



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

Reflections from retreats
for families with children
with a rare condition



Report by Graeme Stuart, Emma Hazelwood, Jessica Altmann, Kirsty Stapylton, Imelda Burgman, Bernice Mathisen and Elizabeth Sinclair



SNUG
Retreats Connecting Families

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S.N.U.G. (Special Needs Unlimited Group)

A Residential Program for Families of Children with Rare Diseases

Assisted by the Steve Waugh Foundation - Australia

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- Finally we would like to express our genuine appreciation and gratitude to all the families who have attended the SNUG retreats. In particular we have valued their willingness to share their experiences and insights, and their generosity of spirit.

All photos are from SNUG retreats. They provide visual impressions of the retreats and do not necessarily correspond to the people referred to or quoted in the text.

Throughout the report, names of people attending the SNUG camps have been changed, usually to names they chose themselves.



Chapter 1: Introduction

CHAPTER OVERVIEW

SNUG (Special Needs Unlimited Group) provides respite for the whole family. The five day retreats for families of children with rare conditions are offered by The University of Newcastle's Family Action Centre and funded by the Steve Waugh Foundation.

- At the retreats families can meet other families, share their experiences and insights, have a break from some of the demands of daily life, reflect on their strengths and challenges, and reconnect as a family.
- Between January 2009 and June 2012 there have been 15 SNUG retreats attended by 72 families and supported by 115 student volunteers.
- The aims of the retreats are to:
 - Create support networks for families caring for a child with special needs
 - Improve the resilience of families caring for a child with special needs
 - Improve access to medical, dental, allied health and complementary therapy services for children with special needs
 - Educate undergraduate students in relation to the issues faced by families caring for children with special needs.



Chapter 1: Introduction



The Steve Waugh Foundation

The Steve Waugh Foundation is committed to a coordinated approach to the service, identification, treatment and research of rare diseases to improve the quality of life of children affected by rare diseases (0 - 25 years of age).

"The Foundation is working to help change things for children with a rare disease by giving hope, providing medicine, equipment and treatment, supporting education and research, partnering with other like agencies and organisations as well as supporting specific projects and programs. The Foundation has already supported over 200 families through generous donations from our Patrons, corporate partners and supporters. Over a million dollars has been used for medication, treatment, specialised equipment and financial support."

<http://www.stevewaughfoundation.com.au/>

Chapter 1: Introduction

In early 2009, four families attended the first SNUG (Special Needs Unlimited Group) retreat. In each family there was a young girl with Rett Syndrome – a rare neurodevelopmental disorder that is almost exclusively found in girls. While their early growth and development may not show signs for concern, between the ages of one and four they can show a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability. After this rapid destructive phase, these symptoms can plateau for some years, before further motor deterioration (loss of movement) occurs. While therapy may assist to slow the deterioration, there is no cure for this disorder, and people with Rett Syndrome have a reduced life expectancy. During the retreat the families were able to connect with other families living with Rett Syndrome, access dental and other health services, and enjoy a holiday with their family.

Between January 2009 and June 2012, there have been fifteen SNUG retreats attended by 72 families and supported by 115 student volunteers. Throughout the process of co-ordinating and evaluating these retreats, The University of Newcastle's Family Action Centre has reflected on what has been learnt, both from the retreats and the families themselves. This report presents what we have learnt over the first fifteen retreats, with a particular focus on:

- The strengths of, and challenges faced by, the families who attend the retreats
- The experience of the families during the retreats
- The impact of the retreats on both the families and the student volunteers.

SNUG Background

When the SNUG retreats began in 2009, they were designed for families who:

- Were caring for a child with special needs
- Lived in a regional or rural area (generally more than 100km from Newcastle or Sydney)
- Had limited or suboptimal access to coordinated health resources and services
- Had difficulty coordinating/accessing family holidays.

Following discussions with the funding body, the eligibility criteria for the retreats were altered slightly after the first nine retreats. The primary criterion is now that the family is caring for a child with a rare medical condition (defined as occurring in 1 out of 10,000 Australians). While families are still recruited from regional and rural areas, this is no longer an essential criterion.

The retreats, funded by the Steve Waugh Foundation, are run by staff from the Family Action Centre (FAC) and assisted by student volunteers from The Newcastle

University. A range of other health and community workers, as well as the staff at Myuna Bay Sport and Recreation Centre (where the retreats are held) also contribute to the program. The aims of the retreats are to:

- Create support networks for families caring for a child with special needs
- Improve the resilience of families caring for a child with special needs
- Improve access to medical, dental, allied health and complementary therapy services for children with special needs
- Educate undergraduate students in relation to the issues faced by families caring for children with special needs.

SNUG provides respite for the whole family by enabling them to attend a five day retreat. During the retreats, families:

- Meet other families caring for a child with special needs
- Gain useful insights from other families about caring for themselves and their families
- Have access to a range of dental, medical, allied health and complementary therapy services
- Enjoy a range of activities offered at Myuna Bay¹ (e.g., swimming, canoeing, archery, low rope activities and a climbing wall)
- Participate in activities facilitated by SNUG staff and volunteers (e.g., ice skating, a bush dance, a picnic, sensory play and family games)
- Reflect on their strengths and challenges in caring for a child with special needs
- Have a break from some of the demands of daily life
- Reconnect as a family.

Student volunteers from a range of university disciplines (to date primarily Occupational Therapy, Speech Pathology and Education) play a crucial role in the retreat by assisting with daily activities, accompanying families to dental and medical visits where required, assisting the FAC and Myuna Bay recreation staff in providing activities for the children, and generally ensuring the smooth running of the retreat. The volunteers allow parents to have a real break from their daily routine and create an exciting, dynamic experience for the children. Through their volunteering, the students deepen their academic learning, share multidisciplinary perspectives, and gain an insight into the experience of families living with special needs.

The number of student volunteers varies greatly from day to day and retreat to retreat depending on the time of year (particularly in relation to university exams). On average there are around eight students each day, but this can vary

¹ While the official name is the Myuna Bay Sport and Recreation Centre, the Centre is known locally as just Myuna Bay.

Chapter 1: Introduction

from only one or two, to 12 or more. There is always at least two paid SNUG staff member on duty during the day and at least one at night.

Originally the SNUG retreats were described as camps (and at times the term camp is used rather than retreat in this report). Now the camps are described as retreats in order to emphasise that SNUG is not just a fun holiday camp. One of the strengths of SNUG is that families are encouraged to share their experiences, challenges and insights; and to support each other, while enjoying a range of fun activities. By providing respite for the whole family, rather than for only some members of the family (e.g., by placing the child with special needs in respite care), the families have the opportunity to enhance their relationships, to reflect on their strengths as a family, and to meet other families in a supportive, encouraging environment.

Methodology

Data for the report was collected from a number of sources:

- Interviews with 44 parents at Retreats 1-8
- Anonymous written evaluation sheets completed by 79 of the 97 parents (81%) at Retreats 3-15
- Brief phone interviews and surveys with seven mothers 12-18 months after the Retreats 1-3
- Three focus groups and four interviews with the staff and committee members who attended retreats
- Six focus groups with 20 student volunteers who attended the retreats
- Two surveys with student volunteers: one completed by 12 students and the other by 23.

Given the relaxed nature of the retreats, the interviews with parents were conducted as informal and unstructured conversations during the retreat. Some of the interviews were held outside (for example, while taking a child in a pram for a walk, while watching activities involving children, or sitting on the veranda of the accommodation lodge). At one retreat, all the mothers were interviewed together at a coffee shop. Transcripts or notes of the interviews and focus groups (most of which were audio recorded) were coded using thematic analysis. The analysis involved systematically taking individual responses and categorising them into larger theme categories or patterns.

Parents were interviewed towards the end of the SNUG retreat for around 30-60 minutes. In Retreats 1-6, informal conversations also occurred during the earlier part of the retreat, which promoted the establishment of trust and rapport. Parents were able to choose whether they would be interviewed individually or with other parents. Nineteen interviews were conducted individually, 14 in pairs, and two were conducted in groups: one with five mothers and the other with six mothers and fathers. The interviews explored the experience of the parents raising a child with special needs, their strengths as parents, and their experience of the retreat.

Two final year Occupational Therapy students and one final year Speech Pathology student, each of whom was undertaking an honours research project, assisted with the research. Part of the analysis of the interviews from Retreats 3-5 was undertaken by the two Occupational Therapy honours students. Jessica Altwood investigated the experience of the parents in raising a child with special needs, and Kirsty



Chapter 1: Introduction

Stapylton explored the experience of the parents at SNUG retreats. The Speech Pathology honours student, Emma Hazelwood (née Grace), surveyed student volunteers to explore the retreats as an example of a non-traditional clinical placement, and the impact of the retreat on the students' professional development, particularly in relation to family-centred and strengths-based practice. All three students also undertook literature reviews relating to their specific focus. Their findings are incorporated in this report.

Ethics approval for the overall study was obtained from the Hunter New England Human Research Ethics Committee; and for the contribution by the students, from The University of Newcastle Human Research Ethics Committee. All participants provided their informed consent in writing and the confidentiality of the families' identities was maintained through the de-identification of data and the use of pseudonyms chosen by the families.

This report relied on a social definition of being a parent, which recognises that parenting involves duties, roles and responsibilities, and is not limited to a relationship "based on biology" (Sullivan, 2001, p. 48). In this report, unless indicated otherwise, the term parent thus refers to people of either gender who undertake parenting roles, which includes biological parents, stepparents, grandparents, adoptive parents and foster parents.

The Families

Seventy two families have attended the fifteen retreats to June 2012 (see Table 1). Seventy five of the parents (68%) were mothers (birth, step, foster or grandmothers), of whom 21 were single mothers and a further 15 attended the retreat without their partner (generally due to the father having work commitments). Of the 36 fathers (once again within the broad definition), none were single fathers and one attended without his partner. Ninety of the parents (81%) were birth parents, 10 (9%) were grandparents with permanent care of their grandchildren, eight (7%) were foster/adoptive parents and three (3%) were stepparents.

Table 1: Number of families and individuals attending retreats

Families	72
Children with special needs	87
Siblings of children	102
Parents	111
Mothers	60
Fathers	30
Step mothers	1
Step fathers	2
Grandmothers	7
Grandfathers	3
Foster/adoptive mothers	7
Foster/adoptive fathers	1
Other unrelated adult	1

Prior to Retreat 10, nearly all the families came from rural or regional NSW, but there are now increasing numbers of families from Sydney (see Figure 1).

Figure 1: Location of families © 2012 Google Map Data® 2012 GBRMPA, Google, Whereis(R), Sensis Pty Ltd



The children with special needs were living with a range of conditions including:

- Autism
- Bladder Exstrophy
- Cerebral Palsy
- Charcot-Marie-Tooth Disease
- Charge Syndrome
- Chromosome 10 deletion
- Down Syndrome
- Dravet Syndrome
- Foetal Alcohol Syndrome
- Perthes Disease
- Prader Willi Syndrome
- Rett Syndrome
- Smith Magenis Syndrome
- Tuberous Sclerosis.

Generally children who had a more common condition also had one or more other condition. For example, one child had Autism, Down Syndrome and Cerebral Palsy; another had Autism and Tubular Sclerosis; and another had Cerebral Palsy and Rett Syndrome. Where possible, children with similar diseases were brought together at the same retreat; however, the limited occurrence of some of the rare diseases combined with difficulties related to timing meant that this was not always possible. Retreats which had a particular focus included retreats for children with Rett Syndrome (two retreats), Cerebral Palsy (where all the children had Cerebral Palsy as well as another condition), Bladder Exstrophy and Williams Syndrome.

Some of the families had more than one child with special needs.

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Ivy² attended the retreat with her two adopted daughters: Lee (aged 11) and Sandy (aged 14). Ivy's husband, James, wasn't able to attend the retreat because he had just commenced a new job. Ivy and James had six children, three of whom were adopted children with special needs. Lee and Sandy were both adopted, as was one of their other four adult children (none of whom came to the retreat). Sandy has Down Syndrome and Lee has Charge Syndrome. Both children were adopted at a young age and have lived with Ivy and James for virtually all their lives.

Retreat activities

The retreats are generally five days (although Retreats 1 and 2 were seven days, Retreats 3 and 5 were six days and Retreat 10 was four days) and encompass a variety of activities. The following program for a fairly typical retreat (Retreat 12) demonstrates the range of activities offered.

Monday: The families arrived in the early afternoon. The retreat had a low key start with an orientation of the Lodge and an opportunity to stroll through the grounds before dinner. Unstructured activities such as playing with Lego and other toys (brought to the retreat by SNUG staff), and craft activities (e.g., door banners and drawing) were also available to assist with the settling in process.

After dinner (as with all meals it was prepared by the Myuna Bay staff and brought to the lodge) the families were formally welcomed and some fun getting-to-know-you activities were played to encourage group cohesion. A retreat orientation/induction was also provided including expectations of families and the role of the volunteers.

Tuesday: A Myuna Bay Recreation Officer led two activities: canoeing (in the morning) and rock climbing (in the afternoon).

Canoeing – Everyone participated in some way, with some children mastering the kayak alone, some went in kayaks with adults and some had a smoother ride in the motorboat. Some friendly within- and between-family rivalry assisted families to bond, creating an atmosphere of encouragement and support.

Rock Climbing – Most adults and children participated in this activity, with the others watching and supporting. This activity encouraged bravery and feelings of mastery and confidence. The Myuna Bay recreational staff focus on encouraging the children and adapting activities to meet the wide range of ages and abilities.

The outdoor activities vary depending on the people at the retreat. Staff try to ensure that children of all ages and abilities can participate in the activities (in a variety of ways) so that children with special needs do not need to be excluded. At all activities, SNUG staff and volunteers help with looking after the children and ensuring that the activities run smoothly. The activities encourage fine and gross motor skill development, confidence and a sense of accomplishment, as well as being lots of fun.

Family free time is an important component of the program. During the afternoon families had the opportunity to choose from a variety of activities to participate in as a family unit, including swimming, soccer, mini golf, fishing, and playground activities. This allowed families to bond away from volunteers, staff and other families. Families were encouraged to build upon each member's strengths, increasing confidence and resilience. This was a time of fun

Seventy two families have attended the fifteen retreats to June 2012.



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within the family unit, and during this time, due to the range of activities and support offered at the retreat, families could participate in activities they had never experienced together.

In the evening after the children were settled in bed, the parents participated in a semi-structured workshop facilitated by Elizabeth Sinclair (the SNUG co-ordinator). Parents were encouraged to identify family strengths, achievements, and resources within their own communities. During this opportunity for reflection, they also identified areas where they felt they still required support or assistance. The wealth of experience each person brought to the discussion allowed the parents to share tips, techniques and resources. Parents commented afterwards how valuable and rare it was to be able to reflect on their family's achievements and progress, rather than problems and challenges. It was also an opportunity to hear stories from others facing similar circumstances. Each parent came away from the workshop with new information and/or advice to assist in their challenges.

Wednesday: Families had the opportunity to visit Dr Peter King's special needs dental service throughout the morning. If the families wanted some support with this, a volunteer accompanied them to help navigate or look after the children. Families alternated between attending the dentist, and spending time in music therapy with Susan Ashley-Brown. Each family was introduced to music in a relaxed and therapeutic manner by Susan, who led individual programs lasting approximately an hour for each family. Based on feedback from parents these music therapy sessions are now a regular feature of the retreats.

During the afternoon, the children participated in creative art play with art therapist Sally Dooner. Various art materials were provided for the children to create pictures of their family. This process allowed for facilitated discussion amongst the group. Children and adults also participated in sensory play consisting of a range of activities (e.g., playing with "goo" and finger painting) to stimulate the senses, and to promote social-emotional development, language, pro-social behaviour and creativity. Parents often comment on how much fun these activities are and how easy they would be to prepare at home. Each activity was run and supervised by SNUG staff (supported by the volunteers), and was modified, if needed, to ensure that all children, regardless of age and abilities, could participate.

As well as participating in the sensory play, the parents enjoyed a massage provided by remedial massage therapist Christina Balint.

Following a relaxed BBQ dinner, a bush dance was held in the large common area of the lodge. Dances were modified to enable all children to participate, regardless of abilities. The music was provided by a small band that includes a local paediatric neurologist who is on the SNUG committee.

Thursday (Australia Day): Hunter Ice Skating Stadium provided access to their facility at a reduced cost. Wheelchairs and strollers are allowed on the ice, and support frames are available for use by those with limited skating ability. Others with injury concerns (including some of the parents) were able to use extra wheelchairs procured by the SNUG team through Hunter New England Health. Ice skating is normally one of the highlights of the retreat with some parents commenting that they would never have thought it was possible to bring their family to such a physical outing.

After ice skating, there was a picnic at Speers Point Park (which has a large all-ability playground) followed by some unique Australia Day games back at Myuna Bay. Children and adults enjoyed the activities which included thong-throwing, bubble blowing, and noise-maker contests. The evening, involved sitting around a campfire, making and eating damper and billy-tea, and continuing conversations and firming friendships.

Friday: After a relaxed breakfast, the families, staff and volunteers said their goodbyes. All the adults swapped contact details and promised to stay in touch. A short 'closing ceremony' allowed each participant to be recognised for their unique contribution to the retreat, and children took home their certificate and encouraging messages from staff, volunteers, and other parents.

It was also an opportunity to hear stories from others facing similar circumstances.



Chapter 1: Introduction

The very early days

In 2000 I travelled to Sweden to visit a Center for Excellence in the oral health care of people with special needs. The director of the Mun H Center introduced me to a unique family stay program provided by a facility called Agrenska, located on one of the many islands that hug the coastline of Sweden. Families of children with rare conditions visited Agrenska for a week-long holiday program that addressed the needs of the parents, siblings and children with rare conditions. Like Australia, Sweden has many isolated communities that find access to specialised services difficult. As I was leaving Agrenska, the director turned to me and said, "Peter, you should set up this program in Australia." I remember a voice in my head saying, "Oh no, I'm going to have to do that now." That thought sat in turn with a myriad of other "must do" items until I moved from Sydney to set up special needs oral health services in Newcastle.

In moving to Newcastle, I quickly formed contacts with other health professionals interested in the needs of children with rare conditions. The challenge posed to me at Agrenska surfaced and I approached Julie Hornibrook, the director of Hunter and New England Oral Health Services with the concept. Julie generously supported the idea and offered funding to evaluate the program. She advised me to contact the Family Action Centre at The University as a body that may be interested to auspice the program. The FAC agreed to take on this role and a steering committee was formed to drive the project. This original steering committee included Judi Geggie, Kim Edmunds, Rob Smith, Bernice Mathisen and Julie Hornibrook. The FAC and steering committee met monthly for two years, discussing design adaptations to the Agrenska program to suit our Australian context, and applying for grants. Securing funding proved to be a difficult task. Persistence paid off and the Steve Waugh Foundation agreed to sponsor the program in 2008.

Peter King
SNUG Founder

Chapter 2: The experience of families

CHAPTER OVERVIEW

From literature:

- Having a child with special needs affects parents in a variety of ways, including emotionally, spiritually, socially and physically.
- Parents of children with special needs often find themselves socially isolated, feel overwhelmed and want more support than they receive.
- Families of children with special needs also display a variety of strengths including flexibility, problem solving and the ability to maintain social relationships.

From the SNUG parents:

- While 35% of the SNUG parents agreed and 30% strongly agreed that they had “a very supportive personal network of social support at home;” 24% disagreed and 8% strongly disagreed.
- Some parents found it hard to meet other parents of children with special needs.

- Connecting with others in a comparable situation meant that the relationships were more likely to be non-judgemental, due to their similar experiences and understanding.
- The parents of children with special needs have to not only act as parents but also have to provide medical and nursing care: they need to learn about their child’s disability, develop new skills and take on additional roles.
- Only 42% of the parents agreed or strongly agreed that local health and community services were able to meet their family’s needs.
- When the parents were asked what helped them meet the challenges of raising a child with special needs, many could not identify particular strategies they relied upon suggesting it was just something they did: they “just kept going”.



Chapter 2: The experience of families

SNUG recognises that although caring for a child with special needs can be rewarding and fulfilling, it can also be quite challenging. The retreats are designed to provide families with respite from some of the demands of daily life. This chapter starts by reviewing some of the literature on raising a child with special needs before discussing the experience of the families who attended SNUG.

What the literature says

Many families across Australia care for a child with special needs at home. In 2009, 7% of Australian children under the age of 14, (approximately 288,300 children) had a disability, of whom 36% (103,500 children) lived in New South Wales (Australian Bureau of Statistics, 2011). Nationally 57% of children with a disability (163,600 children) have a profound or severe disability. Nearly all the children with a disability (99.8%) are cared for in a private dwelling (Australian Bureau of Statistics, 2011). Twenty three percent of children with a severe disability live in inner regional areas and a further 12% live in outer regional, remote and very remote areas (Australian Institute of Health and Welfare, 2009). While the Australian Bureau of Statistics (2011) doesn't provide a breakdown of carers by the age of the people they care for, 33% of the 2,632,100 carers nationally (including carers of adults) lived outside of major cities.

Having a child with special needs affects parents in a variety of ways, including emotionally, spiritually, socially and physically; in terms of the amount and type of care required by their child, and the impact of this care on their paid occupation (Baldwin, McDougall, & Evans, 2008; Cummins et al., 2007; Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008; Hallstrom & Elander, 2007; Lassetter, Mandleco, & Roper, 2007; Mandleco, Frost Olsen, Dyches, & Marshall, 2003). In 2007, Cummins et al. (2007), who (with other colleagues³) have been investigating the sense of wellbeing of Australians since 2001, found that carers of "children or adults who have a disability, mental illness, chronic condition or who are frail aged" (p. 1) had "the lowest collective wellbeing of any group we have yet discovered" (p. vi) and that over 56% of their sample of 3766 carers had a depression rating "consistent with at least moderate depression" (p. 5). The study found that single parents and people caring for one or more children with a disability were particularly at risk of having a lower sense of wellbeing than other carers.

Edwards et al. (2008) found that 51% of the female carers and 31% of male carers (from a sample of 1002) reported having been depressed for six months or more since they had commenced caring. Over 13% of carers had experienced a depressive episode of 6 months or more commencing in the first year of caring. The study found that caring for a child with a disability or caring for more than one person with a disability (as some of the SNUG

families do) increased the likelihood that the carers would have mental health problems including higher rates of depression.

Families caring for children with special needs have major demands on their life, which vary over time (Goldbart & Marshall, 2004; King, Batorowicz, & Shepherd, 2008). Common challenges may include financial hardships, advocacy for their child in access to healthcare and education services, managing day to day family life, delivering therapy, caring for other family members and adjusting to major life changes (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Goldbart & Marshall, 2004; McGuire, Crowe, Law, & VanLeit, 2004; Payne, 2009). Parents may experience a high level of psychological distress and physiological strain (Dellve, et al., 2006; Payne, 2009), which is further exacerbated by less opportunity for rest and recovery as a result of caregiving demands (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; McGuire, et al., 2004).

Raising a child with special needs can be a significant contributor to parental stress (Cummins, et al., 2007; Edwards, et al., 2008; Gupta, 2007; Heiman, 2002; Lassetter, et al., 2007; Mandleco, et al., 2003). The cause of stress may include the burden or cost of care, the physical and psychological needs of their child in relation to his/her disability, and the parents' beliefs regarding their parental ability (Gupta, 2007; Lassetter, et al., 2007). Parents may also experience stress as they attempt to adjust to the unexpected family dynamics and change in lifestyle (Lassetter, et al., 2007; Pelchat, Levert, & Bourgeois-Guerin, 2009). They may experience grief for their expected child, shame or embarrassment, or even a sense of failure, anger and stigmatisation (Gupta, 2007; Heiman, 2002; Pelchat, et al., 2009). Significant increases in arguments and relationship breakdowns commonly occur when families commence caring, and conflict is frequently seen as being problematic (Edwards, et al., 2008).

Parents of children with special needs often find themselves socially isolated and feeling overwhelmed (Carter, Cummings, & Cooper, 2007; Goldbart & Marshall, 2004; Skok, Harvey, & Reddihough, 2006; Yantzi, Rosenberg, & McKeever, 2006). Mothers may hold the belief that they need to be the anchor of the family by consistently holding everything together, and experience a change in roles from caregiver to advocating for the child's needs which can lead to confusion in self-identity (McGuire, et al., 2004). This can be magnified by feeling primarily responsible for the child's wellbeing; often accompanied with feelings of guilt (McGuire, et al., 2004). Parents of children with special needs are more likely to adopt traditional parental roles with the mother as a primary caregiver and the father as family provider (Dellve, et al., 2006; Yau & Li-Tsang, 1999).

Chapter 2: The experience of families

Many carers of children with special needs want more support than they receive. The Australian Institute of Health and Welfare (2004) found that 53% of carers of children aged 0-14 express a need for additional support in their caring role. When asked what their **greatest** need was, 38% of these carers needed financial assistance, 27% needed more respite care and 12% needed more emotional support. Cummins, et al. (2007) found that parents who said that respite was very important to them had a lower sense of wellbeing than those who did not. Burton-Smith et al. (2009) found that 80% of 448 carers needed respite care and 47% were not satisfied with the respite they were receiving.

The emotional wellbeing of carers, as with other people, is affected by the relationships they have with their family and friends (Australian Institute of Health and Welfare, 2004), but social networks, such as family and friends who frequently act as support networks, can become smaller and more emotionally distant for families with children with special needs (Pelchat, et al., 2009; Woodgate, Ateah, & Secco, 2008). In the study by the Australian Institute of Health and Welfare (2004), while 25% of the carers felt their relationship with their partner had been unaffected and a further 13% felt they were closer, 26% felt their relationship was strained and another 20% felt they lacked time alone together. Edwards et al. (2008) found that almost one in three women aged under 50 had separated or divorced since they started caring and that there was an increased risk of arguments within the first year of caring.

Caring also has an impact on relationships with friends. The Australian Institute of Health and Welfare (2004) found that 27% of parents reported losing touch with friends and 23% felt the relationships were strained. Edwards, Higgins,

& Zmijewski (2007) found that 48% of carers wanted more face-to-face social contact with friends or relatives. Social isolation can create the feeling in parents that they are on their own in caring for their child and are unable to ask friends or extended family for assistance (Woodgate, et al., 2008). Whilst mothers still wished to participate in social activities, they reported this was difficult due to the care requirements of their child (Australian Institute of Health and Welfare, 2004); reinforcing the importance of respite (Burton-Smith, et al., 2009).

For families in rural areas of Australia, there are additional factors involved in caring for a child with special needs compared with their urban counterparts. Issues in rural areas such as drought place additional pressure on rural families (Warmington, 2003). Rural Australians experience poorer health outcomes; they are more likely to experience acute or chronic injury, be overweight or obese, and have decreased life expectancy, decreased education and employment levels, and consequently decreased income (Australian Institute of Health and Welfare, 2008; Misan, Lesjak, & Fragar, 2008).

Rural areas are often characterised by a reduced number of health facilities within easy travelling distance and health providers such as paediatricians (Australian Institute of Health and Welfare, 2008). A decreased awareness of services, reduced availability, and extensive waiting lists combine to result in limitations to accessing appropriate general and specialist local health services in rural communities (Bourke, Sheridan, Russell, Jones, & De Witt, 2004; Gruen, Weeramanthri, & Bailie, 2002; Misan, et al., 2008; O'Callaghan, McAllister, & Wilson, 2005; Smith, Humphreys, & Wilson, 2008; Welch, 2000).

Many carers of children with special needs want more support than they receive.



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Families in rural Australia must travel longer distances compared to their urban counterparts to access health services (Australian Institute of Health and Welfare, 2008). The distance required for families to travel in order to access appropriate health services, such as specialist medical appointments, often means they are required to spend time away from their home and support networks (Bourke & Sheridan, 2008). The greater distance travelled also increases the expense of the trip (Bourke, et al., 2004; Patterson, 2000; Welch, 2000) and the distance may influence parents' willingness to access services if they do not feel the services are absolutely necessary.

Interactions with health professionals, and a lack of co-ordination between services, pose additional challenges to accessing the healthcare families require for their children (Doherty, 2007; Scott, 2005). Families are most satisfied with services when they are family centred: that is their practice is supportive, co-ordinated, and recognises the expertise of families (King, et al., 2008; Watts Pappas & McLeod, 2009). Studies suggest, however, that current allied health practice still has some way to go before becoming family-centred in both their attitudes and practice at both an individual and organisational level (Hanna & Rodger, 2002; Scott, 2005; Watts Pappas, McLeod, & McAllister, 2009). Where there is a lack of understanding from health professionals, this further contributes to the feeling of social isolation, as families feel they are unable to rely on health professionals as a source of social support (Woodgate, et al., 2008).

Living in a rural area also offers several benefits to families. Rural areas are often perceived as communities where there are high levels of cohesive community support, which may provide community involvement and support for families (Gregory, 2009; Welch, 2000). For families who have a child with special needs, a small, rural community may provide a positive environment in which to raise their child. Despite reduced access to multidisciplinary health services, some research has found that rural children with special needs have a higher health related quality of life (Thomas, Mitchell, O'Rourke, & Wainwright, 2006). Hegney et al. (2007) suggest that the sense of community in rural areas, being a valued member of the community, people knowing each other, and a sense of interconnectedness contribute to the resilience often seen in rural families.

Family Strengths

Despite the many challenges facing families raising a child with special needs, family strengths can enable them to overcome significant obstacles. Since the late 90s, increasing research has been conducted into the strengths of families that enable them to surpass difficulties. It has been suggested that the family unit provides not only emotional, physical and collective support, but also forms the most intimate and social environment (DeFrain & Asay, 2007).

Families of children with special needs often have a variety of strengths, such as unity, patience, persistence and flexibility (Darley, Porter, Werner, & Eberly, 2002). DeFrain and fellow researchers (DeFrain, 1999; DeFrain & Asay, 2007; Silberberg, 2001) identified six specific categories of family strengths: appreciation and affection, commitment, positive communication, enjoying time together, spiritual well-being, and effective ability to cope with and manage stress and crisis. Focusing on the strengths of families allows both researchers and health professionals to better understand the family and how they succeed in spite of the challenges they face (DeFrain & Asay, 2007).

Unity is a significant strength of many families (Yau & Li-Tsang, 1999), and involves positive familial relationships both within immediate family and with extended family including grandparents, aunts and uncles (Darley, et al., 2002). A strong relationship promotes adjustment, encourages a positive attitude, and has been identified as a key predictor of coping in mothers of children with special needs (Yau & Li-Tsang, 1999).

Flexibility and effective problem-solving skills are important characteristics for parents who can adapt to raising a child with special needs (Darley, et al., 2002; Yau & Li-Tsang, 1999). Problem-solving ability appears to be particularly important for coping in fathers of children with special needs, in that high stress among fathers has been associated with feelings of incompetence (Abdal-Haqq, 1993; Darley, et al., 2002; Yau & Li-Tsang, 1999). Affirming competence may support families to be better problem-solvers, and to adjust well to challenging life changes such as diagnosis of disability (Yau & Li-Tsang, 1999).

In terms of external resources, support from extended family and friends is a key source of strength for families, and utilizing this support may help a family to adapt to changes in a crisis situation (Darley, et al., 2002; Yau & Li-Tsang, 1999). Social support has been identified as a major factor in a family's ability to stay strong and well when faced with adversity (Warmington, 2003; Yau & Li-Tsang, 1999). Maintained social relationships are characteristic of families who adapt well in crisis situations (Lee, Kim, Park, Song, & Park, 2004).

Parent support groups promote coping and resilience by enabling parents to support and empower one another with their own experience of raising a child with special needs (Carter, et al., 2007; Yau & Li-Tsang, 1999). A connection to other families with children with special needs may help reduce feelings of isolation or of being overwhelmed, give carers a voice for advocacy, and empower families as parents meet other parents going through similar situations (Carter, et al., 2007; Warmington, 2003).

Co-operative relationships with health professionals may also play a role in family coping (Lee, et al., 2004). Information is viewed as an invaluable resource by parents, and their

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Parent support groups promote coping and resilience by enabling parents to support and empower one another with their own experience of raising a child with special needs.

need for information is often greater when their child is more seriously ill or disabled (Hallstrom & Elander, 2007).

Whilst a significant portion of the health literature focuses on the challenges or difficulties associated with raising a child with special needs, some research identifies beneficial outcomes for parents with a child with special needs. Raising a child with special needs can be a positive experience for parents and they can feel that their lives, and the lives of their other children, are enriched by their child (Darley, et al., 2002; Pelchat, Lefebvre, & Perreault, 2003).

When parents find meaning in caring for their child with special needs their feelings of powerlessness can decrease, and they may experience the parenting process as transformative and promoting of spiritual growth (Lassetter, et al., 2007). The experience of raising a child with special needs may prompt families to examine and evaluate their belief system, which may result in a strengthening of their values and beliefs (Darley, et al., 2002; King, et al., 2008).

Many stresses parents face at the beginning of their child's life turn to positive feelings of love, joy, acceptance and affection. Parents also gain a sense of satisfaction and a feeling of strength from successfully raising a child with special needs (Heiman, 2002).

The experience of SNUG families

Caring for a child with special needs had a major impact on the lives of the families who attended SNUG. As Norah suggested: "It impacts everything." An indication of the extent of this impact is suggested by the following examples from one of the early retreats:

- Only one of the children with special needs (out of five) was living with both their parents: two were living with a parent and stepparent, one was living with a grandparent and one was living with a grandparent and step-grandparent.
- Two of the couples said having a child with special needs placed a great strain on their relationship. As one of the women said:

It's been very hard. Truthfully, it went from being the most amazing relationship, better than I ever thought a relationship could be, to, we are regularly on the verge – regularly, because it's just so hard to keep everything together... If we had [started with] any worse relationship than what we had, there's no way we'd be together now.

- Two of the women reported having been suicidal and two of the men said they sometimes drank too much.

Renee spoke very movingly about the impact on her hopes for her daughter on learning she had a significant neurological disability.

Renee: We had this child knowing it was the last one we would have, and we have a beautiful little girl. (Long pause as she controls her tears.) You have a child, then you have little goals as they are growing up, getting a job, doing their debut, having boyfriends, getting married, having kids, and to start with, slowly but surely when this first happens, you realise my little girl is not going to get married, not going to have kids. Slowly but surely as the time went on, the big pictures got smaller, so at the end of the day I don't care that she is not going to get married and have kids. It comes down to smaller and smaller things. Then it comes down to tiny things like the kids sitting and watching TV and it is coming up to Christmas time and the other kids will be like, "I want that Barbie doll" or "Mum, I want that car set", and she can't even tell me what she would like for Christmas. Little things like that. I make her a Vegemite sandwich but the poor kid might want avocado, but I keep shoving Vegemite into her. So those big goals like marriage are gone – I don't care. All the little things you took for granted with your other kids, she can't do. And knowing she was going to be our last one [pause] and we were going to hear that "Mum-mum-mum" and "Dad" for the last time, and that "I love you mum" [pause] – it's not there.

Caring for their child with special needs created significant stress on the whole family.

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Sandra: This year Sophie hasn't been in hospital all year, bar her having an overnight sleep study. So this the most normal our lives have been. But when Sophie's in hospital, it definitely affects them and it upsets the family terribly. Now that I look back on it, sort of – a few nights in hospital, equals a month of readjustment, because everybody's exhausted; the kids are unsettled, I'm tired. You come back, Sophie's still sick, the kids want more attention because you haven't been there, Dave's exhausted because he's had the other two kids and it's stressful – it's just really, really stressful. And hopefully our time in hospital will just get less and less, because it just sucks. Even though our relationships with the doctors and nurses in hospital now are really good – and they love us, but yes, we don't really want to be there. We just want to be normal.

Many of the families were also facing other challenges in addition to caring for a child with disabilities. For example some of them had more than one child with special needs or other significant health issues, some of the parents had a disability or serious health issues, at least one woman had experienced domestic violence, some of the non-custodial mothers had major drug addictions and one of the parents had recently completed a difficult custodial battle. The families needed to deal with these additional challenges.

Arnold: Sky [one of the siblings] was actually very violent. She was on Risperdal. She would throw the car in reverse at 80 km an hour and kick mum in the face, or jump out of the car at 60 kilometres. At the age of seven, she had jumped on a train [and went to another town]. So it has been really hectic. After, with Sky to get her settled with the meds, it's

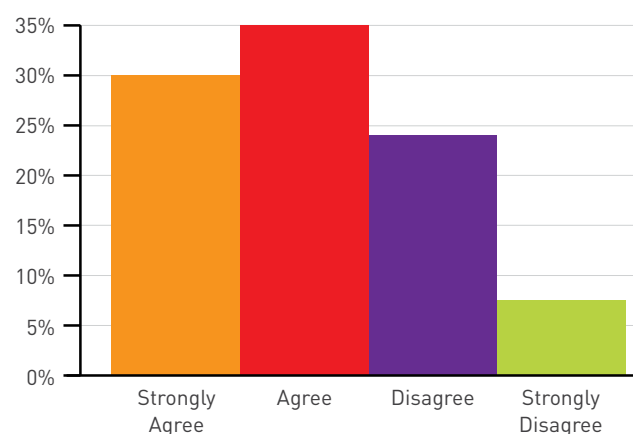
probably taken five to six years – placing with psychologists, psychiatrists and area health. So she's more now starting to really settle. So it's been a long haul.

Social supports

Social support was very important to the parents attending SNUG. While 35% agreed and 30% strongly agreed that they had "a very supportive personal network of social support at home;" 24% disagreed and 8% strongly disagreed (see Figure 2).

Figure 2: Personal social networks

I have a very supportive personal social network at home (e.g., friends or family)



All the little things you took for granted with your other kids, she can't do.



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The parents who attended SNUG were supported physically and emotionally by a variety of sources including their immediate and extended family, friends, families in similar situations, and health and support services. They found that connecting with others in similar situations was a good source of friendship and support. They suggested that relationships with other families of children with special needs meant there was a mutual understanding, and less pressure in maintaining relationships compared with other friends without that shared experience.

Beth: *It's very hard to maintain friends, you don't have time – I mean, you've got to put a lot into a relationship. I think with friends too, you've got to be there for them as well as them to be there for you, whereas people from similar circumstances you don't have to go through the same rigmarole...we've had the same experiences, you don't have to do the big explanation thing trying to get them to understand when they can't.*

Parents indicated that connecting with others in a comparable situation meant that the relationships were more likely to be non-judgemental, due to the similar understanding. Access to a supportive and understanding social network was important in enabling families to cope, regardless of the amount of time between contacts.

Isabelle: *I suppose what connects me [to other people] is people have a real understanding of your life and [w]here you are and vice versa. I really find that if people don't have a disabled child or haven't had [anything] to do with that, [they] really don't have an understanding of what your life is like.*

Sue: *I think it's important to establish networks with people, even if its once every 12 months, once every two years, once every whenever. If you have something that you knew was coming or you're with a group of people who knew exactly what you're going through, who are non-judgemental...*

Some parents found it hard to meet other parents of children with special needs.

Norah: *I mean, there's only one other kid I know in town who has cerebral palsy and she [the mother] is a very private woman; she doesn't get out very much.*

Tamara: *Usually when you've got children with special needs and health issues, you're alone, you don't have that many people in your local area – I don't – who know what I'm going through.*

Even when parents did have a supportive social network, there were limits to the support provided.

Sandra: *Yes we do [have a supportive social network], but again, no one is really willing to take the reins. And we're not really willing to let go all that much, because you can't risk her getting sick, so you don't really want her out in all weathers, or with all sorts of people, because other people just don't realise what can make her sick. They think, oh yes, she's just got a runny nose, but that bit of a runny nose*

will put Sophie in hospital. So I guess we're quite cautious as to what we do, still. So it's quite isolating.

Health professionals can play an important role in assisting parents to develop social support. A number of parents indicated that they relied upon health care professionals to incorporate and organise social support when the parents felt they were unable to access it. One parent accessed a social support group organised through local health services, which aimed to connect parents facing similar challenges. In addition, parents wanted social and emotional support from the health professionals themselves. SNUG parents wanted the health professionals to take on a broader role; by listening to and interacting with families on a more personal basis to meet the families' social and emotional needs.

Families who attended SNUG were able to draw varying levels of support from their immediate and extended families. For some families, having a partner was a key support in raising a child with special needs. Parents described caregiving as a team effort with both partners providing care for their child and respite for each other.

Beth: *We are a total team. We both can do...*

Gavin: *All the same things...*

Beth: *So like I might normally make up the medication and stuff at night, but I know that if I don't Gavin will. So we complement each other...*

Sandra: *Probably we communicate, generally. We work as a team. There's no blame really, we just work as a team. You have to, I think. I have nothing but the utmost admiration for single mothers with special needs child, let alone single mothers with normal children, because I don't know how they do it. I just don't know how they cope. Because we don't cope half the time. But you get there because when somebody's down the other one's up and there's always someone there to talk to and to share with.*

In terms of support from extended family and friends, parents had mixed experiences. Some parents received strong support, while others were disappointed with the level of support and assistance they received.

Phillipa: *As far as people coming around, there's been a few people, but I suppose a lot of people you assume would have been helpful or involved just haven't been able to cope with it all and just avoided us sort of thing and it's been a bit of an adjustment... you know who your real friends are.*

Sandra: *My parents are not particularly – they're here, but they're not very helpful with Sophie. They're good with the other kids, but they're just afraid of Sophie and her vomiting and her this-ing and her that-ing.... And we've got friends. All our friends have got little kids as well, so you can't – yes, you really have to rely on each other. You can't rely on anybody else. We got ourselves into this situation, so we're responsible for it.*

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Role of parents

The parents at the SNUG retreats had to not only act as parents but also had to provide medical and nursing care: they needed to learn about their child's disability, develop new skills and take on additional roles.

Sarah: So it's the thing we do. I guess it's a role of being not just a parent but a carer as well.

Sarah suggested that parents of a child with special needs "do a lot more than an average parent":

Sarah: When we have a child with special needs, we tend to go into autopilot, we organise, we care, we do everything.... A parent sends her child to school and the teachers look after them – with a normal child. My child, I get phone calls to go to school three or four times a day to lift him to different rooms.

One mother, who had previously been employed as a carer for adults with special needs, felt it was much harder being a full-time carer for her own child.

Vanessa: I'm only 37 at the moment, but I feel like 60 something (chuckle). I get tired. Caring for Ethan is no different to what I used to do, as being paid to work. I guess the one thing different to being a full-time worker to a full-time carer, is as a full-time worker you get paid, you get holidays and you get to go home in the afternoon and don't have to worry about that until the next day. But, if you're a full-time carer, you have to worry about everything 24 hours, seven days a week and you don't have the choice of taking a day off today. It's quite different.

Parents often looked for more information in order to help them cope with the demands of their role. They felt that understanding their child's diagnosis helped clarify expectations for the future, and prepared them for the lifetime of care required by their children.

Phillipa: ...but at the moment it's just like you know that there are services out there, but you don't know what is available to you, or you have to find it, or whether you get referred or how it is...

Ellen: Yes, I've done that many courses. While I didn't work I went through the Autism Association and I did quite a few courses and went to lectures and things like that, so that I could cope with Jay...I had to try and learn as much as possible to give him as much help as I could.

In light of their children's long-term care needs, some of the parents (particularly the grandparents and older foster carers) were concerned about who would care for their children when they were no longer able to. This was further exacerbated by the lack of alternatives for providing care in their local communities.

Ivy: It's very long term. Got them for life. I know you have families for life but these children won't grow up and leave home and get a job and do all those things you normally do.

Neil: I'm approaching 60 and it's sort of getting the way where we're a bit worried about our children [and] what's going to happen once we can't look after them. It's becoming a bit of a concern now.

When we have a child with special needs, we tend to go into autopilot, we organise, we care, we do everything.



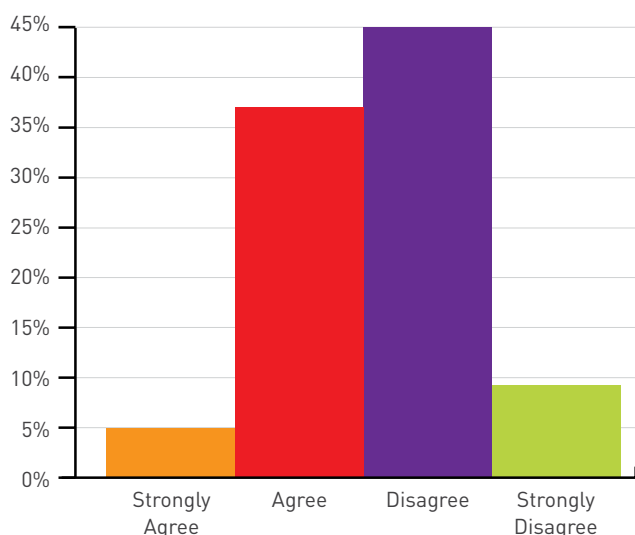
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Accessing health and support services

Given that the families had to frequently access health services, the lack of local health and support services in their area was a major issue for many of the parents. Parents reported this limited access to services meant they were often required to provide more care in their home, which made it more difficult for them to carry out their parenting role. In the written evaluation sheets parents completed at the end of the retreats, only 42% of the parents agreed or strongly agreed that local health and community services were able to meet their family's needs (see Figure 3).

Figure 3: Ability of local health and community services to meet needs of the family

The health and community services in my local area can meet the needs of my family.



Angelica spoke about how they had been on a waiting list to see an occupational therapist for two years when they were waiting for a diagnosis for her son. Extensive waiting lists were a factor in accessing health services, with many parents reporting they had experienced long delays before obtaining services. Once services were accessed, sometimes there was a limit to how much support could be received.

Sarah: We've been waiting for an occupational therapist for six months to come and visit us – and we still haven't heard.

Ellen: Once you've received the eight-week intervention program there's no more help, so you're on your own, really...

Vanessa: I think the one thing I noticed that was different living in a rural area to say for instance, Central Coast, is the rural area doesn't have a lot of resources and if there are resources there are not enough to go around for everyone, and the services have got a long waiting list. Especially say with workers, sometimes they don't know much, when it comes to disability.

Parents spoke about needing to advocate very strongly in order to obtain the services their child needed.

Tahnee: In particular it was just in and out of hospital and dealing with the medical system and trying to get enough help for your child – that's been probably the hardest, just feeling like I'm fighting all the time to try and get even part of the amount of help that my child needs – and that's quite exhausting.

There could also be problems with staff turn-over, particularly with younger allied health professionals, as parents would have to keep dealing with new workers.

Gavin: We'd get one and then [she would] fall pregnant and go off and then we'd get another one and re-train them and get them to know all Georgia's ins and outs and needs and history. But by the time you've brought them up to speed and they've come up with some good ideas, they fall pregnant and go off. Then you start again.

In order to obtain necessary specialist medical services, parents were willing to travel long distances to metropolitan or regional centres. Parents regarded this as a choice they made in order to provide as best as they could for their children. This was often costly for families in terms of both time and money and, in some cases, it involved leaving other children at home. Regardless of these difficulties, parents were willing to travel as far as necessary to access the services that they required for their children.

Beth: We've been hitting Sydney quite frequently lately...a well beaten path...and it's time off work.

Gavin: I get one RDO a month basically and that has been totally used by Georgia, whether it's appointments in Sydney or... used for other medical purposes

Occasionally parents moved so that they were closer to facilities.

Tahnee: There weren't enough services in Armidale for him, so I was already thinking about leaving Armidale to move to Newcastle or Sydney to get enough therapy sessions for him. And then after he'd had a second bleed into his brain and Armidale didn't even have an MRI machine there, let alone be able to do anything about the excess blood. So, yes we had to move down here and leave all of our family, our whole support network, and move down here to be closer to [appropriate services].

Meeting the challenge

When the parents were asked what helped them meet the challenges of raising a child with special needs, many could not identify particular strategies they relied upon suggesting it was just something they did: they "just kept going".

Ron: Everyone's got it in them, just a matter of learning to cope and deal with it, best you can.

Elly: You just do what you've got to do I suppose. That's just life, you're a mum, you put your child's needs before your own and then you just plod along.

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Ivy: I don't know, you just do [cope]. I suppose I'm not a worrier, I just take control. Just get in and do it.

Interviewer: How do you keep going?

Gavin: We don't have a choice.

Beth: We do love her.

Sarah, a single mother of three children, found it helped to think of challenges in terms of the positive factors associated with them:

Sarah: I've had to turn that [being a parent of a child with special needs] around in a positive in my head, to try and get through life.

By focusing on the positives of the situation she was able to keep going and get through the day. This enabled her to continue to look after her children on her own, when support services were not available for her. Other parents also found it helpful to focus on the positives and were able to identify how they had grown through their experience.

Tamara: When it comes down to it, they're just living life a different way. Every child has different abilities. I can't run a marathon, but some people can, but I'm not disabled or anything like that because I can't run a marathon. They just live life differently and experience it differently. They enjoy it more really. They get to go to hospital and most children don't, and so they form friendships with the nurses and the staff there and so do the parents. So, you've got to look at the positives. It is bloody challenging and upsetting and a massive roller-coaster... Yes, you've got to find the positives in it.

Tahnee: Really joyous and really very full on and very stressful ... He's quite a little joy and just is doing very, very well.

Jill: The experience, this opens up a whole new world. It makes – what do they say, “You don't sweat the little things.” After you have a disabled child and have that sort of lifestyle, you don't sweat the little things; you know what I mean, because it's such a different lifestyle you have – and if you did worry about all the little things, you'd go under.

Sandra: Well you just learn to see joy in the little things that you don't see probably as much with normal children. You know everything she does, we think wow, we didn't think we'd get to see this and we are. And things like that.

At times the parents differentiated between the challenges and stress of raising a child with special needs, and their love for their child. For example, one of them spoke vehemently about her hatred of autism but her passionate love for her child.

Some of the parents at SNUG felt they had a closer relationship with their child with special needs, than with their other children, or anyone else. Some parents suggested they had almost a “sixth sense” in relation to their child, where they knew something was upsetting the child before he/she became obviously upset:

Beth: It's like even more than a child/parent thing; it's sort of like nearly a symbiotic relationship...

Gavin: We can feel when things aren't right. It's not even a communication thing. I don't know at what level that sort of thing...whether it's a psychic level or some other sense of putting two and two together of what you hear, what you smell, all your senses; whether it's at that level or at some



You just do what you've got to do I suppose.



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psycho-type level, we don't know what it is, but whatever it is, it works... We're very aware of her needs all the time, 24 hours a day. I can wake up at three in the morning and consciously think about her and she'll wake up.

Beth and Gavin suggested that having a connection with their daughter, Georgia, meant they were able to meet her needs without her having to communicate what they were. Isabelle identified feeling closer to her child with special needs than to her other children:

Isabelle: *As soon as I met him there were these qualities of trust and acceptance that I've never felt or seen in my other two and I just thought, well whatever it is we'll just take it day-to-day. There wasn't time to think about the future really anyway.*

A number of parents identified an almost spiritual quality to their caring. It appeared as if finding a reason or purpose to what they were doing or why they had a child with special needs made it easier for them:

Elly: *You just get over it and just continue. Like, I'm not a religious person but I think I was tested, 'cause I'm not a very patient person.*

Angelica: *To me, it's just a part of life, it's a hurdle. The way I see things in life, you get a path that you go down and every now and then there's a bump in the road and you take a jump over it and you keep going.*

Deb: *Well, they can't speak for themselves and you have to speak for them. I mean, you love your children and it's your job to protect your children. That's what you're put on the earth for, you need to – that's what I was put here for. I'm sure this was my calling.*

Sandra, the mother of three children, captured some of the challenges faced by families with a child with special needs, while still demonstrating the ability to find the positives in the family's experience.

Sandra: *Well, for us it's been a totally life-changing experience. It's been stressful, it's been financially and emotionally debilitating, [we're] flat broke and we just can't seem to get out of that. That's just how it goes I think. Hopefully, by the time Sophie goes to school, we might catch up. I don't know. You're just constantly living on a knife's edge worrying about something.... So, it's taught us to be humble and grateful and even though it's been a pretty horrific experience a lot of times, it's also been a very joyful experience. Sophie's taught us an awful lot of things that we wouldn't have learned if she'd just been a normal child.... You just learn to see joy in the little things that you don't see probably as much with normal children. You know everything she does, we think wow, we didn't think we'd get to see this and we are. And things like that. I think it's brought us a lot closer – well, it either brings you closer together, or it pushes you apart.*

But I think it's brought us all a lot closer together. We still feel guilty about what's it's done to Sinead and Max really. Just so guilty all the time about the effects it's had on siblings. But, on the other hand, to see the compassion and the behaviour that Sinead and Max now have towards other kids, particularly special needs kids, is quite astonishing in kids so little. So even though they don't realise, they've learned stuff that they'll have with them for the rest of their lives. So it's kind of a double-edged sword really.



Well, for us it's been a totally life-changing experience.



Chapter 3: Parent feedback about SNUG

CHAPTER OVERVIEW

- All the parents agreed or strongly agreed that the retreat would have lasting benefits for their family and that they would recommend the retreats to other families.
- Most of the parents agreed or strongly agreed that they had made a real connection with at least one other family at the retreats (95%), that they had been able to offer help or advice to at least one other family (96%), and that they would feel more supported when they returned home (93%).
- SNUG helps increase the resilience of families primarily in two main ways:
 - Providing respite for the whole family that enables parents to have some time out and to refill their “bucket of life,” and
 - Creating a positive experience where families can spend time together and strengthen their relationships.
- Through the retreats, families have attended 276 health related appointments. Most of the parents (94%) agreed or strongly agreed that the retreat assisted them to access health services (including dental and complementary therapy) they would have otherwise been unable to access.
- Virtually all the parents stated that they believed the retreats were beneficial, both for themselves and their families.
- In follow up interviews with seven mothers 12-18 months after their retreats, all of them strongly agreed that:
 - SNUG was a very worthwhile experience
 - It was a holiday their family would remember for a long time
 - They would like to participate in another SNUG retreat
 - They would recommend SNUG to other families.



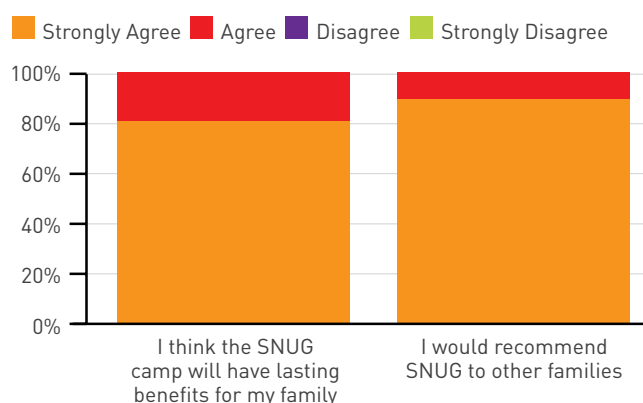
Chapter 3: Parent feedback about SNUG

Parents were generally very positive about the SNUG retreats.

Sandra: *Oh we had a great time. It was just a really enjoyable week for us. And the kids, yes they can't stop talking still about the ice skating. That was, I think, the highlight of their week and they kept going on and on about ice skating and when can we go ice skating – so, yes I guess that means they had a great time. It's always hard work being a mum, but we had no sickness and Sophie had a ball. So as far as I'm concerned it was a great week. There was no housekeeping, no cooking and no cleaning. Excellent. It was good to see the other parents, other families and share stories, compare issues and just feel like you weren't so alone and hopefully help somebody along the way.*

In the written evaluation sheets parents completed at the end of the retreats, all the parents agreed or strongly agreed that the retreat would have lasting benefits for their family and that they would recommend the retreats to other families (see Figure 4).

Figure 4: Lasting benefits and recommend SNUG to other families



The following chapter will explore this positive response from parents in terms of the first three aims of SNUG (the fourth aim will be discussed in the following chapter). SNUG aims to:

- Create support networks for families caring for a child with special needs
- Improve the resilience of families caring for a child with special needs
- Improve access to medical, dental and allied health and complementary therapy services for children with special needs.

Creating support networks

Some of the families attending the retreat felt quite unsupported at home, while others were surrounded by strong support networks (see Chapter 2) and so the retreats supported parents in building new networks that assisted them to feel less isolated. During the retreats parents had the opportunity to share their experiences and strategies with each other through structured activities and informal interaction. The parents generally felt their families had a lot in common with the other families at the retreats and appreciated meeting other people with similar experiences.

Kate: *You live your whole life with people judging you. Your everyday daily life is full of remarks, it's full of people full-on judging you all the time, so it's nice to be in this place, it's almost like a little secure environment where you don't have to stress for the five days that you're here.*

Gavin: *In some ways we speak the same language.*

Parents described one of the major benefits of SNUG as seeing families in similar situations to themselves and realising they were not alone. One mother likened the experience of mixing with other parents of children with special needs as "being in similar shoes," and one father commented that it was nice to be able to mix with people who had similar problems to himself.

Neil: *With the camp... [it's] a change of scenery, change of attitude, change of people, you're mixing with other people with the same problems you have and it just broadens your mind and makes you realise that you're not the only one out there who's struggling.*

Interviewer: *What did you love most about camp?*

Tamara: *The other parents, actually. Just being able to sit down and talk with them and get different ideas from them about different services and the experience of it too.*

Although health professionals play a vital role in providing support, the parents appreciated the opportunity to talk to other parents and to see how they dealt with some of the challenges they faced.

Mabel: *I am really glad that there are two other families here with as many kids as us. And just seeing them doing it and that they can do it and that they've done it long-term and it's no problem. So, you know, people in very similar situations to us: you can't get services, have very little money, have a lot of kids and are still doing ok. That's good to see. And there are people here who are giving me a lot of good tips and I like that.*

Tamara: *Just being able to sit down and talk with them and get different ideas from them about different services and the experience of it too. It's all fantastic. They gave me ideas on the mental health packages and different ways I can get funding for Shane, like [name of service] and things*

Chapter 3: Parent feedback about SNUG

like that. Things that I didn't know about before. And just knowing that you're not alone in the struggle and that I'm not the only one that has to fight for things – that everyone has to fight.

One of the parents said that they found the type of support they received from other parents more useful than the support they received from some professionals.

Norah: I find counsellors not very helpful. Unless they've had some sort of really full-on life experience themselves, then I find – like I said, I find groups like this to be far more supportive and helpful. Because at least they're living it and they can show you strategies of how they've dealt with stuff or whatever.

While building connections with other families at the retreat was appreciated, some parents also found it quite a daunting prospect.

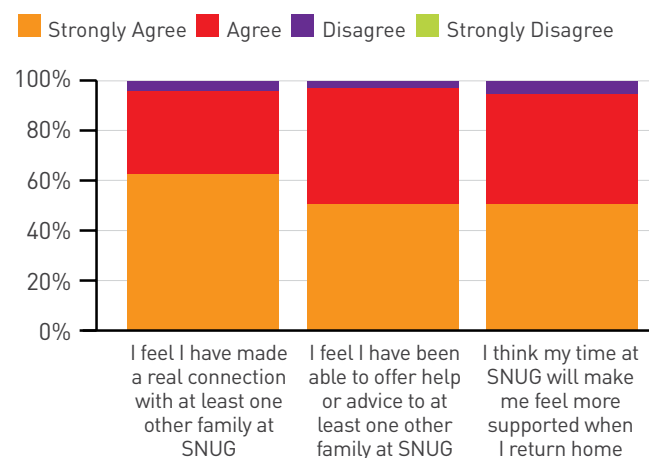
Elly: It was a bit daunting arriving, I'm thinking, "Oh shit!"
Angelica: So was I! And I just kept reminding myself, I've got my car, if I don't like it we can go home at anytime, we don't have to stay.

The fact that all the families stayed in one lodge (with separate bedrooms) promoted interaction between both parents and the children. While on one level, some of the parents would have liked the opportunity to retire to their own cabins, they recognised the benefits of the communal nature of the retreat.

Deb: Originally I thought we'd be in cabins sort of all separated and then just come together for meal times and that. I feel that the way it's set up – it gives you more of a chance to intermingle with everyone else. I'm not a real sort of sociable person so I feel that [being in a lodge] has pushed me a little bit more to get in and talk to people as well 'cause you see them all the time.

Most of the parents agreed or strongly agreed that they had made a real connection with at least one other family at the retreats (95%), that they had been able to offer help or advice to at least one other family (96%), and that they would feel more supported when they returned home (93%) (see Figure 5).

Figure 5: Connection with other families



Some parents from the SNUG retreats said they intended to keep in contact with the other families they had met at the retreat. Others suggested that they would be too busy to keep in contact once they returned home, and others described barriers, such as the inability to email, as to reasons they were unlikely to remain in contact. In the follow-up phone calls with seven mothers, despite distance and "everything being very busy", five of them had been in touch with other families from the retreat, and the other two expressed a desire to be in touch. Most of the contact had been through a phone call to offer and receive friendship, support and advice.

Most of the parents thought it would be beneficial to be able to return to a retreat with the same parents, and some of the felt that, due to their "unique understanding," the time between contacts did not matter.

Jill: I think that if you come together again in a couple of years' time it will be as if you've known them for a while. I think because when you are in close proximity with people like that, I guess you could call it an intimate relationship as far as the families go, you'll always hold that in you and they're always like a friendship, even if it's long distance, because you've lived in an environment with those people under very, I guess, stressful times and – like living in a home with someone, you get to know the little idiosyncrasies of the people and their personalities and everything. And yes it's something that you just don't forget and when you meet these people again, you're not a stranger anymore.

Increase the resilience of families

SNUG helps increase the resilience of families primarily in two main ways:

- Providing respite for the whole family that enables parents to have some time out and to refill their “bucket of life,” and
- Creating a positive experience where families can spend time together and strengthen their relationships.

As discussed in Chapter 2, caring for a child with special needs can be very challenging. By providing some respite to the parents from the challenges of daily life, they were able to have a bit of a break and have their “batteries recharged”.

Deb: A lot happens and I get really tired. I give a lot and sometimes my bucket of life gets very empty and I need to smile and I need to laugh and I need to talk and joke with other people and it fills it up. And when it's empty it's a horrible, horrible feeling. And I do, it gets empty.... I'm very strong, but you can just give so much sometimes and you feel so alone and so isolated that you just haven't got enough to give anymore, you haven't got another smile left in you.

Wanda: The girls taking Paige so I can sort of chill out even if it's only for 5 minutes. I mean, that break – because she is so constant – full on – I mean with Paige it's from the moment she gets up to the moment she goes to bed. If you can catch those little breaks in the day it's great. Really.

Vanessa: I can relax and I don't have to think that I have to cook tonight. Seven days a week I have to think, “Ok what's for dinner tonight?” And it's really nice in some ways to be

able to relax, chat to other parents, and your kids get other things to do and someone's entertaining Ethan and he's just happy to be part of the program, looking around.

At times the retreats allowed parents to grieve and to find strength within themselves and from each other. There were often tears and other parents were able to empathise and offer support.

Sarah: The camp gave me time to grieve and breathe and to find strength.

Anonymous evaluation sheet: We need respite and a chance to relax, breathe gently, and be just like all the others.

Anonymous evaluation sheet: Just knowing we're not alone. All families go through exactly the same emotions just timing varies.

The retreats can be described as respite for the whole family. Some of the families found it difficult to have holidays as a family. When they had accessed respite services, it was an opportunity to do something without their child with special needs. SNUG allowed the families to come away all together, to share an experience while still giving the parents and siblings some respite from daily demands.

Anonymous evaluation sheet: [One of the best things was] not having to cook at all – able to have a REAL rest and let my body relax and recover from tension built up over nearly 5 years.

Isabelle: Yeah, and probably the nicest time I had was Wednesday afternoon. Everybody had gone out and there were just two other parents and the two girls on the floor, and Phillip and me. And just having a level of peacefulness

My son and I have never been on a holiday before. This is our first one.



Chapter 3: Parent feedback about SNUG

to talk and have a cup of tea and not. And it's different to when, if you were to visit each other – 'cause it's just a timeframe, picking kids up from school – you've got a timeframe on your mind, what's for dinner and all those other things. To actually just really relax and chat, and be able listen to somebody else and chat. That's just a real gift really (laughs).

Anonymous evaluation sheet: By taking over the basic routines of meal preparation and activities for the children, the co-ordinators and volunteers created an environment which meant we could share intimately of our experiences, and guide and support each other. It also meant that instead of being the responsible adult, we could actually enjoy the activities ourselves, just like the kids.

In particular the parents appreciated the support in looking after their children.

Ron: Oh yeah. Just to have that five minutes to yourself, to be able to just sit back and just think about things – just to have that five minutes' break without kids coming up: "Dad, can you do this? Dad, dad".

Parents suggested that it had been beneficial being able to spend quality time together as a family doing fun things. Some of the families found it very difficult to have a holiday because of the expense and the complexities of caring for their child with special needs.

Ivy: Most of the holidays we sit home and do nothing, because it's [a case of] just not having the money to go somewhere. And most of the time everybody else is working, it's just me and the girls.

Angelica: My son and I have never been on a holiday before. This is our first one.

Gavin: That's what makes us not have a holiday – the logistics to know in advance when we go somewhere: What is on the ground for her? Is there a ramp? What's going to be there? Where's the closest shop? What's going to be happening? What happens there? To know all that in advance before you attempt to go somewhere. How far away can we park the car? Is it under cover? Is there lighting? Is there flat concrete? You know, all that sort of stuff you need to know.... Yeah, you've got to do that much research.

Some parents were concerned, about the time and energy they needed to dedicate to their child with special needs, and how this impacted on their other children.

Isabelle: But the time factor – the biggest thing is the time factor and feeling like you're not giving enough time to the other children in the family I think – and they feel that.... I think for me personally, the biggest thing is trying to meet children's needs, just bottom-line needs of them feeling loved, feeding them, clothing them, housing them, just the bottom-line needs and life sort of tended to – it's a bit better now, but initially it just did damage to those bottom-line needs for everybody for a while.

The retreat was thus an opportunity for families to strengthen their relationships which could become strained.

Sarah: The travelling with Tray to Sydney, leaving the girls behind, was causing a bit of a rift in the family, because the girls think me and Tray aren't going to Sydney, we're having fun. What they don't realise; we're sitting in a hospital for hours and didn't want to take them out of school. So we really needed to bring us all back together and bond a little bit.

Interviewer: Do you think that's happening?

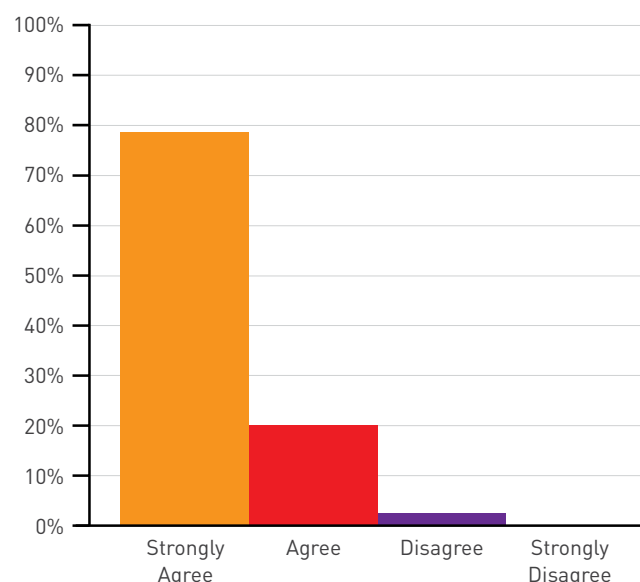
Sarah: It's happened, yeah. We have cuddles again. And life gets a bit hectic and you forget to stop and you're the carer, you [inaudible] but every now and again we forget to just give a cuddle.

Lisa: And the fact that you've [her husband] been able to go canoeing with him [their son] and I went and did the rock climbing with him. Paul's done archery, like ok, we're still not in that family unit, because one of us has to be with Grace, but its allowing one of us to actually have a bit of quality time. We'd get it at home, but you're usually doing all the things, with her or just the routine stuff at home.

In the feedback at the end of the retreat, nearly all the parents agreed or strongly agreed that their children had benefited from meeting other children with similar experiences (see Figure 6).

Figure 6: Children benefited from meeting other children

I think my children have benefited from meeting other children with similar experiences.



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The retreat provided an opportunity for the siblings to have a great time, to receive some personalised attention and to meet other children in similar circumstances.

Deb: And for my Ryan, who really hasn't got a disability, it [the retreat] is good for him. He doesn't have friends, he just loves to get out and do this – we can't do these things under normal circumstances. Normal families can do these things. We can't go ten-pin bowling, we can't go swimming, we can't take the kids anywhere. Especially in my case, we can go nowhere like that. You've seen Anita, she can't even come out of her room, we can't go anywhere and we're very isolated.

Isabelle: Harper's just being so happy, having friends to play with, that's wonderful. And I think to a degree that's nice 'cause he feels like [I can just see from looking at him] he's like, it's not necessarily getting my attention, but he's getting someone else's attention. He's probably feeling a bit special to have that I think, with all the activities that are there for him to do, which he's really joining in, which is great as well.

Anonymous evaluation sheet: [Some of the best things were] great activities for my 8 year old and other boys to play with and share experiences of having a disabled sibling.

In particular, the parent thought it was helpful for their children to realise that they were not the only ones with a sibling with special needs.

Julie: It's showing all the siblings that they are not the only people. They are not the only people that are dealing with having a sister with [special needs].

Don: It's good for them to realize they are not the only kids with disabled siblings. I think it is good for them to come here and know that all these other siblings have sisters or cousins or relations that have [name of rare condition]. And they understand exactly what they are going through, and I think that's been good.

Renee: And you know, just occasionally you need to be there for them, but before here they may have thought they were the only ones that needed to do extra work so they've come here and seen what other families do and see that other kids love their sisters as well.

Sarah felt that through the relationships and friendships he developed at the retreat, her son was able to become a bit more accepting of his disability. She described how he overcame his embarrassment of wearing a brace;

Sarah: For me, I know for Tray, watching him, he was embarrassed if he's braced and the equipment that he has to wear at the moment. He's developed friendships here that have shown him it doesn't matter, the brace is just nothing, it's part of him and it's acceptable. And I think you need that when you feel embarrassed. He has a fear of people looking at him differently and he's overcome that on this camp, so it's been a real bonus.

Some of the parents commented that through the retreat they had realised, or remembered, how special the siblings were and developed a new appreciation for their children.

Deb: I think just to have the break too is good. Because at home even though I never really realised how much Amber does do for me. Just little simple things like running to get a nappy. You know if you are on the floor – I've had my knee done as well. "Grab us a nappy Amber". Things like that. So it was good to have a break and to have the carers to take her off for a little break and that.

Sarah: And I've been able to sit back with the volunteers that are here, I'm able to sit back and watch my children do their activities. And a couple of times I've got teary-eyed because you're viewing your children from a distance, you see a lot more – I mean, you're out of the circle, so you get to see from the outside in and just how beautiful they really are and that it's worth the hard job that you do.

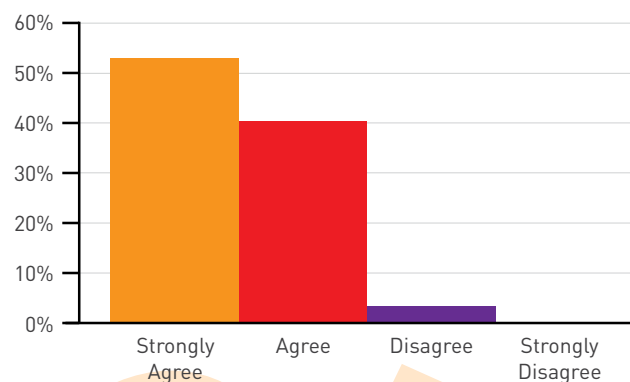
Anonymous evaluation sheet: I'm beginning to appreciate how amazing the siblings are and what wondrous talents they bring to each of our families. We call them to be extra special and they answer.

Improve access to health services

As discussed in the previous chapter, many of the families faced challenges in accessing health services. The SNUG retreat played a role in assisting families to access various medical, dental, allied health and complementary therapy services. Most of the parents (94%) agreed or strongly agreed that the retreat assisted them to access services they would have otherwise been unable to access (see Figure 7).

Figure 7: Assisted to access health services

SNUG allowed my family to access health services (including complementary therapies) I would otherwise not have been able to access.



Chapter 3: Parent feedback about SNUG

Through the retreats, families have attended 276 health related appointments (see Table 2). Appointments are made according to the needs of the families and the availability of practitioners. Initially significant effort was made to organise appointments for families, but this meant families were spending a lot of time travelling to appointments and had much less of a break. There were also concern about people coming from other Local Area Health Districts and using services from Hunter New England, and the lack of continuity of care (as any follow up would be provided by a different Health District). Parents particularly appreciated services that could come to the retreat and so the emphasis has moved to bringing practitioners to the families rather than the reverse.

Table 2: Number of dental, medical, allied health and complementary therapy appointments

Appointment	Camps 1-3	Camps 4-15	Total
Special needs dentist	35	71	106
Massage therapist	0	79	79
Music therapist	9	34	43
Art Therapist	0	20	20
Paediatric neurologist	10	0	10
Dietician	4	1	5
Optometrist	1	3	4
Orthopaedic specialist	2	0	2
Botox therapy	1	0	1
Paediatric physiotherapist	1	0	1
EEG therapy	1	0	1
Audiologist	1	0	1
Speech pathologist	1	1	2
Cleft clinic	0	1	1
Total	66	210	276

The main exception continues to be appointments with Dr Peter King, a special needs dentist and the founder of SNUG, who offers a dental check up and follow up for all the children. Despite having to travel from the retreat to his clinic (approximately 45 minutes), families clearly appreciate the opportunity to see a dentist.

Gavin: *World's most amazing dentist I've seen. Totally awesome.... It was worth a trip here just for that – two and a half years of dodgy teeth out of the way. And it goes to another level of confidence – advice we'd received at Westmead is correct – good to have a second opinion.*

Deb: *Yeah it's been beneficial for me because Courtney hasn't been seen with her teeth. I was having trouble actually getting her in to see about her teeth and when I did get her seen they said more or less she would have to be*

put under. And they didn't really attempt to clean them while she was in the chair, whereas Peter was really good as far as that went. Very calm. And amazingly Courtney just sat there and, you know, let him do whatever he wanted to do in there with her mouth. So that has been good because that was one of the main things that I really wanted to get done.

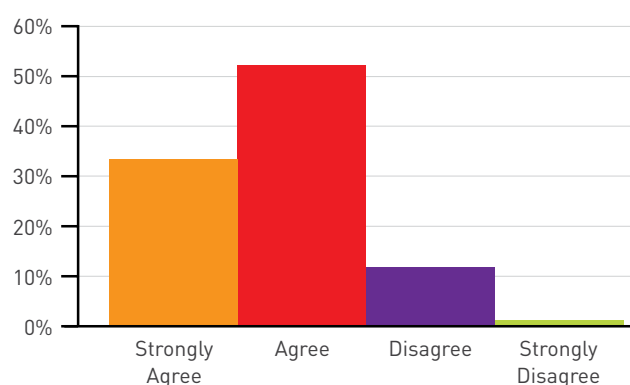
At all but four of the retreats (when he was unavailable), most of the children had checkups and some had fillings or other work where needed. Some of the parents commented that although they knew seeing a dentist was important, their child's other health needs meant that they found it hard to actually find the time. Having it organised for them as part of the retreat was thus very helpful.

Mabel: *The dentist, well that was just so low on the list of priorities, he never would have got there. Like, actually to Newcastle for a Dentist, it's never going to happen, because there are so many other issues that are way more important than that.... But it was great. We would never have done it and he does need to see one, it's just that because it's not life threatening – and the trip [to Newcastle] is, so you've got to weigh up the benefits.*

Most of the parents (86%) believed that SNUG would help them to be more confident accessing health services when they returned (see Figure 8). After the retreats some of the parents reported that they had been able to advocate more strongly for what their children needed.

Figure 8: Feel more confident accessing health services

I will feel more confident access health services when I return home.



Chapter 3: Parent feedback about SNUG

Reflections from a second retreat

Three of the families who had attended the first retreat, also attended Retreat 8 – the first to have more than one family return from an earlier retreat. The following is based on discussion with these families and another family on the last evening of the retreat. Feedback was positive with indications that the retreats are making a difference to the families.

The families appreciated the opportunity to return (although one felt there were other families who probably needed the retreat more than they did). They commented that last time it took them “half of the camp” to settle in, to begin to relax and for the children to make friends. This time, because they already knew some of the families, they felt comfortable very quickly. As one of the mothers suggested, as soon as they arrived, their children went up to the other children and started playing. They also felt that there was greater interaction between the children with special needs and the siblings, and it was great to see the siblings helping children from other families.

All the families felt it worked well having some families who had been to the retreat before and some who hadn't. The family who hadn't been at the previous retreat said they felt more welcome because the other families helped them to “fit in”.

The returning families identified some areas where the retreats had developed and improved, but also missed some features from the first retreat. They felt that there was a better ratio of volunteers to families: at the first retreat they felt there had been too many volunteers at times. They liked

the slightly more structured discussion with other parents in the evenings. As one parent commented, “I feel we can open up at these retreats and know you won't say, ‘Here they go again!’”

They liked the fact that at their second retreat the Recreation Officer had been male and felt that, given all the volunteers at this retreat were female, the male presence was important for some of the boys. They also felt that it was important to have plenty of “boy activities” for the boys.

They thought it was an improvement having the meals in the lodge rather than in the dining hall as happened at the first retreat because it sometimes took them twenty minutes or more to get their children ready to go the dining hall.

The families appeared to feel more confident making suggestions for how the retreat could be improved. Some parents suggested that the siblings could also benefit from an opportunity to discuss their experiences as siblings. Some felt that at the first retreat, it had been great when there had been some non-threatening, but meaningful, discussion over craft activities. It was the type of situation where siblings could participate if they wished, but were also free not to if they preferred. Parents also said they felt it was a shame that there were not as many activities offered by Myuna Bay (e.g., the “Giant Swing” and low rope course) as last time. While they appreciated the need to keep costs down, their children had enjoyed the wide range of activities offered at their last retreat.

They suggested that it might be important to consider how to engage the siblings as they grew older, and this generated discussion about the possibility of older siblings becoming volunteers at future retreats.



*“you
aren't
the only
one.”*



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As the fathers are usually quite “outnumbered,” they suggested it was important to provide some activities (e.g., fishing) specifically for the fathers, where they could “hang out” with other fathers and have informal conversations about their experiences. This normally occurs at retreats, but because of poor weather and the reluctance of one of the fathers to be involved in any group activities, it had not happened at this retreat.

They suggested it was helpful to have as much contact with medical and health staff at the actual retreat rather than having to leave the site. Despite it being quite time-consuming (for one family the visit took around 4.5 hours), they really appreciated the opportunity to see the dentist. They thought Dr King was great, and valued the fact that he also attended to the siblings and was happy to do things “there and then.”

The families who had been to a previous retreat indicated that they believed they had benefited from the first retreat and could see how they had benefited from the second retreat too. In particular they felt that the retreats were beneficial for the siblings by demonstrating that they weren’t the only ones with a brother or sister with special needs. One mother suggested that the siblings often feel like “they are the ones with the disability” because so much of their lives is determined by the need to “go here or there” and that they “miss out on things”.

Another of the parents believed that their children helped more at the retreat than normal (and that this had continued for a while after the last retreat), and that the retreat had illustrated that other siblings help in a variety of ways. One of the siblings had asked lots of questions at both this and

the previous retreat, and had been able to raise a range of issues with her family.

During the retreat, one of the girls had experienced a seizure (a relatively common feature of her condition and that of other children at the retreat) and that, while it had been “not nice to witness,” it had opened up the topic with some of the other siblings and had allowed them to see it before it happened to their sister.

The parents had also appreciated the opportunity to talk with other parents and to know that “you aren’t the only one.” As one of families suggested, it was good to know they “weren’t the only one angered by services.” The daughter of one family was about to have a scoliosis operation, and it was reassuring to see other girls who had gone through the procedure well.

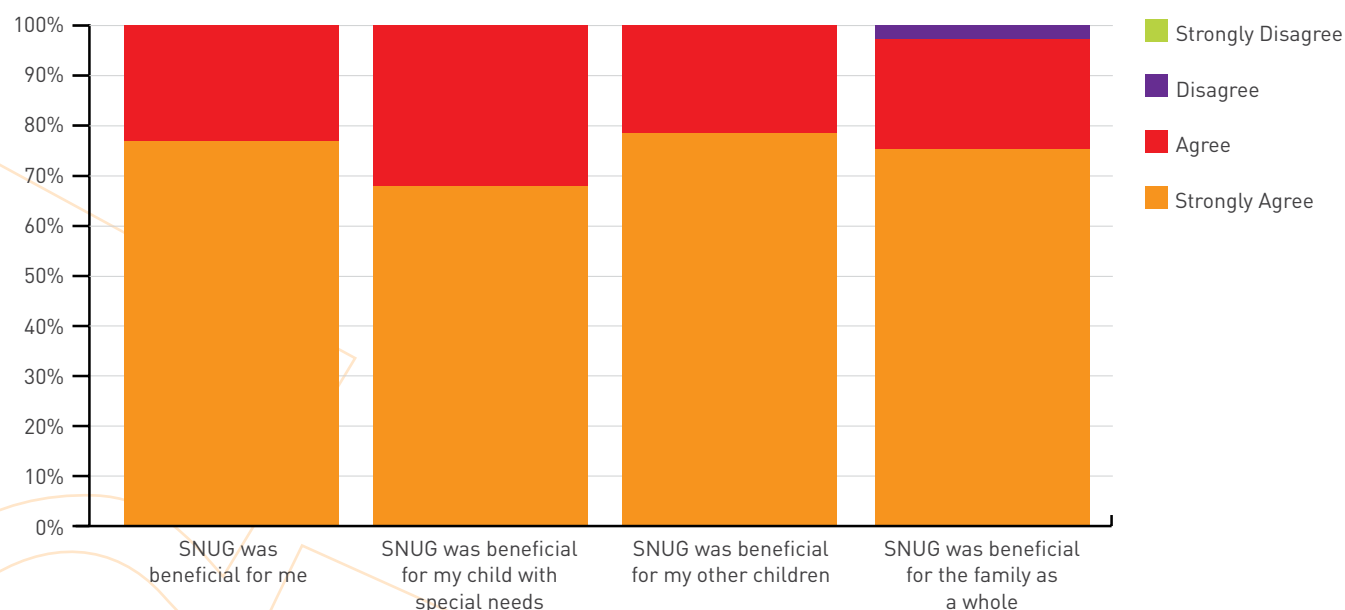
At times, witnessing improvements in other children was a bit difficult. One family had noticed a big improvement in one of the other girls, and this had raised issues about whether or not it was possible for their child to progress in a similar way.

Overall the families were positive about the retreat and hoped they could continue to be involved.

Follow up interviews

In the written evaluation sheets at the end of the retreats, parents stated that they believed the retreats were beneficial, both for themselves and their families (see Figure 9). The limited follow up interviews with families after Retreats 1-3 indicate that the mothers continued to believe the retreats were beneficial 12-18 months after the retreat.

Figure 9: Benefit of the retreat



Chapter 3: Parent feedback about SNUG

In these follow up interviews, all but one of the seven mothers strongly agreed (and the seventh agreed) that they thought SNUG would have lasting benefits for their family. All of them strongly agreed that:

- SNUG was a very worthwhile experience
- It was a holiday their family would remember for a long time
- They would like to participate in another SNUG retreat
- They would recommend SNUG to other families.

The comments made by the mothers about the retreat were also positive. In particular they appreciated spending time together as a family, meeting other families, and being able to access dental care. One mother commented that it had been their first ever family holiday; another said that when they were having a bad day the photos remind them of good memories; and another said, “SNUG enables the whole family to have fun together”.

SNUG clearly had long term effects for many of the families. As one mother suggested, “I have changed the person I am because of camp.” One of the impacts of the retreat was in giving parents more confidence in accessing, and responding to, health services and reminding them that they didn’t need to be afraid to ask for support. One parent said that they had learnt not to be afraid or ashamed of “who we’ve got and what we’ve got.” Based on the information and confidence she gained from the retreat, one of the mothers contacted a physiotherapist and applied for a modified bike. Another parent said that their child had received a new diagnosis as a result of the retreat: “If it wasn’t for camp he never would

have got the correct diagnosis. SNUG gave me the power to challenge the doctors.” The same parent said that from the strength she had received at the retreat, she had formed a support group in her area.

For some families the retreat had given them a time to grieve and to be strengthened. One parent believed that the best thing about the retreat was “being able to cry for three days.” Another said, “The camp gave me time to grieve and breathe and to find strength.” A parent who had gone through some hard times since the retreat commented: “It has been a long journey but because of camp I have the strength to cope.”



“SNUG enables the whole family to have fun together”.



Chapter 3: Parent feedback about SNUG

Sarah's story

Tray had been a fit healthy 8 year old boy 12 months before attending SNUG. By the time of the camp he needed to wear a brace and use a wheel chair. Tray, who attended a small school in rural NSW, was still coming to terms with his diagnosis and changed physical state: he was embarrassed by his braces and didn't like going out in public anymore. Sarah watched Tray "go from winning awards for running races two years ago, to not being able to even do that [walking easily] today."

Sarah had also been diagnosed with cancer in the past 12 months.

This was a family under a lot of stress particularly as they didn't have a strong support network. She didn't even feel she received much support from her extended family:

I do have family members. I have spoken to them. I've asked - because when I was first diagnosed, if I didn't have the hysterectomy I would have six months to live if I didn't go through with the surgeries. I rang up my mother, because she is alive and I spoke to her and asked her, and other family members and they all wanted me to give Tray up! Even Rebecca, because a six year olds a lot for somebody to take on board. That was overwhelming for me. So I guess, I do a lot of self talking and trying to find the time where I can - I do a lot of anger management to deal with the anger - that side of, "How could they say that? How could you deny a child". They'll all take Rosie the older one, she's an achiever - but they're all special.

Without these supports, Sarah didn't want to ring and get the results of the tests, because she was worried about what would happen to her kids if anything happened to her. The trips to Sydney were already placing significant strain on the family.

Travelling with Tray to Sydney, leaving the girls behind, was causing a bit of a rift in the family, because the girls think me and Tray aren't going to Sydney, we're having fun. What they don't realise is we're sitting in a hospital for hours and I didn't want to take them out of school. Because I couldn't leave them with anyone for long, I was leaving when they got on the bus (and I got a few speeding tickets because I had to put him foot down) and I had to turn around and come straight home. So one of their school friends will just watch them for two hours after school and I'd be home by 6 o'clock - back at home doing it all again.

While it would be easy to emphasise the challenges the family faced – Sarah worried about where she would get money for Christmas presents, Rosie had a twin brother who died when he was five days old, and so on – this is really the story of a strong family who are quite resourceful.

Sarah is very positive and optimistic; she just keeps going and refuses to be daunted. She really is an inspiring, strong woman.

So that's what keeps me going is if something happens to me, they've got nobody. So I try to time myself on when I'm allowed to be sick and when I'm not, but it doesn't always work. And a couple of times I found myself in hospital during the day and then the doctors looking at me, because I'm doing that, "Are you going to have this drip and this pain killer out of me by 2.30 pm, I've got to get home for the children?" And he's like, "Can't you ring a neighbour?" And no, I can't, I can't, so I do race home and on the way I learn to put a mask on and just one strong mum and I'm here - and I'm here.

So I do a lot of soul searching, and a lot of talking to myself - "You can make it through this pain today. It's only going to last 10 minutes. You'll be alright. The kids need you. They're outside and they need me". But yes, it has its ups and its downs.

Sarah was also proactive in finding some extra support.



Chapter 3: Parent feedback about SNUG

I advertised in the paper to try and adopt some grandparents, unofficially. Well, I actually applied for respite care first, but we got knocked back.

Then I thought, we should have farmer's relief. I'm in an isolated and rural area, I have no family involved with that, but we've been knocked back numerous times. So I ended up putting an ad in my own local community newsletter and a lovely lady answered and said, "All my kids have grown up". I was a bit uncomfortable about that, so every week she would just turn up with something little for the kids, whether it be a packet of biscuits for after-school snacks and she took the girls last fortnight. And it was wonderful for them. And I still raced down and raced back, feeling, "Are they going to be alright there?" and I got there to my six year old going, "What are you doing? We wanted to stay another night". But it's again, me getting used to having that support too. And at the moment, they're not support for Tray and I, they're support for his sisters, when we're away at the doctors. So, coming to the camp makes me know that we do need to find a support network.

During SNUG, the family had a chance to reconnect.

We really needed something to bring us all back together and bond a little bit. And it's happening. We have cuddles again. Life gets a bit hectic and you forget to stop. Every now and again we forget to just give a cuddle, and I've been able to sit back with the volunteers that are here, I'm able to sit back and watch my children do their activities. And a couple of times I've got teary-eyed because you're viewing your children from a distance, to see a lot more - I mean, you're out of the circle, so you get to see from the outside in and just how beautiful they really are and that it's worth the hard job that you do. Yeah--- And that's what your volunteers do, by taking them out and - John [one of the volunteers] taking Tray out yesterday to kick a soccer ball. He and I were arguing about putting the brace on and John got him out there, but it took me to walk away. I stood from the front door peeping through and watching him and it was amazing just watch him bond with somebody else.

She said the camp gave her strength to cope and that she was a changed person because of the camp. SNUG gave her a chance to recharge her batteries and to rediscover her strength and resourcefulness. She also said:

The camp gave me time to grieve and breathe and find strength. Because parents don't do anything at camp it gives them time to think.

Since the camp she has formed a support group because she is convinced about the need to teach people to embrace disability. As she said:

Tray's changing and we need to change to support him for example finding sports that don't exclude Tray. SNUG made me aware that I had to look in my own backyard for support. It is about making a strong community. I have set up a support group and have used ideas from camp. I told people that children with disabilities could go ice skating and they said "No"; and I said, "I have done it."

The other really big thing the camp did (and this is not usual) was that it helped change Tray's diagnosis. A local paediatric neurologist brings his band to the camp for a bush dance. During the dance he observed Tray and discussed potential alternative diagnoses with Sarah. When she returned home, she raised these possibilities with Tray's medical team which led to a new diagnosis.

Sarah was also great for the volunteers

I think the volunteers are really gaining something from the camp. We've been able to communicate with them as well and they tell us their stories what they're studying and then we encourage them to move out of Newcastle and head rural, would be really good for us. Because they're always looking for staff; we don't have resources and there's a lot of them studying and it's nice to see that. I told them all, "Please don't stay in Newcastle - branch out."

I was telling an occupational therapy student my story and where we're at and how we've been waiting for an occupational therapist for six months to come and visit us - and still we haven't heard. She goes "Yeah, I need to study this, I need to keep moving along." So I think we inspire them with our stories that there's a need for what they're studying and encourage them.

Sarah's story demonstrates the way in which SNUG provides the families with the opportunity to regain strength and hope; to strengthen their relationships with each other; to learn from other families in similar situations and to help volunteers gain insights into some of the challenges faced by families with rare conditions living in rural areas.

Chapter 4: The volunteers

CHAPTER OVERVIEW

- One of the aims of SNUG is to assist students from The University of Newcastle to increase their understanding of issues faced by families of children with special needs. For students, SNUG is a form of service-learning where they not only provide support to the families but also receive valuable experience in working with families caring for a child with special needs.
- 115 students have volunteered at the retreats (to June 2012), most of whom have come from a discipline with direct relevance to children with special needs (e.g., occupational therapy, speech pathology and education).

The vast majority of students agreed or strongly agreed that:

- SNUG made them more aware of issues facing families of children with special needs (95%)
- SNUG made them more aware of the strengths of families of children with special needs (96%)
- They would recommend volunteering at SNUG to other students in their program of study (100%).

In terms of their learning all the students agreed or strongly agreed that:

- They learnt a great deal through their involvement in SNUG
- Their experience at SNUG would be useful in their current or future careers
- SNUG made them more confident in working with families of children with special needs.



Chapter 4: The volunteers

One of the aims of SNUG is to assist University students to increase their understanding of issues faced by families of children with special needs. By volunteering at the retreats, students not only provide support to the families but also receive valuable experience in working with families caring for a child with special needs.

Student volunteers play a crucial role in SNUG retreats by assisting families with daily activities, accompanying them to dental or other appointments, assisting the Family Action Centre and Myuna Bay staff in providing activities for the children, and generally ensuring the smooth running of the retreat.

SNUG student volunteers come from The University of Newcastle: primarily undergraduate students from disciplines that involve working with children with special needs (e.g., occupational therapy, speech pathology and education). All volunteers receive specific training for the retreats including an introduction to strengths-based practice, working with children with special needs, team work, and health and safety issues.

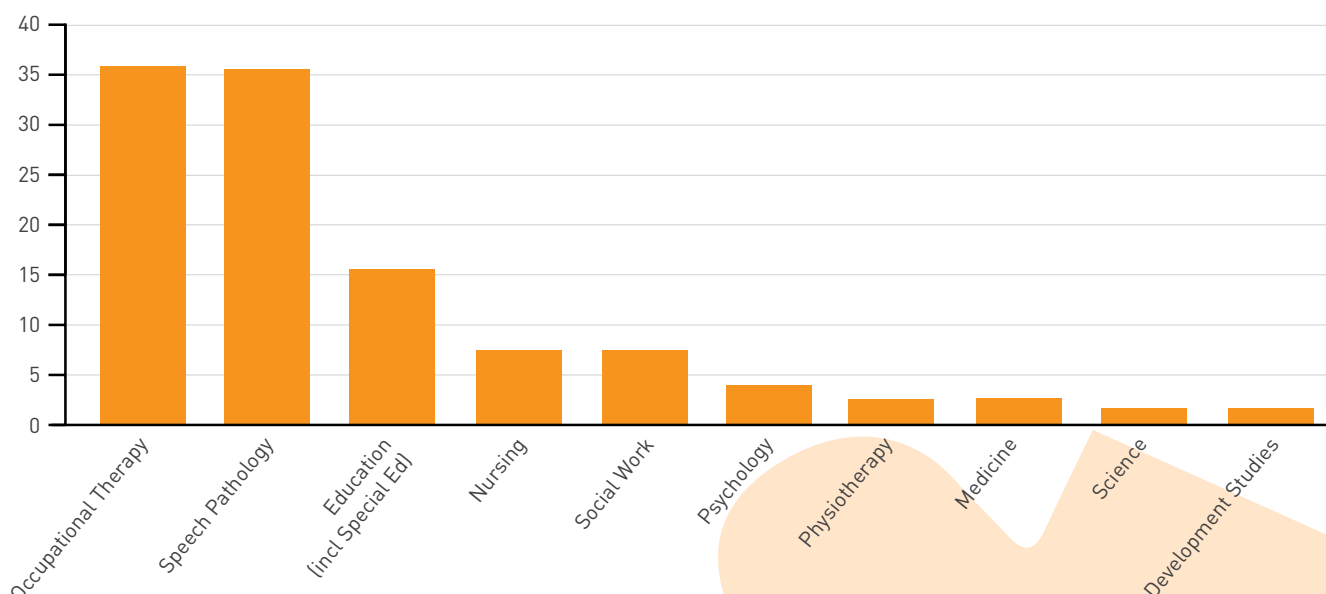
With a few exceptions, volunteering at the retreats was not an official component of their degree nor did students participate as a work placement: it was completely voluntary. At the same time, feedback from students demonstrates that volunteering at the retreat was a valuable learning experience that deepened their professional training and provided them with important insights into working with families of children with special needs.

Traditionally, student clinical experience occurs in a setting where the profession is well established (Fieldhouse & Fedden, 2009) although the limited number of available

traditional placements, changing caseloads, and emerging areas of practice have lead to a range of other approaches (McAllister, 2005; Overton, Clark, & Thomas, 2009). In non-traditional placements, students are placed in a setting where services are not regularly provided, or the setting is not typical of the profession (Faller, Dowell, & Jackson, 1995; Overton, et al., 2009). Non-traditional placements have been developed in a range of health disciplines (Baxter & Gray, 2001; Faller, et al., 1995; Fieldhouse & Fedden, 2009; Overton, et al., 2009) where settings have included schools, town halls, fast-food restaurants, and developing communities (McAllister, 2005). The benefits of non-traditional placements include the opportunity for self awareness, active and self-directed learning, building connections to the community, creative problem-solving, the ability to explore and develop a professional identity, and greater inter-professional collaboration (Lekkas et al., 2007; Overton, et al., 2009; Vickers, Harris, & McCarthy, 2004). These are considered key skills required in family-centred practice and in the changing nature of healthcare (Caudrey & Dissinger, 2007; King, et al., 2008; Mathisen, 2009; McAllister, 2005).

While SNUG is not a formal placement (traditional or non-traditional), there are similarities with non-traditional placements. Through the retreat, students are able to assist in facilitating activities for the children and/or families; provide support in caring for the children with special needs; and gain insights into the day-to-day experience of the families. General supervision is provided by staff from the Family Action Centre rather than specific discipline-based supervision.

Figure 10: Number of students and discipline



Chapter 4: The volunteers

Likewise the SNUG experience provides students with the opportunity to participate in a form of service learning. According to Seifer and Connors (2007), service learning is a:

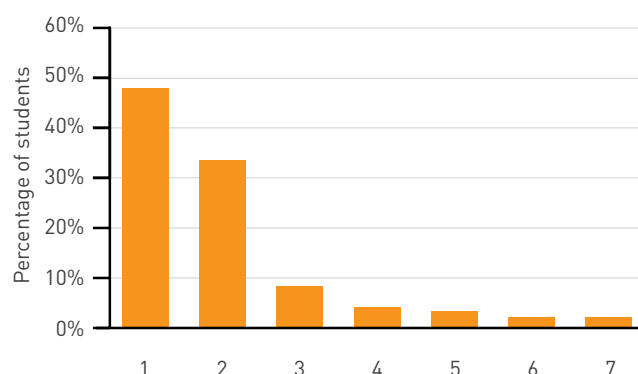
Teaching and learning strategy that integrates meaningful community service with instruction and reflection to enrich the learning experience, teach civic responsibility, and strengthen communities. Service-learning is a structured learning experience that combines community service with preparation and reflection. Service-learning provides college and university students with a “community context” to their education, allowing them to connect their academic coursework to their roles as citizens (p.5).

Service-learning can be much broader than skill-based learning within traditional professional placements, and students can learn much about the context of people’s daily lives (Reynolds, 2009) and have “transformational learning experiences” (Seifer & Connors, 2007, p. 6). Reynolds (2009) suggests that as students become aware of the reality of the lives of the people they will work with, their view of their professional role can be transformed.

Generally, an important component of service-learning is that there is an “explicit link of course objectives with structured community interaction to meet community-driven needs” (Flecky, 2011, p. 2). The students who volunteer in SNUG come from a variety of disciplines, and there is rarely the direct link to course objectives normally found in service-learning (Eyler, 2002; Eyler & Giles, 1999). During the SNUG retreat, however, students are encouraged to reflect on what they are learning through the retreat and how their experience at the retreat relates to their University studies, and participate in structured reflection sessions.

To date 115 students have volunteered at the retreats, most of whom have come from a discipline with direct relevance to children with special needs (see Figure 10). Most students (82%) only attended one or two retreats, although six students have attended five or more retreats (see Figure 11). Over half of the students (56%) have only attended four days of a retreat or less (see Figure 12).

Figure 11: Number of retreats attended



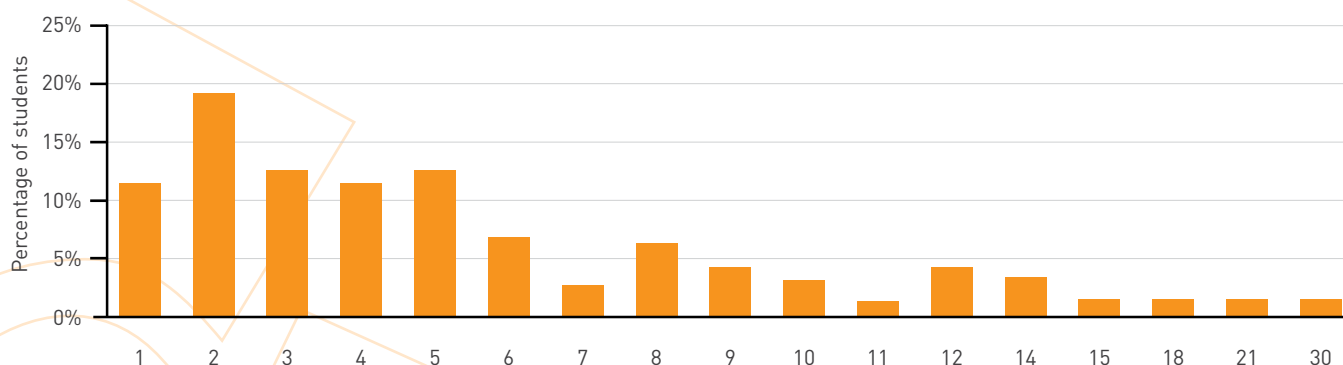
Despite the limited time most students spend at the retreat, volunteer feedback indicates that SNUG increased their awareness about issues facing families of children with special needs, was relevant to their university study, and was a valuable experience. The vast majority of students (see Figure 13) agreed or strongly agreed that:

- SNUG made them more aware of issues facing families of children with special needs (94% in survey 1 and 96% in survey 2)
- SNUG made them more aware of the strengths of families of children with special needs (96%)
- They would recommend volunteering at SNUG to other students in their program of study (100%).

In terms of their learning all the students agreed or strongly agreed (see Figure 14) that:

- They learnt a great deal through their involvement in SNUG
- Their experience at SNUG would be useful in their current or future career
- SNUG made them more confident in working with families of children with special needs.

Figure 12: Number of days attended



Chapter 4: The volunteers

Figure 13: Impact of SNUG on students' awareness

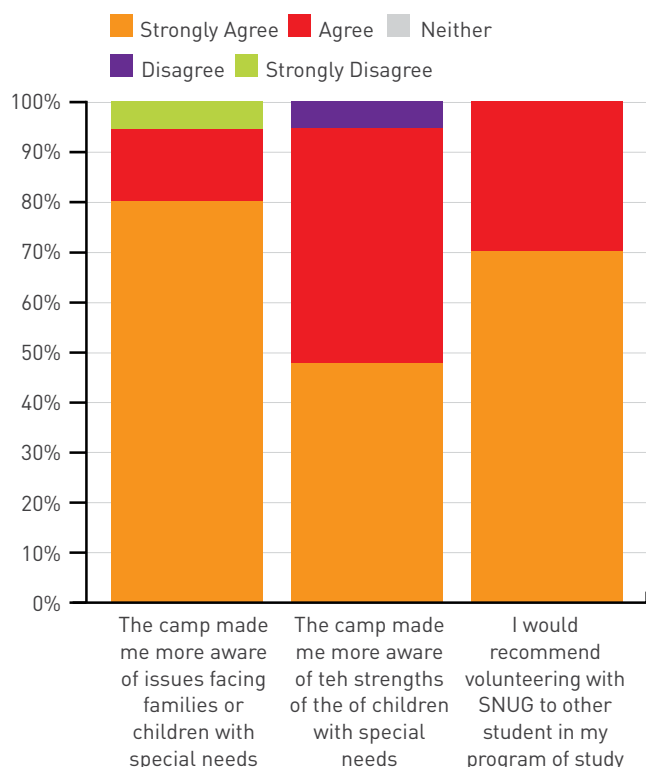
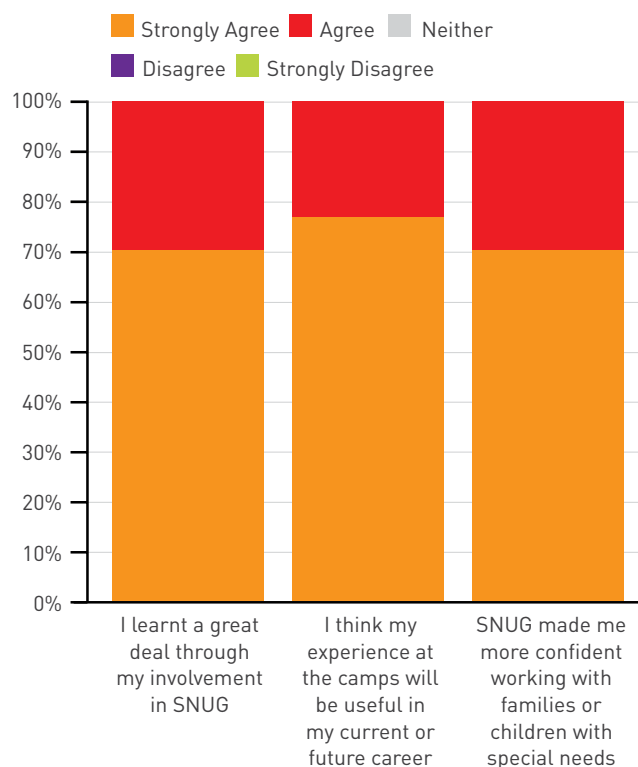


Figure 14: Impact of SNUG on students



The focus groups and responses to the open-ended survey questions provide greater insights into the way the students felt they benefited from volunteering at SNUG. Students gained valuable insights into the lives of families and were better able to understand the reality of everyday life.

It has really opened my eyes to see, and really understand, the reality of everyday life when caring for a special needs child. I have learnt that it is physically, emotionally and often financially challenging. I really gained a lot from speaking with the parents/carers and learning this. (Survey 1)

It gave me an insight into how they live their daily lives with a child/sibling with a disability. It made me aware of the effort many families put into caring for their child/sibling but also the recognition that for them, their child/sibling is a part of their family and can have the same opportunities and experiences as any other child. (Survey 1)

Seeing that disability in the long term – not just when the parent comes to a session or see them once a week in therapy or whatever when you're on prac. It's very different to seeing them from the minute they get up and they give them breakfast and all that kind of thing. (Focus group 3)

The Family Action Centre operates from a strengths perspective and through the retreats student volunteers were able to discover strengths of the families.

The most important thing I learnt from these extraordinary families, parents in particular, is that no matter how tough the situation is, things could be worse. They have such a

positive way of thinking and never give up. I also learnt to keep fighting for what you believe in, because in so many cases, the parents are fighting for the rights of their child and for general acceptance by the wider community. With little support for special needs children, they are alienated and pushed away from social equality. (Survey 1)

Like in the pool yesterday I had one of the girls, and one of the other siblings came up and was playing with her and yeah normally you wouldn't get kids to do that, they'd just back away. A lot of strength in the kids. (Focus group 1)

Having contact with the whole family encouraged students to recognise the importance of families and to become more family-centred.

I guess I learned to take the whole family approach and not just the person in front of you. I think that was the biggest thing I learned. (Focus group 6)

I think it helped because we don't – we shouldn't just deal with – like in our special teaching – just deal with the child. It helps to talk to the families whether it be a grandparent, mother, father: we know how to approach them and how to talk to them. And be on their side rather than just the person asking the questions. (Focus group 1)

Meeting the siblings has been fantastic. They are amazing. Seeing the way they are not only with their siblings with a disability, but the other children with disabilities. (Focus group 2)

Chapter 4: The volunteers

Students also identified strengths within the children with special needs, and described how meeting the individual children gave far more information than a diagnosis and their understanding from theory alone.

You're led to believe that anyone with Autism is not going to be able to interact with anyone – he was doing well, sharing his trains and he was really trusting of us. (Focus group 4)

Through the retreat, students recognised the positive impact of the informal support families gave each other during the retreat.

It was just so encouraging to see them teach each other and bounce ideas off each other. I think Lisa was really positive. I think Beth was really encouraged to be able to help someone like that. That really blew me away. (Focus group 4)

Some of the student volunteers reflected on their practical placements during the degree, and spoke about how the retreats had now changed their perspective.

I just remember back to my second year in prac and it was all about the child sitting in front of me – that's it – rather than considering everything else that's going on in their lives. (Focus group 6)

I've got a few clients at the moment, at my placement and they'll come in with parents and say, "Oh sorry, we're just so busy, we didn't get time to do the homework." Before I was at the camp I would just think, "Oh they don't care much" or, "They're just a bit lazy", but you can really see why people just don't get the homework done. When you see people's lifestyle and you forget what it was like when you were a kid,

especially when things were a little bit tougher or you can't understand them or whatever. (Focus group 6)

At times experiences at the retreat made them question some things they had been taught during their study.

In the text book it pretty much writes off this kid participating in any sort of physical activity... because they can't control their tongue properly, you won't be able to understand what they say and they won't have any friends. And then you get there and you see [child] and sure, he has a bit of trouble walking and he isn't going to walk as far as all the other kids, [but] he'll have a go and he loves to be around the other kids – like, it frustrates him that they can't understand his speech, but it's not like he can't do this and he can do this. Kind of wipes the slate clear of the whole black and white thing. (Focus group 4)

In particular students described taking part in the daily lives of families with children with special needs as an important and unique component in developing this new perspective.

It's very different because you see their daily life rather than just a couple of hours. (Focus group 1)

Yeah, and to see them relax and stuff and you see how run off their feet they are – and if they relax they get to feel free to open up and share aspects of their life and so it gives us that greater insight, than we would normally get in this – you know the initial assessment, where you tick off questions on a box. What were your child's milestones? Blah, blah, blah. Do you have any queries or concerns? And they've got two minutes to give you that initial assessment session. (Focus group 3)

I have encouraged many students in my discipline to volunteer for the SNUG program.



Chapter 4: The volunteers

Many students could identify specific skills or insights they gained through the experience.

SNUG is a eye opening experience that develops your rapport with clients, empathy, understanding of family-centred practice and strengths based practice, confidence to talk to clients and professionals alike and confidence to interact with children with disabilities and their siblings. (Survey 2)

It has provided me with a greater understanding of what is involved for families who have members with special needs. It has also provided me with a number of strategies that I may not have thought about utilising without direct exposure to these families, including a greater sense of patience, how to be assertive without being overbearing, and what can be achieved by thinking about things from a strength perspective. (Survey 1)

I think this is a great way of developing confidence in interacting and communicating with families and children without the pressure you feel (especially initially) whilst on placement (Survey 2)

Some students thought it would be helpful if volunteering at the retreats was part of their formal placements, whereas others thought it was better as a separate, voluntary activity.

The SNUG camps have been an invaluable part of my clinical training. I think it would be highly beneficial for all SP [speech pathology] students to be involved in the program as part of their practical placement requirements. I have encouraged many students in my discipline to volunteer for the SNUG program. (Survey 2)

I think the SNUG camps could be used as a practical

placement for students who are interested in pursuing careers in this field, for students who are not interested I don't think they will gain from this experience. (Survey 2)

I disagree with the SNUG student experience being used as placements within any course. In my experience, students which have attended SNUG camps as part of their course clinical placements, have only been there to 'complete their hours' and were uninterested in participating completely with the experience. These students which I have encountered tended to stand aside rather than getting involved with the families/children. I believe that the SNUG program benefits more from having student volunteers who are attending because they want to and are therefore motivated to be involved with the families. (Survey 2)

I believe that SNUG is great exposure for occupational therapy students into the lives of families of children with disabilities, however as there is no full time OT at the camp I believe its use as a practical placement is limited.... Unless you had intense debriefing with someone from your profession on interventions that would be of benefit to particular children, I don't think SNUG replaces practical placement. I do believe that there is a place for SNUG in the program however I think it is an added extra not to replace placement. (Survey 2)

A number of students felt there was the potential for more to be done to support the learning of students and, based on this feedback, the reflection sessions for students were introduced in later camps. There is still the potential to increase the opportunities for students to learn from their experiences at the retreats in relation to their professional training.



Chapter 4: The volunteers

The interactions with the families were fantastic. However to make it a little more clinically relevant then the different professionals involved dentist, OT etc could have come to speak to the volunteers. (Survey 2)

I would have liked more explanation about the sensory play – evidence behind it, other ideas, how to work with a child using these techniques, how to set-up/ create the goo etc so I can incorporate sensory integration strategies into therapy. (Survey 2)

Through SNUG, students have the opportunity to be immersed in families' lives for a short time, and to provide support to the families while also receiving an experience that can enhance their professional development. The reciprocal nature of the student involvement meant that the families have also appreciated the students' involvement, and have been happy to share their experiences with them.

Norah: *I think a lot of therapists, when they first come out, they have trouble finding the ground with the actual client, because it's still at that point where they've learned all the year about people with the special needs, but they still haven't had a huge amount of experience.... And I think just them watching other people interact within their families has been really good for them [the students] because I found the ones who have been here over a couple of days, usually on the second day they're starting to interact a bit more and talk to the kids.*

Vanessa: *Yeah, they ask a lot of questions and they ask, "How do you feel and how hard it is to be a full-time carer. And, what do you do?" They're more eager to – "Oh, I'll help you with that – will you show me what to do?" And it's really great.... Personally I love it because they ask the question they're always willing to do something for you, so that was really, really good.*

For students who make the most of the experience, SNUG provides them with an opportunity to learn from the families and to deepen their awareness of issues affecting families caring for a child with special needs.

Conversing with parents of children with disabilities is very meaningful, providing us with an understanding of what life really is like when caring for a special needs child and the physical, emotional and financial challenges accompanying it. It is almost like you can visit the other side of practice, gain an understanding of clients wants and needs, and I feel I will become a better therapist because of this understanding. It can also play a part in problem solving and developing ideas for families experiencing many challenges through promoting community participation and social inclusion. (Survey 2)



Chapter 5: What makes SNUG work?

CHAPTER OVERVIEW

In the final chapter we reflect on what we believe are some of the features of SNUG that make it successful:

- Strengths-based practice is a foundation for the retreats.
- The retreats are built on family-centred practice.
- SNUG relies on skilled volunteers.
- Families have the opportunity to try new activities.
- Flexibility is an important part of the approach.
- SNUG receives strong professional support.
- The camps are free.
- The families are the key to the success.



Chapter 5: What makes SNUG work?

The SNUG retreats were built on the belief that by bringing together families of children with special needs they would be able to provide each other with support, encouragement and useful information. Health and medical professionals play important roles in caring for children with special needs, but it is the families who provide the ongoing love, stability and care.

Since the first camp in early 2009, the Family Action Centre, the SNUG steering committee and the student volunteers have learnt a great deal from the families who have attended the 15 retreats. Based on this experience, the retreats have been refined, student volunteers have gained valuable insights and experience, and staff have been inspired by the families who have attended. This report has presented some of what we have learnt about the experiences of families caring for a child with special needs, and the impact of SNUG for both the families and student volunteers.

The families and students clearly appreciate the retreats and find them beneficial, and so in this final chapter we thought it would be worthwhile to reflect on what we consider to be some of the features of SNUG that make it successful.

Strengths-based practice is a foundation for the retreats.

SNUG recognises that the families are experts in living with a child with special needs, and have much to teach each other. Thus, an important focus of the retreats is encouraging families to share their experiences, their challenges and their successful strategies with each other. Rather than “expert” professionals trying to teach the families about how to care for their children, the retreats encourage the families to reflect on and celebrate what works for them, and to learn from what works for other families. Families caring for children with special needs are often asked to plan for the future and to address immediate concerns. SNUG also invites them to reflect on their past achievements, and to recognise the value of the knowledge and experience they have accumulated while caring for their families.

Many of the families who attend the retreats are inspirational in the way in which they care for their families, face some of the challenges of caring for a child with special needs and remain positive and optimistic. At times families who have been struggling might be inspired or receive renewed hope and confidence from other families at the retreat, or they might simply recognise that they are not alone. SNUG also recognises that the families have a great deal to teach future (and current) professionals.

The retreats are built on family-centred practice.

Family-centred practice begins with the strengths of families, treats families with dignity and respect, recognises the centrality of the family in children’s lives and is guided by informed choices made by families (Moore & Larkin, 2005). Families are the focus of SNUG. Throughout the retreat, including the recruitment and registration process, the expertise of the families is recognised and the individual retreats are shaped according to the interests and wishes of the families. The role of staff and volunteers at the camp is to support decision making by the families, and most activities involve all family members.

Because SNUG is family-centred, the retreats provide respite for the whole family. Traditionally, respite services look after children with special needs so that the rest of the family can do other things. While such respite is very important and much appreciated (Burton-Smith, et al., 2009), SNUG provides an experience for the whole family and encourages them to enjoy activities together. The parents do not need to worry about cooking meals and cleaning up, there is help with entertaining and supervising their children, and they have a break from their normal routines; and so the parents can focus on enjoying their time with their children.

SNUG relies on skilled volunteers.

The student volunteers play a crucial role in the retreats. Through their energy, enthusiasm, and willingness to become involved, they help create an exciting, dynamic atmosphere for the children, and assist the parents to have a break from some of the demands of daily life. As most of the student volunteers come from disciplines at The University of Newcastle that involve working with children with special needs, they already have useful knowledge or skills. Before the retreats, students also receive specific training in relation to strengths-based practice and their role in SNUG.

Because the students also learn a great deal from the families and gain valuable experience that will help with their study and future careers, students recommend volunteering at SNUG to other students and there is thus a constant supply of new volunteers.

Families have the opportunity to try new activities.

Through the retreats, families are encouraged to try new things. Activities that might be considered too difficult in a normal situation (e.g., archery, ice-skating), can be attempted because they are organised and facilitated by FAC and Myuna Bay staff, and there is plenty of support from the student volunteers. Frequently parents say they wouldn’t have considered trying ice-skating, yet it is often

Chapter 5: What makes SNUG work?

one of the highlights of the retreat. The families also have the opportunity, often for the first time, to experience complementary therapies such as massage, music therapy and art therapy.

Flexibility is an important part of the approach.

While there are similarities from one retreat to another, there is no set program that is followed from retreat to retreat. The retreats are modified according to the interests and requirements of the individual families. Before the retreat, information is obtained from the families so that activities can be planned that are appropriate for the children with special needs and their siblings. There are a range of activities that can be adapted so that adults and children with differing physical and intellectual abilities can participate. While the current focus is on children with rare conditions, the approach taken by SNUG could easily be adapted for a wide variety of children with special needs.

SNUG receives strong professional support.

From the early days of establishing SNUG, the initiative has received strong support from professionals with relevant skills and experience. The steering committee has helped plan and develop the retreats and ensured that the retreats are based on good practice. Dr King has provided dental care at all but four of the retreats (when he was unavailable). Dr Rob Smith (a paediatric neurologist) has been involved since the start through the steering committee; he has held consultations with children and has regularly brought his band to the bush dance (at no cost). University staff have supported SNUG by helping to promote the program to potential volunteers. A range of other professionals have visited the retreats providing specific services or support.

The camps are free.

Caring for a child with special needs can place financial strain on families, and some families simply cannot afford to go on holidays. The support of the Steve Waugh Foundation and other professionals or organisations means that there are no costs involved for the families (except for travel to and from the retreat). All the activities, food, accommodation, additional equipment (e.g., hospital beds, wheelchairs for ice skating) and appointments cost the families nothing.

The families are key to the success of SNUG.

SNUG aims to bring out the best in families. All the families have faced many challenges, but have also shown determination, resourcefulness and love. SNUG staff and volunteers are continually inspired by the families, and the retreats could not be a success without them. Their generosity, their willingness to be involved and their

optimism are crucial. This isn't to say that families are optimistic, positive and get along wonderfully all the time. As with all families, there are tears, arguments and low-points, but it is the families' strengths and resourcefulness that allow SNUG to be successful.

Rather than focusing on the many challenges and difficulties faced by families, the focus is on the strengths and insights of the families. The problems and challenges aren't ignored, and families are welcome to grieve or unload, but the emphasis is on what families have achieved, what they have learnt and how they can support each other. SNUG staff work hard to create an atmosphere that is safe and welcoming, encourages sharing and respect, and recognises the expertise of the families.

Family feedback has consistently shown that the families have appreciated their time at SNUG retreats. The Family Action Centre has been privileged to work with these families and hopes to be able to provide the opportunity to many more families in the future.

The final word can go to one of the parents:

Katie: I'm just amazed about how I am more relaxed now – because it's really hard [caring for a grandchild with special needs]. I'm just like a little kid in a lolly shop. I'm that happy with everything that I've found out [at SNUG]. It's even boosted my confidence... that I've been doing everything right and things like that. So yeah, I think, it can only go ahead from here. I feel like a little kid in a lolly shop because everything has just turned out better than I ever, ever expected.



Further Information

THE FAMILY ACTION CENTRE

The Family Action Centre is located within the Faculty of Health at The University of Newcastle, New South Wales, Australia. We are a multidisciplinary centre that works to strengthen families and communities. This is done by developing and implementing family and community programs, undertaking research, providing teaching and training, and actively disseminating our learning and experience. In this way the Family Action Centre combines community service, teaching, dissemination and Indigenous collaborations to inform and advance Australian family policy and practice.

<http://www.newcastle.edu.au/research-centre/fac/>

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References

- Abdal-Haqq, I. (1993). Integrated services: New roles for Schools, new challenges for teacher education. Retrieved 7 August 2003, from <http://www.eric.ed.gov/PDFS/ED355197.pdf>
- Australian Bureau of Statistics. (2011). *Disability, ageing and carers: Summary of Findings (4430.0)*. Canberra: ABS.
- Australian Institute of Health and Welfare. (2004). *Children with disabilities in Australia*. Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare. (2008). *Rural, regional and remote health: Indicators of health status and determinants of health*. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2009). *A picture of Australia's children 2009*. Canberra: Australian Institute of Health and Welfare.
- Baldwin, P. J., McDougall, J., & Evans, J. (2008). An exploration of spirituality, spiritual beliefs and paediatric rehabilitation. *Spirituality and Health International*, 9(4), 249-262.
- Baxter, S., & Gray, C. (2001). The application of student-centred learning approaches to clinical education. *International Journal of Language and Communication*, 36, 396-400.
- Bourke, L., & Sheridan, C. (2008). Understanding rural health- key concepts. In S.-T. Liaw, S. Kilpatrick & Australian Rural Health Education Network. (Eds.), *A textbook of Australian rural health* (pp. 31-44). Canberra: Australian Rural Health Education Network.
- Bourke, L., Sheridan, C., Russell, U., Jones, G., & De Witt, D. (2004). Developing a conceptual understanding of rural health practice. *Australian Journal of Rural Health*, 12(5), 181-186.
- Burton-Smith, R., McVilly, K. R., Yazbeck, M., Parmenter, T. R., & Tsutsui, T. (2009). Service and support needs of Australian carers supporting a family member with disability at home. *Journal of Intellectual and Developmental Disability*, 34(3), 239-247.
- Carter, B., Cummings, J., & Cooper, L. (2007). An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of Clinical Nursing*, 16, 527-539.
- Caudrey, D., & Dissinger, M. (2007). Health Support of people with disabilities in South Australia: Innovations in Policy and Practice. *Disease Management & Health Outcome*, 15(6), 341-353.
- Cummins, R. A., Hughes, J., Tomy, A., Gibson, A., Woerner, J., & Lai, L. (2007). *The wellbeing of Australians: carer health and wellbeing*. Geelong: Deakin University.
- Darley, S., Porter, J., Werner, J., & Eberly, S. (2002). Families tell us what makes families strong. *The Exceptional Parent*, 32(12), 34-36.
- DeFrain, J. (1999). Strong families around the world. *Family Matters*, 53(1), 6-13.
- DeFrain, J., & Asay, S. (2007). Strong families around the world. *Marriage and Family Review*, 41(1), 1-10.
- Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. R.-M. (2006). Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing*, 53(4), 392-402.
- Doherty, S. (2007). Could we care for Amillia in rural Australia? *Rural and Remote Health*, 7(4), 22.22KB.
- Edwards, B., Higgins, D., Gray, M., Zmijewski, N. A., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia*. Melbourne: Australian Institute of Family Studies.
- Edwards, B., Higgins, D. J., & Zmijewski, N. (2007). The Families Caring for a Person with a Disability Study and the Social Lives of Carers. *Family Matters*(76), 8-17.
- Eyler, J. (2002). Reflection: Linking Service and Learning – Linking Students and Communities. [Article]. *Journal of Social Issues*, 58(3), 517-534.
- Eyler, J., & Giles, D. (1999). *Where's the learning in service learning?* San Francisco: Jossey-Bass Publishers.
- Faller, H., Dowell, M., & Jackson, M. (1995). Bridge to the future: nontraditional clinical settings, concepts and issues. *Journal of Nursing Education*, 34(8), 344-349.
- Fieldhouse, J., & Fedden, T. (2009). Exploring the learning process on a role-emerging placement: a qualitative study. *British Journal of Occupational Therapy*, 72(7), 302-307.
- Flecky, K. (2011). Foundations of service-learning. In K. Flecky & L. Gitlow (Eds.), *Service-learning in occupational therapy education : philosophy and practice* (pp. xxv, 309 p.). Sudbury, Mass.: Jones and Bartlett Publishers.
- Goldbart, J., & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC. *Augmentative and Alternative Communication*, 20(4), 194-208.
- Gregory, G. (2009). Impact of rurality on health practices and services: Summary paper to the inaugural rural and remote health scientific symposium. *Australian Journal of Rural Health*, 17(1), 49-52.
- Gruen, R. L., Weeramanthri, T. S., & Bailie, R. S. (2002). Outreach and improved access to specialist services for Indigenous people in remote Australia: The requirements for sustainability. *Journal of Epidemiology and Community Health*, 56(7), 517-521.

References

- Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Developmental and Physical Disabilities*, 19(4), 417-425.
- Hallstrom, I., & Elander, G. (2007). Families' needs when a child is long-term ill: A literature review with reference to nursing research. *International Journal of Nursing Practice*, 13(3), 193-200.
- Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, 49, 14-24.
- Hegney, D., Buikstra, E., Baker, P., Rogers-Clark, C., Pearce, S., Ross, H., et al. (2007). Individual resilience in rural people: a Queensland study, Australia. *Rural and Remote Health*, 7, online. Retrieved from <http://www.rrh.org.au>
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping and future expectations. *Journal of Developmental and Physical Disabilities*, 14(2), 159-171.
- King, G., Batorowicz, B., & Shepherd, T. (2008). Expertise in research-informed clinical decision making: Working effectively with families of children with little or no functional speech. *Evidence-Based Communication assessment and Intervention*, 2(2), 106-116.
- Lassetter, J. H., Mandlco, B. L., & Roper, S. O. (2007). Family photographs: Expressions of parents raising children with disabilities. *Qualitative Health Research*, 17(4), 456-467.
- Lee, I., Lee, E., Kim, H. S., Park, Y. S., Song, M., & Park, Y. H. (2004). Concept development of family resilience: a study of Korean families with a chronically ill child. *Journal of Clinical Nursing*, 13, 636-645.
- Lekkas, P., Larsen, T., Kumar, S., Grimmer, K., Nyland, L., Chipchase, L., et al. (2007). No model of clinical education for physiotherapy students is superior to another: a systematic review. *Australian Journal of Physiotherapy*, 53, 19-28.
- Mandlco, B. L., Frost Olsen, S., Dyches, T., & Marshall, E. (2003). The relationship between family and sibling functioning in families raising a child with a disability. *Journal of Family Nursing*, 9(4), 365-396.
- Mathisen, B. (2009). Working with families of children with dysphagia: an interdisciplinary approach. In N. Watts Pappas & S. McLeod (Eds.), *Working with Families in Speech-language Pathology* California: Plural Publishing.
- McAllister, L. (2005). Issues and innovations in clinical education. *Advances in Speech-Language Pathology*, 7(3), 138-148.
- McGuire, B. K., Crowe, T. K., Law, M., & VanLeit, B. (2004). Mothers of children with disabilities: occupational concerns and solutions. *The Occupational Therapy Journal of Research: Occupation, Participation and Health*, 24(2), 54-63.
- Misan, G., Lesjak, M., & Fragar, L. (2008). Health of rural populations. In S.-T. Liaw & S. Kilpatrick (Eds.), *A textbook of Australian rural health* (pp. 71-81). Canberra: Australian Rural Health Education Network.
- Moore, T., & Larkin, H. (2005). "More than my child's disability..." : a comprehensive literature review about family-centred practice and family experiences of early childhood intervention services Glenroy, Vic.: Scope (Vic).
- O'Callaghan, A. M., McAllister, L., & Wilson, L. (2005). Barriers to accessing rural paediatric speech pathology services: Health care consumers' perspectives. *Australian Journal of Rural Health*, 13(3), 162-171.
- Overton, A., Clark, M., & Thomas, Y. (2009). A review of non-traditional occupational therapy practice placement education: a focus on role-emerging and project placements. *British Journal of Occupational Therapy*, 72(7), 294-301.
- Patterson, C. (2000). The emergence of rural health in Australia. *Australian Journal of Rural Health*, 8(5), 280-285.
- Payne, J. (2009). Supporting family caregivers: The role of speech-language pathologists and audiologists. *The ASHA Leader*, 14(3), 22-25.
- Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 7(4), 231-247.
- Pelchat, D., Levert, M.-J., & Bourgeois-Guerin, V. (2009). How do mothers and fathers who have a child with a disability describe their adaptation/ transformation process? *Journal of Child Health Care*, 13(3), 239-259.
- Reynolds, P. (2009). Community engagement: what's the difference between service learning, community service, and community-based research? *Journal of Physical Therapy Education*, 23(2), 3-9.
- Scott, D. (2005). Inter-organisational collaboration in family-centred practice: A framework for analysis and action. *Australian Social Work*, 58(2), 132-141.
- Seifer, S., & Connors, K. (2007). *Faculty toolkit for service-learning in higher education*. Scotts Valley, CA: National Service-Learning Clearinghouse
- Silberberg, S. (2001). Searching for family resilience. *Family Matters*, 58(1), 52-57.
- Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability*, 31(1), 53-57.

References

- Smith, K. B., Humphreys, J. S., & Wilson, M. G. A. (2008). Addressing the health disadvantage of rural populations: How does epidemiological evidence inform rural health policies and research. *Australian Journal of Rural Health*, 16(2), 56-66.
- Sullivan, R. (2001). Fathering and children. *Family Matters*, (58), 46-51.
- Thomas, C., Mitchell, P., O'Rourke, P., & Wainwright, C. (2006). Quality-of-life in children and adolescents with cystic fibrosis managed in both regional outreach and cystic fibrosis center settings in Queensland. *The Journal of Pediatrics*, 148(4), 508-516.
- Vickers, M., Harris, C., & McCarthy, F. (2004). University-community engagement: exploring service-learning options within the practicum. *Asia-Pacific Journal of Teacher Education*, 32(2), 129-141.
- Warmington, R. (2003). *Family carers' health and well-being and community capacity building in rural areas*. Paper presented at the 7th National Rural Health Conference.
- Watts Pappas, N., & McLeod, S. (2009). Parents' perceptions of their involvement in pediatric allied health intervention. In N. Watts Pappas & S. McLeod (Eds.), *Working with Families in Speech-language Pathology* California: Plural Publishing.
- Watts Pappas, N., McLeod, S., & McAllister, L. (2009). Models of practice used in speech-language pathologists' work with families. In N. Watts Pappas & S. McLeod (Eds.), *Working with Families in Speech-language Pathology* California: Plural Publishing.
- Welch, N. (2000). *Understanding the determinants of rural health*. Paper presented at the National Rural Health Alliance.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083.
- Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2006). Getting out of the house: The challenges mothers face when their children have long-term care needs. *Health and Social Care in the Community*, 15(1), 45-55.
- Yau, M. K., & Li-Tsang, C. W. P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: a review of the characteristics and attributes. *The British Journal of Developmental Disabilities*, 45(88), 38-51.



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