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This is the original unrefereed submission (preprint) of paper published asMcGill P. Summer holiday respite provision for the families of children and young people with learning disabilities. *Child: Care, Health & Development*. 1996;22(3):203-212. doi:10.1111/j.1365-2214.1996.tb00788.x

**Summer holiday respite provision for the families of children and young people with learning disabilities**

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*Summary* While the provision of respite care is a relatively recent development in the provision of services to families, it is an area of considerable growth and apparent importance. Most service development and research has focused on the provision of residential or family-based respite care though some studies have commented on the apparent demand for other kinds of relief. This study describes a pilot summer playscheme for children with learning disabilities and the reactions of mothers to its provision. The characteristics of families who used the scheme are described and their felt needs for additional respite care explored. Mothers found the scheme very useful and expressed felt needs for substantially more such provision both during the summer and at other times. The findings are discussed in the context of the importance of developing respite services which meet the varied needs of families.

***Keywords:*** *respite care; learning disability; families; holiday relief.*

INTRODUCTION

With the development of community care more children and adults with learning disabilities have remained in the care of their natural families (Thompson, 1993). Increasingly this has included people with multiple impairments or challenging behaviour who, formerly, would mostly have been placed, from an early age, in long term care, usually in an institution (Qureshi, 1991‑92). Long-term admission rates to such institutions began to reduce in the 1970s but it is well recognised that, in general, sufficient alternative facilities have not been developed (Thompson, 1993). Indeed family care (at least for children and young people) has come to be seen as a positive outcome which should be supported rather than replaced (Beresford, 1994). One of the key supports is undoubtedly respite care. To quote Hubert (1991), "one of the most vital services, which often make[s] it possible for parents to keep going, is the provision of regular periods of short term care" (p.13).

Traditionally, respite care has been provided in residential services often in combination with long-term care. Such services have been heavily criticised for the quality of care which they provide and their frequent lack of understanding of the emotional needs of both parents and their sons or daughters (Flynn, 1994; Hubert, 1991; Oswin, 1981). As respite services have developed the models used have become more imaginative and family-centred with, in particular, attention being paid to the development of more individually focused support either through Link family schemes or through the provision of support in the home.

The development of respite services has been accompanied by a limited amount of research on their effects. Such research has usually been conducted in the context of care provided in residential units. Respite appears, at least under some circumstances, to have beneficial effects on families, especially mothers. Mothers have been found to experience less stress at the time of receiving respite (Botuck & Winsberg, 1991), to suffer less stress if they are using respite services for a child with behaviour problems or multiple impairment whether their child is in or out of respite at the time (Pahl & Quine, 1985), and to be able to engage in a wider range of activities (Botuck & Winsberg, 1991). Much less research has focused on the degree to which respite benefits the children or adults receiving care. What evidence there is suggests that they frequently do not benefit (Flynn, 1994), sometimes receiving less stimulation than they should (Robinson & Stalker, 1991), sometimes being outright neglected (Hubert, 1991). There is also evidence, at least of a qualitative kind, that respite may help to reduce the need or demand for long term care. As one of the parents interviewed by Hubert (1991) said: "it's the short term care which makes it [long term care at home] tolerable" (p.68).

While respite care may have significant benefits for parents, they have often been critical of its availability. Sherman (1988), for example, found that respite services were perceived as the most helpful family service by those who had received it and the most needed by those who had not received it. Robinson (1991) found that a third or more of respite users would like more than they were getting, in some cases substantially more. Similarly, Grant (1990) found high expressed needs for additional help with "minding", especially amongst those caregivers who "were lonely, younger, encountering problems of challenging behaviour, had daughters needing care at home, and faced financial burdens" (p.645). Parents have also commented on the frequent lack of availability of respite at the times when they need it most, such as at weekends or during the school holidays (Flynn, 1994; Robinson & Stalker, 1991). "During the holidays his mother Jean 'climbed the walls and went on to valium'" (Hubert, 1991, p.67). In addition, parents have expressed great concerns about the way in which respite services are often organised such as having to book far in advance and not always getting the dates they wanted (Robinson & Stalker, 1991).

It seems clear that respite care is very important to the maintenance of children and adults with their natural families. It is also clear that it is provided in insufficient amounts and in inflexible ways which fail to adequately meet the expressed needs of families. This paper focuses on the needs for respite of the families of children and teenagers during the school holidays. Grant (1990) found that 41% of the caregivers of children and young people up to 19 years wanted additional help during school holidays. Similarly high percentages were found by Quine (1986) in her survey of 200 families, with holiday care being their highest priority after financial help.

The paper describes a day summer holiday scheme, looks at the characteristics of families who used the scheme, reviews their reactions to the scheme and describes their felt needs for additional respite both during the holidays and at other times.

DESCRIPTION OF SCHEME

The scheme was set up and run by The Children's Society Medway Project. It ran during the summer school holiday period with between 2 and 5 places available on each of 4 days for 6 weeks. Children attended from 9 AM to 5 PM with transport to and from the scheme being provided, if possible, for those families who requested it. The scheme was based in a large, ordinary house which also provided a long-term home for 4 children and young people with learning disabilities. A 1-1 staffing ratio was provided. All families who expressed a wish to use the scheme were visited at home to gather basic information about the child, the family's use of other respite services and to provide families with more information about the scheme. All families who wished to use the scheme and who could either get their child there or lived close enough to benefit from the available transport were offered places. As far as possible, when allocating particular children to particular days, account was taken of the age of the children, their mobility and their likes/dislikes. A variety of in-house and outdoor (garden) activities were available. A number of planned outings were also made to: swimming, the Zoo, parks, dockyard and so on.

METHODS

Following the scheme the author was asked by The Project to collect information from families who had used or enquired about the scheme on both their reactions to it and their opinions about the types and characteristics of expanded respite care services that they would find most useful. A semi-structured interview schedule was developed, informed by previous research (e.g., Pahl & Quine, 1985). The schedule contained a mixture of open and closed questions with some information (e.g., on likely future use of respite) being categorised on a 3 point rating scale and some lists of items (e.g., of different types of respite) being rank ordered in importance. Families who had either used or enquired about the scheme were contacted by the Project to seek their agreement to be interviewed. Those who could be contacted and agreed to be interviewed were sent a copy of an abbreviated interview schedule. They were then telephoned by the author and interviewed using the schedule. Interviews took approximately half an hour to complete and were conducted with 18 families who had used the scheme and 5 who had not. One of these interviews (with a mother who had used the scheme but whose first language was not English) was conducted by an interpreter.

RESULTS

*Family characteristics*

All interviews were conducted with the child's mother. Children ranged in age from 6-18 years with an average of 13 years. There was a slight tendency towards older children with 8 being 17 or 18 years. There were approximately twice as many boys as girls. Most families found out about the scheme through the posters distributed by the Project, especially those which went to their children's schools. Most children attended the scheme for between one and three days, this being the maximum amount of time made available to them. 12 (out of the total of 23 families) used some other kind of respite service during the same summer holiday period, including other day schemes and locally available residential respite services. 16 had used some form of respite care in the past. Mainly this referred to their use of the two locally available residential respite care units, one provided by the NHS, the other by Social Services. 13 families had used one or both of these units, 3 had used a Family Link Scheme and small numbers had used other sorts of day facilities or one-off schemes. Experiences of the respite units were mixed with a number of mothers criticising aspects of the units. Experience of the Link Family Scheme was positive though, in 2 cases, new families were currently being sought.

*Family reactions to the scheme*

Reaction to the summer scheme was almost universally positive, the only common criticism being that there wasn't enough of it. Mothers were very happy with most aspects of the scheme. All 18 children and young people were said to have enjoyed going. A number of very positive comments were made e.g., "he said `had a nice time' and he was thoroughly exhausted"; "he said `aren't I staying for tea' and, later in the summer, `we haven't been again'". 14 of the young people were said to have done things that they would not have done at home including mixing with other children, going out, swimming and painting. All 18 mothers were happy with the standard of care which had been provided. Again there were many positive comments e.g., "she was lovely and clean"; "I forgot the packed lunch but they fed her with no fuss".

17 of the 18 mothers reported that the scheme was a success from their and their families' point of view. All 17 felt that they (and sometimes their other children) had had a break and 14 reported being able to do things that they could not have done otherwise e.g., taking their other children out, having a rest, shopping and housework. 2 of these mothers reported minor problems around getting their young person to go or problems while they were there (seizures) but these did not affect their overall evaluation. 1 mother had a more qualified opinion. As a result of her son having tantrums when she collected him she was not sure if the break had been worth the disruption that resulted.

*Felt needs of families for additional respite*

All mothers were asked about how much they would like to use a similar scheme in the future. Of the 18 families who used the scheme, 16 would like to use it more in the future. Of these 16, 3 would prefer to use it 1 day a week, 1, 1 to 2 days a week, 9, 2 days a week, 2, 2-3 days a week, and 1, 3 days a week, all for the duration of the school holidays. Of the 2 other families 1 would want to use the scheme at about the same level as this summer (this was the family interviewed by the interpreter and the amount of use this summer was not entirely clear) and another described herself as "iffy" because of problems with her young person's behaviour this year. Of the 5 families who did not use the scheme, all would like to use it in the future though 1 was concerned that their young person might be too old. Of the other 4, 1 would prefer to use it 1 day a week, 1 would prefer to use it 1-2 days a week, 1 would prefer to use it 5 days a week, and the fourth was not able to specify a number of days.

Mothers were given a list of "some of the things parents say they would like more help with" (after Pahl & Quine, 1985) and asked to say which they would like more of and which were most important to them. Almost all the mothers reported wanting more help in one or more ways:

18 would like more help during the school holidays, not just the summer ones, and for 10 of these mothers this was the most important kind of help that could be offered;

11 would like more day time care particularly clubs that their young person could go to after school but also relief for a few hours if the young person is not at school;

10 families would like more short term care, especially during the summer, and this was the highest priority for 2;

8 families would like more weekend care and this was the highest priority for 1;

5 would like more short term care with another family and this was the highest priority for 3;

5 would like help with sitting and this was the most important help for 1.

In addition 2 said they would like more overnight care, 1 home care to be available in an emergency and 1 phased care.

Mothers were also asked to comment on a list of potentially important features of respite provision:

*Localness* All mothers preferred local services and, for 6, it was very important usually because they did not have their own transport.

*Provision of transport* This clearly depended on how local the provision was. 2 mothers said that the provision of transport would make things more convenient, and 6 that it was very important.

*Cost* For 8 mothers the cost was not important while another 9 said they would be willing to pay more than the £2 a day they had paid for The Children’s Society scheme. 4 mothers said that they would not want to pay more than £2 a day or that cost was an important limitation.

*Way in which the service is arranged* 8 mothers commented here on the length of notice that existing respite care services required and said that they would like to be able to arrange care at much shorter notice. 2 commented on the importance of choice and flexibility in the arrangements made - being able to get what you wanted rather than what happened to be available.

*Degree of parental involvement* None of the mothers expressed a desire to be directly involved in the management of services but 11 said that they would like to have a say and to be properly listened to by the service providers.

*Kinds of activities* Most mothers felt it was important that their son or daughter was not left to their own devices with nothing to do. 10 mothers mentioned the importance of their young person being kept active, 3 commented that the activities should be enjoyable (it should be like a holiday for the young person).

*Nature of the staffing*  All mothers felt this was very important. They "had to trust so many people with their child who couldn't give feedback". 9 felt that it was important that there should always be at least 1 qualified member of staff, 4 felt that staff should be thoroughly vetted before being allowed to work with the young people.

*Nature of the other children or young people* Some mothers felt this was important and drew attention to a number of features: 6 preferred their young person to be mixing with other young people of about the same age; 3 preferred their young person to be with young people having similar physical abilities; 2 preferred their young person to mix with others having similar intellectual abilities; 1 preferred mixing with, predominantly, young people of the same gender; 1 was concerned about the other young people being fragile and being hurt by her young person.

DISCUSSION

This study confirms previous findings regarding the needs of families for respite during the school holidays. The families interviewed indicated that, if a similar scheme were available in the future, they would want to use it an average of **six** times more frequently. In addition, many of the mothers mentioned other families who had not known about the scheme but would be likely to use it. It is clear, therefore, that a much larger scheme (or several such small schemes) would be required to meet the expressed, and possibly understated, needs of parents.

It is clear, also, that the scheme was seen very positively by families and benefits were attributed to it for all family members especially mothers. While such positively stated reactions may have been partly instrumental (since families wanted further such provision to be made available) they contrast sharply with much more mixed reactions to other available respite provision and to similarly mixed findings in other research. The scheme also appears to have proven attractive to families who did not use more traditional respite services.

Expressed needs for respite were consistent with previous research. Families want more of all kinds, especially during holiday times. The variety of expressed needs is particularly notable reflecting the varied circumstances and needs of individual families. Attention was drawn in particular to the need for the further development of three types of services:

1. Holiday schemes as discussed above.

2. Day time and evening activities such as youth and after-school clubs. While professional service providers have tended to advocate the use of generic services it is clear that parents have not, in the main, been able to access such services and see the lack of leisure activities and friends as important deficits in their young people's lives. Such services also, of course, provide respite for parents and may be crucial for mothers, in particular, in allowing them to resume or take up careers.

3. Residential respite care either in existing or new facilities or with other families. While mothers were critical of both existing facilities, a reasonable number appear to have settled for one or the other and to be satisfied with the service they receive. It was notable, however, that there was a very wide variation in such provision for the families surveyed. Some were receiving high rates of respite care (e.g., one week every two months) while others were receiving nothing. The extent and severity of unmet need should not be understated here e.g., one mother, who had received 5 days residential respite care in the past year said simply "I'm desperate". The expressed need suggests that the families interviewed would use at least twice as much residential respite care if it was available and acceptable.

There is clearly, then, scope for the further development of respite services. Families seem much more likely to use such services if they: are local and/or provide transport to and from the young person's home; allow parents choice and flexibility; listen to what parents have to say both about the needs of their own young person and about the organisation of the service more generally; emphasise the value of the service to the young people as well as the parents; and employ sufficient competent and caring staff.

Above all, such services will be more successful the more they respond to the individual needs of families. While families share many needs and perspectives on respite care it was clear from the interviews that there was also a great deal of variation in what parents wanted. Often, their only choice is between taking what they get or not getting anything. The challenge facing future service developments is not just to provide more respite care but to support families by providing relief locally, when it is needed, and in the manner preferred by the individual family.

ACKNOWLEDGEMENTS

I am grateful to the mothers who gave their time to be interviewed and were willing and helpful. The study was funded by The Children's Society Medway Project whose staff contributed to its development and commented helpfully on an earlier draft of this paper. More information about the summer holiday scheme can be obtained from: The Children's Society Medway Project, Chatham House, 14 New Road, Chatham, Kent ME4 4QR.

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