

## CARERS AND PEOPLE WITH LEARNING DISABILITY IN BIRMINGHAM, UK

V. Prasher, D. J. Clarke, C. R. W. Harris and J. Hunt

### Introduction

Few people with learning disability (LD) now reside in long-stay institutions, and relatively few in local authority hostels or group homes. Most reside in the community with their families, or in supported housing schemes operated by Housing Associations and other independent providers. Community care for people with LD is highly dependant on family carers, who are often the main or only support the person has (Heller and Factor, 1993; Krauss and Erickson, 1988). Recent studies have demonstrated that carers may experience considerable "stress" (Myers *et al.*, 1985; Seltzer and Krauss, 1989), the effects of which may be buffered by strong social support networks (Cobb, 1976).

This study examines differences between single and dual carers of

individuals with LD, and the people they care for. Demographic factors, disabilities and health problems, and age are among the variables examined in an attempt to provide a picture of the pattern of caring in one large metropolitan centre.

### Method

The Birmingham LD Register (BLDR) is a computer database which was formed in 1984 with the support of five local authorities and five health authorities. It records the needs and abilities of people with LD living in or originating from the Birmingham area. Information is gathered from two settings, the residential setting in which the person lives, and a day setting such as a local authority day centre. The

\* **Dr. V. Prasher, M.Med.Sc., M.R.C.Psych., M.D.**

Lecturer in Psychiatry, Department of Psychiatry, University of Birmingham,  
Queen Elizabeth Psychiatric Hospital, Mindelsohn Way, Edgbaston, Birmingham B15 2QZ

**David J. Clarke, M.R.C.Psych.**

Senior Lecturer in Developmental Psychiatry

**C. R. W. Harris**

Medical Student

**J. Hunt**

Head of Registers, Botanic House, 2A Harrison Road, Birmingham B24 9AA

\* *For Correspondence*

information presented in the study was gathered between 1985 and 1993 by trained visiting information officers who visited both settings. At the time of the study there were over 2,800 records on the register. Some adults who did not receive day care at an adult training centre or who resided in a hospital were not recorded on the register. Information for children younger than 10 years of age was not recorded.

The study population consisted of individuals who were living in a family home on 31.06.93 and who were aged 10 years or older. Using the information available from the computer database, the study population was divided into

people living with one carer (the 'single carer' group) and those with two ('dual') family carers. The two groups of people with LD, and their carers, were then compared with regard to a number of demographic and disability-related characteristics. Definitions of terms used in the study are given in Appendix 1.

## Results

Two hundred and fifty-seven people with LD lived at home with a single carer, and 951 with dual carers. The relationship of the carers to the people with LD is summarised in TABLE Ia and TABLE Ib. Mothers constituted by

**TABLE Ia**  
Relationship of Single Carer to person with learning disability

	Number	%
Mother	188	73.1
Father	31	12.1
Brother	13	5.0
Sister	10	3.9
Husband	2	0.8
Other	13	5.1
	257	100

**TABLE Ib**  
Relationship of Dual Carers to person with learning disability

	Number	%
Father and Mother	774	81.4
Mother and Brother	39	4.1
Sister and Mother	30	3.1
Stepfather and Mother	27	2.8
Brother and Sister-in-Law	14	1.5
Brother-in-Law and Sister	14	1.5
Stepmother and Father	12	1.3
Father and Brother	11	1.2
Others	30	3.1
	951	100

far the largest proportion of single carers (approximately 73%). 85% of people were cared for by a parent. Parents accounted for four fifths of all dual carers.

The mean age of single carers was 64.0 years, and 56% were aged 60 years or more (TABLE II). For dual carers, the person most directly involved in the caring process (the 'principal' carer) was identified. Principal carers had a mean age of 57.0 years, and 42.8% were over the age of 60 years. Single carers were significantly older than dual carers ( $P < 0.05$ ).

The analysis by age of the people with LD who were cared for is given in TABLE III. The mean age of people living with a single carer was 36.5 years, and of people living with dual carers was 28.3 years. People with LD living with a single carer were significantly older than those living with dual carers ( $P < 0.05$ ).

Additional problems and disabilities, and services received, are summarised in TABLE IV. People with LD living with dual carers had significantly greater problems with physical disability, incontinence, communication, self-help-self-care skills, community living skills and behavioural problems, and also had a higher prevalence of epilepsy. In contrast, however, people living with single carers had greater contact with support services and significantly greater access to day centres ( $P < 0.005$ ).

## Discussion

People with LD registered with the BLDR and living with single carers have fewer disabilities than those being cared for by dual carers, have greater contact with support and day services, but are older than people living with dual

TABLE II  
Age Distribution of Single and Dual Carers

Age Group (years)	Single Carers		Dual Carers			
	Number	%	Carer 1		Carer 2	
			Number	%	Number	%
0 - 9	0	0	0	0	0	0
10 - 19	0	0	0	0	3	0.3
20 - 29	2	0.8	0	0	31	3.3
30 - 39	11	4.2	28	2.9	72	7.5
40 - 49	31	12.1	185	19.4	180	18.9
50 - 59	43	16.7	313	32.9	263	27.7
60 - 69	48	18.7	244	25.7	235	24.7
70 - 79	61	23.7	72	7.6	71	7.5
80+	35	13.6	19	2.0	17	1.8
Not known	26	10.2	90	9.5	79	8.3
	257	100	951	100	951	100

**TABLE III**  
**Analysis by Age of People with Learning Disability**

Age Group (years)	With Single Carer		With Dual Carer	
	Number	%	Number	%
0 - 9	0	0	0	0
10 - 19	12	4.7	165	17.3
20 - 29	71	27.6	449	47.2
30 - 39	67	26.1	231	24.3
40 - 49	64	24.9	71	7.5
50 - 59	32	12.4	25	2.6
60 - 69	7	2.7	10	1.1
70 - 79	4	1.6	0	0
80+	0	0	0	0
Not known	0	0	0	0
	257	100	951	100

**TABLE IV**  
**Findings for Associated Disabilities for People with Learning Disability**

	Living with Single Carer		Living with Dual Carers		P Value
	Number	%	Number	%	
Physical Disability	16	6	111	12	<0.025
Incontinence	24	9	147	15	<0.025
Sensory Disability	11	4	41	4	NS
Communication Problem	47	18	275	29	<0.001
Difficulty with Self Help - Self Care	82	32	431	45	<0.001
Difficulty with Daily Living Skills	61	24	247	26	NS
Difficulty with Community Living Skills	103	40	501	53	<0.001
Behaviour Problem	59	23	291	31	<0.025
Epilepsy	38	15	213	22	<0.01
Support Services	141	55	487	51	NS
Day Centre	168	65	511	54	<0.005

NS = Not Significant

carers. Single carers are older than dual carers.

A large proportion of people with LD living with single carers probably once lived with two carers, one parent eventually dying. In the United Kingdom the life expectancy for women is greater than for men, which is consistent with the observation that most elderly single carers are mothers.

The differences in additional difficulties or disabilities may reflect previous policies favouring hospital care for severely or multiply disabled people (leaving a relatively higher proportion of less severely disabled people at home with their families). Day services may be felt to be more relevant or appropriate for older carers and older people with LD, irrespective of the severity of associated disabilities. Other hypothesis could be advanced to account for the observations, but research into attitudes and service needs is better than speculation.

The data presented in this paper do provide an 'order of magnitude' assessment of numbers of people and their problems which may be of value when planning services. Some people with LD living with elderly single carers (notably those with mild LD) are not in contact with services, and not recorded on special needs registers. They often come to the attention of service providers only when a parent dies and there is no other family member to take over the caring role.

We hope that this study will lead to a wider recognition of the enormous contribution to caring for people with

disability which is made by relatively elderly people, who may well have significant health problems or disabilities themselves. Further research would be valuable to address this issue, and to document the inevitable changes which will occur over time as a result of alterations in societal attitudes and expectations, changes in the structure of families and the pattern of employment and the varying service needs of people from different ethnic and cultural backgrounds.

The observation that there are 96 single carers over the age of 70 known to services in the Birmingham area reinforces the importance of such data for policy-making and service planning. Such knowledge will go some way to help service planning for them and for the unknown number of elderly people whose disabled relatives' needs have not been assessed.

## Summary

A study of 257 people with learning disabilities (LD) resident in family homes and living with a single carer were compared with 951 people with LD living with two or more carers. Single carers were significantly older (56% were aged 60 years or older, and 13.6% aged 80 years or older) as were the people with LD for whom they cared.

People living with two or more carers were more likely to have additional disabilities or problems such as incontinence, epilepsy, physical disabilities or behavioural problems.

Possible reasons for the differences, and implications for service provision, are discussed.

## Appendix 1

### Definitions

*Physical disability:* difficulty with mobility on the level (i.e. needing the use of a chair - frame, needing the use of one person, needing the use of two people or being immobile), or difficulty with use of hands (i.e. limited use of both hands, limited use of one hand only, unable to use hands).

*Incontinence:* difficulty with use of toilet (i.e. in need of reminding and help, or in need of toileting).

*Sensory disability:* poor quality of vision (assessed as guiding sight only, perceiving light or totally blind) or poor quality of hearing (assessed as having a severe defect, able to hear loud noises only or being completely deaf).

*Communication problem:* either impaired use of speech (assessed as communicating basic needs only, can communicate but will not, inappropriate communication and no speech - few words) or impaired understanding of the speech of other people (assessed as understanding - recognising basic speech only, very few words or no recognition).

*Self-help skills:* either impaired ability to feed (assessed needing much help/prompting, or being unable to undertake the activity due to disability), or impaired bathing ability (assessed as needing much help/prompting, or being unable to undertake activity due to disability), or impaired ability to prepare main meal (assessed as needing much help/prompting, or being unable to undertake the activity due to disability).

*Community living skills:* problems with road sense (assessed as needing much help/prompting, or being unable to undertake activity due to disability) or with ability to budget (assessed as needing much help/prompting, or being unable to undertake activity due to disability).

*Behaviour problem:* temper tantrums, or self-injury, or excessive noise, or wandering off, or physical destruction of property. A behaviour problem was said to exist if any of these had been assessed as occasionally causing a severe problem, frequently causing a severe problem, or causing a severe problem most of the time.

*Support services:* contact with a psychologist or clinical psychologist, social worker or educational social worker, or community nurse.

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