COMMUNITY-BASED RESPITE CARE FOR DISABLED CHILDREN

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INTRODUCTION

This article is an overview of community based respite care programmes operating in the metropolitan area of Sydney. The term "community-based respite care" in this article refers to a model where the care is given by other families within the community. The term "families" encompasses traditional two parent families, single parents and other caring adults. These families are identified as "host families" and "respite care" is defined as provision of short term relief from 2 hours to 2 weeks to disabled persons and their families on a planned basis or in emergency situations.

The underlying philosophy of community respite care is that services to the disabled should be based on making available to them the same patterns and conditions of everyday life which most citizens enjoy.

HISTORICAL CONTEXT

Prior to the late 70's respite care was traditionally given in large institutional settings, but this model was not always seen as being appropriate to many families. Rather, the need was expressed for a flexible service which offered care more comparable to the child's own home.

The first community-based respite care scheme to be established was derived from a service run by the Church of England Welfare Office in Newcastle, N.S.W. This service provided emergency care for children in a network of foster homes within the community. This was expanded to include disabled children.

In Sydney, Australia, Action for Handicapped Citizens (a parent group) set up a community-based respite care scheme, known as Interchange. One member of the parent group had had first hand knowledge of a short-term care scheme for handicapped children in Somerset, England, which had been set up in 1976. This scheme was referred to in the original submission drawn up by Action for Handicapped Citizens. Once funding was provided by the Department of Youth and Community Services, the Interchange Programme was established and administered by the Mercy Family Life Centre at Waitara.

By 1981 a number of similar schemes were operating. However, the concept of community-based respite care was slow to develop partly because care of disabled children had traditionally taken place in medical/institutional settings. The real impetus came in 1981, the "International Year of the Disabled", when there was a more receptive attitude to integration. As society's awareness of the needs of disabled people and their families grew, so too did the responsibility of the community to share in the provision of these services.

MEETING THE NEEDS OF DISABLED CHILDREN AND THEIR FAMILIES

The emergence of community respite care services arose in response to the particular needs of families with handicapped children. These were defined as:

1. To give families time out from constant demands of caring for a child with disability.
2. To extend the handicapped child's social network.

The effects of having a disabled child in the family are great. Relationships within the marriage come under enormous strain; there is often serious contention with other members of the family as mothers try and stretch themselves between all members of the family in their efforts to compensate for the extra time spent with the disabled child. Feelings of isolation are common as these families struggle with the emotional and physical problems of caring for their child at home.

All parents appreciate and need a break from their children. Calling a baby sitter for the evening or packing them off to grandparents for a weekend are standard facts of life for most families. It is a welcome break for parents to relax, have some time for themselves, or to spend some special time with other members of the family.

For the family with a disabled child these breaks are not so accessible. Most handicapped children need constant supervision and, all too often, there is simply no one available to help. With a handicapped child, people don't offer to help because they don't know what is involved and doubt their ability to cope.

Temporary care, as offered by respite care agencies, provides the short breaks a family needs. This does not mean that the handicapped child is excluded from family activities but sometimes it is impractical to expect a child with special needs to participate fully.

Community-based respite care provides children with a chance to make special friends of their own by giving them the opportunity to interact with other children and other families. Mostly these children attend special schools out of their area and have little chance to mix with able-bodied children in their neighbourhood.

In this way, respite care in a host family allows the disabled child new horizons and perhaps begins to prepare him for a living situation, independent of his family, as some will ultimately move from their family into group homes, or larger residential facilities.

In the normal course of development, able-bodied children gradually widen their social networks and eventually leave the family to make an independent life of their own. Within this normalisation framework respite care can be seen as the first step for a disabled child attaining these same goals. In allowing families time out, the need for seeking residential care is postponed until the child is of the appropriate age to live apart from his family.

STAFFING AND FUNDING

For the purpose of this article, ten respite services were surveyed. All were established by parent groups in conjunction with the N.S.W. Department of Youth & Community Services personnel. Of these schemes, nine are funded by this Department and one by the Office of Child Care. They all operate within the guidelines set down by these funding bodies. The services are:

Illawarra Family Care for Disabled Children
Newcastle Temporary Family Care
The Therapy Centre, Arncliff
Westlink – Telopea
Interchange – Wiatara
Interchange – Narrabeen
Campbelltown Temporary Family Care (Handicapped)
Bankslink – Bankstown
Sharecare – Liverpool
Family Respite & Network Support (FRANS) – Summer Hill

These schemes are staffed by coordinators employed either part or full-time. The role of the co-ordinators is to recruit and train host families, arrange and supervise placements, promote an awareness of the schemes to families of disabled children and to act as a support person to both host and client families. They are responsible to either a management committee or their sponsoring body.

HOW RESPITE CARE OPERATES

Recruitment of host families is mainly carried out through advertising in the local paper, contact with various community groups and word of mouth. Whilst many hosts may have had some experience with disabled children, it is not a requirement.

Respite care as offered by these services is available to any child from birth to 18 years of age with a disability, which may be physical, intellectual, emotional or sensory. The degree of disability can range from mild to the more severe and multiple disabilities.

No one disability group is excluded, although the age of clients has some bearing on placements, the older children being the hardest to place. Some agencies, in an attempt to give respite to the client families, have established social groups for these harder-to-place children.

Access is through referral, either from client families themselves or various community and government agencies, special schools and early intervention groups.

The ability to meet the needs depends more on the availability of suitable host families rather than on the specific disability of the client.

The success of all programmes depends on the willingness of host families to give of their time, and the ability of the agencies to support them. All of the services surveyed provide ongoing support, with regular contact by home visits or by phone. This enables the co-ordinator to monitor the placements and adapt care to the changing needs of the families.

EVALUATION

An evaluation of one service, INTERCHANGE, was conducted in 1983. Whilst INTERCHANGE emerged as being an important and worthwhile service, there were some areas of concern. The constraints of lack of sufficient numbers of host families meant an inability to fully satisfy the damands for care by client families. It was considered that approximately twenty hours per month was the minimal amount of care required to provide a regular break for parents. It was also found that amongst most client families there was a reticence to ask for more hours of care even though they needed the extra assistance. The reasons given were feelings of guilt or embarrassment or not wanting to impose on an already busy host family.

This evaluation highlighted that, while INTERCHANGE endeavoured to meet the need for respite care, most families considered that further services were required to assist them in caring for their disabled child. The evaluation recommended that INTERCHANGE consider a structured Family Day Care type model in addition to the current system.

CONCLUSION

In conclusion, temporary care offered by respite care agencies goes a long way to providing the short breaks families need. Most importantly, these schemes have been able to provide the flexible service that parents want to assist them in maintaining their child at home. Nevertheless, constraints due to lack of sufficient numbers of hosts and ever-increasing referrals mean that these services have difficulty in meeting the identified needs.

The success of community respite care services in meeting the identified need will depend on a growth in the number of families offering their time.

APPENDICES – Experiences of Participants

A CLIENT FAMILY'S EXPERIENCE WITH RESPITE CARE

I first heard of INTERCHANGE about a year ago when a friend of mine, who has a handicapped child, was telling me enthusiastically of the great relief it had given her family. She gave me a name and telephone number to contact if I was interested. At the time I thought – well, it's a great idea but not for me, thanks. I'm not sending one of my children off to stay with a family I don't know.

We have three children, a boy, twelve, and two girls, one seven, one five. Our middle child, Jo, is a Downs Syndrome

Photographed by Anthony Owen

child. Jo is very much a part of our family. She has received the benefits of current thinking in education and medical care of children with Downs Syndrome. Whilst attending to Jo's special needs, we have always tried to be aware of, and attend to, the needs of our other two children.

As the next year progressed we became increasingly aware that our leisure time, weekend and holiday activities and general family conversation was being markedly limited, and, in some instances, destroyed by Jo. Our youngest child had passed Jo developmentally and the rest of the family were ready to move to higher levels of conversation and more physically and mentally demanding activities. Love her as we do, many a family outing seemed to end up with no-one – even Jo – enjoying themselves. Outings such as a visit to the museum were a misery for Jo because she had to walk slowly and stay with us, and then got into trouble when she did run off and get lost or climb on exhibits (all the rest were "too boring" as she put it). The visit, for the most part, was a waste of time for the rest of the family because discussion and looking was constantly interrupted by watching Jo and chasing after her. It was after such a day that we decided to find that 'phone number and name. It just wasn't fair to my other two children or my husband and I for that matter. It took a month or two, an informal interview and a couple of 'getting to know you' visits and we were matched up with another family who were keen to look after Jo for a day or two a month.

Jo's first visit was a great success. She was delighted that she, and only she, had been invited to spend the day with 'her friends', and thoroughly enjoyed herself, and we had an interesting and relaxing outing.

For Jo, INTERCHANGE, has meant she has established a relationship with a group of people outside her family and our circle of friends and relatives. She feels confident going off to spend a night at her friend's home, as her brother and sister do on occasions.

For us it has meant renewed energy, time to pursue activities and engage in conversation previously limited by Jo's presence, and at the end of the day we're all so glad to see her again and more able to cope with the extra demands of a handicapped child having had a bit of breathing space ourselves.

JENNY RIX – GORDON, N.S.W.

A CLIENT FAMILY'S EXPERIENCE WITH RESPITE CARE

My wife and I have three children, James 7 years, Mary 6 years and John 5 years, who is severely handicapped (Cerebral Palsy and blind) who requires everything to be done for him. He is unable to sit or stand on his own, or help himself in any way, e.g. in dressing feeding etc., no speech and very limited other means of communication. John is confined to a wheelchair.

We have been associated with MacArthur District Temporary Family Care, Handicapped, for 4 years of John's life. During that time we have had to use Foster Families provided by the scheme to have John cared for on many occasions, to enable our family to survive. John has been cared for at times when it just has not been physically possible to take him to particular places, or for the family to have a break from the continual demands of a child with John's handicaps. When we have gone on holidays (camping) which most times are not geared for such people.

The scheme has been able to supply these caring families to care for John which we as individuals were unable to find. We have been able to find people to care for our other two children, but they have not been so willing to take the responsibility of John.

To us respite care has been an answer to our prayers, for unless a family has experienced the strain of caring for the handicapped they really don't know what it is to go 24 hours a day, 7 days a week without a break. Particularly when that person can't communicate and can't see, you are talking to them constantly hoping they understand but get no reply. Respite care has kept us sane, has kept our family together, which I doubt it would have been without that help, and has given us time to spend with our two other children who when John is home, suffer a shortage of time.

THE HOME FAMILY – CAMPBELLTOWN N.S.W.

A HOST FAMILY'S EXPERIENCE WITH RESPITE CARE

Laurie and I feel that we have been very fortunate in the happy, healthy sons we have – none of them, thank God, appears to have any physical or emotional problems. We felt we wanted to make some sort of contribution in return for this good fortune.

We see INTERCHANGE'S main role in providing some relief to the family of the handicapped child. The child having a happy visit is also, of course, very important – but, a secondary benefit is to us and our children. We accept Bradley as just another child – loveable, naughty, giving, manipulating, just like our own children and they accept him as one of the family, not "someone different". He broadens our experience and I guess we broaden his. We don't much notice his comings and goings by now, he just "belongs". We don't, however, feel we have quite the same control over him that we do over our own boys but I guess that would apply to any visitor. We love him and we have enormous respect for his lovely family – they too are fortunate – just like us. I aksed my boys what they thought of Bradley coming. This is what they said:

Christian 5: "He's good because we like each other. He's good fun. We like watching TV together."

Andrew 7: "He's OK but I like playing with my other friends better, but I like having baths with him."

Simon 10: "At first I didn't really like him coming because he wasn't as good at things as me, but I understand him better now, and I think its done me good to understand people like him."

James 12: "I think its good because his parents, although they love him very much, must need a bit of a rest sometimes. Also he keeps my little brothers away from me."

THE LAWSON FAMILY – BEECROFT N.S.W.

A HOST FAMILY'S EXPERIENCE WITH RESPITE CARE

I am a Caregiver with Campbelltown District Temporary Family Care and have been since February 1984.

I originally started with the Scheme after leaving work, and was looking for something completely different and new to do with my spare time. I have always loved dealing with children so I decided that that was what I would enjoy doing most. Caring for handicapped children interested me greatly, so I contacted Youth and Community Services for some advice as to where my services could be best utilised. They suggested Campbelltown District Temporary Family Care.

Since joining the scheme, both my husband and myself have enjoyed sharing our home and time with some very special people. Not only the caring time of Co-ordinators and Caregivers, but the children and their families have become a big part of our lives. We do not have any children of our own, but with each new child that comes into our lives we can share the new experience and accomplishments that these very special children make.

I feel that this Scheme is so successful and rewarding because of the personal, caring approach that is taken with each placement. The Co-ordinator of the Handicapped Scheme ensures that both the parents of the children and the Caregivers get together for a bit of a chat before the placement and is available on a 24 hour call during the placement. This puts both groups of families at ease and helps to maintain the personal quality which is so unique to a Scheme such as ours. All in all, I feel that I have been very lucky to have been accepted so readily into such a sharing, caring and worthwhile team of people.

A CHILD'S EXPERIENCE WITH RESPITE CARE

It was a Wednesday afternoon and I had just arrived home from an exhausting day at school. In the driveway I saw a strange car I hadn't seen before. "Who's that?" I wondered. When I got inside, Mum introduced me to some ladies from a scheme for handicapped children called INTERCHANGE. Their names were Coral and Vandra. Vandra was the lady in charge of the scheme and Coral was becoming a host mum.

After a long chat and some afternoon tea, it was decided that we would visit Coral in her home at Castle Hill.

When we visited Coral a few weeks later, we met Coral's husband, Michael, and her daughter Karen who is 21. I was very nervous. On that afternoon we made arrangements for me to stay from Friday afternoon to Saturday evening for the first time. WOW! It was great fun. About once a month I go to the Barfoot's. Now I go for two nights and two days or more in the holidays.

WOW! What fun I have when I go. We do crafts and hobbies like knitting, stamps, sewing and projects. Other times we go to places, play music and just have a great time. Plus it's good for me to meet other people; Mum and Dad to have a break and good for the Barfoots. I LOVE IT. *Carolyn Murray*