

## Link Family Support – an evaluation of an in-home support service

H. FORDE<sup>1</sup> B Soc Sc CQSW, H. LANE<sup>2</sup> BA MA, D. MCCLOSKEY<sup>1</sup> BSc MSW CQSW RGN Dip Ed, V. MCMANUS<sup>3</sup> BA RSCN RGN & E. TIERNEY<sup>4</sup> BA MA

<sup>1</sup>Social Worker, <sup>2</sup>Psychologist, <sup>3</sup>Research Co-ordinator and <sup>4</sup>Consultant Researcher for the Project, Research Department, Enable Ireland, Ballintemple, Cork, Ireland

---

Correspondence:

V. McManus

Research Co-ordinator

Enable Ireland

Ballintemple

Cork

Ireland

E-mail:

[vmcmanus@enableireland.ie](mailto:vmcmanus@enableireland.ie)

FORDE H., LANE H., MCCLOSKEY D., MCMANUS V. & TIERNEY E. (2004) *Journal of Psychiatric and Mental Health Nursing* 11, 698–704

### Link Family Support – an evaluation of an in-home support service

A significant body of research has shown that parents who have a child or a dependent adult with a disability experience significant and persistent levels of stress. One of the recognized strategies for coping includes the provision of in-home practical support. Enable Ireland provides a range of services for children and adults with a physical disability. The present study explored home support services with a sample of 16 families of service users of Enable Ireland Cork. Practical support was deemed to be whatever support or intervention requested by the parent of the child/dependant adult which afforded the service user the opportunity to engage in social/recreational opportunities and that gave the parent free time. Sixteen members of the chosen families were interviewed (15 mothers and one father) using a semi-structured interview schedule and a standardized stress measure before and after the introduction of Link Family Support (LFS). LFS was put in place for a period of 12 months, tailored to the families and service users' individual needs. Although levels of stress continued to be high and scores on the Parenting Stress Index (PSI) did not show a statistically significant reduction after the programme, reported stress levels had improved. Parents reported LFS to be very helpful in reducing perceived stress and improving family's quality of life through providing free time and access to leisure and recreation facilities. This study provided limited but clear evidence of the need for regular, flexible, in-home support for families with children and dependent adults with a disability. LFS provided a personal, regular and effective means of meeting this need as the findings of this study demonstrated.

**Keywords:** family support, learning disability, parental stress, physical disability, special needs

*Accepted for publication:* 9 June 2004

---

## Introduction

'The emotional and physical demands on the parent of a child with special needs are over-whelming. The special parent is on call twenty-four hours a day, seven days a week. No one can function under such conditions. Respite is essential' (Clarke *et al.* 1989). A considerable body of research indicates that families of children with disabilities experience significant amounts of stress and that this stress

may be chronic and persistent over time (Beckman 1983, Bruce *et al.* 1994, Sloper *et al.* 1999).

Home-based support is seen as vital to parents of children with a disability. Only 1.7% of all service provision for people with learning disability in Ireland is home-based (Mulvany 2000). There are 3108 young people with a moderate to profound range of learning disability in Ireland, 18 years of age and under. Of these, 900 availed of respite in the years 1989–99 (Mulvany 2000).

Redmond *et al.* (2000) found mothers to be experiencing severe strain from the caring for their baby or young child with a disability and direct support in the home was found to be of great value to them. It allowed them to continue to care for their child without feeling that they were neglecting their household tasks and the needs of their other children. The study concluded that these families should have flexible, responsive and reliable services to allow them to continue caring for their children without suffering increased social, psychological, financial and emotional strains.

The Commission on the Status of People with Disabilities set up by the Irish government in 1993 in their *A Strategy for Equality* noted that the well-being of people with severe disabilities living at home is closely linked with the well-being of their parents. It recommended that respite care and home support services be provided to promote health and well-being of carers (Department of Health 1993).

The report *Towards an Independent Future* (1996) stated that the objectives of health and personal social services should be to enhance health and quality of life for families who have a family member with a disability. Respite has been recommended as the key to enhancing quality of life (Department of Health 1996).

This research study was designed to evaluate the Link Family Support (LFS) service, a pilot scheme set up to provide in-home practical support to families who had a child/young adult with a disability. The LFS scheme was an attempt to begin to address the overwhelming and ongoing demands on parents in their day-to-day lives. LFS was designed to give families a break and in doing so provide a positive experience for both families and the person with a disability. The purpose of the support was designed to be twofold: primarily that parents be given a break from caring constantly for their children or dependant adult and also that service users be given social opportunities and exposure to other people other than family, and places and activities. For example, community-based activities were undertaken and they included socialising (shopping, walks, cinema, library, meeting new people) and trying new experiences such as playing games with neighbours. Support was designed around individual family's needs, in partnership with the families and within budget constraints. Experienced care workers (graduates with experience in child care), with a diversity of experience, were placed with clients in their own homes or in the community for one 3-h session per week to undertake these activities. The LFS scheme was funded for 12 months as a pilot scheme. This research study was designed to evaluate the scheme.

## Methodology

The aims of this project were to:

- profile the 16 families who were offered the LFS service;
- identify supports available to parents' before receipt of LFS service and identify the respite needs of parents;
- assess the degree of stress experienced by parents before and after receiving the service; and
- investigate the impact of LFS on the lives of service users and families.

## Research strategies

Pre- and post-LFS intervention interviews and questionnaires were used to evaluate the service. Therefore, two research strategies were used for the purpose of this study. For the purpose of getting qualitative data, semi-structured interviews were used. To collect quantitative data measuring stress levels, a tried and tested measure was used [the Parenting Stress Index (PSI); Abidin 1995].

See Tables 1 and 2 for outlines of the pre- and post-interview schedules.

## Participant sample

Sixteen service users were prioritized for inclusion in consultation with a multidisciplinary steering group comprising, teachers, social workers, psychologists and nurses. Criteria for selection included families who stated a need for support, families with more than one child with a disability, single parent families, families who provided a high level of physical care or supervision, extent of support and other stresses in the family. (The practical support required was deemed to be whatever support or intervention

**Table 1**  
Outline of pre-Link Family Support (LFS) intervention interview schedule

Interview schedule	Types of questions
Section 1	Demographic details and medical profile of carer
Section 2	Service user profile; demographic details, medical profile, and assistance needs
Section 3	Exploration of current respite provision, how often, from whom, stress levels on carer and family, free time, benefits of respite and open-ended questions about what difference would LFS make to carers' life
Section 4	Current social and recreational opportunities of service users, types of activities, friends, the use of LFS to provide social opportunities. Open-ended questions

**Table 2**  
Outline of post-Link Family Support (LFS) intervention interview schedule

Interview schedule	Types of questions
Section 1	Demographic details and medical profile of carer
Section 2	Service user profile; demographic details, medical profile, and assistance needs
Section 3	Exploration of current respite provision post-LFS, how often, from whom, how helpful was LFS, in what ways, benefits of LFS to carer and family members, reduction of stress levels, free time of carer, open-ended questions about what difference LFS made to carers' life, how LFS could be improved
Section 4	Current social and recreational opportunities of service users, how was it improved; types of activities, friends, the use of LFS to provide social opportunities. Open-ended questions

requested by the parent of the child/dependant adult which afforded the service user the opportunity to engage in social/recreational opportunities and that gave the parent free time).

## Procedure

### *Pre-LFS intervention*

Before receiving LFS, interviews were conducted with the child's main carer in their home ( $n = 16$ ) – this was a parent in all cases. A semi-structured interview schedule was designed to elicit information about the profile of the service user, carer profile, current and future respite needs/level of support, level of assistance needed, stress levels and the difference LFS may potentially make to the life of the service user, parents and siblings (Table 1). The Parenting Stress Index/Short Form (PSI/SF) questionnaire (Abidin 1995) was also administered to measure the amount of stress experienced by parents.

### *Post-LFS intervention*

After a period of 1 year in which the parents and clients were in receipt of the LFS, parents were again interviewed about the service using a similar interview schedule. Questions varied from the earlier interview in that parents were asked about the LFS and its benefits (Table 2). The PSI was also re-administered to measure stress levels after receipt of LFS.

## Data analysis

Data analysis was of a qualitative and quantitative nature. Quantitative data were analysed using descriptive analysis (using SPSS for windows). The interviews

yielded a great volume of qualitative data. Thematic analysis was employed to explore the personal opinions, attitudes and feelings of family members towards LFS. This thematic analysis focused on identifiable themes and patterns of responses. From the interviews, patterns of experiences were listed, either from narratives or from paraphrasing common ideas. Themes that emerged from the parent's stories were pieced together to form a comprehensive picture of their collective experience. This followed the application of thematic analysis as defined by Leininger (1985).

Stress levels were examined by examining the PSI scores before and after the LFS. A paired sample *t*-test and a Wilcoxon signed ranks test were carried out on pre- and post-PSI scores to determine whether there was a statistically significant reduction in stress levels as measured by the PSI after receipt of LFS.

## Ethical considerations

The designated families were asked if they were interested in taking part in the LFS pilot scheme. As part of the selection process family members were asked if they would also participate in the research process of the project. Ethical considerations were paramount at all stages of the research process. For example, the purpose of the interview was described in detail by the interviewer. It was made clear to all families that their participation in the LFS scheme did not oblige them to take part in the research study. In fact participants/parents were given the opportunity to withdraw from interviews and/or the LFS scheme at any stage. Consent was sought from each participant individually to record their responses and to publish findings of the project. Assurances were given of confidentiality and anonymity throughout. The LFS co-ordinator was also available to answer any queries, which participants had about the LFS scheme or the research process.

## Results

### Profile of service user

Eleven service users had cerebral palsy, two had spina bifida and three had a diagnosis of developmental delay. Of the 16 service users who received LFS 11 had a learning disability in addition to their physical diagnosis. The age range varied from under 6 years to adult (18+ years). Ten of the service users had a second condition and some more than one other condition. Conditions ranged from asthma ( $n = 1$ ) and epilepsy ( $n = 5$ ) to a heart condition ( $n = 2$ ). For profile of the service users, see Table 3.

**Table 3**  
Service user profile ( $n = 16$ )

Variables	<i>n</i>	Per cent
Age range		
0–5 years	4	25.0
6–12 years	6	37.5
13–18 years	3	18.8
18+ years	3	18.8
Gender		
Male	8	50
Female	8	50
Diagnosis		
Developmental delay	3	18.8
Spina bifida	2	12.5
Cerebral palsy	11	68.8
Additional complications	14	62.5
Learning disability	11	68.8
Assistance needs		
Totally dependent	9	56.3
Needs a lot of help	5	31.3
Needs a little help	2	12.5

**Table 4**  
Carer/parent profile ( $n = 16$ )

Variables	<i>n</i>	Per cent
Relationship to SU		
Father	1	6.25
Mother	15	93.75
Marital status		
Married	9	56.25
Single	4	25
Separated	2	12.5
Widowed	1	6.25
Number of other dependants		
0	2	12.5
1	4	25
2	6	37.5
3	3	18.8
4	1	6.3
Work outside home	8	50
Carer diagnosed illness	6	37.5
Undiagnosed reported illness	14	87.5

### Profile of parents as carers

Fifteen mothers and one father were interviewed. Six of the mothers were parenting alone. Dependants of the 16 families ranged from one to four children. Six parents reported that they had a 'diagnosed' medical diagnosis, for example, heart conditions, arthritis, colitis, hernias. Fourteen reported non-diagnosed conditions, which ranged from headaches, depression and anxiety to 'tired all the time'. For profile of carers (parents), see Table 4.

### Dependency needs

When asked about the 'assistance needs' of their 'children', nine service users were reported to need total assistance or were totally dependant, five needed a lot of help and two

needed a minimal physical help but had very high needs in terms of full-time supervision. The most frequently cited dependant tasks were lifting, transferring, bathing, dressing, washing hands, supervision and getting in and out of the car.

### Reported respite needs

The parents were asked how regularly they received respite care for their children and dependant adults. Ten parents reported receiving a respite break *a few times a year or less* and only four reported getting a *weekly break* from continuous caring. Further exploration revealed that the extended family provided this support for 11 of the sample group. When asked 'when did parents get a break' and 'how often'? Findings demonstrated that one of parents 'never got a break from caring', only 14 got a break 'yearly' before LFS service. After the LFS service provision 14 parents reported that they would prefer to have access to respite a few times a week.

### Stress

Stress was measured by reported parental stress elicited in the interviews and objective stress as measured by the PSI. The PSI measures stress related to parenting. Before receiving LFS, 14 of 16 parents reported that caring for a child with a disability placed extra stress on themselves as parents – 10 reported 'severe extra stress'. Twelve of the 14 parents reported *additional stress* for other family members. After participation in LFS, all 16 parents reported a reduction in stress levels. All parents reported that 'other family members had benefited from the breaks'. This is evidenced in the following citations:

We [Mother and child] did a lot more activities together. [I]t allowed children to do homework without disturbance.

[T]here was less fighting and disturbance at home.

We think that it is vitally essential for families just to get that small break. It might not seem much but to us it was like a weeks holiday.

She (link worker) gives my child such wonderful care and attention for a couple of hours which is really nice for him and it gives me a chance to catch up on so much needed chores which I often feel guilty for doing because I feel I should be concentrating on my child.

Stress reduction is implied in the following comment where a chance to be normal was the main effect of respite, 'Gave me a chance to be normal . . . could live a little'.

It was also evident in the comments that one mother made about the effect it had on her relationships with other family members:

I had time to talk to my two other children after school. It is difficult to do this as (service user) wants attention all the time. I could talk to my husband about his day without interruption. Link Family Support meant freedom for me. It was difference between coping and not coping.

The PSI yields a percentile score which places stress levels within normal or high ranges. (High scores are those at or above the 85th percentile and scores at or above the 90th percentile are considered to be clinically significant requiring intervention and follow up.) Before receiving LFS, 13 of the 16 parents scored clinically significant levels of overall stress. After LFS, 11 of the 16 parents scored clinically significant levels of stress. Although a statistically significant difference was not found in overall PSI scores, nor in PSI subscale scores, parental distress, parent-child dysfunctional interactions, and difficult child subscales (see Table 5 for PSI scores), parents reported in interviews a reduction in their overall stress levels.

### Impact of Link Family Support

Before the introduction of LFS, the prospect of a break and an anticipated return to some normality was important to parents. Numerous parents mentioned the importance of 'a break and support', 'freedom' and a 'normal routine for a few hours'. One parent talked about the ability to plan ahead; 'It gave us three hours of freedom and allowed us definite free time in the week to plan something'. While all the parents found it helpful, 15 perceived it to be very helpful, because of LFS 'giving a sense of freedom' and 'time to do what one wanted'. After availing of LFS, 15 parents reported a reduction in their perceived stress levels. Typical parent responses included 'life was less of a rush since we availed of LFS' and one parent said 'I did not feel as much on my own'. All parents reported that other family members had benefited from the regular breaks as siblings had more time with parents. 'It was great. . . . could do things with other children that I normally couldn't do'. Parents revealed that the free time facilitated bonding with other children in the family. Before the introduction of LFS, 12 service users had no opportunity to meet with friends outside of school. All parents reported that LFS had provided

many varied social and recreational opportunities both inside and outside the home. Social opportunities inside the home included reading, arts and crafts, playing, singing and continuation of specialized home programmes. 'She gave us a great opportunity to do things we would not normally be able to do with fulltime childcare. She gave us a day of normality each week . . .' or 'he needs a lot of stimulation every day so Fridays have become a great outlet. It is truly appreciated when link worker call to us and gives my child her time. It's a lovely treat and is really a huge support to me'.

### Discussion

The profile of families who availed of the LFS scheme showed the complexity of care and multiplicity of needs that the service users in our study presented. Wilkin (1979) and Romans-Clarkson *et al.* (1986) found the majority of care fell to the mother and this study revealed six of the mothers were parenting alone. The pressure of this level of responsibility may be evident in this study as six of the parents reported having a diagnosed medical condition and 14 reported a 'non-diagnosed medical condition'; these reported conditions ranged from backache to headaches to anxiety. These 'non-diagnosed' medical conditions have been linked in previous research to caring for a family member with a physical and learning disability and clearly has an impact on the physical and mental health of parents (Gross 1996). Undoubtedly, over time, this would impact on their ability to care for their children. We argue that respite provides a cost-effective means to enable parents to get sufficient breaks to continue with the care demands placed on them. Cobb & Hancock (1984) found that parents of physically disabled children have demands not required of other parents; they must care for greater physical needs without overprotection.

The majority of families caring for children and adults with disabilities in this study found themselves in a situation where there was very little support and respite. What few breaks families did receive were from extended family. This research revealed that more than 10 of the parents only received a respite break a few times a year or less. All parents who participated in the study felt that respite should be an integral part of service provision and should not be time-limited. In addition, 12 parents reported they would have liked a break at least weekly.

This study reinforced the findings of previous research, which found that parents of a child with a disability experience significant additional stress both on themselves as parents and also on siblings in the family. The majority of the families reported severe levels of stress at both the pre- and post-LFS service interview. This stress was evidenced

**Table 5**  
Parent Stress Index (PSI) scores pre- and post-Link Family Support (LFS) intervention

PSI scores	Mean pre-LFS	Mean post-LFS
PSI total	113.31	110.19
Parental distress (PD)	42.06	41.19
Parent-child dysfunctional interaction (P-CDI)	31.5	31.81
Difficult child (DC)	38.25	37.81

by their comments on their lives such as 'the break helped me cope', 'it was great not to be rushing around', 'the breaks take pressure off mothers', 'I don't have to keep checking', 'the break put my mind at ease for the first time in years'.

After participation in the LFS scheme, all parents interviewed reported a reduction in overall stress levels. The PSI measures parental stress specifically in relation to a parent's personal distress, interactions with the child and the impact of the child's behaviour. Non-significant changes in stress level scores on the PSI may be explained by its insensitivity to measure all aspects of *life* stress. Moreover, reduction in stress levels was reported by all parents. For example, 15 of the parents reported that the provision of weekly respite reduced stress levels in their lives. Over 10 parents mentioned that it had reduced their stress levels a lot. The stresses on parents of children with a disability are multiple and varied and there is significant areas of unmet need. This is evidenced by the continuing high levels of measured stress in the participating families and supports Knussen & Sloper's (1991) finding of substantial levels of unmet needs.

However, the extent to which parents benefited was unexpected and disproportionate to the weekly respite offered. One 3-h break a week for 12 months is minimal in comparison to the 24-h, 7-days-a-week care that families may provide. However, parents reported that this support greatly enhanced the quality of their lives as families by alleviating stress in the lives of carers, by allowing parents some free time to look forward to each week, through facilitating more time with other siblings and through providing social opportunities for service users. These findings are supported by the study of siblings of children with special needs (Grossman 1972). The Irish government in its 2001 Health Policy Report has acknowledged that services in Ireland need to be 'people centred' (Department of Health and Children 2001), a service such as LFS provides such a focus for families.

### Development of the service/evaluation of the service

The needs of families in the study were very varied and types of support offered to families were diverse and tailored to the needs of individual families. Therefore, professional, flexible and well-motivated staff was the essential resource to effective respite service provision in the community. This type of worker provided flexibility to the needs of the parents. Because the care workers work alone in the community, it can be isolating. Therefore, staff who work in this area need to be motivated and supported. Comprehensive training and ongoing support of care workers therefore are vital. For this study, support was delivered by a multidisciplinary team within Enable Ire-

land. Individual and peer supervision was an integral part of supporting staff in this challenging and isolating position. Secure funding of community respite projects would facilitate retention and future development of LFS care workers staff.

### Conclusion

This study provided limited but clear evidence of the need for regular, flexible, in-home support for families with children and dependent adults with a disability. LFS provided a personal, regular and effective means of meeting this need. This outcome was predictable, as parents in Enable Ireland have for years stated their need for practical support in the form of respite breaks. Research has also supported this need for respite (Department of Health 1996). The impact of this small amount of support had improved the quality of lives of families, by alleviating stress levels of parents, offering free time each week to parents, providing more time with other family members and facilitating social and recreational opportunities for people with special needs. This study is a clear example of a win-win situation for everybody involved, parents, person with disability and other family members.

### Acknowledgements

The authors would like to thank the parents who took part in the project for their participation which was sometimes difficult, the children and adults who showed willingness and enthusiasm to participate, the management and staff of Enable Ireland for their support during the project and the Southern Health Board, Ireland for the funding of the pilot respite service.

### References

- Abidin R.R. (1995) *Parenting Stress Index: Professional Manual*, 3rd edn. Psychological Assessment Resources, Florida.
- Beckman J.P. (1983) Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency* 88, 150–156.
- Bruce E.J., Schultz C.L., Smyrniotis K.X. & Schultz N.C. (1994) Grieving related to development: a preliminary comparison of three age cohorts of parents of children with an intellectual disability. *British Journal of Medical Psychology* 26, 847–864.
- Clarke P., Kofsky H. & Lauruol J. (1989) *To a Different Drumbeat*. Hawthorn Press, Stroud.
- Cobbs L.S. & Hancock K.A. (1984) Development of the child with a physical disability. *Advances in Developmental and Behavioural Paediatrics* 5, 75–107.
- Department of Health and Children (2001) *Quality and Fairness. A Health System for Youth Health Strategy*. Government of Ireland Publications, Dublin.

- Department of Health (1993) *A Strategy for Equality*. The Report of the Commission on the Status of People with Disabilities. Irish Government Publications, Dublin.
- Department of Health (1996) *Towards an Independent Future*. Review Group Report on Health and Personal Social Services for People with Physical and Sensory Disabilities. Irish Government Publications, Dublin.
- Gross R. (1996) *Psychology: The Science of Mind and Behaviour*, 3rd edn. Hodder and Stoughton, London.
- Grossman F.K. (1972) *Brothers and Sisters of Retarded Children. An Exploratory Study*. Syracuse University, Syracuse.
- Knussen C. & Sloper P. (1991) Stress in families with disability: a review of risk and resistance factors. *Journal of Mental Health* 1, 241–256.
- Leininger M.M. (1985) Ethnography and ethnonursing: models and modes of qualitative data analysis. In: *Qualitative Research Methods in Nursing* (ed Leininger, M.M.), pp. 33–72. Grune & Stratton, Orlando, FL.
- Mulvany F. (2000) *National Intellectual Disability Database*. Annual Report of the National Intellectual Database Committee 1998/1999. Health Research Board, Dublin.
- Redmond B., Bowen A. & Richardson V. (2000) *The Needs of Parents of Fragile Babies and Young Children with Severe Developmental Disability*. UCD. Phd Thesis.
- Romans-Clarkson S.E., Clarkson J.E., Dittmer I.D., Flett R., Linsell C., Mullen P.E. & Mullen B. (1986) Impact of a handicapped child on mental health of parents. *British Medical Journal* 293, 1395–1397.
- Sloper P., Knussen S., Turner S. & Cunningham C.C. (1999) Factors related to stress and satisfaction with life in families of children with Downs Syndrome. *Journal of Child Psychology and Psychiatry* 32, 655–676.
- Wilkin L. (1979) *Caring for the Mentally Handicapped Child*. Croom-Helm, London.