

Evaluation of the Demonstration Support Networks Program

Final Report

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Report for: Ageing, Disability and Home Care, Department of Family and
Community Services
SPRC Report 8/11

Social Policy Research Centre
University of New South Wales
September 2011

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ISSN: 1446-4179
ISBN: 978-0-7334-3057-2

Published: September 2011

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Suggested Citation

Newton, BJ, Rajkovic, M., Adamson, E., and valentine, k., (2011), 'Evaluation of the Demonstration Support Networks Program Final Report', SPRC Report 8/11, prepared for Ageing, Disability and Home Care, Department of Family and Community Services (ADHC), September 2011

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Key Points

- This report describes findings from the seven projects reviewed for the evaluation of Ageing, Disability and Home Care, Department of Family and Community Services (ADHC) Demonstration Support Networks Program.
- The evaluation objectives are to determine the effectiveness of the program model and the features of effective support networks. The evaluation does not assess the outcomes of individual projects and all the organisations and projects have been ascribed aliases to maintain confidentiality.
- Each of the seven projects provides social opportunities and the provision of information and support.
- Projects for children and young people with a disability provide opportunities for recreation and fun, and social interactions with other children and young people with a disability. They also encourage the development of social confidence and living skills.
- Projects for siblings provide opportunities for respite and recreation, including camps and excursions, and social interactions with other siblings of children and young people with a disability.
- Projects for parents provide opportunities for respite and recreation, including weekends away and information evenings.
- Reported benefits for children and young people with a disability include increased confidence, a sense of independence, and expanded friendship networks.
- The projects targeted at children and young people are not structured interventions to change behaviour or provide training in social skills. Neither are they designed to build support networks for individual children with a disability. Nevertheless, some parents are reporting improvements in their children's behaviour and social competence as a result of participating in the groups.
- Reported benefits for siblings and parents include respite and time out from the responsibilities of care, increased awareness of shared experiences, and expanded friendship networks.
- The evaluation found that the most significant benefits of the projects are in assisting to overcome social isolation of children and young people with disabilities and their families, and assist parents and children to build informal networks of support and information.
- Different service models may be required for children and young people with disabilities and their families. Support networks for family members appear to be successful in building informal support and independent friendships when based around activities such as weekends away and recreational events.

In order to build informal support networks and friendships for children and young people with disabilities, especially those that facilitate participation of in 'mainstream' activities, different strategies from those undertaken so far may be required. Recreational activities and social groups are highly valued, but will not lead to the higher order objectives of the Program without further intentional strategies. Models may be found in existing projects in Australia and internationally.

Executive Summary

The Support Networks Program is designed to provide support networks for children and young people with a disability, their parents and siblings. Ageing, Disability and Home Care, Department of Family and Community Services (ADHC) has funded seven demonstration projects to develop, test and implement flexible and innovative practices that address the needs of children and young people with a disability and their families. This report describes findings from each of the seven projects reviewed for the evaluation of the ADHC Demonstration Support Networks Program.

Social support networks

Social support networks can provide material support, emotional support and referral and information. They may also complement existing support programs. The Demonstration Support Networks Program emphasises the importance of informal support for children and young people with disabilities and their families, and the importance of opportunities for participation in a wide range of mainstream settings. The Program is intended to provide formal activities, which are designed to build sustainable friendships and support, rather than providing benefits derived only from the activities themselves. For children and young people with a disability, the Program has additional goals of increased knowledge of activities within their community and skills to participate in them, and increased social independence and personal development.

Evaluation methodology

The evaluation used qualitative methodologies to gather information on the program's strengths, difficulties and achievements, from a range of stakeholders. The initial evaluation design included the development and piloting of quantitative survey instruments. However, as we commenced discussions with each of the projects it became clear that qualitative instruments were more appropriate for the purposes of the evaluation. All the names of the organisations, projects and interview participants have been changed.

Projects for siblings

Research evidence on social networks for siblings indicates that social events and recreational activities can be successful in achieving ongoing benefits, including the development of informal support networks. Supporting this evidence, the evaluation found that emergent friendships and support networks are resulting from Demonstration Support Network projects for siblings.

Evidence from the projects is that they have been implemented in line with the program principles. In particular, the projects have provided siblings with activities that are highly valued and appropriate to the diversity of their experiences and social context, and have supported siblings in building social support, especially from the organisations providing the project activities and from developing friendships. Siblings have been included in the planning and evaluation of activities.

Feedback from siblings in each of the projects about the activities offered was overwhelmingly positive. All siblings interviewed enjoyed attending their group and always looked forward to the next activity or event.

Projects for parents

Research evidence on social networks for parents indicates that reasonably infrequent activities can be sufficient to generate independent friendships and increase use of formal support services. Supporting this evidence, the evaluation found that facilitated groups and recreational activities provide benefits for participants, and lead to relationships beyond the formal projects.

Evidence from the projects is that they have been implemented in line with the program principles. In particular, the projects have provided parents with activities that are highly valued and appropriate to the diversity of their experiences and social context, and have supported parents in building social support, especially from the organisations providing the project activities and from developing friendships.

Projects for children and young people with disabilities

Research evidence on social networks for children and young people with disabilities indicates that these networks differ from support networks for parents and siblings. While formal events and activities often facilitate the development of independent friendships and increased support for parents and siblings, formal events are unlikely to be sufficient on their own to build independent friendships and increased inclusion for people with disabilities. The growth of these networks supports the recognition that people with disabilities are entitled to mainstream, rather than disability-specific or segregated, social and educational opportunities. Social networks can complement person-centred thinking, in which the capacities and interests of the person with a disability are the basis for developing support. This is in contrast to other approaches, in which professional expertise is central and the support available is determined by agencies and organisations.

Research on the capacity of mainstream schools to be genuinely inclusive of children with disabilities, and on the Circle of Friends model of support networks, indicates positive but inconclusive findings, and suggests that sustained efforts are needed. The literature also suggests that while support networks show promise in improving the attitudes of people without disabilities towards inclusion, they are less strong in building the skills and participation of people with disabilities.

Supporting this research, evidence from the projects is that they have been implemented in line with the Program principles, although they do not focus explicitly on facilitating relationships with peers who do not have a disability. Instead, they focus on providing social opportunities and the kinds of recreational activities that are typically available to children and young people. The development of independent friendships is an emerging development from these projects, and some improvements in social competence and social interactions are also being reported. The projects for children and young people with a disability have all reported improvements in the interpersonal skills and confidence of participants.

Sustainability

Most agencies used the Demonstration Support Network funding to enhance or expand services they were already delivering. This is likely to support the sustainability of these services, as they are already core business. On the other hand, it seems also to have impeded innovations in practice, such as the introduction of activities based on person-centred

thinking or a focus on activities which increase community acceptance and inclusiveness of people with disabilities.

The one project that experienced difficulty in sustaining interest and participation was a new service, rather than an extension of an existing project. One other project was also new, but its place in a large non-government organisation (NGO) means that referral pathways have been relatively easy to establish. In contrast, those projects that have sufficient numbers or are over-subscribed are longstanding and well known in the community. This suggests that projects need time to develop, and that innovative projects may appear, in the short term at least, to be less sustainable than more established service models.

Conclusion

Each of the projects in the Demonstration Support Network Program has provided benefits to participants, and has been implemented according to the Program principles. The projects have also, in some cases, facilitated the development of independent relationships and informal support networks likely to be sustained beyond the life of the projects. This is particularly the case for projects for parents and siblings. However, lessons from research indicate that while there are challenges and benefits in delivering social and recreational opportunities to children and young people with disabilities, there are other, distinct challenges and benefits in developing support networks. The Demonstration Support Network Program indicates agencies are skilled in meeting the challenges faced in delivering services, but changes to workforces in terms of skills and knowledge, organisational practices and planning may be necessary to build support networks for children and young people.

1 Introduction

This is the final report of the evaluation of Ageing, Disability and Home Care, Department of Family and Community Services (ADHC) Demonstration Support Networks Program. The Social Policy Research Centre was commissioned to evaluate the program. The report describes the activities, strengths and challenges of the seven projects that make up the program.

The Support Networks Program is designed to provide support networks for children and young people with a disability, their parents and siblings. ADHC has funded seven demonstration projects to develop, test and implement flexible and innovative practices that address the needs of children and young people with a disability and their families. These demonstration projects were established over a three year period (2008-11) across metropolitan, regional and rural settings of NSW and consist of the following:

- Two support networks with a focus on autism spectrum disorders: one for children and young people (between 8 - 18 years of age) with an autism spectrum disorder (peers); and one for parents of children and young people (up to 18 years of age) with an autism spectrum disorder.
- One support network for peers and siblings (between 8 - 18 years of age) and parents of children and young people with a disability in a rural area.
- One support network for children and young people aged between 8 and 18 years who have a sibling with a disability.
- One support network for children and young people with a disability, aged between 12-18 years.
- One support network for children and young people with a disability, and/or siblings of children and young people with a disability, from culturally and linguistically diverse (CALD) backgrounds.
- One support network for Aboriginal¹ families, children and young people with a disability.

1.1 Program outcomes

The Demonstration Support Network Program description (ADHC, 2007) describes the intended outcomes of the support networks.

As a result of participating in support networks, **siblings** will:

- increase their ability to identify their specific needs at particular points in time;
- develop a range of strategies to cope with their concerns and feelings about their brother or sister with a disability;

¹ The authors acknowledge the diversity of Aboriginal and Torres Strait Islander peoples, who have different languages, cultures, histories and perspectives. For ease of reference, this report refers to Aboriginal and Torres Strait Islander peoples collectively as 'Aboriginal'.

-
- have developed and maintained sustainable relationships and friendships with others in similar circumstances;
 - increased community awareness, understanding and acceptance of children and young people with a disability; and
 - have established strong linkages with existing supports in the community.

Following participation in support networks, **parents** will:

- increase their ability to identify their specific needs at particular points in time;
- have an improved perception of their ability to manage a range of different issues that impact on their family well being;
- develop a range of strategies to cope with their concerns and feelings;
- have developed and maintained sustainable relationships and friendships with others in similar circumstances;
- have established strong linkages with existing support and report increased integration within the community;
- increased community awareness, understanding and acceptance of children and young people with a disability; and
- report reduced stress and increased cohesiveness in the family.

As a result of participating in support networks, **children and young people with a disability** will:

- increase their ability to identify their specific needs at particular points in time;
- develop social and interpersonal skills;
- have opportunities to develop and maintain sustainable relationships and friendships;
- have increased awareness and access available support networks;
- increased community awareness, understanding and acceptance of children and young people with a disability; and
- have increased opportunities for social independence.

1.2 Evaluation

The purpose of the evaluation is to:

- determine how effectively the Demonstration Support Network Program is delivering the intended outcomes.
- identify the key features of effective support networks and the extent to which each of these features contributes to the effectiveness of the network in relation to the specified target groups for this Program;
- identify how the outcomes for families, peers and siblings can be sustained and those features that will enable the support networks to have the capacity to operate beyond the life of the demonstration; and

-
- identify improvements to the current demonstration support network model which would inform future service system development.

Table 1.1 shows that the seven projects are being delivered by six agencies in Sydney and regional New South Wales.

Table 1.1: Support Network Program projects

Project ^a	Agency	Target group	Location	Current participants ^b (n)	Activities
'Teen Fun'	'Creative'	Children and young people in high school with a disability	Regional NSW	37	After school activities and opportunities for social interaction
'Positive Connect'	'Pinnacle'	Parents and carers of children and young people with a disability from culturally and linguistically diverse backgrounds	Metropolitan	59	Peer support, parents' evenings
'Group Connections'	'Mansfield'	Siblings of children and young people with a disability	Regional NSW ^c	15-20	Weekend camps
		Parents and carers of young people with a disability	Regional NSW	15-20	Weekend camps
		Children and young people with a disability	Regional NSW	5-10	Social activities
'Fun With Friends'	'Alliance Creations'	Siblings of children and young people with a disability	Metropolitan	54	After school and holiday activities

'Kool Kids'	'Pinnacle'	Children and young people with autism spectrum disorder	Metropolitan	50	After school activities and opportunities for social interaction
'Deadly Times'	'Prime Care'	Children with a disability and their siblings	Regional NSW	15-20	After school activities and opportunities for social interaction
'Prime Parents'		Parents of children with a disability	Regional NSW	2-4	Parent support and education
'E-Connect'	'Cultural Connect'	Siblings of children and young people with disabilities	Metropolitan	6	Media project

- a. The Demonstration Support Network projects are called 'programs' within their agencies. They will be referred to as 'projects' in this report, to differentiate them from the overall Demonstration Support Networks Program.
- b. Demonstration Support Network Program projects are not distinct projects within agencies in all cases. These participant numbers may include participants of projects funded from multiple sources and/or activities that are collaborations with other agencies.
- c. Based on the NSW Department of Industry and Development's division of NSW into 14 regions, of which Sydney is one.

2 Background

People with disabilities are entitled to the benefits of social, community and economic participation, and a range of support strategies may be useful in facilitating this. Support strategies may also be needed to address barriers to participation. A large body of literature discusses the diverse challenges facing children with disabilities, and their families, in receiving social support. The literature notes a number of difficulties for children with disabilities, mostly issues relating to social acceptance, forming relationships with peers and siblings, and for many a dissatisfaction with the relationships they do have (Heiman, 2000; Abells et al, 2008). In many situations, the barriers faced by people with intellectual (Abells et al, 2008) or physical disabilities (Heiman, 2000) prevent children from being able to participate in a number of activities with peers, both in and out of school. Additionally, Abells et al (2008: 92) found that adolescents with disabilities were more likely to engage in activities with their family or alone than with peers, and when they did interact with peers it was through organised activity, rather than relationships occurring naturally.

Raising children is rewarding and challenging experience for all parents. Families with a child with a disability are no different in this respect from other families within their community, but may require additional support to develop social networks, as the birth of a child with a disability may significantly alter family life (Dodd, 2004). Research has found that parents of children with a disability can experience financial, technical and emotional difficulties (Dyke, 2009; Ainbinder, 1998; Abbott, 2005; King, 1999; Krahn, 1993). There may be difficulties accepting and adjusting to the child's disability (Ainbinder et al, 1998; Owen et al, 2002); or in negotiating complex technical and medical issues (Abbott, 2005; Ainbinder, 1998; Krahn, 1993); financial strain (Krahn, 1993; Dyke, 2009); strained family relationships and social isolation (Krahn, 1993). These factors can lead to high levels of stress for parents, and feelings of anxiety, depression, loss, loneliness and hopelessness (Ainbinder et al, 1998: 100). Positive community attitudes and informal support networks are key strategies to support children with disabilities and their families (Owen et al, 2002: 97). Formal services and practitioners have an important role in facilitating informal support to occur (Owen et al, 2002; Levy et al, 1996). Owen et al cite strategies for facilitating informal support, including: group approaches targeting extended family and close friends; parent-to-parent programs; volunteers visiting family homes to provide support and advocacy; informal exchange networks; deliberate inclusion of extended family in sessions with professionals; and linking parents to another parent for mutual support (Owen et al, 2002: 107).

In line with strategies for facilitating informal support for families, Canary (2008: 413) also states the importance for families with children with a disability to access long-term support 'from various organisations, their friends and family members'. Additionally, research has indicated that access to formal care (i.e. respite) can facilitate informal support, such as enabling parents to spend time with each other and siblings to spend time with friends (Owen et al, 2002; Dyke, 2009). Dyke (2009) argues that families are often unaware of support and network opportunities and medical practitioners could be informed about the support groups that are in operation so that they can provide families with information.

A study (Levy et al, 1996) examining the support networks of mothers of children with a disability found that many mothers received little informal support (from parents and relatives) and, rather, professional support (case management) was regarded as most helpful. Possible reasons for this were that mothers using case management services had limited sources of informal support and that case managers' recommended professional support, rather than drawing on available sources of informal support. The authors argue that a challenge for case managers is to identify and recommend informal

supports that have not been used (i.e. grandparents) and to try to encourage empowerment rather than dependency in the parents they are supporting (Levy et al, 1996).

This model of linking formal and informal support has also been applied to the school environment for children with a disability. One study on the school experience of students with disabilities and chronic illnesses found that health professionals and teachers can play an important role ‘through helping others in the school to understand the condition and its impact on school life’ (Lightfoot et al, 1999: 267). The authors go on to ‘urge professionals...to pay closer attention to the social system of peer relations in addition to their traditional focus on the family’ (Lightfoot et al, 1999: 269).

2.1 Purposes and models of social support

Krahn (1993) presents two models to explain how social support works and is effective. First, the stress-buffering model which suggests that social support can help to reduce the negative impact of stress during times of high stress; and the second, the direct-effect model, which argues that social support is always beneficial, and the higher the level of support available the less distressed an individual will feel in a stressful situation (Krahn, 1993: 6).

Looked at from a perspective of empowerment, Thomson (1997) identifies different pathways to family empowerment: family-level empowerment; service-level empowerment and empowerment at the community/political level. Thomson argues that families achieve empowerment is through family-centred delivery of services, where service coordinators to help families identify supports in their social networks as a substitution for services.

Often, the term social support refers to the ‘supportive assistance from important others that addresses perceived needs. However, it can be divided into social support from the provision of services, social support by providing resources and the ‘sense of support that arises from social relationships with others’ (Krahn, 1993: 2).

Social support is thought to complement formal support services, by providing assistance that formal services do not or cannot; and to improve the quality of formal support services, by ensuring that families are receptive to the support that is available, and have the capacity to find and utilise it.

2.2 Support networks

Support networks are one form of social support, for people with disabilities and their families. However, the theoretical and practical basis of support networks for people with disabilities is different from the basis of support networks for family members. Support networks for family members of people with disabilities bring benefits by providing emotional and practical support, complementing formal services, and providing information. Support networks for people with disabilities have these benefits, and are also designed to facilitate inclusion and social integration.

One body of literature concerns support network for family members, especially parents of children with disabilities. Seligman & Darling (cited in Owen et al, 2002) argue for the importance of better understanding the impact of social support in families with children with disabilities, specifically the nature of social support networks. The authors outline that social network theory and empirical research formed the basis of a body of practice known as social network intervention, in which there are three levels of social support: intimate relationships (i.e. spousal); friendships; and, neighbourhood or community support (Seligman & Darling, 1989). Other authors (Turnbull and Turnbull, 1990; Cited in Owen et al, 2002) argue that social support networks can provide material support, emotional support and referral and information, which is a variation of other models

suggesting informal networks can provide either emotional support or instrumental support (Blacher, 1994; Cited in Owen et al, 2002: 106).

The purpose and approach to a support network can be to complement existing support programs. For example, Ainbinder et al (1998) suggests that a mutual support group for parents can be a good starting point for families to discuss disability. The literature indicates that parents and siblings typically enjoy interaction with the program and would like it to be long-term or ongoing (Smith & Perry, 2004; Naylor & Prescott, 2004; Dodd, 2004; Solomon et al, 2001; Law et al, 2001; Ainbinder et al, 1998).

Some support network programs are designed for people to train or teach others about their experiences; an example of this is a parent-to-parent program (Ainbinder et al, 1998). It is suggested that some parents benefit from parental support before they are able to effectively help their children with their issues. There is also opportunity for these types of programs to be developed for peers and siblings, where a facilitator provides information about the disability or condition of the child (Lightfoot et al, 1999; Ciechowski et al, 2001).

A second body of literature concerns support networks for children and young people with disabilities. In addition to the benefits already cited, such as complementing formal support services, support networks for children with disabilities are also designed to facilitate the full social integration of children with disabilities in schools and other activities (Webster and Carter, 2007). Social supports, specifically informal support networks, are often designed to achieve a specific goal such as developing sustainable relationships or providing therapy and teaching to ease stress and anxiety experienced by children with disabilities and their families. Naylor and Prescott (2004) suggest that support networks can help to establish a sense of permanency of support for the child and family.

Specific models and purposes of support networks, and findings from evaluation research on their effectiveness, are described below. Because support networks for people with disabilities involve the same principles and benefits as networks for their family members, plus additional benefits, the networks for family members are presented first.

Siblings

Research has found positive impacts associated with siblings of children with a disability. These include: increased tolerance and awareness of difference; a caring and compassionate nature; increased maturity; enhanced appreciation of their own health and abilities (Dyke, 2009); and enhanced social environment (Dodd, 2004). While earlier research indicated primarily negative psychological effects on children whose siblings had a disability, more recent research suggests that the overall family functioning is more likely to determine sibling adjustment (Dyke, 2009).

Notwithstanding the development of these positive personal characteristics, siblings of children with a disability also face challenges. They may experience increased difficulties in terms of their relationships with their families, compared with children who do not have siblings with disabilities. These may include depressive symptoms and emotional distress and greater withdrawal, aggression and anxiety (Naylor & Prescott, 2004; Ross and Cuskelly, 2006); risk of poor peer relations and lower levels of participation in outside activities; a sense of embarrassment and ostracisms by their peers; and isolation (Naylor & Prescott, 2004; Dyke, 2009; Conway & Meyer, 2008). Some studies have shown siblings are more aggressive and have anger as a usual response, and are therefore at an increased risk of developing behavioural problems (Ross & Cuskelly, 2006). Dyke (2009)

suggests that these difficulties are more concentrated in families where mothers experience more stress and depressive symptoms, and are more likely to occur when the child has behavioural problems or the family faces socioeconomic challenges as well.

A growing body of literature argues the importance of providing specific, appropriate support for siblings (Conway and Meyer, 2008; Dodd, 2004). Studies have found that siblings benefit from sharing emotions and experiences with others in similar situations (Conway and Meyer, 2008: 113; Naylor and Prescott, 2004). Naylor and Prescott's (2004) summary of the potential benefits of sibling support might include reducing the negative impact such as isolation, embarrassment, anger, neglect and guilt; and enhancing the positive impacts such as social competence, insight, appreciation, pride, and maturity (p200).

Social support has also been identified as a potential coping strategy for this behaviour (Ross & Cuskelly, 2006: 80; Naylor and Prescott, 2004) with research showing that support programs for siblings with a disability can decrease depression and anxiety, improve self-esteem, decrease sibling-related stress, improve knowledge and increase perceived available social support (Canary, 2008: 418-419; Dodd, 2004).

Conway and Meyer's (2008) study examined the Sibshops sibling support model in the U.S., which aims to provide opportunities for brothers and sisters of children with a disability to access peer support and education within a recreational context, and provide siblings with opportunities for peer support (p114). The authors note that, in reality, they are only an 'event'; however participants responded that the Sibshops has a positive effect on the feelings they had for their sibling. A similar program in the UK, Sunsibs, found similar positive impacts, including the establishment of life-long relationships between siblings and other supports.

Dodd (2004) discusses the outcomes of a support program for siblings that lasted two days, and while benefits were found relating to sharing feelings and an enhanced ability to cope with difficult situations, it was believed that the program should consider on-going meetings and interaction with other siblings, and a medium for siblings to communicate on an ongoing basis. The idea of ongoing interaction is also recommended by Dyke (2009), who discusses opportunities for siblings to talk to other siblings about their experiences through online chat rooms. They also stated that practitioners and professionals should be made aware of these types of supports, so they can inform families of the different avenues for support.

Naylor and Prescott's (2004) findings from an in-depth study of a sibling support group in England provides evidence on the positive effect of support groups. Parents identified a number of benefits to the support program such as the chance for siblings to meet others in a similar situation. Overall, siblings enjoyed being part of the support group and reported making new friends; however they all also stated that they would have liked the group to last longer.

Parents

Social support is recognised as an effective 'buffer' against the stress and isolation faced by parents of children with a disability who may experience high levels of stress (Ainbinder et al, 1998: 100). Research has found that social support and the extent of support networks (Ciechomski et al, 2001) available for parents can benefit the wellbeing of the parent and the child (Canary, 2008; Ainbinder et al, 1998; Law et al, 2001).

Research shows mutual support groups have positive effects on mothers' control/agency, indicating that information helped ease their sense of uncertainty; sense of community and belonging through sharing similar experiences and circumstances; and also resulted in self change or personal growth, as parents said they felt more confident and reported changes in the relationships with their disabled child (Solomon et al, 2001: 121-124). White's (2004) research on the types of social support that help parents in terms of their stress, anxiety and depression found that parents' 'rating of the helpfulness of informal sources of support was most reliably associated with parental well-being', rather than their access to service and professional support. Based on these findings, the authors state the importance of considering that parents may be 'especially vulnerable to the disruption of their informal support networks' (White, 2004: 181).

Program evaluations have identified challenges to establishing and maintaining parent support groups and support networks, such as logistical barriers due to busy lives and transportation; a lack of perceived sameness; inconsistency between individual preferences and values; and differences in downward and upward comparison depending on the severity of the parents' children's disability (Ainbinder et al, 1998: 107).

An example of a mutual support group for parents of children with a disability, Parent to Parent, programs offer support to parents of children with similar diagnoses where the supporting parent has completed training on support techniques and offers informational and emotional support (Ainbinder et al, 1998). The authors found a number of benefits from Parent to Parent programs examined in the study. Parents reported a perceived sameness with parents in the program and that they had made sustained friendships. They also learned practical skills and useful information from parents' stories and experiences and they gained practical parenting tips and linkages with other supports for their own child's disability. In line with other research (Krahn, 1993) Ainbinder et al found that parents benefitted from the availability of support, stating 'it is the ongoing sense that the support parent can be called upon as needed that gives referred parents a feeling of dependability'. Additionally, parents reported a mutuality of support, perceiving an equitable relationship between the supporting and referred parents. Overall, referred parents reported positive outcomes related to personal growth, empowerment, reduced isolation and emotional well-being.

Law et al's (2001) study explored parents' perceptions of the effect of parent-led support groups in providing support and knowledge for parents of children with a disability. Through interviews and observation of nine groups, the study found that the effects of belonging to a parent-led parent support group were 'substantial', as parents gain increased skills, and increased sense of power and belonging. Owen et al (2002) research supports these findings, stating that parents value 'parent-to-parent information exchange and the support from others with shared experience'. Also, ethnic community or cultural bonds, or groups based on the disabling condition of the child are important in establishing effective support groups.

Solomon et al (2001) examined what parents of children with a disability found helpful about mutual support groups. These groups were parent run and aimed to encourage mutual support between families of children with disabilities and special needs. Overall the results were very positive, as parents found the groups to be helpful; they were satisfied with the groups, and they rated the groups high on cohesion and task orientation. The authors reported the positive benefits experienced into three domains: socio-political, where parents benefited from a range of coping resources such as access to information, increased self-efficacy, increased focus and sense of control, learning and subsequent cognitive change and positive thinking; the interpersonal domain, where parents reported belonging to community and being understood and accepted; and, also the intra-individual domain,

where parents reported improved self-esteem and confidence and loss of guilt and self-blame. The authors argue that the study highlights the value of communal ideology, rather than parents being individual recipients of services.

Children and young people with disabilities

Support networks for children and young people are characterised by a network of connections with friends, family and other informal support, with these connections rather than professional expertise facilitating the inclusion of people with disabilities within the broader community. Research has found that ‘opportunities for social interaction for people with intellectual disabilities can facilitate increased community integration, improved quality of life, greater sense of life-satisfaction and wellbeing, the development of friendships and increased social skills’ (Abells et al, 2008:89).

Efforts to build support networks can face challenges. Owen et al (2002) cites a number of barriers to the development of social networks by young people with disabilities, which include: the young person’s own embarrassment; societal attitudes about people with a disability; structural barriers such as income and transport; adequate resources (and age appropriate); mobility needs; insufficient social skills and parental attitudes and capacity to facilitate social contacts and leisure opportunities (Owen et al, 2002: 68). One area of literature in the field focuses on the differences and potential benefits of children with disabilities attending mainstream schools and interacting with peers without disabilities (Lightfoot et al., 1999; Heiman, 2000; Pijl, 2008; Webster & Carter, 2007; Siperstein et al, 2009).

Lightfoot et al. (1999) study looked at the needs of students with disabilities in mainstream schools, and explored the issue from the perspective of the student. With one issue identified as ‘relationships with peers’, the study found that some students developed close relationships with their peers, who helped them in practical (i.e. medical health) ways, deal with other peers (i.e. curiosity) and emotional support. Data showed that young people ‘routinely draw on informal sources of support’ including family and close friends.

One specific model of support networks for children (and all people with disabilities) is a ‘Circle of Friends’ (Fredrickson & Turner, 2003), which is set up when classmates or community members of a person with disabilities form a volunteer group to support their participation in mainstream activities or a mainstream classroom. The Circle of Friends model uses the classroom peer group to improve the social competence of the classmate with a disability (Frederickson and Turner, 2003: 234). It aims to teach behaviours that can be emulated and develop into natural occurrences and interactions with peers. The model begins with a facilitated session (by a trained professional) with the classmates and teacher, selects a number of peers to act as the support (Circle of Friends) and then meets regularly with the focus child to discuss improvements and goals. The group is generally facilitated by a single paid support worker.

The program has a number of different elements: it teaches behaviours that are likely to be emulated or naturally reinforced; trains across people and settings that the child encounters every day; reinforces applications of skills to new and appropriate situations; facilitates training arrangements, such as special reinforcement, until they are likely those that occur naturally; and they include peers in training (Fredrickson & Turner, 2003). The Circle of Friends approach was developed to support the process of including: a) people with a disability in local communities where they had previously lived in institutions, and b) students who experienced special education needs in mainstream schools where they had previously been educated in separate special schools.

A program evaluation found that ratings by children in the Circle of Friends were statistically significant with a positive effect on the social acceptance of the focus children in their classroom; however it did not have an effect on the focus children's perceptions of their social acceptance and behavioural conduct. The authors conclude that the Circle of Friends appears to be useful for changing peers' perspectives and judgements about the focus child, but 'needs to be supplemented to achieve other aspects of social competence' (Frederickson and Turner, 2003: 240). It is suggested that this approach promotes changes in behaviours of the children around the focus child, but not necessarily for the focus child themselves. Also, it seems that the focus child remained recipients of support rather than equal partnerships within the Circle members (Frederickson and Turner, 2003: 244).

Heiman (2000) examined the differences in perceived and experienced relationships for children with a disability in different educational settings – in special needs schools, and in self-contained classes. Students with a disability in self-contained classrooms were concerned with having friends and were more likely to conform to other behaviours to make friends. Also, students in special education schools were more likely to identify siblings as peers. Overall, the study found that students in mainstream school are influenced students without disabilities and 'learn and imitate the conduct and attitudes of the general population' and appears that being in self-contained classes promotes better social skills.

Lightfoot et al (1999) found that improved relationships were not universally experienced by all students with disabilities, indicating that these relationships do not occur spontaneously in all cases. Similarly, Pijl (2008) examined the social position of students with special needs in regular schools and indicated that physical inclusion of special needs children in activities is 'only a very basic condition and this group may need extra support in participating in the group' (p387). Findings are mixed, as Siperstein et al (2009) present very positive findings from a study of a summer camp for children with and without disabilities. They found that the majority of children were accepted by their peers and that 'children with and without disabilities did not differ in the degree to which they were accepted by others in the program' (p102).

Pijl (2008) indicates that parents often expect that inclusion in schools will lead to increased opportunities for contact in the neighbourhood and promote 'inclusion in the local community' (p388). However, as Webster and Carter (2007) argue there are inconclusive findings in the field regarding 'best practice' for the inclusion of children with disabilities in schools, and that more research is needed to develop strategies to promote and support these relationships.

The Demonstration Support Networks Program

The Demonstration Support Networks Program emphasises the importance of informal support for children and young people with disabilities and their families, and the importance of opportunities for participation in a wide range of 'mainstream' settings. The Program Description (Ageing Disability and Home Care NSW, 2007) provides examples of activities which could support the goals of building informal support networks for siblings, parents and children and young people with a disability: structured programs of activities, social and recreational activities, camps, drop-in facilities, and mentoring and counselling activities. In each case these activities are designed to build sustainable friendships and support, rather than providing benefits derived only from the activities themselves. For children and young people with a disability, the Program has additional goals of increased knowledge of activities within their community and skills to participate in them, and increased social independence and personal development.

3 Method and Sample

3.1 Evaluation questions

There are four evaluation questions:

1. To what extent has the *Demonstration Support Network Program* been effective in achieving the intended Program outcomes for children and young people with a disability, their parent and siblings, and specifically, for Aboriginal and CALD communities and for children and young people with autism and their families?
2. To what extent is the planning and delivery of support funded under the Program in line with the Program principles and the goals of the three types of networks (parent, peer, and sibling)? (Appendix B)
3. What factors will enable the outcomes for children and young people with a disability, their families and siblings to be sustained and the support networks to be maintained beyond the life of the Demonstration Program?
4. What improvements could be made to the current Demonstration Support Network model and what else could be provided which would achieve similar outcomes?

Qualitative data were analysed in relation to the Demonstration Support Network Program's results logic (Appendix A) and the evaluation questions.

3.2 Instruments and recruitment

We interviewed staff and parents at each of the projects. For projects targeted at children and young people with a disability, and those for siblings of children and young people with a disability, the researchers interviewed parents and children. All children had an adult present during the interview. Usually the parents and the children were interviewed together. Interpreters were present for two of the interviews with adults.

The initial evaluation design included the development and piloting of quantitative survey instruments. However, as we commenced discussions with each of the projects it became clear that qualitative instruments were more appropriate for the purposes of the evaluation. The advantages of quantitative instruments in an evaluation of this type are around comparability of outcomes across programs; however this also requires conditions relating to sample size which would have been difficult to achieve. Moreover, the projects were not designed to meet evaluation criteria for outcome studies, and even if standardised instruments were used to measure improvements in social or cognitive functioning, for example, it would be difficult to attribute these changes to the projects. The advantages of quantitative instruments for evaluations, therefore, are not relevant to this study.

The data collection instruments for the evaluation have been designed to assess the success and impact of the program model, rather than individual outcomes. Data from the qualitative instrument piloting have been incorporated into the report.

We intended to recruit a total sample size of 60-80 for interviews and focus groups, representing 8-10 participants from each project site, on the basis that this would be sufficient to generate a significant qualitative data set, and to detect appreciable variation in themes.

Interview participants were recruited by two means:

Project staff: Letters/emails were sent to projects with a request to nominate project staff or other stakeholders (for example, representatives of other services) to participate in an interview or focus group.

Children and young people, their parents, siblings and peers (project clients): The letter sent to projects requested assistance from project staff in recruiting. Project staff notified clients about the evaluation and advised them how to participate. Families could contact the researchers directly, or provided their details and permission to project staff to pass these details on to us. Flyers and ads (appended) were displayed on noticeboards and newsletters as relevant. Participants in interviews and focus groups were asked to invite others who may be interested to contact the researchers.

All interviews with children and young people were conducted with a parent or adult support person in attendance. Children and young people with disabilities were interviewed only if they had the capacity to read and sign consent forms, and were supported by an adult or peer to participate.

All interviews were recorded and transcribed verbatim. Identifying information was removed and aliases applied to all interviews, projects and organisations.

The project has ethics approval from UNSW (Approval No. HREC 09250).

Interview topics with staff include the purpose of the project, its intended outcomes and sustainability. Particular focus has been given to relationships developed with other organisations to deliver or support the project. Parents were asked about the particular outcomes for the children, the networks developed (particularly friendships) and benefits derived from participating (Appendix C).

A total of 73 people were interviewed across the seven projects: six children and young people with disabilities, six siblings of children and young people with disabilities, 25 parents, four volunteers and 27 staff. Data collection is summarised in Table 3.1

Table 3.1 Data collection

Service	Target group	Staff	Volunteers	Parents	C/YP with disabilities	Siblings of C/YP with disabilities	ADHC regional managers	Total
Pinnacle- Positive Connect	Parents	4	3	1	N/A	N/A		8
Pinnacle- Kool Kids	Peers	4	1	4	0	N/A		9
Alliance Creations	Siblings	2	0	1	N/A	0		3
Cultural Connect	Siblings	1	N/A	0	N/A	N/A		1
Mansfield	Parents, siblings and peers	8	N/A	9	0	3		20
Prime Care	Parents, siblings and peers	6	N/A	3	3	3		15
Creative Inc.	Peers	2	N/A	7	6	N/A		15
							2	2
Total		27	4	25	9	6	2	73

3.3 Qualitative data analysis

Transcripts were analysed using NVivo qualitative software, using open and axial coding, based on the research questions and emergent themes. Primary themes in the coding frame include:

- Clients (Client information; Client preparation for participation; Client's expectations; Client's feedback; Client's issues or concerns; Outcomes from participation; Prior support)
- Participation in project (Participation statistics and information; Recruitment, Why clients joined)
- Planning and delivery (Barriers to participation; Collaboration with other services; Effectiveness; Planning for project)
- Project improvements (Alternative ways of achieving outcomes; General suggestions for improvement; Improvements to meet clients needs; Improvements to meet the needs of Aboriginal and CALD clients; Informing improvements to models of operation; Lessons about project effectiveness)
- Project information (Activities; Criteria for participation; Overview; Staff to client ratio; Waiting lists)
- Project outcomes (Client's capacity for accessing support; Factors which helped or hindered achievement of outcomes; General outcomes; Meeting needs of clients in different geographic locations; Meeting the needs of CALD and Aboriginal clients; Outcomes from a client's perspective; Project's effectiveness in achieving outcomes; Sustainability of outcomes; Unintended outcomes)
- Project staff (Job roles and responsibilities; Staffing requirements and information; Support for staff)
- Volunteers (Expertise and appropriateness; Feedback about project and staff; Recruitment; Relationships with clients; Support; Time commitment; Training)

Analysis involved the ongoing development and revision of codes to capture the themes as the process of analysing the interviews proceeded. Three researchers coded the interviews, commencing by double coding, then when coding became consistent between researchers, by single coding and intermittent checking to ensure that coding remained consistent. Quotes illustrative of the themes emerging in the data are presented.

3.4 Limitations and caveats

A number of limitations to the evaluation findings should be noted. A pre-test post-test design to assess outcomes for children and families was not possible, as the evaluation period allowed for only one wave of data collection. A number of the projects are extensions or expansions of existing projects, so it is not possible to identify the effect of the Demonstration Support Network Program. The evaluation methodology has therefore been designed to gather information on the program's strengths, difficulties and achievements, from a range of stakeholders.

In order to ensure that the research was conducted according to ethical standards, and in common with similar evaluation projects, interview participants volunteered to take part in interviews, and all children and young people were interviewed in the presence of an adult. Evaluation participants may not therefore be representative of the program.

We attempted, but did not succeed, to recruit families who had considered participating in a project but not participated, or those who attended for a short time before dropping out.

As noted, illustrative quotes are presented in this report, to allow the voice of practitioners and families to emerge in their own words. The authors do not vouch for the accuracy of participants' accounts.

4 Project Descriptions and Implementation

4.1 Group Connections: Mansfield. A project for parents, siblings and peers

Group Connections provide annual or biannual weekend camps for mothers, fathers, and siblings of a person with a disability. It also organises social events for children and young people with a disability. The project is co-ordinated by Mansfield, an NGO which offers programs for people with disabilities and their families across NSW. The project was established to provide environments in which people can form friendships and interact with others in similar circumstances.

The agency has been providing sibling camps and mothers weekends away for some years. The ADHC funding has enabled them to put in place a co-ordinator and expand the project to offer fathers weekends away as well. By utilising their connections with other projects internal to the agency, as well as other service providers, they are able to offer a range of activities that build networks with people from other areas,

Sibling Support

Siblings attend either a primary or secondary school age group. The groups attend shorter activities during the term, such as bowling or sport and recreation activities, and during the school holidays generally go on a weekend trip. Through the activities participants can learn new skills, such as abseiling, canoeing, horse riding and surfing.

There are school holiday camps for children 8 to 11 years old and for older children 12 and up. The camps provide an opportunity to take a break and, in some cases, have a break from their regular caring role. They provide a chance for the young people to have fun and relax.

As the sibling camps drew from a large regional area the camps also gave the participants the opportunity to mix with children and young people from different areas, farms, inland regional towns and beachside towns. The project gives these children and young people opportunities to take part in activities they may not be able to do due to financial and time constraints of their families.

Mothers weekends and fathers weekends

The mother's weekends have included trips away, where the mothers get the opportunity to shop, be pampered, and enjoy a restaurant meal. The fathers have attended fishing trips and sport and recreational activities.

The sibling and parent projects also provide an opportunity for people to debrief about their situations and connect with others who may be feeling the same way. As this is not a counselling program, this process happens in a non-confrontational way with which people are comfortable, through informal conversations over a fishing trip or card game.

There is significant interest in the camps and the waiting lists are quite long as limited places are available. The number of participants for each camp varies depending on the availability of transport, funding and accommodation. For sibling camps the numbers range from about fifteen to twenty, and approximately the same for the parent's weekends. A number of Aboriginal mothers and young people attend the camps, though the project has had more difficulty generating interest from Aboriginal fathers.

There are mothers who are unable to participate in the program due to work and farming commitments. The agency makes every effort to provide support for mothers so they can attend, and the respite service gives priority to families where the mother is going on a weekend away. An advantage of offering this type of project through a large organisation such as Mansfield is the capacity to offer additional, flexible support.

Initially participants for the camps were recruited through the agency's client list, but since forming partnerships with various organisations in other areas of the region, the groups are widely promoted. Having to cover the whole region, which spans over four hours travelling time, the staff have managed to establish and sustain various partnerships with service providers both internal and external to Mansfield to assist them. Forming relationships with other service providers has proven very important for engaging and sustaining program participation in areas outside of the region's administrative centre.

Social activities for young people with disabilities

The purpose of the club is to offer activities in which the children can interact with each other. This is a new project and the range of activities has been determined by the facilities available in town. At the moment activities centre around ten pin bowling. Bowling provides the opportunity for young people with disability to interact with staff and their peers independent of their family, with parents seeing this experience as a way of building confidence in their child. Mothers interviewed regarding the ten pin bowling found that their child was otherwise dependent on their family for entertainment, and they really enjoyed the activity.

4.2 Teen Fun: Creative Inc

Teen Fun provides after school activities and social interaction for high school age children and young people with a disability. It is part of Creative Inc., an organisation that provides services and employment services to young people. Teen Fun runs at a ratio of one staff member to every five participants. Currently 37 young people participate in the Teen Fun program and attendance is spread across two locations in regional NSW.

Teen Fun aims to provide a place where young people with a disability can come and make friends with peers after school through social and recreational opportunities. Parents and practitioners also described friendships as a goal of the project.

While the Teen Fun project has been active for three years, the contribution of ADHC funding has enabled the organisation to purchase a bus for the purposes of transporting clients and travelling on excursions. This has enabled the project to expand its range of activities and services that it can provide.

Participants attend the group one or two days per week after school. The staff plan the activities well in advance and provide this information to parents at the beginning of each school term. Activities include arts and crafts, cooking, playing sport, bowling and bike safety lessons and social skills workshops. During school holidays the young people participate in excursions and overnight camps. In addition, the agency runs a variety of programs with which participants can connect, including the Transition To Work program for those children who are about to leave school.

Staff liaise with a disability worker from the Department of Education and Training who promote the program to schools. Brochures and expression of interest forms are distributed to both public and

private schools. Practitioners emphasised in their interviews the importance of maintaining working relationships with other organisations.

Additionally, participants are made aware of the project through word of mouth. These methods have proven very successful and consequently Teen Fun has had no difficulty recruiting participants. The project has an extensive waiting list which they manage by alternating the young people's participation each term: that is, by asking young people to take a 'term off' on a rotating basis. This enables them to give as many young people a turn at attending as their capacity allows.

The project employs two full-time workers and one part-time employee. Staff are required to obtain minimum a Certificate III in disability support and currently two staff members are completing this. The organisation also provides ongoing training for staff in a variety of areas.

4.3 Positive Connect: Pinnacle Inc

The CALD Positive Connect project is aimed at parents or carers from culturally and linguistically diverse (CALD) backgrounds who have a child with autism. It is co-ordinated by Pinnacle Inc, which provides a range of services and programs by families with a child or young person with autism spectrum disorder. Positive Connect provides moral support and practical advice to parents over the phone by matching them with volunteers, who are also parents of a child with autism. The objectives are to provide peer support, reduce isolation and build capacity.

The agency has been managing the Positive Connect parent support project for some years. It identified that there was a big gap in their service provision pertaining to culturally and linguistically diverse clients, and the CALD project is designed to address that gap. The agency works with members of particular ethnic communities, who act as a gateway into the broader community, for example, a father who had good connection with one ethnic community acted as a link, while a trusted translator within another community provided a connection with the project.

A designated worker was hired to develop the cultural diversity component of the Positive Connect project. Their job description involves recruiting, training, matching and supporting volunteers to parents and connecting parents through carers' days and fathers' evenings. The coordinator establishes relationships with communities through community leaders, and promotes the program through community-language newsletters and forums. Clients also find out about the program through other avenues, including referrals from other services and word of mouth.

However, the agency's continuous improvement process identified problems with reaching these communities. One of the challenges to delivering the peer support project has been the desire of some participants to be matched with volunteers who are not from their own ethnic background, because they do not want people in their community to know that their child has autism. Instead, they prefer to discuss their situation with paid service providers, preferably from outside their community. It is important to note that this reluctance is probably widespread rather than limited to a specific ethnic community. Moreover, as the agency recognises, it is important to respect the preference of families to speak to experts rather than volunteers. However, staff and volunteers also recognise this as a barrier to delivering the project as it was originally designed.

Another challenge reported by parents and volunteers is matching the appropriate volunteer to the parent. Similar cultural backgrounds are not the only priority for parents when matched with a volunteer. They also want to speak to someone who has a child of similar age and level of

impairment. As matching is a difficult process, there are families of specific cultural backgrounds waiting to be matched to an appropriate volunteer at any one time.

The agency has identified difficulties reaching these communities and the nature of the project has now changed. The CALD project has proven more successful when it is incorporated into other projects, namely fathers evenings and pamper days for mothers. These events are designed to provide information and support and are held across the metropolitan area. Events are run on a quarterly basis and offer access to counsellors, staff and local ethnic community groups, and a chance to network in an informal, fun setting. These events can have up to 30 fathers and up to 80 mothers attending at each event. These events can be useful for networking between parents and matching volunteers with parents.

4.4 Kool Kids: Pinnacle Inc

Kool Kids is a project provided to 8-18 year old children and young people with autism spectrum disorder (ASD). The aim of the project is to provide participants with the opportunity to make friends and develop social skills. Kool Kids is not intended to provide learning or social skills training, but staff reported that providing a comfortable social environment facilitates social interaction and the development of social skills.

The project is broken up into two groups, a junior club for 8-12 year olds, and a teen club for 13-18 year olds. A total of approximately 200 families are enrolled in the database, and approximately 50 families are actively attending. The junior club is located in several schools and is facilitated by teachers who have extensive experience in working with children with ASD. These groups are facilitated by one teacher and one volunteer, with the participation of approximately eight to ten children in each program. These groups run once fortnightly for one hour after school. Participants spend this time enjoying a range of activities, including indoor (board) and outdoor (trampolines, tennis, scooters, bikes) games. Initially the teen club was set in a community hall, but it now moves around various venues and includes activities such as ten-pin bowling, putt-putt golf, movie and games nights and Halloween parties. Two staff members attend the teen clubs, generally with the help of one volunteer. The numbers of young people attending range between ten to fifteen participants, and staff noted the importance of varying staff ratios to the needs of the group.

Participants are recruited through various avenues: the agency's infoline, word of mouth, promotion through other agency projects, such as Positive Connect, and also the agency website.

Pinnacle Inc reported on the difficulty of recruiting staff with the appropriate skills to facilitate the activities due to the flexible hours the groups are run. Initially it was intended that one person would be hired to facilitate all the groups, however it was not possible to find the right person. Consequently, the facilitation of the groups is shared between agency teachers. Other staff include the Program Director, Program Coordinator, and part time administration officer.

4.5 Fun with Friends: Alliance Creations

Fun with Friends is co-ordinated by Alliance Creations, an organisation that provides services to disadvantaged groups. The project runs one day a week after school during term at several different venues around the region. It also takes the young people on excursions during the school holidays. Currently a total of 54 young people between the ages of eight and 17 attend the groups. To be eligible to attend the participant must have a sibling with a disability and reside within the catchment area. The project does provide transport for participants, however there is waiting list for this and the lack of transport in the area can keep many people from participating. The groups run on a ratio of

one worker to every 15 participants during the weekly sessions, and increasing to one worker to every eight participants during excursions or camps. The project does not have a waiting list for the weekly sessions, but can only take a maximum of 15-20 students away on camps and there are waiting lists for these activities.

The Fun with Friends project provides a space for siblings of people with a disability to connect and share their experiences, and have fun in a safe setting with other young people in similar situations. Activities during the weekly sessions may include arts and crafts or cooking, and team building activities. The project also offers information on specific disabilities, so the children and young people have a better understanding of their siblings' needs and strengths.

Interaction and networking between parents is encouraged by the providing of occasional social opportunities, such as 'parents versus siblings' trivia nights. The project is also in the process of setting up an online chat room so that participants can interact with one another outside of attending the program. Additionally the project is establishing a Facebook page so the young people are able to easily stay in contact with other group members and know what future activities are planned.

The project is promoted through a number of different mediums, through schools, service networks, interagency forums and other services (ADHC, family support, young carers) and the Siblings Australia website. The project is also advertised in local newspapers. Word of mouth is often reported as the means by which new participants find out about the group. The agency works closely with other organisations in the area and during interviews staff emphasised how much these partnerships are valued.

Project staff are one full-time coordinator, one part-time worker, and several volunteers. All staff are required to have experience or qualifications in welfare or a related field. Experience working with youth, community work or disabilities is also desirable. The organisation provides accredited training for workers, which is relevant to their role in the Fun with Friends project.

4.6 E-Connect: Cultural Connect

E-Connect provided a multimedia project for siblings aged 12-18 of children and young people with a disability. It is co-ordinated by Cultural Connect, an organisation that provides individual advocacy for people with disabilities, their families and carers.

A total of six participants engaged in the project. They were split into two groups of three and each group attended one block of sessions. The project was carried out over four days during the Easter and winter school holidays, and a few additional Saturdays, at a location where participants could engage in multimedia activities and education.

A non government organisation was commissioned to develop the young people's skills in creating videos and graphic art; they also created a blog to be able to keep in contact with one another. The course gave participants an opportunity to communicate their stories through graphics and video. During the sessions the young people were given time to discuss the impact of having a sibling with a disability. Much of this discussion went on in the van during pick up and travelling to the venue.

The project was facilitated by one coordinator. Attempts to recruit participants for this project were via a letter sent to school principals, and then a follow up to the disability officer at each school. The coordinator also spoke with parents during information evenings and an information day about the

project. These strategies for recruitment were unsuccessful. Participants were successfully recruited through referral from Community Liaison Officers, youth services, and disability services.

At the time that evaluation data was collected, staff identified reasons why the project was less successful in recruiting than expected, including that young people are very busy with a lot of academic and other pressures on their time. There were a number of enquiries from families of younger children who could not be accommodated.

4.7 Deadly Times/Prime Parents: Prime Care

Deadly Times is an Aboriginal project for children and young people with a disability and their siblings. It is co-ordinated by Prime Care, a large non-government organisation that delivers advocacy and services across Australia. Separate groups are held fortnightly for boys and girls between the ages of 8-18 years (though currently the age range is 6-17 as a younger sibling of participants has been invited to participate). These groups are made up of children and young people with and without a disability to encourage social inclusiveness and promote acceptance and capabilities of people with a disability.

The group is usually held on the agency premises and activities have included jewellery making, arts and crafts, scrapbooking, and playing Nintendo Wii. The activities work as an ice breaker to engage the young people and encourage social interaction. Parents are also encouraged to attend to spend this time with their children. During the school holidays the groups go on outings, such as to the movies or bowling. The agency also runs a parent's group for parents of children and young people with a disability. These groups are generally run once a month and each meeting is focused around a different topic in response to parent's needs or concerns. For example, one previous meeting invited a guest speaker to speak about child behaviour management.

The Deadly Times girls group also completed the Shine program which has since had ongoing positive effects for all the young girls involved. The program aimed at promoting self-esteem and confidence, and included teaching girls grooming and deportment skills, and discussion based workshops around body-image.

The project is managed by one part-time worker who works solely as the coordinator of the programs. As the project is attached to Prime Care this staff member had access to various training opportunities and resources.

While the program is highly valued by participants, participant numbers are lower than anticipated. The number of participants in the parent's group averages at two parents (four being the highest number), the girls group consists of nine participants, and the boys group consists of five. At the time of the evaluation data collection referrals were from other Prime Care services and word of mouth, and the agency was actively trying to recruit more families. A service provider stressed the importance of quality over quantity especially when targeting the Aboriginal community which are traditionally the hardest group to reach and engage with service providers. It is likely that to build the numbers will take time.

Every service user interviewed discussed how much they valued the activities and opportunities provided. The only thing participants and their parents would change would be to increase the frequency of the group. Parents reported increased confidence and self-esteem in their children since joining the program, as well as them making new friends.

5 Key Features and Outcomes

This section describes the projects and their reported benefits . As described in Section 2, research indicates that support networks can have benefits for each of these groups, with additional specific benefits for people with disabilities. There are also specific challenges to developing support networks for people with disabilities.

5.1 Projects for siblings

While there are positive experiences associated with growing up with a brother or sister with a disability, there is also recognition of the difficulties that siblings may sometimes experience. Support networks have been developed in recognition of the benefits that facilitated social groups and events can bring for siblings of children and young people with a disability.

There are two implications for the Program from the literature on social groups for siblings. The first is that similar projects have generated feedback that the activities run by projects are enjoyable, but not able to be run at the frequency or intensity that participants would like. However, and more importantly, the literature suggests that social events and recreational activities can be successful in achieving ongoing benefits, including the development of informal support networks.

Findings from the projects

Evidence from the projects is that they have been implemented in line with the program principles. In particular, the projects have provided siblings with activities that are highly valued and appropriate to the diversity of their experiences and social context. Siblings have been included in the planning and evaluation of activities.

Feedback from siblings in each of the projects about the activities offered was overwhelmingly positive. All siblings interviewed enjoyed attending their group and always looked forward to the next activity or event. On behalf of the girls in the Deadly Times group, one of the participants explained why they enjoy going to the group, ‘we have fun doing what people like, we can scrapbook, we can make stuff for our mum and dad, we just drop everything and do fun stuff, drop all the hard things and do fun stuff’ (Tabatha, sibling).

The camaraderie which develops when there is common bond helped many of the siblings develop confidence and maturity.

That camaraderie of being able to realise they’re not alone, and that there are other kids out there in a similar sort of situation and dealing with some of the same stuff that they deal with, whatever that is, whether they’re teased at school, or picked on because of their brother or sister or left out of things or they just don’t have the same opportunities because of other priorities in the household. (Elise, service provider)

The camps focus on having fun, experiencing new activities and meeting other siblings. However they have resulted in some quite in depth discussions particularly amongst the girls. This has lead to a sharing of information on a level that could not be achieved in any other way. Camp staff would maintain a presence but allow the free flow of conversation between the children.

Yeah so you get to see other like find out new autisms or new disabilities and you find out how you cope and you can tell them how you cope. (Tasha, sibling of young person with a disability)

Siblings of children with a disability may miss out on the opportunities of their peers, for example, they may have limited opportunities for extra-curricular activities as their parents' time and involvement in their lives may be constrained (Cass et al., 2009; Llewellyn et al., 1999). Many of these children and young people are providing significant support in either caring for the child with a disability or supporting the household. The project therefore offers the opportunity for young people to talk about any anxieties, and concerns including about their future. It also gives people with similar experiences the chance to learn about what other young people in their situation are going through, to know that they are not alone, and to share their stories.

I suppose the highlights for them would be making friends, that they know what's going on and they can say oh my brother, you know, is doing this and they're like, 'oh my brother does that as well'. So for them just to, you know, debrief and just ... not to be isolated. (Jill, service provider)

Siblings of children with a disability may be subject to bullying at school (Barr and McLeod, 2010; Stalker and Connors, 2004). At the camps they all learn to encourage each other and by trying new skills develop their own internal confidence.

Through attending the camps the siblings have established long term friendships with other children. The girls in particular swap Facebook details and mobile numbers to stay in touch. The boys, while more laid back in their relationships, also text each other to see if they are attending the next camp. The children all reported their enjoyment of the interaction with agency staff.

All the staff had attended 'accidental counselling' courses and found the girls in particular used the opportunities to discuss their circumstances and challenges. If the opportunity presents itself, the staff use it to give the children a chance to reframe their experiences from a more positive or strengths-based perspective.

Two young people who attended sibling camps comment on changes within themselves since attending

A little bit more confident with people that I talk to. (Ben, sibling of young person with a disability)

To do things we haven't done before to not hold back, just go for it (Tasha, sibling of young person with a disability)

Although experiences of having a sibling with a disability are often positive, the camps also allow the opportunity to discuss challenges as well as strengths. One service provider talked about the opportunities it provided to meet other siblings and discuss their circumstances in a safe environment, where others have had similar experiences.

Well, they loved it. The feedback was [...] they loved it. [...] One night I was in their room and they were talking about, one of them spoke about something that happened in their family and [...] before you knew it they were all sort of talking while they were laying on their beds sort of thing, and it sort of made them realise

that they're not that different, like it does happen in other homes as well. So it was good for them to be able to talk to others that understood. (Kelsey, service provider)

Parents commented on improved confidence and maturity as a benefit. Two mothers spoke of their child gaining a new perspective on their own situation through hearing the stories of others. One of the incidental benefits of the camps was that the siblings became more familiar with agency staff and used the centre as a drop in centre, so much so that the staff are now thinking of setting up a monthly meeting for siblings at the centre.

Participants in the Deadly Times sibling groups have formed friendships which extend outside the project. Some of the young people who don't attend the same school reported difficulty maintaining contact outside of the group. This difficulty is related to the majority of group participants not having personal access to a computer or a mobile phone to electronically stay in touch with each other. Additionally, living in a regional area with limited transport options means it is very difficult for group members to meet outside the group activities offered through Deadly Times. This is one reason the participants highly value the project, for if this opportunity to see each other was not available then they would not get the chance to maintain friendships with one another.

5.2 Projects for parents

Support networks for parents have been developed in the context of recognition of the difficulties they sometimes experience, and of the benefits that facilitated social groups and events can bring.

The implications for the Demonstration Support Network Program from the literature are similar to those relating to the literature on support networks for siblings, especially that reasonably infrequent activities can be sufficient to generate independent friendships. This is unlikely to be true in all circumstances, or for all parents, but it appears that facilitated groups and recreational activities both provide benefits for participants and lead to relationships beyond the formal projects.

Findings from the projects

Evidence from the projects is that they have been implemented in line with the program principles. In particular, the projects have provided parents with activities that are highly valued and appropriate to the diversity of their experiences and social context, and have supported parents in building social support.

Two of the projects provided support for parents of children with a disability as a primary activity: Positive Connect and Group Connections. In addition, Prime Parents is an emergent project for parents delivered by the same agency that co-ordinates the Deadly Times groups for Aboriginal young people with a disability and their siblings.

Parents who attend Positive Connect events make connections with other parents. They are also linked with formal services and support. A couple of the parents who had used Positive Connect found it invaluable in the period immediately after diagnosis.

I feel like I finally have someone I can talk to because I'm a bit, I didn't tell this thing to most of my friends or other people. So, I feel a bit isolated but after this program [...] at least I can talk to someone. (Charmaine, mother)

In at least one instance the parent-to-parent support model had fostered the development of informal support, as per the Program intentions. One volunteer had maintained communication with one of the parents he supported as they lived nearby and their children went to the same school. The nature of their relationship changed to one of friendship and mutual support.

The Group Connections project supports mothers and fathers of children with a disability to have a weekend away. The mothers all talked favourably about the weekends away. Many mothers are isolated due to their physical location or their role in meeting their children's support needs. The weekends away give them an opportunity to socialise and, as everything was organised, a chance to re-charge their batteries. Two parents commented on the weekends away:

Probably the companionship. Everyone in the group has a child with a disability, not necessarily the same disability, but they have a story. It's the companionship of women in a similar situation [...] To find out what other supports are out there. Its good networking (Cheryl, mother)

I went with the intention of getting some rest but ended up chatting to 1 a.m. Some of the women are quite entertaining. I still felt refreshed when I came home (Pattie, mother)

The mothers weekends also have a great deal of information sharing, from which were the best schools to support their child through to financial support available. Mothers participated in the weekends away for a variety of reasons. One simply wanted a rest, a 'sleep in'. Other mothers commented that it was good to see that the family could cope with the child with a disability without her for a weekend. It made them feel that their children were not as dependent on them as they had thought.

Many of the mothers remain in touch either by telephone or email and arrange to meet up on subsequent weekends away.

Research indicates that historically most mothers have been primary caregivers of children with disabilities, and fathers have not engaged as much as mothers with services (Bristol et al., 1988; Green, 2007). However, practitioners reported that often the father is the 'backup' or background support worker, caring for the siblings without disability, assisting with household chores as well as working outside the home to provide the family with an income.

The agency launched a fathers' weekend series successfully by providing activities which could interest a wide range of men. These include fishing, sports and recreational activities such as abseiling, and a weekend to attend the State of Origin. Both fathers interviewed noted that they would be unable to afford these activities otherwise.

The staff that accompany the fathers are all male. They have all completed the 'accidental counselling' course. One of the service providers who accompanied the fathers commented on the difficulty many had in attending the weekends as many of them work on the land. Many fathers were reluctant to attend initially but, having gone once, they were prepared to do it again.

A Mansfield practitioner described the feedback that she received from a father after one of the camps:

[A father] said to me, which is really, you know, like just knocked me for six, so he went ‘thank you so much for that’, he said, ‘I did not realise that I was actually at breaking point.’ He said that now I can actually go home and I’m going to be okay ...To me that kind of sums up everything about what we do, you know, that guy’s okay to go home and to continue. (Magda, service provider)

Fathers seemed to develop a bond with others, although it was unclear if they followed up with them as the mothers do. It should be noted, however, that the fathers’ weekends away are new and so this may build over time.

The fathers tended to only opt for one weekend away a year but they spoke of that being enough to allow them to manage the following year. Two fathers described the benefits they received from participating.

It’s not just a boys weekend away but it’s, I don’t know, it’s just a different way of sharing different things with it all and I think it makes you appreciate the things that you have got [...] It’s just a good way to recharge your batteries in your own little way too. (Philip, father)

You find by the second day on the weekend [...] that you started to get to know people. And then you started to talk and then you found out what was up with their kids and, yeah. Being able ... having somebody else to talk to that you knew understood what you were going through because they were going through it too. (Fred, father)

The Prime Parents program offered through Prime Care offers information sessions from professionals and experts to parents of children with disabilities. Guest speakers are selected based on the expressed desire from parents to learn about a particular topic, for example, child behaviour management. These information sessions provide practical and valuable advice to parents that can assist them both within the home and generally. Parents also expressed an interest in having someone from Centrelink come and speak about their caring entitlements; which could build connections between generalist community organisations and the families of children and young people with disabilities.

5.3 Projects for children and young people with disabilities

Projects for children and young people with a disability implemented within a person centred framework encompass the capacities and interests of the person with a disability and form the basis for developing support. Person-centred thinking is characterised by ‘actively searching for a person’s gifts and capacities in the context of community life; and strengthening the voice of the person and those who know the person best in accounting for their history, evaluating their present conditions in terms of valued experiences, and defining desirable changes in their lives’ (O’Brien and O’Brien, 2002: 5) and relies on the use of everyday rather than technical or professional language,. This is in contrast to other approaches, in which professional expertise is central and the support available is determined by agencies and organisations.

The implications for the Program from the literature on support networks for children and young people with disabilities are different from support networks for parents and siblings. While formal events and activities often facilitate the development of independent friendships and increased support for parents and siblings, formal events are unlikely to be sufficient on their own to build

independent friendships and increased inclusion for people with disabilities. Research on the capacity of mainstream schools to be genuinely inclusive of children with disabilities, and on the Circle of Friends model of support networks, indicates positive but inconclusive findings, and suggests that sustained efforts are needed. The literature also suggests that support networks show promise in improving the attitudes and inclusiveness of people without disabilities, however they are less strong in building the skills and participation of people with disabilities.

It should also be noted that the Demonstration Support Network Program description (ADHC, 2007) lists possible activities for funding under the Program, and this list guided the agencies in developing the projects. Listed examples include time-specific workshops, drop in facilities, sport and recreational activities, camps, and internet and on-line activities; and, as described above, the projects operate several of these activities.

Findings from the projects

Evidence from the projects is that they have been implemented in line with the Program principles, however there is less evidence that relationships with peers who do not have a disability have been developed through participation on this project. Instead, the focus has been to provide social opportunities and recreational activities that are typically available to children and young people. The growth of independent friendships is an emerging development from these projects, and some improvements in social competence and social interactions are also being reported. The projects for children and young people with a disability have all reported improvements in the interpersonal skills and confidence of participants.

The Kool Kids group activities enable the young person to learn about turn taking, expressing themselves within a group. The project aims to teach the children social skills indirectly whilst ensuring they have fun. For example playing board games teaches them sharing and participation skills in a relaxed manner.

I think he just has fun there, to tell you the truth and then the fun transfers to an acceptance and the acceptance gives him an idea of what good and proper friendships are. (Sarah, mother)

There seemed to be some clear benefits of the project in improving children's behaviour and disposition. One mother said that though her daughter was tired after attending the club she was calmer and her behaviour improved. Another mother said that the opportunity to widen her child's network of friends had reduced their isolation.

The parents of the young people participating in the social club for teenagers had varied opinions as to changes in their children's social skills. One parent had seen a noticeable improvement, which she had attributed to attending the groups. She said that her son had been participating for three years and had gained confidence in a variety of social settings as well as being able to cope more in unfamiliar social settings. Other parents talked about their child's enjoyment of the activities as the main benefit.

What I really treasure about having the social group is the exposure he gets and the different variety of people and of situations that he actually sees which I find is really good. (Wanda, mother)

I would also like to add that [the staff] are really skilled in how they handle the children at the club. My daughter loves going there. It's her lifeline here as school is not working for her. (Moanna, mother)

A benefit of Teen Fun is enabling the young people who participate to interact and form relationships with others from different schools. One parent, interviewed with her daughter, said that the project offers social opportunities which are otherwise difficult:

I really like the chance for [my daughter] to socialise as she doesn't have other opportunities to socialise with other children [...] I get satisfaction just seeing her talking to others and joining in. (Dora, mother)

In one project, networks were reported to have developed between the participants. Several of the children meet outside the formal activities, and the agency is in the process of establishing a networking page on Live Wire so that the children can connect with each other.

The projects are also facilitating the development of independence and skills. One agency has purchased a bus which collects the children from school and takes them to the centre. Whilst this relieves the parents of travelling it also is part of the process of teaching the children independence in a controlled safe setting. During our visit to the site, we observed children actively helping each other in different ways. The supervisors were very skilled at only involving themselves when necessary, for example when the stress of completing the task was proving too much for one child. Otherwise the children assisted and supported each other.

School can be a difficult environment for children and young people with a disability, and their parents (Carter and Spencer, 2006; Lightfoot et al., 1999; Mishna, 2003) Four parents reported that their child was struggling at school either with bullying or with the school-work itself. They said that the projects gave the young people an opportunity to discuss their difficulties with an adult.

Parents reported that the projects had allowed their child to socialise in a fun safe setting that was away from school. Two mothers reported that their child had developed life skills and also found friendships that may be sustained beyond the life of the project.

Well I felt that he would get more experience of being with other students other than at his own school which he has. I didn't expect that he'd make friendships as quickly as he did from other schools and you know we've even talked to some of the other parents which I didn't expect that which was good, that was a big positive. I think I just expected that he would improve socially with ... mainly I think that was the biggest thing that I expected but he has found a lot of independence which was a big plus for us. (Sarah, Mother)

Some children participating in the projects are home-schooled and the project provides opportunities to socialise with children their own age that would otherwise not be available. Families valued very highly a combination of varied programming combined with a relaxed style of delivery which allowed the children attending to develop their independence at their own pace. Indeed, some parents spoke of their child's growing maturity and willingness to do things without their parents attending, and attributed positive changes in behaviour (increased confidence and reduced self-harm) to participation in the project.

The social groups for children and young people with autism spectrum disorder are very important in providing an environment where disability is accepted and understood. As the child flourishes in this environment, parents and practitioners reported that their self esteem and self confidence improves.

I guess the structures that we are able to put in place to facilitate easy and sometimes instant interaction between the children. They are delighted to be somewhere where they're accepted and liked and having fun with other kids in the right sort of structures and activities. (Leanne, service provider)

Both staff and parents from the Prime Care projects commented on positive changes to children and young people with a disability who participate in the Deadly Times groups. A number of participants in interviews commented on the positive changes in the girls since the completing the Shine program. One mother said:

Even at school she's a bit shy, but after coming here and being a girl and doing all the silly stuff that girls do, she's got more confidence, and I can see that at school and it's a big difference in her attitude, and she's happy, she's bubbly again (Amy, parent).

One mother explained that her daughter's anxiety has lessened:

[We] have seen a difference in her, because she gets a bus from here to over there as well, whereas before I couldn't leave her, I had to take her to school and be there when she got out of school, but on the day they go over there she's happy to get the bus over now (Renee, parent).

This mother then went on to describe how her daughter's behaviour has changed from when she first started attending, 'when we first started I had to stay there and she was very quiet...she's heaps more confident to go over there and stuff' (Renee, parent).

The Shine program also provided an opportunity for mothers and daughters to strengthen their relationship and for mother's to spend some quality time with their other children. While Shine was originally intended for high school girls without a disability, the coordinator of the Deadly Times project adjusted it to suit pre-teen girls and people with intellectual disabilities. . Young people both with and without a disability participate in the groups, which offer an inclusive social context for both groups.

Participants with a disability in the boys Deadly Times group are also experiencing positive changes. One mother said that before joining the group her son was very shy and avoided making friends and talking to people, but since coming to Deadly Times he has made friends with the other boys and is now more confident talking to people, 'he's a completely different kid' (Amy, parent). The change in this boy has also translated into the school environment as his teacher had reported to his mother that he is always talking about Deadly Times, seems much happier, and has much more confidence.

6 Outcomes Summary

This section summarises the benefits for children and young people with disabilities and their families in terms of the intended program outcomes.

6.1 Projects for siblings

The siblings of children and young people with a disability received benefits from their participation in Demonstration Support Network Program projects. These include:

- Improved understanding of their siblings disability, the frustration they sometimes feel and the impact it has on family dynamics. In particular there appeared to be a greater understanding of their role in supporting the family.
- Creating and maintaining social connections with other children and young people in similar circumstances. It was reported that there was ‘an instant connection’.
- Recognition of the opportunities they are afforded in being part of a sibling group. Two siblings said that they would never have had the opportunity to try some of the skill development they had had if they had not had a sibling with a disability.
- Recognition of the qualities they had developed such as compassion, leadership and ability to encourage others.

This section describes the achievements of the projects against anticipated outcomes described in the Demonstration Support Network Program description (ADHC, 2007: 13).

Increase their ability to identify their specific needs at particular points in time

The interviews did not capture information on the capacity of siblings to identify their specific needs. One of the projects provided integrated activities for children and young people with disabilities, and their siblings. This had proven beneficial in a number of ways:

- Families sometimes feel the effects of stigma around disability. By attending these groups this stigma is broken down.
- Children and young people with disabilities learn to mix with peers without disabilities in a safe environment.
- Siblings without disabilities learn to appreciate and care for the child with a disability in a setting in which they can all flourish.

Develop a range of strategies to cope with their concerns and feelings about their brother or sister with a disability

Three key features of the sibling support projects were identified:

- The activities gave the siblings an opportunity for recreational time away from their family, and to explore activities they would not otherwise have the opportunity to participate in either due to time constraints as a family or financial pressures.
- They provided an opportunity to discuss their circumstances in a positive way. This included recognising how they had ‘grown’ as people, and are perhaps more mature than their peers.

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- They allowed interaction with adults in a less formal way than school but in an atmosphere of trust and support.

Participants in the sibling groups made friends and maintained a connection outside the sessions. At one project, an emerging friendship between three participants had led to the participants without disabilities becoming active in intervening when a young person with a disability was being teased at school. Prior to attending the sessions there was little contact between them.

Increased community awareness, understanding and acceptance of children and young people with a disability

The projects are yet to focus directly on broader community awareness, but have focused on increasing the awareness and acceptance of siblings. All of the sibling projects focused on the positive benefits of having a sibling with a disability, including maturity, leadership and mentoring skills.

Strong linkages established with existing supports in the community.

Each of the projects has developed or is developing relationships with formal support organisations, including disability services.

6.2 Projects for parents

There are reported benefits for parents who participate in each of the projects. These are:

- The development of new friendships
- Respite and time away from family responsibilities
- Opportunities for information provision, especially information that is requested by parents
- Increased receptiveness to support, including informal support from other parents

This section describes the achievements of the projects against anticipated outcomes described in the Demonstration Support Network Program description (ADHC, 2007: 15).

Increase their ability to identify their specific needs at particular points in time

The focus of the projects has been providing parents with a break, and putting them in contact with other parents. The projects are highly valued, especially the weekends away, which have enabled some parents to recognise the importance of a break and contact with other parents.

The information sessions run by one of the projects are designed to meet the specific needs as requested by parents. These provide specific information and link parents with formal services.

Have an improved perception of their ability to manage a range of different issues that impact on their family well being; and develop a range of strategies to cope with their concerns and feelings

The primary achievements of the projects in this area have been in providing information about formal support, and facilitating the development of friendships, which contributes to improved resilience and ability to cope.

Have developed and maintained sustainable relationships and friendships with others in similar circumstances

In one project, some families have established meeting groups at a private house to let parents from a specific cultural background provide support to each other on an ongoing basis. One parent who had participated reported that he had since become friends with his contact parent and they met regularly for 'playdates' with their children.

At another project, which was active prior to the Demonstration Support Network Program and has been extended to fathers, one of the intended outcomes of the parent's weekends away is to connect families who are experiencing the same difficulties. A number of mothers contact each other on a regular basis and a few have occasional lunches together when their children are at school.

Parents, especially mothers, reported feeling less isolated as they could now pick up a telephone and talk to the other mothers. This is important, as the literature indicates that awareness of support and its perceived accessibility benefits parents (Canary, 2008; Krahn, 1993).

Have established strong linkages with existing support and report increased integration within the community

Many of the parents have developed closer links with the service providers in their areas through getting to know them on a sustained basis.

Reported reduced stress and increased cohesiveness in the family

Parents found that participation in the weekends away recharged their batteries, and found the connection to both services and other parents very useful.

6.3 Projects for children and young people with disabilities

There are reported benefits for children and young people with disabilities participating in the projects. These include:

- Increased confidence with social interactions, and in group situations
- A greater sense of independence
- Enjoyment of the project activities and desire to participate in future activities
- The development of friendships and support which are sustained outside the service.

This section describes the achievements of the projects anticipated outcomes described in the Demonstration Support Network Program description (ADHC, 2007: 17).

Increase their ability to identify their specific needs at particular points in time; and develop social and interpersonal skills

Each of the projects focused on providing children and young people with disabilities with social opportunities in relatively structured settings. Any increases in social and interpersonal skills, or capacity to better identify their own needs, have been largely incidental but are promising as they suggest that the principles of support networks are in place and leading to anticipated benefits. Some improvements were noted by parents in these areas, as described in the examples below.

The first example is a boy who hated school and often pleaded illness would insist on going to the group. The boy had joined Facebook to communicate with the other children he had met through the project, and his mother noted that he had grown in confidence and would initiate conversation with peers where before he had been withdrawn. Another example is that a girl who is homeschooled and was very dependent on her mother has reportedly grown in confidence and was less focussed on her disability, and had expressed a desire to go on excursions with the group.

Have opportunities to develop and maintain sustainable relationships and friendships

The projects are facilitating the development of friendships, including via social networking media such as Facebook.

One boy with autism had developed such confidence from attending that he was able to give a report at school and he used his activities at the group as his news. His interaction with the co-ordinator at the agency had improved his communication with his teacher as well, who had reported she had noticed a considerable improvement in his self confidence since attending the group.

Have increased opportunities for social independence

Young people who had been away to camp reported that they had enjoyed the experience and had made contact with their peers that they would not otherwise see.

7 Sustainability, Facilitators and Barriers to Implementation

Each of the seven projects is unique and offer different activities for children and young people with a disability and their families. This section looks at the Demonstration Support Networks Program as a whole to identify what particular factors are necessary for all of the projects to function successfully.

Most agencies used the Demonstration Support Network funding to enhance or expand services they were already delivering. This is likely to support the sustainability of these services, as they are already core business. On the other hand, it seems also to have impeded innovations in practice, such as the introduction of activities based on person-centred thinking or a focus on activities which increase community acceptance and inclusiveness of people with disabilities.

- Assistance from other programs or services

Each of the projects that have managed to recruit and retain participants into their project have an ongoing relationship with other programs within their larger organisation, or with external services. Collaboration with other programs and services is pivotal to the promotion phase of the project, and is also vital in providing assistance during the implementation of activities or events so that the project can continue effectively. This assistance is generally in the form of offering resources, such as extra staff to bolster supervision numbers, or the lending of a venue to accommodate the group.

Most of the projects have dedicated staff, however, were they to leave they had a pool of other staff who could provide the program in some form. The Prime Care projects are probably the most dependent on the support funding and the skills and dedication of one practitioner.

- Established relationships and activities

The one project that had difficulty achieving the outcomes for participants reported by other organisations in the funding period was a new project. The time required to get referral pathways and programs established is worth considering when future projects are undertaken. Deadly Times is also a new project, but its place in a large NGO means that referral pathways have been relatively easy to establish, although participant numbers are lower than anticipated. In contrast, those projects that have sufficient numbers or are over-subscribed are longstanding and well known in the community. This suggests that projects need time to develop, and that innovative projects may appear, in the short term at least, to be less sustainable than more established service models.

7.1 Barriers and facilitators to planning, implementation and management

Planning

The projects within the Demonstration Support Network Program are at different stages of planning and delivery. Those projects which have been active for a considerable time prior to receiving the additional funding have had the opportunity to experiment with different ideas and ways of delivering the service, such as offering service to fathers where previously only mothers were targeted. These projects already have an established client base and are known in the community. Other projects which have only just been established with the allocation of ADHC funding have had to spend more time on planning and implementation during this funding period. These new projects reported more difficulty in promoting their projects and recruiting participants than projects that were already established as they have had to put additional resources into raising awareness about the project.

Each project is run within a larger organisation that provides a range of supports and services to children, families and people with a disability. An advantage for each of these projects is that they are able to draw on existing clients who use the organisation as potential participants for the Demonstration Support Network Program². This has been particularly useful for Deadly Times/Prime Parents and Group Connections who have recruited all of their participants for their projects through internal referrals.

The project participants are involved in planning, through the use of internal evaluations and feedback processes; and through the opportunity to contribute to discussions about the specific timing and location of activities. These represent early stages in the development of person centred planning. Amendments to organisational governance structures, to allow children and young people with disabilities to participate more extensively, would require specific resources and training, but would also enable these people greater roles in decision making and the opportunity to develop their skills.

Service delivery

Information from the projects indicates that the key determinants of effective service delivery are:

- Transport
- Staff qualifications, skills and capacity, and the contributions of volunteers
- Capacity to respond to support needs, especially during group activities for children and young people who have diverse support needs

Transport

When transport is provided by the projects it becomes much easier for participants to attend. Of the six projects that require participants to attend group activities, five provide transport. One agency used much of the funding from ADHC to purchase a bus to transport participants from school to the project venue. One project provides limited transport to participants using pool cars from the organisation when possible. Another has not had the capacity to provide transport for participants to attend the various recreation venues across the metropolitan area, nor the capacity to provide support for the young people to develop independent travel skills. Transport is not central to social networks or person centred planning; however, in common with evaluations of similar programs, it did emerge as a significant practical element in engaging participants.

Staff and volunteers

Staff have appropriate qualifications for working with children and young people with disabilities and their families. In some cases staff have attained or are attaining qualifications in disability services or social work degrees, and each agency has provided training in the specific areas in which staff are working. One way to bolster the capacity of projects is through volunteers, which also increases the opportunity for informal support networks to develop as volunteers and participants may develop independent friendships. The Pinnacle Inc projects rely heavily on volunteers; Positive Connect is a volunteer dependent program and Kool Kids relies on volunteers in both the Teen and Junior clubs to provide assistance in supervising participants and to increase the supervisor to client

² An exception to this is E-Connect who recruited participants without referrals from Cultural Connect

ratio. Without the help of volunteers the Kool Kids program would not be able to invite as many participants to attend the events. Likewise, Alliance Creations, Mansfield and Creative Inc. rely on a number of volunteers to attend when they take participants on trips away.

Support needs

Interview participants described difficulties in providing support needs to children and young people with disabilities when there is a small number of staff or volunteers working with the group. At one project, staff have found it challenging to ensure appropriate support to young people with different support needs in a public venue, especially as some participants have very high support needs. Another project has faced the same challenges; with only one staff member to supervise a large number of young people, the coordinator found it very difficult to spread his time evenly between group members because of the high level of support needed by one of the participants. These issues reflect the dilemma of projects needing to cater within their capacity to provide support to all participants, whilst providing the risk of excluding some participants from some activities, based on their support needs.

Aboriginal families

Aboriginal communities are faced with specific challenges in addition to those experienced by non-Aboriginal communities. Among these are the difficulties in identifying disability in Aboriginal communities. Firstly, disabilities are so common for Aboriginal people that they are sometimes not perceived as disabilities as such, rather an individual's impairment is just accepted as a part of life (Aboriginal Disability Network 2007:11). Another reason is that Aboriginal people are coping with the impact of colonisation and the trauma associated with dispossession of land, oppression, and other social injustices that the impact of disability is difficult to measure amongst the other sources of hardship (Aboriginal Disability Network 2007:2). Furthermore, some Aboriginal people do not want to segregate themselves further by identifying as having a disability and risk further discrimination and exclusion from social entitlements such as employment (Aboriginal Disability Network 2007:11).

In the Demonstration Support Network Program there is one Aboriginal-specific project, run by Prime Care. As one of the newer projects of the Demonstration Support Network Program, the Prime Care projects are still finding their feet and their place within the wider disability and Aboriginal community. Because it is a new project, staff are conscious that it will take time for the community to develop trust in the project, and it is for this reason that the time needs to be taken to engage participants at their own pace. As the project coordinator has taken the time to get to know families on a personal level this trust has been built and conversations are being had regarding the issues of disability and the needs and concerns of family members. This has been expressed by both participants and staff during consultations.

The Prime Care projects were initially supposed to be specific to children with autism and their families, however, as has been expressed by Prime Care staff, it has been very difficult to target this specific group of people, and the coordinator chose to include children with autism and their families in an alternative way, 'bringing Aboriginal families together with a child with a disability is difficult enough without trying to segregate people into specific groups, so it's more around bringing expert kind of support into existing supports' (Summa, service provider).

The structure of the Deadly Times groups has proven to be effective for the project. To promote inclusiveness of people with disabilities, and break down social stigma and segregation, children and

young people with disabilities and siblings enjoy activities alongside one another in the same group. While this project was developed to provide support for young people with disabilities and their families, the focus is not around disability, rather it is about support and acceptance of all people.

The splitting of the Deadly Times groups into boys and girls groups is also beneficial to the project. This enables the participants to engage in activities that they may be more interested in depending on their gender. For instance, the Shine program focused on the promotion of self-esteem for girls. This separation of boys and girls groups is also respectful to cultural traditions of separate men's and women's business.

8 Areas for Future Development

This section discusses the areas in which program activities have been successful in meeting the intended aims of the program, areas in which there are gaps, and the possible future directions the program could take. To summarise: the projects are highly valued in all cases, and in the case of projects for family members of children and young people with disabilities, appear to be successful in building informal support networks. However, the literature on person-centred thinking and support networks for people with disabilities indicates that specific, purposive activities are often necessary to build informal support networks, and these require different skills and activities from those undertaken by the projects. The outcomes of projects for children and young people with disabilities are consistent with this literature, and suggest new areas of focus for future projects.

The program logic for the Demonstration Support Networks Program (Appendix A) identifies increased community awareness and inclusion as a high-order, long-term outcome. To date, the projects have not focused on increasing broader community awareness, understanding or acceptance of people with disabilities. A number of activities that provide social opportunities in ‘mainstream’ settings, such as ten pin bowling, and one group organises activities for both children with and without disabilities. These are contributing to the increased participation of children and young people with disabilities, which should in turn contribute to greater community awareness and understanding.

It should also be noted that the projects demonstrate the unmet demand for services in some areas, including respite, transport and recreational activities for children with a disability. The projects are filling service gaps for opportunities that could be regarded as basic entitlements for all children and young people and their families, such as after-school care, sport, supportive environments for the young people and respite for their families. They are highly valued by participants for their provision of these essential services, as well as for the friendships, capacities and networks they are helping to develop.

Nevertheless, if community awareness and increased participation of people with disabilities in mainstream activities is a goal, more sustained and targeted activities may be necessary.

8.1 Lessons from research and practice

Support networks for parents and siblings

As noted earlier, research indicates that support networks for children and young people with disabilities are in many ways distinct from support networks for family members of people with disabilities. Previous studies have shown that formal activities for parents and siblings can lead to the development of independent friendships, more informal support and better use of formal support services. As this report describes, the projects for siblings and parents are being implemented in line with the Program principles, and are achieving benefits for participants.

Support networks for children and young people with disabilities

Formal activities for children and young people with disabilities tend not to lead to the development of informal support networks and increased community participation, unless additional, purposive efforts are made. Key elements which contribute to support networks for people with disabilities are complemented by principles of person-centred thinking. The use of informal support networks to support mainstream participation is central to these principles. The projects for children and young people with disabilities in the Demonstration Support Network Program do not align exactly with

these principles, in that formal activities delivered by an organisation are central to the project, and the role of paid staff is primarily to deliver those formal activities.

Programs with similar objectives to the Demonstration Support Network Program, in Australia and internationally, have undertaken different strategies. For example, the Connexions program employs a coordinator to work closely with families, who are supported to assist the person with a disability to follow their interests and participate in mainstream social opportunities, work and sport. This includes identifying ‘natural, ordinary ways of problem solving, using what the person and their family have available to them’ (van Dam and Hill, 2009: 14) and supporting them to become more influential in the decisions made about their lives. This approach is quite different to the Support Network Program, in which group activities are the primary focus.

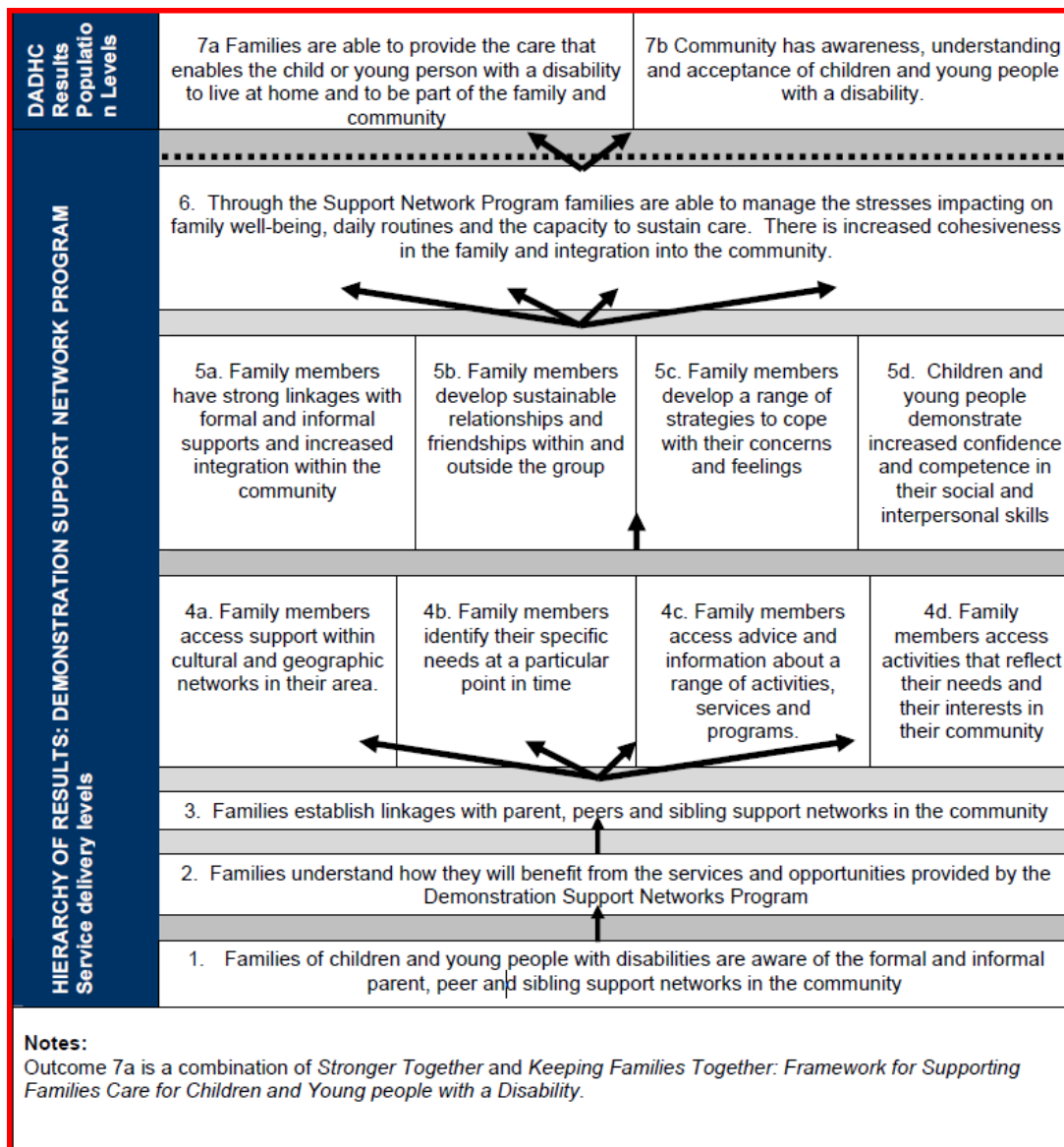
Studies of person-centred thinking in Australia and the UK indicate that there are challenges involved in changing approaches to delivering support from a ‘service-focused’ to a ‘person-centred’ model. These include the inaccessibility of activities and employment opportunities, and uncertainties around the level of support required to ensure that mainstream groups are genuinely inclusive. One-to-one support can reinforce the assumption that people with disabilities cannot participate without intensive support and so are not a good fit with mainstream groups. On the other hand, providing less intensive support can cause difficulties which result in the reinforcement of negative perceptions of disability within the broader community (van Dam and Hill, 2009).

Other identified challenges include the limited capacity of organisations to employ facilitators with specific skills in person-centred thinking and building circles of support; organisational barriers including lack of advocacy and interagency collaboration; and community barriers including reluctance from people in the community to give their time and support to facilitate inclusion (Robertson et al., 2007; Van Dam et al., 2008). The skills involved in facilitating person-centred thinking are different from those of delivering services. Leadership and the development of skills and values in the workforce are necessary to implement models of support that align closely with person-centred thinking, rather than those that continue a focus on organisational provision of services. While recreational activities and social groups are beneficial for participants in their own terms, informal support networks and greater participation for people with disabilities within their community may require increased support to develop.

8.2 Conclusion

In conclusion, each of the projects in the Demonstration Support Network Program has provided benefits to participants, with each being implemented according to the Program principles. The projects have also, in some cases, facilitated the development of independent relationships and informal support networks likely to be sustained beyond the life of the projects. This is particularly the case for projects for parents and siblings. However, lessons from research indicate that while there are challenges and benefits in delivering social and recreational opportunities to children and young people with disabilities, there are other, distinct challenges and benefits in developing support networks. The lessons from the Demonstration Support Network Program are that agencies are skilled in meeting the challenges faced in delivering services, but changes to workforces, organisational practices and planning may be necessary to build support networks for children and young people.

Appendix A: Demonstration Support Network Program Logic



(Ageing Disability and Home Care NSW, 2009)

Appendix B: Demonstration Support Networks Program Principles

The delivery of support through the parent, sibling and peer networks will:

- Respect the diversity of experiences of parents, siblings and children and young people with a disability, and provide the social context within which family members develop capacity and confidence to deal with their experiences.
- Focus on the needs of the family as a whole and support individuals to address their own issues in a way that contributes positively to family functioning.
- Support parents, siblings and children and young people with a disability to self-direct and self-manage, build on the social supports provided by extended family and friends and the broader community.
- Respect the individual care responses of families and ensure that all providers understand the cultural mix of their communities and design access and service delivery strategies that specifically target people from Aboriginal and CALD communities in their area.
- Recognise and respond to the needs of parents, siblings and children and young people with a disability living in metropolitan, rural and regional areas.
- Include participants in the planning, delivery and evaluation of activities that have been designed to respond to the needs of each target group, including people from CALD backgrounds and Aboriginal communities.
- Promote effective co-ordination and inter-sectoral collaboration across the range of services and supports accessed by parents, siblings and children and young people with a disability.

(ADHC, 2007)

Appendix C: Interview Discussion Guides

Program Managers Interview Schedule

Evaluation of the Demonstration Support Network Program

Interview Schedule - Program Managers

(This is an indicative guide to the issues to be explored in the interviews)

Introductions – about the project, about the researchers.

- What is your job role and responsibilities?
- Could you explain a bit about your program (*prompts: organisational structure, activities, families/peers attending, demand*)
- Can you tell me a bit about your experience in the first year of the network?
- How do families/peers find you? What methods have you used to recruit and maintain participants? Have they been successful?
- How have you managed the logistics for the program? (Advertising, establishing the setting etc)
- What are the staffing requirements? Have you been able to fill the posts appropriately?
- Please tell me a little about the strengths and achievements of your program.
- Are there any barriers to delivering the programs effectively?
- What lessons have you learnt this year in delivering the program? What would you advise others who were about to set up similar programs?
- Have there been relationships established between the program and other services or agencies?
- What measures have been put in place to ensure the sustainability of the services?

Program Staff Interview Schedule

Evaluation of the Demonstration Support Network Program

Interview Schedule - Program Staff

(This is an indicative guide to the issues to be explored in the interviews)

Introductions – about the project, about the researchers.

- What are your job roles and responsibilities?
- Could you tell me about your program? (*prompts: organisational structure, activities, families/peers attending, demand*)
- How do clients find this program? (*prompts: flyers, referrals*)
- What are the criteria for clients joining this program? (*prompts: special needs, age, gender*)
- What feedback are you getting from your clients about the program?
- Please tell me a little about the strengths and achievements of your program.
- From participating in the program, what are the desired outcomes for families?

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- Are there any barriers to delivering the programs effectively?
 - How do you think the program could be improved?
 - Thanks for participation. Process of feedback to participants. Where the project goes from here.

Parents Interview Schedule

Evaluation of the Demonstration Support Network Program

Interview Schedule - Parents

(This is an indicative guide to the issues to be explored in the interviews)

Introductions – about the project, about the researchers.

- How did you find out about the program?
- What were your expectations of the program and were these met?
- Have you noticed an improvement in your child since joining the program?
- What have you liked most / least about the program?
- Do you have any suggestions for improving the program?

Children and Young People (including siblings) Interview Schedule

Evaluation of the Demonstration Support Network Program

Interview Schedule – Children and Young People (including siblings)

(This is an indicative guide to the issues to be explored in the interviews)

Introductions – about the project, about the researchers.

- What kinds of things do you do at [program name]?
- What have you learned from [program name]?
- What do you like most about [program name]?
- Tell me about the kinds of things you have learned through the program? (*prompts: increased confidence, social skills*) Do you practice what you have learned outside of the program? (*prompts: at home, at school, when meeting new people*)
- Have you made any friends through the program that you contact outside of the program? (*prompts: see socially, email, facebook*)
- What activities would you like to do more of at [program name]?

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