

RESPIRE CARE FOR CHILDREN WITH MENTAL HANDICAP: SERVICE EVALUATION AND PROFILE OF CHILDREN

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Introduction

The care of a child with developmental disability is a continuous process and can be very demanding and exhausting in the absence of adequate support. The main responsibility of care usually falls upon the shoulders of the mothers who are often the only carers (Grant, 1986). This has been confirmed in a recent survey carried out in Central Scotland by Mitchell (1990) who reported that mothers were the main carers in 80% of the families surveyed. Similar findings were reported by Grant and McGrath (1990) from North Wales. These figures put the widely reported findings in perspective that mothers of mentally handicapped children experience excessive stress compared to the mothers of non handicapped children (Beckman, 1983; Bradshaw and Lawton, 1978; Butler *et al.*,

1978, Chetwynd, 1985; Tew and Laurence, 1975). These authors also suggested that this level of higher stress is related to physical impairment and behavioural disorders in children rather than to the degree of their intellectual impairment.

Since the decline of institutional care, development of adequate and satisfactory support services for the families of mentally handicapped people has acquired an increased importance. However, success of community care will largely depend on achieving a correct balance between the needs of carers and that of people with mental handicap (Pahl and Quine, 1984; Tyndall, 1987). Respite care services for mentally handicapped children living with their families are considered an integral part of community care. Sherman (1988) in his study of families of mentally handicapped

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people reported that respite care was the commonest service needed but was not received by as many as 25% of these families. The importance of regular respite care has been further highlighted by other authors (Tyndall, 1987; Mitchell, 1990).

The success of a respite care facility depends on the acceptance, satisfaction and participation by the parents of children who use the facility. The questionnaire survey described in this paper was carried out primarily to assess the views of parents whose children were using a respite care facility in Solihull, West Midlands. At the same time it was intended to draw a clinical and demographic profile of the children to identify the characteristics of regular users.

Lyndon House

Respite care facility in Solihull is provided by Lyndon House, a unit run by the local District Health Authority which has a catchment area population of 203,000. It was originally opened in 1975 as a home for children discharged from the nearby mental handicap hospital. This building was initially owned by the local police authority and consists of a pair of three bedroom two storey houses joined on the ground floor by a small common office. It is in an ordinary street with detached and semi-detached houses. There is a block of shops a few doors away and a large shopping centre about a mile away. The house has a large garden at the back which adjoins the playing ground of a local comprehensive school. In 1982 its function was changed

and respite care was provided to a group of children with mental handicap from the local community (Martin and Oliver, 1986). Additional ground level bedrooms were added with a specially equipped bathroom, a fitted kitchen and a soft play area. At present it provides respite care to seven children at a time, under the supervision of 15 full time staff (seven with mental handicap nursing qualification) who share a day and night duty rota. The house has an open referral policy and all new referrals are first assessed in a joint interview by the Consultant Psychiatrist/Senior Registrar and a qualified nurse. This is followed by a home visit by a qualified nurse after which a decision is made in a multidisciplinary meeting. Following the acceptance, the child is introduced to the house in stages of increasing duration ending with an overnight stay.

Methodology

At the time of study 52 children had received respite care at Lyndon House. A 32 item questionnaire with a stamped self addressed envelope was sent by post to the parents/main carers of these children. It was accompanied by a letter explaining the purpose of the survey and requesting their views to help in evaluating and improving the service received by their children. They were also made aware of the anonymity and confidentiality of their replies.

The Questionnaire

Most questions offered a choice of two or more answers with some questions having additional space for general

comments. These questions can broadly be classified into five categories i.e. characteristics of the child, pattern of use of the service, parents knowledge about the organisational aspects of the service, parents satisfaction and the psychological aspects of respite care (Appendix A).

Results

Characteristics of children:

Of the 52 questionnaires sent 36 were returned giving a response rate of 69%. There were 23 male and 13 female

children, 75% of them were fully mobile and more than one third (36%) had epilepsy, of whom nearly two thirds had more than 10 seizures in a year. Over two thirds (70%) of the children had impairment of speech. Behaviour problems were present in two thirds of the population. Temper tantrum (58%), overactivity (54%), self injurious behaviour (38%) and aggression (29%) were the commonest problems (Table I). Fully mobile children were most likely to have behaviour problems but age, sex, epilepsy, impairment of speech and frequency of use of

TABLE I Characteristics of Population		
		(N = 36)
		%
SEX	MALE	64
	FEMALE	36
MOBILITY	WITHOUT HELP	75
	WITH HELP	8.3
	CANNOT WALK	16.6
EPILEPSY	HAS EPILEPSY	36
	NO EPILEPSY	64
FREQUENCY OF EPILEPSY (per year)	MORE THAN 50 FITS	8
	10 TO 50 FITS	14
	LESS THAN 10 FITS	8
	LESS THAN 1 FIT	3
SPEECH	SENTENCES	31
	SINGLE WORDS	39
	NO SPEECH	31
BEHAVIOURAL PROBLEMS	NO PROBLEMS	33
	PROBLEMS	67
		(N = 24)
		%
	AGGRESSION TO OTHERS	29
	AGGRESSION TO SELF	38
	OVERACTIVITY	54
	TEMPER TANTRUMS	58
	OTHER	17

the respite facility did not differ significantly from those who did not have behaviour problems. The regular users were more likely to be male, with impairment of speech and suffering from epilepsy when compared with occasional users (i.e. those using the facility for less than 6 times per year).

Organisational aspects:

More parents learned about the service from social workers (31%) and schools (22%) than from the doctors (3%) and nurses (8%). Nearly 28% did not know that it was run by the Health Authority. When asked who they would discuss their complaints with, 91.6%

expressed their preference for Lyndon House staff.

Pattern of use:

Two thirds of the children had used the service for 1 to 5 years. Prearranged rota care (69%), occasional overnight stay (42%), and occasional weekends (25%) were the commonest pattern of use (Table II). The reasons given for using the facility were respite (89%), emergency (28%), holidays (22%) and preparation for long term residential care (22%) (see TABLE II and III). Except for one child none had respite care in any other facility before and none had received additional respite elsewhere.

TABLE II Use of Respite Care		
LENGTH OF USE (in years)		(N = 36) %
	< 1 YEAR	19
	1 TO 5 YEARS	67
	> 5 YEARS	14
FREQUENCY OF USE (times/year)		
	1 TO 2/YEARS	3
	3 TO 6/YEARS	11
	>6/YEARS	86
TYPE OF USE		% USE
	ROTA CARE	69
	HOLIDAYS	31
	EMERGENCY	28
	OCCASIONAL - WEEKENDS	25
	OCCASIONAL - OVERNIGHTS	42
	OTHER TIMES	25

Satisfaction:

All the respondents were satisfied with the quality of care and accommodation offered and were willing to recommend it to other parents. However 22% did not think that they were receiving enough care. When asked to suggest other types of additional service, most suggested a "baby sitting" service (44%) and day care during weekends and holidays (36%). When asked if they would accept respite care in a mental handicap hospital, 81% said they would not. (Table III).

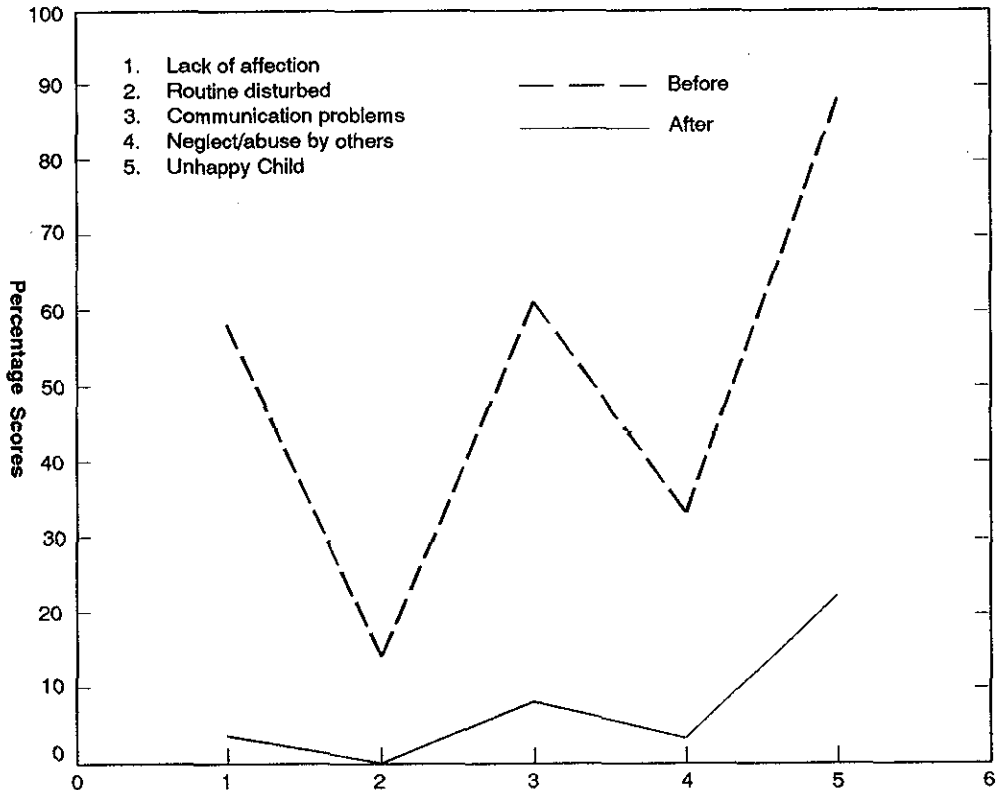
Psychological aspects:

There was a significant reduction in perceived anxiety about the service once parents had used it (Figure 1). Their initial feelings about sending their child for respite care varied from sense of guilt (78%) to fear of losing the child (14%). However only 56% had an opportunity to discuss their worries and feelings with a professional beforehand. While 50% of children showed no reaction on their return, 19% showed clinging behaviour. One third of the siblings felt relieved but

	(N = 36)
ARE THEY GETTING ENOUGH OF CARE	%
YES	72
NO	22
DON'T KNOW	6
SPECIAL NEEDS	
SPECIAL NEEDS NOT MET	3
NEEDS MET	86
NOT SURE	6
NO ANSWER	6
SUGGESTED SERVICE	
ANOTHER FAMILY	6
"BABY SITTING"	44
DAY CARE (Weekends/holidays)	36
OTHER WAYS	8
WHEN DO YOU USE LYNDON HOUSE?	
RESPITE CARE	89
HOLIDAYS	22
FOR LONG TERM CARE	22
EMERGENCY	28
OTHER	11

FIGURE 1

WORRIES ABOUT RESPITE CARE - Before and After



about the same number also questioned the absence of their handicapped sibling from home (Table IV).

Discussion

We have pointed out earlier that the stress resulting from the continuous care of a mentally handicapped child is well recognised. In the absence of adequate

support this may even result in the so called "burn out syndrome" which has been described as "the exhaustion of a person's psychological and or physical resources usually after long and intense caring" (Sullivan, 1979). This stress is related, apart from the familial factors, to the nature and degree of a child's handicap. Our survey suggests that in male

TABLE IV	
Psychological Aspects	
	(N = 36) %
INITIAL FEELINGS ABOUT CARE:	
SENSE OF RELIEF	44
SENSE OF GUILT	78
SENSE OF FAILURE	33
FEAR OF LOSING	14
OTHERS BURDEN	22
NONE	8
CHILD'S BEHAVIOUR ON RETURN FROM CENTRE:	
CLINGING	19
CRYING	6
IGNORING	3
POOR APPETITE	0
POOR SLEEP	8
NO REACTION	50
OTHER BEHAVIOURS	25
OTHER SIBS REACTION:	
QUESTIONS ABSENCE	33
PROTESTS	3
FEELS RELIEVED	36
UNHAPPY	8
OTHER BEHAVIOURS	17

children, impairment of speech, presence of behavioural problems and epilepsy are important child related factors. However, as the number of children studied is relatively small and limited to those who are utilising the respite care facility no firm conclusion can be drawn.

The high level of satisfaction expressed by the parents of children using this facility is remarkable. The direct expression of satisfaction is equally well supported by indirect measures e.g. sole use of facility, confidence in staff to discuss any complaints and significant reduction of expressed anxieties following

the use of the facility. This high degree of satisfaction is probably due to the ordinary, home like accommodation and it is noteworthy that 81% of the respondents did not wish to accept respite care facility in the nearby mental handicap hospital. The proximity of the house to the service users, flexibility and regularity of care, as shown by the pattern of use, and the ability of staff to relate well to both parents and children also appear to have contributed to the high degree of satisfaction with the care provided.

Some of the parents suggested provisions of baby sitting and day care

facilities on weekends and during school holidays which is important to note. Oswin (1984) stresses that group home type of respite care should be offered along with a package of alternative models of respite care e.g. short term foster family care, a system of sitters to go into the parents' own homes and a day care system for school holidays. Unfortunately in this country, unlike in the U.S.A., we have not established, to any significant extent, "in home" respite facilities despite its many advantages and popularity among the parents (Cohen and Warren, 1985).

Another area of concern is the lack of awareness of the psychological needs of parents. Our survey suggests that nearly half of the parents did not have an opportunity to discuss their worries and feelings beforehand. It is apparent from our results that most parents have worries and feelings ranging from a concern about the practical aspects of care to very delicate feelings related to the issues of separation and "perceived abandonment" of the child. It is, therefore, essential for the care staff and other professionals involved not only to be aware of these issues but to provide an opportunity for all parents to discuss these worries and feelings at an early stage.

Respite care, offered by many mental handicap hospitals in the past, had been described as inadequate, of poor quality and as being insensitive to the psychological needs of children and their families (McCormack, 1979; Oswin, 1984; Richardson and Ritche, 1989). There is a need for continued evaluation of respite services offered by the homes in

the community not only to monitor services but also to further improve the standards of care. There is also a growing demand for "in home" respite facilities, and planners of future services should take this felt need into account.

Summary

An anonymous postal questionnaire survey was carried out to evaluate the quality of respite care services, for children with mental handicap, offered by a health authority unit in Solihull, West Midlands. Secondary aims of the study were to build up a demographic and clinical profile of the children using this facility and also to identify the characteristics of regular users of the service. Children receiving respite care were more likely to be male, mobile, suffering from speech difficulties and displaying behaviour problems while epilepsy emerged as an additional distinguishing feature for frequent users.

APPENDIX A ITEMS IN THE QUESTIONNAIRE

1. *Characteristics of the Children:*

Age range, sex, level of mobility, presence of epilepsy, communication skill, presence and nature of behavioural problems with a check list of some common behavioural problems and details of medication taken by the child.

2. *Details of pattern of use of the Service:*

Length of attendance, frequency, reasons and type of use, respite care before and in addition to the care at Lyndon House.

3. *Details about the organisational aspects of the service:*

Questions related to the personnel and the parent organisation. How and from whom they learnt

about the service, and awareness of the complaints procedure and counselling service.

4. Parental satisfaction:

Separate items dealing with the perceived adequacy of respite care; parents satisfaction with the quality of care and accommodation; their willingness to recommend the service to other parents were included. In addition they were asked to make separate suggestions to further improve the service.

5. Psychological aspects:

Questions relating to the parental worries about their child lacking love and affection, his routines being disturbed; being physically neglected, abused or getting home sick were asked; parents were also asked to identify their feelings about their child for respite care, for example sense of relief, guilt, failure and being a burden on others and fear of losing the child. Questions on the realisation of any of these anxieties were asked. Answers regarding the effect on the behaviour of the child attending the centre and effects on the other siblings at home were also collected.

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