Community care for severely disabled people on low incomes

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Abstract

***Objective*—To examine the volume and distribution of formal and informal care received by severely disabled adults living at home in the community on low incomes according to type of disease.**

***Design*—Analysis of computerised reports from social workers which include information on disabling conditions and on the weekly hours of care at home from formal and informal sources.**

***Subjects*—1298 severely disabled people aged 16 to 98 who received financial assistance from the Independent Living Fund in 1991-2.**

***Results*—Over half (733; 56·6% (53·8 to 59·2)) of the sample were completely unable to perform five or more of the basic activities of daily living. On average the whole sample received 6·8 (6·1 to 7·6) hours of care at home a week from formal sources and 64·2 (62·4 to 65·9) hours from informal sources. In seven out of 14 disease groups, less than half in each group received any formal help at home. There were large differences in the volume of formal care within groups. In most cases no significant differences were found within diagnostic groups between those receiving care at home from district health authorities or local authorities, or both, and those who received no help at home with regard to age, dependency score, and duration of disability. Weekly hours of informal care were an important determinant of who received formal help in nine out of 14 groups.**

***Conclusions*—The amount of care received at home by low income, severely disabled people from formal sources differs across and within diagnostic groups. The fact that the variation was not systematically related to age, dependency, or duration suggests that the existing distribution of community care resources needs to be examined. Weekly hours of informal care and diagnosis seem to affect the volume and type of care received. The methods by which people in need of assistance receive help merit further investigation.**

Introduction

Providing care in the community is the foundation of current health and social service policy.[1] Recent legislation reflecting this orientation has generated increased responsibilities for local authorities, such as determining who, in some cases, enters publicly funded residential care. It has also increased the need for cooperation between local authorities and district health authorities to coordinate services at home.[2] Community care, as an explicit system of provision of health care, is evolving as legislation related to it is implemented.[3-6] Little is known, however, about what to date has constituted community care, particularly care at home, and hence on what foundation the new system will be building.

Care at home consists of medical, personal, and domestic services and may be provided by formal or informal sources. Possible formal carers are district nurses, local authority home helps, private agency carers, and people from voluntary organisations. Data are available on the total volume of services provided at home by district health authorities through records of visits by district nurses.[7] Total yearly visits by home helps are also documented.[8] Informal carers—relatives, friends, or neighbours—may work for free, receive nominal payments, or collect the invalid care allowance if they are unemployed and provide at least 35 hours of care a week. The volume of this input of labour is rarely quantified.[9]

Generally, how the supply of service at home compares with demand or how such services are distributed within populations of patients is not known. Given their needs for medical and personal care, severely disabled people represent an important test case for the performance of a community based system of care. An estimated 6·5 million people in Britain are disabled.[10] Information about severely disabled people, however, is lacking because of their inadequate representation in national surveys.[11]

Methods

Unique national data on the type, volume, and distribution of all care services received at home by poor, severely disabled people who live in the community are available from the files of clients of the Independent Living Fund. The Independent Living Fund, a charitable trust, provided direct financial aid to people meeting strict income limits and requirements of physical dependency from 1988 to 1993 to help them pay for care at home.[12] Age limits, modified over the life of the fund, are shown in the appendix.

The fund's clients were primarily adults in receipt of income support and the attendance allowance or the severe disablement allowance. In May 1990, 461 000 people in Great Britain were receiving these benefits.[13] Over half of the fund's clients (52·7%) and beneficiaries (50·6%) were aged 60 or over. Other comparisons between the two groups are not possible because of a lack of published social security data.

The study population comprised a 25% sample from among those awarded financial assistance from March 1991 to March 1992. From a printout of 6000 clients enrolled during the 12 month period every fourth entry was selected for analysis. Information on the source and extent of disablement, duration of disability, age, and client's living circumstances, performance in activities of daily living, and care arrangements were recorded for 1500 subjects. This group represents 7% of the fund's total client base.[14]

Of the 1500, 34 people were in residential care waiting to move out and 168 had no diagnosis listed; they were excluded from this study. No significant differences existed between those with a diagnosis recorded and those without across the variables examined here. The remaining sample of 1298 was

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divided into 14 categories based on primary diagnosis as listed in the appendix.

ANALYSIS

For each disease group mean age, dependency scores based on activities of daily living, and proportion living alone were calculated. Dependency scores are explained in the appendix. Duration of disability was calculated from the recorded year of onset of the primary disabling condition. Weekly hours of care at home by source (formal or informal) and type of provider were computed from the client applications. The proportion of each diagnosis group receiving any formal help at home was also determined.

The diagnostic groups were then subdivided into two categories: those receiving help at home from either district health authorities or local authorities and those who were not receiving any help at home from these two providers. Within each diagnostic category the two groups were then compared across a series of measures.

TABLE I—*Sample characteristics by diagnostic group*

Diagnosis	No of subjects	Mean (SD) age (years)	Percentage (SD) who live alone	Mean (SD) dependency score (1-24)	Mean (SD) total weekly No of hours of care at home*	Percentage (SD) of weekly care from district nurse or local authority home help
Multiple sclerosis	156	51·6 (11·8)	21·1 (41·0)	20·2 (3·0)	68·9 (28·1)	9·7 (17·1)
Cerebral palsy	79	27·9 (11·7)	6·3 (24·5)	21·4 (2·8)	68·4 (24·6)	4·3 (11·9)
Spinal injury	119	47·3 (18·6)	26·9 (44·5)	20·2 (2·8)	67·7 (32·4)	9·1 (20·2)
Stroke	231	70·1 (12·2)	15·1 (35·9)	20·5 (2·7)	74·5 (29·7)	6·9 (16·0)
Epilepsy	47	39·1 (18·3)	4·3 (20·4)	19·6 (3·1)	73·6 (19·6)	4·0 (11·7)
Brain damage	61	34·7 (18·3)	11·5 (32·1)	19·3 (4·1)	70·4 (21·7)	6·4 (19·6)
Arthritis	225	69·9 (15·7)	32·0 (46·7)	19·6 (2·9)	69·1 (33·9)	8·1 (18·1)
Mental handicap	121	29·4 (12·3)	0	19·3 (3·6)	79·6 (28·1)	2·1 (8·3)
Heart disease	72	71·7 (15·6)	20·8 (40·9)	18·1 (3·2)	66·2 (28·4)	8·1 (19·0)
Parkinson's disease	39	71·7 (9·4)	15·4 (36·6)	20·5 (2·7)	73·4 (23·4)	3·9 (10·6)
Dementia	67	72·7 (17·1)	22·4 (42·0)	18·1 (4·7)	71·0 (31·4)	7·0 (18·8)
Lung disorders	33	60·3 (19·8)	15·1 (36·4)	19·0 (3·1)	75·4 (24·9)	4·1 (10·1)
Cancer	35	56·6 (17·2)	20·0 (40·6)	17·5 (3·7)	73·1 (26·8)	7·1 (16·3)
AIDS	13	36·3 (10·5)	84·6 (37·5)	14·5 (2·5)	33·1 (31·3)	25·2 (42·9)

*Hours of help at home recorded at time of application to fund before any financial award.

TABLE II—*Mean (SD) number of weekly hours of care at home from formal sources by source and diagnosis group*

Diagnosis	No of subjects	District nurses	Local authority home help	Private agency	Voluntary organisation	Total formal hours
Multiple sclerosis	156	2·0 (3·8)	3·2 (7·9)	3·7 (12·6)	1·3 (6·1)	10·3 (16·6)
Cerebral palsy	79	0·4 (1·4)	2·3 (9·4)	1·0 (7·1)	0·3 (1·5)	4·0 (12·4)
Spinal injury	119	2·5 (8·0)	2·1 (7·1)	2·8 (10·9)	1·0 (3·4)	8·5 (16·6)
Stroke	231	2·7 (8·7)	1·1 (2·6)	2·5 (6·8)	0·4 (1·9)	6·8 (11·8)
Epilepsy	47	1·6 (6·9)	1·4 (3·9)	1·9 (10·3)	0·2 (0·6)	5·1 (14·2)
Brain damage	61	0·6 (1·8)	1·5 (5·0)	1·4 (5·3)	0·4 (1·3)	4·0 (8·5)
Arthritis	225	1·9 (8·0)	2·2 (6·3)	3·4 (11·2)	0·5 (4·3)	8·0 (15·9)
Mental handicap	121	0·6 (4·9)	1·5 (6·6)	0·6 (2·4)	0·3 (2·4)	3·0 (9·2)
Heart disease	72	2·2 (8·4)	1·4 (3·7)	3·8 (13·0)	0·6 (3·2)	8·2 (15·8)
Parkinson's disease	39	2·3 (10·1)	1·2 (3·8)	1·7 (4·4)	2·1 (7·4)	7·3 (13·2)
Dementia	67	0·4 (1·3)	1·6 (3·3)	3·7 (10·1)	0·8 (3·7)	6·5 (10·5)
Lung disorders	33	0·5 (1·5)	2·7 (8·6)	2·7 (12·5)	0·5 (2·8)	6·5 (15·4)
Cancer	35	1·2 (2·6)	2·8 (8·4)	0·9 (3·7)	0·4 (2·5)	5·4 (11·1)
AIDS	13	0·7 (1·5)	1·3 (2·5)	1·4 (3·0)	0	3·4 (3·2)

TABLE III—*Percentage (SD) of diagnosis group receiving care at home from formal resources by source and diagnosis group*

Diagnosis	No of subjects	District nurse	Local authority home help	Private agency	Voluntary organisation	Any formal source
Multiple sclerosis	156	39·1 (49·0)	35·3 (47·9)	30·1 (46·0)	14·7 (35·6)	71·1 (45·4)
Cerebral palsy	79	10·1 (30·4)	25·3 (43·8)	6·3 (24·5)	7·6 (26·7)	39·2 (49·1)
Spinal injury	119	33·6 (47·4)	23·5 (42·6)	17·6 (38·2)	15·1 (36·0)	57·1 (49·7)
Stroke	231	37·2 (48·4)	21·2 (41·0)	22·9 (42·1)	8·2 (27·5)	63·2 (48·3)
Epilepsy	47	21·3 (41·4)	21·3 (41·4)	10·6 (31·2)	8·5 (28·2)	40·4 (49·6)
Brain damage	61	14·7 (35·6)	14·7 (35·8)	13·1 (34·0)	13·1 (34·0)	42·6 (50·0)
Arthritis	225	26·7 (44·3)	28·4 (45·2)	19·6 (39·6)	5·8 (23·4)	55·6 (49·8)
Mental handicap	121	7·4 (26·3)	12·4 (33·1)	7·4 (26·3)	4·1 (20·0)	26·4 (44·3)
Heart disease	72	23·6 (42·8)	27·8 (45·1)	15·3 (36·2)	8·3 (27·8)	48·6 (50·3)
Parkinson's disease	39	28·2 (45·6)	12·8 (33·9)	18·0 (38·9)	10·3 (30·7)	51·3 (50·6)
Dementia	67	16·4 (37·3)	28·4 (45·4)	23·9 (43·0)	9·0 (28·8)	53·7 (50·2)
Lung disorders	33	18·2 (39·2)	18·2 (39·2)	9·1 (29·2)	3·0 (17·4)	36·4 (48·8)
Cancer	35	20·0 (40·6)	25·7 (44·3)	11·4 (32·3)	2·9 (16·9)	40·0 (49·7)
AIDS	13	23·1 (43·9)	30·8 (48·0)	23·1 (43·8)	0	69·2 (48·0)

Results

Table I outlines key characteristics for the sample by diagnosis. The mean age of the sample was 55·9 (95% confidence interval 54·7 to 57·1) years. The mean (range) proportion of those living alone was 18·9% (16·7% to 21·0%). Dependency scores indicate severe disablement across most disease groups: 44·2% (41·5% to 46·9%) of the sample had no ability to perform six or more of the basic activities of daily living on their own.

The final columns indicate the average number of total weekly hours of care at home received and the percentage of that total provided by district health authorities and local authorities by diagnosis group. The mean weekly total hours of care for the sample when they applied to the fund from informal and formal sources was 71·0 (69·4 to 72·6) hours a week. District health authorities and local authorities together provided on average 7·0% (6·1% to 7·9%) of the total hours of care received by disabled people in the community each week.

Table II provides more information on levels of formal care at home by source of provider by diagnosis. District nurses provided on average 1·7 (1·4 to 2·1) hours a week across the sample. Home helps provided an average of 1·9 (1·6 to 2·3) hours a week. Private agencies provided the greatest volume of care across the sample at 2·6 (2·0 to 3·1) hours a week whereas voluntary organisations provide the smallest amount. The final column shows the mean total hours of weekly care at home provided by formal sources. The average was 6·9 (6·1 to 7·6) hours a week.

Table III shows how the hours of care at home provided from each formal source are distributed within a diagnostic group. In seven out of the 14 groups under half in each group received formal assistance at home. On average 26·0% (23·6% to 28·4%) of the full sample received help at home from a district nurse; 24·1% (21·8% to 26·4%) from a local authority home help; 18·2% (16·1% to 20·3%) from private agencies, and 8·8% (7·2% to 10·3%) from volunteers. Of the whole sample, 52·7% (50·0% to 55·4%) of the sample received no weekly formal help at home.

Table IV presents additional data on the help-no help dichotomy. It shows mean age, dependency score, duration of disability in years, and weekly hours of informal care at home for those receiving and those not receiving local authority home help or visits from a district nurse. *t* Tests indicate that significant differences ($P<0·05$) exist between the two groups within the same disease group in only four of the 14 groups in relation to age; in only two groups in relation to dependency scores; and in only three groups in relation to duration of disability. In relation to weekly hours of informal care received at home, however, significant differences existed in nine groups.

Discussion

The data reveal a stark picture of what constitutes community care for poor, severely disabled adults living in the community. They are generally an extremely to completely dependent population. Despite this, over 20% of people in half of the disease groups live alone. They receive substantial amounts of care at home; sample mean (range) 71·0 (69·4 to 72·6) hours a week, mostly from informal carers.

The data show that district health authorities and local authorities provide less care at home than private agencies. The use of private agencies is a somewhat surprising finding given the group's low income. Voluntary organisations seem to cater for particular disease groups, such as multiple sclerosis, spinal injuries, and Parkinson's disease, possibly as a result of the manner and age at which they access the system.

TABLE IV—*Age, dependency score, years of disability, and weekly hours of informal care for those receiving local authority or district nurse help at home and those not receiving such help by diagnosis†*

Diagnosis	Mean age (years) (No (SD))	Dependency score (No (SD))	Years of disability (No (SD))	Weekly hours of informal care (No (SD))
Multiple sclerosis:				
Help	53 (91(12))	20 (91(3))	16 (68(9))	54 (91(30))
No help	50 (65(12))	20 (65(3))	16 (48(10))	65* (65(31))
Cerebral palsy:				
Help	34 (25(15))	21 (25(3))	41 (9(15))	56 (25(34))
No help	25* (54(9))	22 (54(3))	24* (22(7))	68* (54(20))
Spinal injury:				
Help	48 (55(18))	20 (54(2))	10 (39(10))	46 (55(31))
No help	47 (64(19))	20 (64(3))	15 (39(12))	70* (64(38))
Stroke:				
Help	73 (116(12))	21 (116(3))	8 (88(10))	63 (116(33))
No help	67* (115(12))	20 (114(3))	7 (86(6))	73* (115(28))
Epilepsy:				
Help	50 (13(18))	20 (13(3))	11 (12(12))	53 (13(18))
No help	35* (34(17))	19 (34(3))	24* (25(15))	74* (34(17))
Brain damage:				
Help	42 (16(23))	18 (16(4))	32 (9(16))	51 (16(32))
No help	32 (45(16))	20 (45(4))	22* (35(10))	72* (45(18))
Arthritis:				
Help	74 (103(12))	20 (103(3))	16 (41(11))	54 (103(36))
No help	66 (122(17))	19 (122(3))	13 (53(10))	67* (122/33))
Mental handicap:				
Help	33 (20(16))	20 (20(4))	28 (19(13))	81 (20(28))
No help	29 (101(11))	19 (100(3))	28 (79(12))	76 (101(27))
Heart disease:				
Help	74 (28(19))	18 (28(3)	9 (9(13))	49 (28(31))
No help	70 (44(13))	18 (44(3)	10 (21(14))	64* (44(31))
Parkinson's disease				
Help	71 (14(12)	21 (14(3))	13 (9(7))	62 (14(14))
No help	72 (25(8))	20 (25(3))	14 (17(11)	68 (25(26))
Dementia:				
Help	81 (24(7))	19 (24(4))	7 (12(3))	57 (24(36))
No help	68* (43(19))	17 (43(5))	12 (18(11))	69 (43(30))
Lung disorders:				
Help	60 (11(23))	20 (11(3))	11 (6(6))	72 (11(29))
No help	60 (22(19))	18* (22(3))	12 (5(11))	67 (22(23))
Cancer:				
Help	58 (13(14))	20 (13(3))	12 (8(23))	55 (13(27))
No help	56 (22(19))	16* (22(4))	4 (11(6))	75* (22(29))
AIDS:				
Help	33 (6(6))	15 (6(3))	3 (1(0))	21 (6(26))
No help	39 (7(13))	14 (7(2))	4 (4(1))	37 (7(36))

*Significant difference between means ($P < 0.05$).
†Numbers are rounded.

Combining data on the volume and distribution of formal care from tables II and III reveals some startling facts. The distribution of care is extremely polarised. Over half (52·7% (50·0% to 55·4%)) of the sample received no formal help at home and were entirely dependent on informal carers. Table IV indicates that these differences are not related to age, dependency, or duration of disablement. Hours of informal care received at home, however, do influence the amount of formal care received. These findings underline the system's dependence on informal carers and indicate that the process by which some disabled people obtain help at home and others do not is not related to certain indicators of need.

Community care has some features that need to be examined. Services for care at home do not seem to be systematically allocated except in relation to available hours of informal care. Also, the data suggest that substantial unmet need may exist within the community. In implementing community care previous care allocations need to be investigated while an equitable system is developed for dealing with new cases. Appropriate support for informal carers must be provided if the system is to remain viable.

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Key messages

- Data on the level and type of services provided at home to at risk groups who reside in the community are scarce
- A recent study of low income, severely disabled people living in the community revealed extremely high levels of disability within the population
- Over two fifths of the sample were unable to perform six or more of the eight standard activities of daily living
- Local authorities and district health authorities provided on average a little over three hours a week of care at home whereas informal carers provided 64 hours of care a week
- Over half of this highly dependent group received no formal help at home from local authorities or district health authorities

Appendix

Limits of age for eligibility for Independent Living Fund

Date	*Eligible age groups*
June 1988 to April 1990	All ages
April 1990 to August 1990	Fund temporarily closed
August 1990 to March 1991	Ages 16 to 74
March 1991 to March 1993	Ages 16 and over

Diagnostic categories

AIDS related diseases
Arthritis
Blood based diseases
Brain damage
Cancer or tumours
Cerebral palsy
Cerebrovascular (including stroke)
Dementia
Diabetes
Down's syndrome
Epilepsy
Friedreich's ataxia
Heart disease or attack
Hodgkin's disease
Huntington's disease
Hydrocephalus
Lung or respiratory disease
Mental handicap
Motor neurone disease
Multiple sclerosis
Muscular dystrophy
Osteoporosis
Parkinson's disease
Physical malformation (from birth)
Polio damage
Skin disease
Spasms
Spina bifida
Spinal injury (including quadriplegia)
Vision/hearing impairment
Unspecified poor health

Dependency score

The dependency score is based on how well the disabled person performs eight activities of daily living: feeding self, washing self, bathing or showering, getting dressed, using toilet, getting up-going to bed, moving indoors, and moving outdoors.

Three scores are possible for each activity: 1=can do; 2=can do with difficulty; 3=cannot do at all. The dependency score ranges from 8 to 24, and the higher the score the more help the person in question requires to remain in the community.

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