

# General practice and the provision of information and services for physically disabled people aged 16 to 65 years

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**SUMMARY.** *The study reported here was part of a larger survey investigating the nature and extent of disability in the Grampian region. Interviews with 212 people aged between 16 and 65 years who had a wide range of physical disabilities elicited perceptions of current and past service provision. Respondents expressed a strong need for information on disability services and reported difficulty in knowing whom to approach for this. General practitioners were the most commonly reported source of such information and low usage of the Department of Social Security, social work departments and voluntary organizations was identified. No significant relationship was found between degree of disability and frequency of consultation with a general practitioner. However, the more severe the disability the more likely it was that the general practitioner initiated contact rather than the patient. Although in general those interviewed were satisfied with medical information given regarding their diagnosis, they were more critical of information provided in relation to coping with the disorder, including that concerning benefits and services. The study confirmed the pivotal role of the general practitioner in the care of physically disabled people in the community aged between 16 and 65 years. The need to re-evaluate the role of the general practitioner in the provision of information and services is discussed.*

**Keywords:** *physically handicapped; information sources; patient needs; patient information.*

## Introduction

IN 1989 Grampian Regional Council social work committee undertook a survey of people with disabilities to establish a local database. This represented the first large scale investigation of this group in the north east of Scotland. The region has a distinctive character — a low population density, low levels of social deprivation, low numbers of people in ethnic minority groups and low levels of unemployment. This suggests that it may not be possible to use the findings of the survey of disability carried out by the Office of Population Censuses and Surveys in 1988<sup>1</sup> or other more recently completed regional surveys<sup>2,3</sup> as a basis for service planning.

The part of the study presented here aimed to obtain an in-depth understanding of the perceptions of people aged between 16 and 65 years with physical disabilities (excluding purely sensory disorders), regarding current and past service provision.

The use of general practice by people with physical disabilities

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is of interest, given the controversy surrounding the three-yearly health checks<sup>4</sup> and the role of the general practitioner in the assessment of health needs and the provision of community care.

## Method

### Main survey

To determine the nature and extent of disability in the region and to identify those with disabilities, for subsequent interviewing, a sample survey was carried out. In total, 5042 people were sent a questionnaire in May 1989 (a random sample of approximately one in 40 households in Grampian). The questionnaire was a shortened and simplified version of the Office of Population Censuses and Surveys postal screening questionnaire, and was returned by 4213 people, a response rate of 83.6%.

From the questionnaires, and in particular from individuals' self definitions, it was concluded that 1289 households had at least one person with a disability, disability being defined as someone who is disadvantaged or restricted in his or her daily life as a result of a health problem or disability.<sup>5</sup> While the majority of households reporting disability contained only one disabled person, households with two and three disabled people accounted for 25.9% of all households with disability.

### Interview survey

Of the respondents with a disability, 59.3% were willing to be interviewed, as intimated by their response to the final question of the questionnaire. Only 55.1% of those aged 45 years and under were willing to be interviewed compared with 63.6% and 67.2% of those aged between 46 and 65 years and over 65 years, respectively. Since the interview survey was to relate only to younger physically disabled people, respondents over 65 years together with those under 16 years and those not suffering from a physical disability were excluded from the pool of potential interviewees. Of the 765 respondents willing to be interviewed approximately half (371) were eligible for the study.

Of the 371 respondents, a purposive sample of 250 was selected. A major objective was to ensure that people with differing experiences of the impact of physical disability, regardless of whether these were of social, psychological or physiological origin, were included. Two hundred and twelve interviews were carried out between October 1989 and January 1990, including one partial interview. For a variety of reasons it was not possible to complete interviews with 38 people.

Interviews were carried out by 15 experienced interviewers. Both open and closed questions were asked and responses recorded on interview schedules. The main topics covered included the nature of disability; employment status, benefits and allowances; receipt of medical information; sources of information on disability services; and contact with general practitioners. At the same time a self completion questionnaire for carers was distributed, to be returned to the interviewer.

### Assessment of disability level

In order to analyse the data it was necessary to distinguish between different levels of disability. The aim was for interviewees to determine their own levels of ability and to elucidate their

own motivations and attitudes to their disability. It was therefore considered inappropriate to use a scale such as the Barthel index of physical dependence<sup>6</sup> since it depends on an external assessor. While both Arber and colleagues<sup>7</sup> and Townsend's<sup>8</sup> self reporting disability scales were given careful consideration, both were rejected because they focused on a narrow range of activities.

As no measurement scales met the requirements of the study, it was decided to develop and pilot a battery of self report measures, which would yield an assistance score.<sup>9,10</sup> This was based only on the respondents' assessments of the assistance they required in everyday life. Respondents were scored on the basis of their replies to three questions regarding help with mobility, household tasks and self care, which contained seven, eight and 18 items respectively. For each item, where people said they required help a single point was awarded, up to a maximum of 33. To avoid a subjective judgement regarding which problems caused greater disability to any given individual no weighting was placed on different aspects. In effect, however, self care was weighted more heavily since there were over twice as many items. On account of the unique experience of wheelchair users they were considered as a separate group.

### Analysis

Data were analysed using *dbase 3*. Chi square tests were used to test the association between variables.

## Results

### Profile of the interviewees

Of the 212 interviewees, 117 were women; 55 women were aged between 56 and 65 years and 16 were aged between 16 and 35 years. Ten of the 95 men were aged between 16 and 35 years and 52 between 56 and 65 years. Despite attempts to increase the representation of younger age groups, 50.5% of all interviewees were aged over 55 years. Only 24 (11.3%) interviewees were in single person households. Over three quarters of the study group (163, 76.9%) were married, with a higher proportion of women being single or widowed than men (24.8% versus 16.8%). A total of 29.7% were in paid employment, 22.2% being in full time work.

The majority of the interviewees (140) reported having a musculoskeletal disorder. The other most commonly reported disorders were of the circulatory system (85), the respiratory system (48) and the nervous system (42). A total of 119 people had two or more disorders. The majority of those interviewed (156) had at least one health disorder which had been present for five or more years. A further 13 had a congenital disease including one person with Huntington's chorea and three people with spina bifida.

### Assistance scores

The assistance scores of the interviewees and their reported economic status are shown in Table 1. Less than half (95) had assistance scores below seven while 44 had a score above 15 or were wheelchair users. There appeared to be a relationship between interviewees' economic activity, receipt of mobility allowance and/or attendance allowance and their assistance score, a greater percentage of those with lower scores having employment.

### Communicating medical information

A total of 80.2% of interviewees believed that they had been given appropriate information on their condition when a firm

**Table 1.** Assistance scores and economic status of the 212 interviewees.

Economic status	% of people with assistance scores: <sup>a</sup>				% of wheelchair users (n = 13)
	0-7 (n = 95)	8-15 (n = 73)	16-23 (n = 22)	24-33 (n = 9)	
Economically active	41	22	23	11	15
Receiving mobility allowance	2	15	18	25	92
Receiving attendance allowance	0	0	9	56	46

n = number of interviewees in group. <sup>a</sup> Assistance required with mobility, self care and household tasks.

diagnosis had been made, most commonly in the hospital setting and were, moreover, satisfied with the timing and nature of the information conveyed. However, 19.8% of interviewees felt that either there was an unacceptable delay in communicating the diagnosis or that this had never been given directly to them. Five interviewees reported that they had learned inadvertently of their condition. For example, one interviewee said she discovered she had multiple sclerosis while taking part in a drug trial and in another case the diagnosis had been found out on assessment for registration as a disabled person. Criticism was also voiced concerning the occasion on which information was conveyed. One young person said that she was told that she had epilepsy when accompanying her mother who was on a routine visit to her general practitioner's surgery.

Most satisfaction was expressed by interviewees who had been given their diagnosis in a straightforward informative way with a realistic picture being presented of the prognosis. Nine interviewees considered that the worst possible outcome for their particular disability had been described to them at diagnosis. Although in general interviewees were satisfied with information regarding their diagnosis, they were more critical of that given in relation to coping in the future. At the time of diagnosis only 11 interviewees (5.2%) said that advice had been forthcoming on potentially useful services and contacts. Nine respondents were especially distressed when told there was no cure without being given information on how the disorder could be managed and how they could help themselves. In the words of one interviewee, it was like being 'left in thin air, there was a void'. On reviewing interviews as a whole, only 13.2% of interviewees did not at some point express the need for information on services and benefits.

### Sources of information

General practitioners were the most commonly reported source of information on disability services (Table 2). Over 10.0% of respondents, including three wheelchair users, had never used any standard sources of information and a further 10.4% had used only one service. Relatives, friends and the media were more frequently used to gain information than statutory services. The Department of Social Security was more frequently used on an occasional basis for information than social work departments, and health visitors were more commonly approached than district nurses. A wide range of information was sought on topics such as housing, benefits and transport.

Little use was made of voluntary organizations as information providers, reflecting low levels of membership (22.2% of

**Table 2.** Sources of information on disability services reported by 211 interviewees, and their frequency of use.

Source of information	No. of patients receiving information:		
	Regularly <sup>a</sup>	Occasionally <sup>b</sup>	Never
General practitioner	32	77	102
TV/radio	14	58	139
Booklets	14	52	145
Newspapers	12	51	148
Relatives	10	43	158
Friends	8	49	154
Department of Social Security	4	41	166
Social work department	4	27	180
Library	4	25	182
Health visitor	4	16	191
Voluntary organizations	4	15	192
District nurse	4	6	201
Information/advice office	3	5	203
Citizens advice bureau	2	9	200
Other	10	19	182

<sup>a</sup> Used more than once or recurrently. <sup>b</sup> Used on a one-off basis.

interviewees). The groups with the highest number of study members were the Arthritis and Rheumatism Council and the Multiple Sclerosis Society (eight and seven respectively). Only 11 members attended meetings although two interviewees had attempted to attend those of the Arthritis and Rheumatism Council but for one there were 'too many stairs' and for the other transport was stopped.

#### Contact with general practitioners

Of the respondents, 80.7% had seen their general practitioner in the previous six months. Approximately half (108), had had frequent contact (four or more visits) during this period. For 160 interviewees (75.5%) general practitioner consultation time represented their only contact with community health care services, including chiropody but excluding dentistry. Current visits from a health visitor were received by 16 interviewees, from an occupational therapist by 10 and from a district nurse by eight. Only seven interviewees were having home help.

No relationship was found between degree of disability and frequency of general practitioner consultation. Those with less severe disability were just as likely to have contact as those with severe disability (Table 3). The greater the degree of disability, however, the more likely it was that general practitioners initiated contact rather than the patient. It appeared that those with similar levels of disability could receive very different levels of service from their general practitioner; a wheelchair user with multiple sclerosis in south Aberdeenshire had not seen her general practitioner for eight years (her husband collected repeat prescriptions from the surgery) whereas a similar patient living north of Aberdeen was visited monthly.

Data on access to community facilities revealed that 11.3% of respondents (24) had problems in visiting the general practitioner's surgery. While this mainly related to factors associated with transport, in six cases there were difficulties in gaining physical access to the surgery. None of the latter respondents were patients at the same practice.

Communication and psychological problems, such as depression and withdrawal, also created difficulties over contact with the general practitioner. As a consequence carers were depended on to seek a home visit when appropriate if the general practitioner was not in the habit of calling. Of the interviewees 32

**Table 3.** Initiation of contact, and frequency of contact with general practitioner, by severity of disability.

	% of people with assistance scores:				% of wheelchair users
	0-7	8-15	16-23	24-31	
<i>Initiation of contact with</i>					
GP	(n = 72)	(n = 62)	(n = 20)	(n = 8)	(n = 9)
Self initiated	78	68	65	38	44
GP initiated	18	19	30	25	33
Other <sup>a</sup>	4	13	5	38	22
<i>Frequency of contact with</i>					
GP <sup>b</sup>	(n = 95)	(n = 73)	(n = 22)	(n = 9)	(n = 13)
0	24	15	9	11	31
1-3	47	37	64	33	46
4-5	7	7	5	0	0
6+	21	41	18	56	23

n = number of respondents. <sup>a</sup> Mutually arranged contacts and appointments. <sup>b</sup> Over previous six months.

(15.1%) had no telephone, four of whom lived alone; 25 respondents said that they needed help with using a telephone.

When carers were asked, 'If things get difficult who do you turn to?', 40.0% of the 35 carers who completed the form stated that this would be the general practitioner, the same proportion as indicated a relative. By contrast, only 11.4% and 5.7% respectively said they would turn to a district nurse or health visitor, or minister of religion.

Although respondents' level of satisfaction with primary health care was not explored specifically, 24 interviewees volunteered their opinions. Thirteen were negative and 11 positive. From this, albeit self selecting group, it was apparent that the two main aspects of general practice stimulating comment were those of willingness to make home visits and ability to communicate effectively.

#### Discussion

An unexpected outcome of this study was the relatively high proportion of respondents with disability who indicated on the postal questionnaire that they did not wish to be interviewed. It is unlikely that this can be explained by reference to sponsorship of the study by Grampian Regional Council. A response rate of 83.6% had been obtained for the questionnaire, the distribution of which coincided with the first community charge demands. It is difficult to find studies which have asked people in advance if they were willing to be interviewed and response to this option gives rise to speculation regarding reluctance to participate. Given that the 1990 National Health Service and community care act calls for a needs led rather than a service led approach to provision of care, the above finding has considerable implications. The opinions of the vocal and willing may not necessarily be those of the total population. In addition, some individuals may choose not to receive services or be reluctant to seek assistance. The data highlight the complexity of assessing need.

The Grampian study confirmed the pivotal role of the general practitioner in the care of physically disabled people aged between 16 and 65 years in the community. Despite the changes which have occurred in health and social services in the 1980s the survey indicates that general practitioners continue to have more contact with physically disabled people than any other pro-

fessional or agency. The frequency of contact found here is congruent with both the findings of the 1988 Office of Population Censuses and Surveys disability survey and those of Patrick and colleagues,<sup>11</sup> and regional surveys such as that carried out in Gloucestershire.<sup>12</sup> In the light of these results, it is perhaps surprising that those within general practice have not had greater involvement in developing systems of case management and needs assessment. Certainly general practitioners have had a long tradition of care in the community and many would see their role as care managers. The findings indicate that this was the expectation of patients too since general practitioners were often expected to meet social as well as medical needs, as reflected in their request for information on such topics as housing, benefits and so on.

Respondents were more likely to use their general practitioner as a source of information on benefits and services than the Department of Social Security or social work department. However, the strong emphasis among those interviewed on stressing the need for more information on services, together with the low uptake of services, and other findings that not all benefits to which individuals were entitled were being claimed<sup>9</sup> would suggest that a less than comprehensive service was being offered by practices in this respect. Broadly based research on physically disabled people,<sup>13</sup> young physically disabled people<sup>14</sup> and more narrowly focused work on multiple sclerosis patients<sup>15</sup> would indicate that doctors may not be well informed regarding either application/referral procedures for benefits and services or eligibility criteria. The complexity of these processes and lack of coordination between social and medical services have been well documented.<sup>16</sup> Further changes will occur with the implementation of the remainder of the National Health Service and community care act 1990 in April 1993, with social services having a bigger role to play.

It has been argued that general practitioners should become better acquainted with the benefits and services available and more knowledgeable regarding application procedures.<sup>13</sup> This cannot be achieved easily. Despite recent simplifications of some benefits, eligibility is seldom a straightforward case. The changing nature of benefits and services also make it difficult to be confident that information is sufficiently up to date and reliable. Even the most conscientious may have problems keeping abreast of current developments following the 1990 National Health Service and community care act. Pressures on consultation time may also make it difficult to allocate sufficient time for the communication of often complex information. General practitioners may be reluctant to award a priority to such tasks even though Buckle suggested that help in obtaining a benefit may be cost effective since improving the patient's financial position may reduce the number of future consultations.<sup>13</sup> Greater recourse could be made to information-giving databases at practice level. These offer the opportunity for both the general practitioner and the patient to improve knowledge of services and benefits available. Indeed direct patient access could reduce the general practitioner's workload in this respect. However, it may be argued that such information giving is a role for social work and other health care staff rather than general practitioners.

It would seem that at practice level an instrument for assessing patient need especially regarding services could be of use. A self completion assistance questionnaire could be sent to patients with conditions likely to cause disability. The information from this, including the assistance score, could be retained as part of the patient's records and also entered into a database. While further testing for reliability and validity is required for the assistance scale used in this study, it can be seen that there was a strong internal consistency between interviewees' economic

activity, receipt of mobility and/or attendance allowance and their assistance score. Patients with high scores could be offered information on potentially useful services and facilities. The information could be updated on a regular basis, for example annually, to monitor change and the need for general practitioner intervention or to offer further information. This would provide a longitudinal picture of the changing nature of an individual's situation. The assistance score could be used in a variety of ways. Different degrees of disability could be identified by bandings within the score. Specific problem areas could be identified, such as mobility, self care and difficulties with household tasks, and information or appropriate interventions could be offered accordingly. Non-respondents would need to be investigated.

The national disability information project has recently been set up in England, aiming to improve the quality and accessibility of information services for disabled people, their carers and service providers, and to develop a national framework for the coordination of disability information services.<sup>17</sup> It would seem timely to evaluate the role of the general practitioner in the provision of information and services.

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