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# Respite Care Needs of Families with Disabled Children

Barbara Szwarc,

Research Officer

The Victorian Children's Aid Society

## History of respite care

The idea of respite care is of recent origin, having come about largely as a result of the deinstitutionalization movement of the 1960's and 70's.

Before that time, it was generally not expected that families keep a disabled member at home; and there is considerable evidence to show that those families who chose to do so, were expected to cope with the consequences on their own. No-one asked how they did it; and only the provision of crisis-orientated counselling indicated that care-providers recognized that these families might sometimes have hardships.

With the advent of deinstitutionalization, the possibility of choice was eliminated for many families who were generally expected to assume responsibility for caring for their disabled family members themselves. Many families had great difficulties coping with it. The new situation made their problems obvious and gradually the concept of "respite care" as a means of helping the families, began to emerge.

Respite care is a unique service in that it is a service for those who give care, rather than those who normally receive care. This concept makes it unique in the field of health care systems.

## Objectives of the study

Following concerns expressed about the lack of knowledge of respite care, The Children's Bureau of Australia saw the great necessity that a study be undertaken in this area. The aim of the research was to discover what kinds of experiences families with intellectually disabled children at home have had in using respite services. In particular, parent's perceptions and understanding of available and alternative services were closely examined.

## Methodology

Data was gathered by means of a questionnaire put to a random sample of 216 families. All the families have a disabled child living at home with them, and all were registered with the Office of Intellectual Disability Services. This sample represented one eighth of the total number of families with disabled children living at home.

To enable the broadest possible range of responses to be gathered, the method of data collection used was the direct interviewing technique. Where necessary, interpreters were used.

The response rate for the study was 68 per cent — involving 142 families out of the 216 families selected.

The three major variables looked at were:

- (a) use of respite care — in terms of whether the family was currently a user or non-user of respite care — ie. whether the family had used some form of respite care over the twelve month period prior to the study.
  - Nearly two thirds (61.0%) of the study group were currently users of respite care, whilst just over one third were not.
- (b) region where the family lived — in terms of whether the family lived in the metropolitan or country region.
  - Of the study group, 60 per cent lived in the metropolitan regions, whilst 40 per cent lived in the country regions.
- (c) stress level of the family — in terms of whether the family was considered to be a stressed or non-stressed family. This judgement was based on a specially devised scoring technique which gave a stress rating score to each family — based on issues such as extent to which the child is considered difficult to manage; extent to which the child is considered to have behavioral problems; extent to which the child is easy to keep occupied; and the extent to which the parents feel they get enough sleep.

Based on this stress-rating score, just over half (56.3%) of the families fell into what was considered to be the "low-stress group", and hence were regarded as "non-stressed families". The remaining 43.7 per cent were considered to be "stressed families"

## The research

The research provides a wealth of information on the various issues concerning the provision of respite care. The issues are seen from the point of view of those who actually use the service. It would be impossible to go into all of these issues in any great depth during this talk. These will all be discussed in detail in the final report, and many of these warrant a separate talk of their own.

This paper will highlight some of the major findings and identify problems which have arisen.

## Issues Arising from the Study

Respite care undoubtedly seen as an invaluable service

The limited previous research in this area suggests that the availability and quality of social supports and community services must be considered, along with such features as family characteristics, in order to understand why some children are placed, while others are able to remain with their families.

The study supports the concept that respite care is an extremely important tool in helping maintain intellectually disabled children in their home. It also lends support to the belief that respite care is needed to provide relief from the emotional strain; to help in emergencies; to enable parents to attend to other family or social-recreational needs; and more generally, to normalize the family.

Evidence from the study has undoubtedly shown that respite care is an invaluable service, and is doing what it is intended to do. It also suggests that respite care does improve family functioning. Furthermore it suggests that it also supports parental emotional well-being and social interaction within the family. In 82 per cent of the cases, such factors were mentioned as advantages.

Furthermore, the study demonstrates that respite care services are most likely used by families with limited natural support networks, and in cases where the day to day care of the disabled child is particularly burdensome. Most of the families (82%) who were not using respite care, have alternative family supports — usually in the form of other family members.

Respite care services are most often used by stressed families (i.e. families where the burden of care is extremely heavy, and where the natural support system is not equal to the task of shouldering the burden). About three quarters of the stressed families were currently using respite care.

In respect to the type of respite care service preferred by families, out-of-home respite is currently more in demand, than in-home respite. When looking at specific service needs of those who want to use respite care, 40% want out-of-home respite services only; the next most popular option was a combination of in-home and out-of-home respite services — mentioned by one third of the families; whilst only one quarter said they want in-home respite services only.

However, despite the fact that most parents who were using respite care services (84%) said that they were satisfied with the type of services available, the study has identified the following issues of concern:

## Stressed families are not being adequately served

Although it is apparent that respite care has enabled most families to cope more effectively with their disabled child, it has not enabled all to do so, to the same extent.

The study has highlighted the fact that respite care is a service identified as not always avail-

able, but greatly needed. It was identified as suitable, but inadequate, to meet the needs of one third of the families who were currently using respite care!

Furthermore, when asked whether they were satisfied with both the type and amount of respite care currently available, only 60 per cent said that they were satisfied with both these factors, whilst 37 per cent said that they were satisfied with only one of these. The following view of one particular family that "there should be more numbers in more areas, and more choice" was typical of the opinion of numerous families.

The Study has also highlighted the fact that, although respite care is recognized as an important service to families with disabled children, it is often not adequate or available to those who need it most! In particular, families who have children with severe disabilities, or challenging behaviour, are frequently the most needy and the least served. Although a number of models of respite care have been developed which may meet the respite needs of some families, most tend to underserve or exclude the families with severely disabled children. Major reasons given for this are that firstly, the settings or services are often seen to be inappropriate to the child's needs; secondly, the staff are inadequately trained, and/or have limited timely backup or support for crises; and thirdly, and most commonly, the amount of respite time allocated to those with enormous needs is, in many cases, far from being adequate.

Two thirds of those who were not satisfied with the amount of respite care they were currently receiving, were stressed families. Furthermore, two-thirds of the stressed families felt there were ways in which respite care services could be improved. In addition, when the stressed families who were not using respite care, were asked why they were not doing so, one quarter said that they felt current respite services were not suitable or appropriate for their child; and another one third said that they were not aware of any services available.

Furthermore, all but one of the user families who found long waiting-periods to be a problem, were stressed families, and nearly all those who found the location of the service to be a problem, were also stressed families.

#### **(b) Lack of information about the services available**

Another of the major conclusions was that there is a considerable need for more education for both the general community, and in particular, for families with disabled children, about the nature of respite care programs and their availability.

Of particular concern is the finding that three quarters of the families who were not using respite care and who gave "lack of awareness" as a reason for this, said that they would be interested, if they knew it were available. This appears to indicate that too many families that could benefit from respite care, do not even know that such a service exists!

On the whole, many families are unaware of the range of services available to them. Especially the following services; group home care. More than one quarter of the families were unaware of either group home care or Interchange



programs, daytime and overnight holiday programs for disabled children and nearly half were unaware of either.

As one family put it, "something should be done about providing information to families of disabled children who wouldn't necessarily have the ability to push for services. If you haven't got a good doctor or contact, you may never find out about the services".

#### **Ethnic minority families tend not to use respite care**

Families in which at least one parent was not born in Australia seem to be at a marked disadvantage in respect to awareness of services currently available. Nearly half of such families were currently non-users of respite care. Furthermore, in just over half the cases where both parents were migrants, respite care services were not being used. Furthermore 82 per cent of the families who said that "lack of awareness of the services available" was their reason for not using respite care, were families, in which one or both parents, were not born in Australia.

What also emerged from the study was that misconceptions and misunderstandings of many migrant families about the concept and nature of respite care services, seemed to be amongst factors contributing to their hesitation to use the services. This hesitation clearly comes forward in one family's comment; "it is the family's responsibility to care for their child".

#### **(d) Current respite services are inflexible**

Another conclusion was that many of the services currently available were not flexible enough to cater for the needs of many of the

families. Most of the user families felt that there were ways in which these services could be improved.

In respect to the availability of respite care services, some families feel that the amount of respite care they are receiving is far from adequate. Nearly one third of the families expressed dissatisfaction in this respect.

The reasons relayed to families for which respite care is allowed to be used, also seems to influence their utilization of the service. For example, if the feeling is put across to families, as one family felt that, "the worker seemed to think that as they provide a service, the client should be grateful for whoever, or whatever, is provided, even when they feel that the person is not best suited to the child", then many families are bound to develop a hesitation to utilize the service, even when they desperately need it.

Levels of utilization, as well as the types of functions that respite care serves and the effects it can have, can also be influenced by the duration, in respect to the time of day and days of the week that the service is made available. A major problem seems to be that the services are often not available, or booked out, during weekends, school-holidays, and after hours.

Similarly, problems were cited in respect to the inability of services to respond to the family's needs. Many felt that they had to "negotiate each visit". More than one third of the user families had heard about certain services, but had not used them, because they felt that the services were inappropriate. Furthermore, nearly one third had tried to use some form of respite care, but found it was unavailable. One eighth of the users of home help had come across this problem. Users of group home care

also complained of having to book months ahead, thereby not responding to the spontaneous needs of the family. One third of the families who made suggestions for improvements, wanted increases in the availability of community residential units for respite care purposes.

Overall, more than one third of the families felt restrictions existed either in long-waiting periods, location, or regional boundaries.

The actual respite activity or interaction, i.e. what actually takes place between the respite care provider and the family, can also influence the parent's perceptions of the quality, and value, of respite care, and therefore affect their likelihood of utilizing it. For example, several families felt that there is often a lack of understanding, by the home help workers, of what they are supposed to do. Another factor which was found to be off-putting by several families was the fact that the family was unable to choose their home help caregiver. This was often said to result in such things as the caregiver being not liked by the child, or as one mother put it, "some home helpers made her feel inadequate".

Typical of the opinions were the comments that: — "families should have the right to feel good about the person coming into the house, otherwise they won't use the service", and that there is a need "to provide a reliable and safe service they wouldn't have to beg for".

In respect to group home care, several families were put-off by what they perceived to be inappropriate staff-child ratios, or inappropriate matchings of children placed in them, in terms of age and sex.

Overall, it is of concern that utilization of certain services is generally very low. Just over one third of those who had heard of the specific home help scheme, were actually using it; only one third of those who had heard of group home, care were actually using it; less than one tenth of those who had heard of either special daytime or overnight holiday programs for disabled children, were actually using them; and less than one eighth of those who had heard about Interchange, were actually using this program. Yet despite this low utilization, most families say they currently want some kind of respite care to meet their needs. In fact, more than half of those who were not currently using respite care, say they want it in some sort of form.

These findings indicate that underutilization is not caused by lack of need for the service, but because of factors centering around the inappropriateness and inaccessibility of the services — particularly for those families who do not have other family supports to help them get by.

### **(e) Lack of respite care options**

The lack of respite care options, was a further issue highlighted by the Study. More than one third of the families felt that there were some types of respite care services, which are unavailable but are needed. The need for someone to be available to come into the home, and sleep there, when necessary was one most commonly mentioned.

One quarter of the families who wanted improvements, mentioned this as a need.

Furthermore, indications are that more families tend to want out-of-home care than in-home care, the proportions do not vary considerably — indicating that there is a clear need for both types to be increased.

Special attention was given to the idea of using specially trained families in the community as a form of respite care. This family based respite care option is already available in a limited way through the Interchange program, and through some foster care Agencies. However the concept of using this form of care, on an "as needed" basis, as an alternative to residential care, has yet to be fully developed here in Australia.

The reactions of families in the Study, to the idea of developing this form of care, indicates that this option is one that definitely needs to be looked into.

Only one sixth of the families said that they would definitely not be willing to use specially trained families in the community, as a form of respite, if such a service were available to them. However, nearly all the users said that they definitely would be interested in using such a service, if it were made available.

Yet, despite the reasonably high approval by users towards the development of such a service, many families have a number of misconceptions and apprehensions towards using such a service, especially if it were known as respite foster care and provided by a foster care agency. Just over one quarter of those who said that they were in favour of family-based care, said that they would have hesitations about using it under these conditions.

Major apprehensions appear to be centered around issues such as: the negative connotations of the word "foster care"; the associations made by many families of the term "foster care" with that of "unwanted children"; the fear by parents that if they used such a service, then responsibility of their child would be taken away from them. The perceived guilt felt by many families, if another family helped them care for their child, also contributed to these hesitations.

The lack of understanding by parents that the respite-care families would be well-screened, thoroughly assessed, and properly trained, before they would be eligible to provide any respite care service — was another strong contributing factor.

## **RECOMMENDATIONS**

The results of the study do suggest that generally, parents appear to be quite satisfied with the quality of respite care services. However, while such positive feedback is supportive and reinforcing, several areas of corrective feedback must be responded to.

The survey results have revealed several major problems in the provision of respite care. As a result, the research puts forward specific strategies which can be undertaken, to increase the likelihood that an intellectually disabled child can stay in the family setting, without the child's presence having a devastating effect on family life. Hopefully, these recommendations will assist in the determination of the required supports and services that will increase the capacity of families to maintain their child at home.

### **(1) Improvement of the mechanisms to make families more aware of the nature and availability of respite care services**

There is a need for improvements and changes in the way families are informed of the nature, and availability, of respite care services. Suggestions made by families which need to be looked into, include:

- 1.1 Clear information about the respite care services which are currently available, needs to be drawn up. This information should contain details and explanations about the services, and should include such things as contact names and listings of what each service has to offer.
- 1.2 Mechanisms through which families are notified and informed about respite services need to be improved. This includes easier access to the knowledge of the available services. Furthermore, more information needs to be available and given to families about such services, when the child is first diagnosed.
- 1.3 Along with the creation of more awareness of families of respite care services, the need to educate parents about the effective use of such services, needs to be given high priority.
- 1.4 There needs to be more publicity in the community about respite care services, so that families are aware of their existence, and do not feel guilty, or apprehensive, about using them.
- 1.5 There should be an up-to-date listing of respite care services, regularly distributed, to all families with disabled children at home.

### **(2) Increased awareness and understanding about respite care services for migrant families**

There is a need to encourage the use of respite care services by migrant families. In accordance with this, the following recommendations are put forward:

- 2.1 Information on respite care services should be shared in a manner which is linguistically and culturally appropriate, to families with ethnic minority backgrounds.
- 2.2 Planning and evaluation committees on respite care should include representatives from ethnic minority communities.
- 2.3 Information on the concept and benefits of respite care to migrant communities should be provided in their native language, and with studied sensitivity to cultural factors.

### **(3) The Skills of the Respite Care Providers need upgrading**

A critical issue appears to be the need to upgrade the skills of the respite care providers — in both in-home, as well as out-of-home care. In order to achieve this, the following recommendations are put forward:

- 3.1 Standards need to be set for training and screening respite care providers.
- 3.2 The training of new workers, and/or the upgrading of the skills of those already hired. This could be improved by giving them either extra or ongoing training.
- 3.3 Evaluation tools for respite care providers need to be developed.

#### 4. Increased Accessibility

An emerging issue concerns the structures and the mechanisms families can use, to gain access to respite care services. The study highlighted a desperate cry by families to "make the services more widely available".

In order to improve existing services, the following changes are recommended:

- 4.1 The number of home help workers needs to be increased. So too does their availability and the frequency that families are able to obtain the service. For example, if a worker is unavailable, it should be possible to replace them with another worker. Similarly, more standby staff need to be employed, so arrangements for in-home help will not have to be made so far ahead.
- 4.2 Under certain circumstances, the specific home help service desperately needs to be increased to a twenty-four hour service. Furthermore, the workers should be able to live-in for a few days.
- 4.3 Ways to overcome major restrictions, such as the inflexibility of the services and their inability to cater for the individual needs of the families, should be immediately looked into and rectified.
- 4.4 More places providing respite in a small group home type setting, need to be set up.
- 4.5 The financial demands imposed on those families who need to use a large amount of respite care, needs to be reassessed.

#### (5) Need to develop more respite care options

- 5.1 It is essential to recognize that some families need frequent, regularly scheduled respite services. Some provision, some type of ongoing relief services must be made available for these families. Accordingly, service provision should be based on the following principles:
  - (a) Respite care should maximize the family's control over the services and must be based on the assumption that families, rather than service providers, are in the best position to determine their respite needs. The services should respond to the expressed needs of the families, and as such, they should be determined and directed by the family — not the other way around. In line with this principle, it should be upheld that service agencies should be "case managers" not "family managers", and as such, the roles of the professionals should be to help the family identify what long and short-term support services they need access to;
  - (b) Respite care services should respond to spontaneous need;
  - (c) Respite care should support the entire family, and be broadly defined in terms of the needs of the whole family.
- 5.2 New and creative approaches to services need to be incorporated which will both provide relief for the carers, and a stimulating atmosphere for the child. Currently, many families believe that some services only carry out one of these functions.
- 5.3. The relief potential of services not recognized as respite care — such as day care programs, should be looked into. These

services should be developed in such ways that will enable interested families to meet at least some of their ongoing relief needs whenever possible.

- 5.4 A program providing regular family based care with specially trained families in the community, needs to be developed within each region.

However, concurrent with this development, a wide education program needs to be undertaken. This could be done through various publicity means such as seminars and workshops.

To remove the misconceptions and misunderstandings that many families have regarding the concept of family based care, the education program should give families a clearer understanding of concept and should aim to:

- (a) remove the negative connotations of the word "foster care";
- (b) remove the feelings of guilt many families have, in using other families as a form of respite;
- (c) remove misunderstandings by families of the feeling that "control" of their child would be taken away from them, if they used other families;
- (d) give families an understanding that all family-based respite care families would be properly assessed, well screened and specially trained, before being allowed to take a child into their home.

These measures would hopefully increase the confidence of families in considering this option, as one of the most ideal forms of respite care for their child.

#### CONCLUSIONS

From a broad perspective, the study indicates that there is a need to create appropriate policy and funding mechanisms for family supports. These must aim to provide support on an equal basis, for all families. As such, funds need to be redirected away from permanent out-of-home

placement, instead they need to be directed towards a variety of services and resources which promote and provide "as needed" respite care.

When one looks at such things as how much is currently being spent on family supports, what services are being provided for those dollars, and what percentage of the total State budget is being dedicated to family supports, the findings are most disturbing. For example, according to figures taken from the 1986-87 Annual Report of the Department of Community Services — Victoria, the maximum OIDS budget during that period for community supports for people with disabilities was only 7.7% of the total OIDS budget. In contrast, a minimum of 43.6% of this budget was for residential institutions expenditure.

There are both enormous philosophical, sociological, as well as economic arguments for supporting families in caring for their disabled children at home.

In order to encourage, rather than discourage families to maintain their child at home, they should receive all the support services necessary to undertake this task. Where possible, the removal of the disincentives to do this, needs to be given high priority. These support services should be based on "whatever it takes".

In respect to respite care services, this study, based on the perceptions of those using the services currently available, highlights the fact that there still needs to be major changes made in respect to the development of services which are flexible, individualized, and designed to meet the diverse needs of families.

There are still many families in a desperate position when it comes to caring for their disabled child at home. They have nowhere to turn to, and limited options available to them. It is our responsibility to help these families. And so, I will end this talk by leaving you with thoughts taken from the Bob Dylan song "Blowin In The Wind", which concludes with the question of:

"How many ears must one man have,  
before he can hear people cry?"

