

CARERS NSW CONFERENCE
June 11th and 12th 2009

Support to Hidden Carers: Successful Initiatives and Strategies

Presented by: Katharine Carney. Northcott Disability Services.

Northcott Disability Services has a long history of providing a wide range of services to people with disabilities across NSW and the ACT including; therapy services, case management, family support leisure, and recreation services, equipment and computer assistive technology services, respite, accommodation, All services are delivered with an wholistic approach whereby the needs of both clients and carers are considered.

Many of Northcott programs have identified groups of carers where strategies must be implemented to make services bot effective and appropriate.

Today, I am going to discuss two separate groups of carers, The first, Aboriginal Carers and secondly, siblings. During the course of this presentation, I will be discussing the individual needs of these two groups of carers and highlighting Northcott programs and initiatives that have been very successful in reaching our target group.

The Australian Bureau of Statistics define carers as;

"A person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or persons who are elderly (i.e. aged 60 years or over). The assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities:¹

¹ Australian Bureau of Statistics, (1998), "Disability, Ageing and Carers: Summary of Findings", Cat. No. 4430.0.

The term hidden carers refers to those carers who do not self identify as carers or who are not recognised as carers by professionals and/or the community²

This paper examines some initiatives that have been employed at a local level to target services and support to hidden carers.

Aboriginal and Torres Strait Islander people have a complex system of family relations, where each person knows their kin and their land. These extended family relationships are the core of Indigenous kinship systems that are central to the way culture is passed on and society is organised.

Kinship systems define where a person fits in to the community, binding people together in relationships of sharing and obligation. These systems may vary across communities but they serve similar functions across Australia. Kinship defines roles and responsibilities for raising and educating children and the structures and systems of moral and financial support within the community.³

Indigenous communities have strong family values that are rarely endorsed or understood by government authorities. Children are not just the concern of the biological parents, but the entire community. Therefore, the raising, care, education and discipline of children are the responsibility of everyone - male, female, young and old.

Northcott has a number of programs specifically targeted at Aboriginal families. One of these programs, Aboriginal Play Links is a playgroup based service run in the Macarthur area.

The Aboriginal Playlinks Program was originally based on a "Take it to the Streets" model, similar to our other playgroups. The playgroup was held at a local park and any one was invited to join. Whilst a few families regularly participated there were Aboriginal families in the park, at the same time who did not participate. Clearly, simply taking the playgroup to them was not enough.

The coordinator of the Aboriginal Playlinks program has very good networks within the area and whilst we continue to run out other supported playgroups at local parks and venues, it was decided to further establish this playgroup at Tharawal Medical Corporation. By operating the playgroup from a centre such as this, Northcott was able to access families that were attending the centre and similarly,

² Carers NSW, (2001) Reaching Hidden Carers, a Position Paper by the Carers Coalition.

³ Summarised and adapted from, Australian Museum. (2004). Indigenous Australia downloaded from <http://www.dreamtime.net.au/indigenous/family.cfm#about> on 28th February 2009.

families that accessed the playgroup are able to be linked into other essential health services.

The playgroup continues to be successful and offers more than just a chance for play. The "Bonding with Baby" program has been incorporated into the playgroup and parents and carers of children are offered advice on topics such as parenting skills and nutrition.

Whilst it took some time to get the playgroup functioning at an optimum level, with time, patience and investment in the local community Northcott is able to continue providing valuable supports and services to clients. The key elements to the success of this program were

- 1) Have a presence in the community, BEFORE you introduce your program. – some of the strategies that our manager used were, participating in local events, having promotional material around, but not forcing it on people. Research ⁴ has shown, that having a presence in the local community assists in building trust as well as establishing relationships.
- 2) Staff need to be prepared to be active in the community. For example. Staying on after the event / planned activity for the day has finished. Participating in activities that you are asked to, not just the ones that serve a purpose for your program.
- 3) Be flexible. Be prepared to change your routine at a moments notice. The coordinator of our playlinks program was asked to run a group the next day, rather than the one scheduled. She was able to be flexible with the time and as such earned a great deal of respect within the local community.

Another difficulty is that of attracting and retaining workers to the program. Advertising for workers has proved to not be very productive; the workers employed in this program have been sourced from the local community, through word of mouth or they have approached the program after seeing the presence that it has had in the community. We have had Aboriginal workers start as volunteers and then be offered a more permanent position in the program.

Although there are difficulties in attracting appropriate staff to these programs, having Aboriginal workers for the program is key for a number of reasons.

- 1) Aboriginal clients engage easier and are often able to relate better to an Aboriginal workers.

⁴Summarised from: Calgaret. T (2007), Enhancing the planning and delivery of services to Aboriginal people in Western Australia: Department for Child Protection.

- 2) Having an Aboriginal worker builds trust and respect within groups.
- 3) Ensure a local Aboriginal person works alongside you in developing and building relationships with Aboriginal communities. - . An Aboriginal person taking you to any Aboriginal community or family group does so because they are respected and trusted by that community/group.
- 4) Seek advice from your Aboriginal colleagues about all the different family groups in an area and who is related to whom. Aboriginal communities are often a combination of distinct families and extended families.
- 5) Ensure you make yourself aware of whom the local Elders are and arrange to meet with them early on.⁵

As a result of the partnerships that we have build with the local Tharawal Community, Aboriginal workers have been able to access training and resources offered by Northcott and as such have increased their skills, knowledge and experiences and are able to take these back and share with the community as a whole. It has been a great exercise in community development.

⁵Summarised from: Calgaret. T (2007), Enhancing the planning and delivery of services to Aboriginal people in Western Australia: Department for Child Protection.

The second group of hidden carers that I would like to touch on are Siblings.

There are a number of issues relating to children who have a sibling with a disability have been documented by many authors and Siblings Australia has very comprehensive information and resources for families. Before talking more about Northcott's annual sibling camp, I will quickly summarise some of these concerns.⁶

This is a quick overview with information obtained from a paper written by Rocky Bay Inc (one of Northcott's Ability First Affiliates)⁷

Isolation – Children who have a sibling with a disability may feel isolated from those around them. They may feel that the sibling with a disability requires more attention from parents and other family members. They may have difficulty in interacting with their sibling because of the disability. Additionally they may believe that their feelings do not matter and that only those of the brother or sister with a disability do.

Information or misinformation may lead them to believe they are the cause of the disability and they may be unsure how to explain it to others.

There may be a range of emotions in relation to the care needs of the person with a disability, such as, disappointment, guilt, fear, and perhaps sorrow at what the brother or sister experiences. Sometimes shame about how they feel towards the sibling.

Pressure to be perfect. Siblings may feel they have to be perfect to gain attention or avoid giving their parent's any more distress.

Anger and resentment following on from the disruption to family routines and the disproportionate amount of time and energy directed to the child with a disability.

Grief. Including feelings about wanting a "normal" Brother or Sister.

⁶ Summarised from: Strohm, Kate. (2002). Siblings. Wakefield Press: Kent Town, S.A.

⁷ Rocky Bay Inc.(2006) Psycho-Social and Behavioural Support for Children with Physical Disabilities A Resource for Parent's, Carers, Teachers, and Allied Health Workers: Rocky Bay Inc.

The Future. Siblings may be concerned about their own future, and that of their brother or sister with a disability,

Care giving and responsibility. Children who have a sibling with a disability may be asked to take on additional caring responsibilities. They may feel they have no option, or are attempting to ease their own guilt, or want to take some pressure off the parents. There may not be the time or resources to do other activities for themselves. because of the caring role. There may also be considerable conflict between their feelings for the sibling or resentment on missing out on activities for themselves.

Much of the research into siblings shows that without support, they are at a higher risk of developing mental health issues, particularly anxiety, depression and issues to do with self esteem, so running camps is a preventative strategy⁸

Northcott runs an annual camp for siblings of clients within our Metropolitan Family Support Team. The camps began as a result of a letter that was received by the Metropolitan Family Support Team from a Sister of a client who was asking "What about services for me?" As a direct result of this letter, the team decided to hold an annual Siblings Camp

It gives children who have a sibling with a disability, the opportunity to spend some time away, as a group, to be able to share experiences, feelings, frustrations, and concerns as well as just having some time away from the usual family situation to be "just a kid"

These camps are very popular and have a great attendance each year.

Why do we run Sib Camp?

- Sib Camp is for siblings who have a range of caring responsibilities
- To have the chance to be the focus of attention
- To hear first hand from others in similar circumstances
- To normalise otherwise alienating experiences.

We have, at times, found it difficult to engage with siblings and this may be for a number of reasons.

Firstly, the team members often have a much closer relationship with other family members, Mum, Dad, the client. Siblings don't often see themselves as requiring support in their role and so may not participate in the planning or support program as much as other

⁸ Strohm, Kate. (2002). Siblings. Wakefield Press: Kent Town, S.A.

family members. In an attempt to overcome these difficulties, social workers will try and build a relationship and include the sibling, where appropriate to establish a basis for opening up communication about the types of support that are available to them, including Sib Camp.

Before each camp, The Metropolitan Family Support Team will hold a "Pizza Night" where children are invited to come and meet the staff and other children that will be going on the camp. During the course of this evening, the camp agenda is discussed and the children have a chance to say what they would like to get out of it.

I have an outline of the program to share which will assist in understanding the nature of the camp and how we engage with the children.

Day 1

- Arrive at camp site – currently Challenge Ranch at Somersby
- BBQ and games to "get to know each other"
- Settle into cabins
- Introduction to the camp and further "ice breaker games"
- Supper

Day 2

- Breakfast
- Centre based activities
- Morning Tea
- Centre Based activities
- Lunch
- Beach
- Afternoon tea
- Discussion / Activities – these activities are the "serious" side of the camp and give the children the chance to discuss their feelings and experiences. Whilst this is the only formal time set aside for this type of discussion, all the activities are planned so that they open pathways for communication and build networks between children. During this time, children are provided with information about who they can talk to, where they can go for help etc. These sessions are facilitated by our social workers.
- Dinner
- Beach by Night

Day 3 – Concluding the camp

- Breakfast
- Beach
- Morning Tea

- Pack up cabins
- Lunch
- Evaluation and autograph books – the children are all given an autograph book where they can leave messages for each other and share contact details. The evaluation is completed as a group exercise and recorded on a large sheet of butcher’s paper. All of the comments are recorded (as long as they are not offensive) and kept for reference for future camps.
- End of Camp.

Following the end of the camp, a sibling’s newsletter is distributed to the participants with the evaluation results and photos of the camps. There is also information about how to keep in touch with others that they met at the camp.

Thankyou for listening today, I hope that you enjoy the remainder of the conference.

We now have time for some questions if there are any.

REFERENCE LIST

- Australian Bureau of Statistics, (1998), "Disability, Ageing and Carers: Summary of Findings", Cat. No. 4430.0.
- Australian Museum. (2004). Indigenous Australia downloaded from <http://www.dreamtime.net.au/indigenous/family.cfm#about> on 28th February 2009.
- Calgaret. T (2007), Enhancing the planning and delivery of services to Aboriginal people in Western Australia: W.A. Department for Child Protection.
- Carers NSW, (2001) Reaching Hidden Carers, a Position Paper by the Carers Coalition. Downloaded from <http://www.carersnsw.asn.au/storage/pdfs/hidden.pdf> on 15th April 2009
- Rocky Bay Inc.(2006) Psycho-Social and Behavioural Support for Children with Physical Disabilities A Resource for Parent's, Carers, Teachers, and Allied Health Workers: Rocky Bay Inc.
- Strohm, Kate. (2002). Siblings. Wakefield Press: Kent Town, S.A.