaborative and equal partnerships between families and service providers, the provision of easy read information, and sensitivity to cultural diversity in service delivery.


Summary of the main findings: Enablers and barriers of family agency

In summary, the literature shows that ‘family agency’ is synonymous with or related to a number of other terms, all of which capture its various notions:

- Empowerment
- Power
- Self-determination
- Self-determined life
- Self-advocacy
- Causal agency
- Efficacy
- Competency
- Capability
- Control
- Confidence
- Self-directed support seeking
- Participatory action research methods
- Emancipatory research
- Freedom in goal setting, decision making, problem solving
- Process and outcome
- Family and individual quality and life
- Family and individual resilience, and
- Family capacity.

Enablers: Factors that enhance family agency

The results show that a number of factors are involved in the support and strengthening of family agency. Importantly, one of these is ‘co-design’, which was important to establish in this study. However, all other reviewed factors include:

- Co-design, co-production and co-creation strategies that meet the needs and expectations of the family
- Family resilience
- Family-centred practice
- Family choice over services
- The use of family systems theory and an ecological framework
- Informal social supports especially friends and grandparents
- Strong and empathic relationships within families
- Attending support groups
- Parental employment
- Families’ housing quality
- Families’ availability of health care
- Parents’ active involvement in goal setting
- Tailoring family-centred practice to be primarily child-focussed if that is the priority of the particular family
- Strong links and partnerships with key specialist and universal child and family services
- Good collaborative partnerships are marked by communication, commitment, equality, skills, trust, and respect
- The age of the child; parents of younger children (0-5 years) seem to report higher satisfaction with collaborative relationships than parents of older children (6-12 years), and
- Good interpersonal and counselling skills in professionals, including setting aside sufficient time for families, self reflecting and receiving supervision and parental feedback.
Barriers: Factors that can compromise family agency

The results also show that a number of factors can compromise the support and strengthening of family agency. These include:

- Co-design, co-production and co-creation strategies that do not meet the needs and expectations of the family
- Unmet support needs and challenging behaviours of the child with disability
- Poor (collaborative) relationships with professionals
- Heavily reliance on specific key individuals and their understandings, attitudes to, and practice of, person-centeredness
- Lack of ongoing training and monitoring
- Parental stress and/or pessimism in parents, especially mothers
- Low socio-economic status
- Poor provision of, or access to, up to date, easy read, hopeful and translated information
- Lack of sensitivity to cultural diversity in service delivery
- The underutilisation of families as a resource, given that they are the experts in their child
- Principles of family centeredness and family collaboration not being built into systems, processes and practices, but instead being tokenistic
- Practitioners failing to assist families to navigate their way through the often complex and overwhelming maze of people, services, supports and funding streams
- Failing to deliver services at flexible times outside the usual nine-to-five, five days a week
- Formal support that is not provided with sensitivity to the realities of daily family life, thus adding to the stress of parents
- Decision-making not shared because families are seen as consumers rather than as equal partners with whom professionals need to form a symbiotic relationship
- Professionals failing to encourage families to take control over their decision making
- Inter-organisational, intra-organisational, inter-professional, inter-personal, and intra-personal conflict, and
- Professionals focusing on the child’s disability to the exclusion of helping families gain balance in their life so that family life is not all about their child’s disability, and
- Monitor changes in enablers and barriers.
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