

# **THE ADMINISTRATIVE PREVALENCE OF MENTAL HANDICAP IN THE CITY OF CARDIFF: AN EXAMINATION OF GEOGRAPHICAL DISTRIBUTION**

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## **INTRODUCTION**

This study examines the geographical distribution of the occurrence of mental handicap in the City of Cardiff. It evolved from the necessity to identify and establish a 'comparison' community for the purposes of the long-term evaluation of a comprehensive, community based mental handicap service which is being introduced in part of Cardiff: the NIMROD service.

### **The NIMROD Service—Overview**

The NIMROD service will operate for an initial period of 7 years as a pilot project, jointly funded by the Welsh Office, South Glamorgan County Council and South Glamorgan Health Authority. It will be available to all mentally handicapped people and their families who live in, or come from a clearly defined catchment area of approximately 60,000 population situated in the west of Cardiff. The service, which has been described by Mathieson and Blunden (1980), is based upon an individual plan for each client and contains residential provision in ordinary houses, domiciliary services and support, advice and a resource centre for families.

The project catchment area is divided into four 'communities', each of approximately 15,000 population. Planning of service delivery and evaluative research have developed simultaneously. A multiple baseline experimental design is to be adopted in which the pilot service will be introduced into each of the four NIMROD communities sequentially. In addition, research measures will be taken in a fifth 'comparison' community of 15,000 population which will not receive the NIMROD service. Implementation of the new service began in July, 1981, with the operation of NIMROD services in the first community, and evaluative research will continue until 1986.

### **Background to the Study**

A previous attempt to establish a 'comparison' community was made shortly after the selection of the four NIMROD communities. A fifth community of 15,000 population was selected in accordance with the criteria adopted for selection of the NIMROD communities, (NIMROD: Joint Working Party Report, 1978). However, on receipt of returns from all agencies having contact with mentally handicapped clients, and after extensive checking of hospital and social services records, only eleven clients out of an 'expected' forty were identified in the selected 'comparison' community. The reason for this very low number remains speculative, although subsequent analyses of the characteristics of the various communities within the city are suggestive of possible reasons for these findings, and will be referred to in the Discussion.

Clearly, the area originally selected as a 'comparison' community was unsuitable for evaluative purposes—such low numbers of mentally handicapped people in one community being quite unrepresentative of the total pattern. Consequently, on the basis that mental handicap might not be evenly distributed, it was decided to examine administrative prevalence throughout the city, and then to use this information to select a 'comparison' community.

### **Previous Studies of the Prevalence of Mental Handicap**

The emphasis of the present study is the classification of mentally handicapped individuals according to geographical location within one large city. This approach differs somewhat from that of some previous surveys of administrative prevalence of mental handicap (e.g. Stein and Susser, 1963; Ross, Innes and Kidd, 1967; Kushlick and Cox, 1968; Innes, Kidd and Ross, 1968) which have examined aetiology and severity of mental handicap in association with socio-economic status for comparatively large populations. Nevertheless, the findings of the relationships between the prevalence of mental handicap and socio-economic status will have some bearing on the results of the present study because of the variations in socio-economic status between residential areas of cities.

A number of prevalence surveys have concentrated on mentally handicapped individuals under the age of 20 years; (Lewis, 1929; Goodman and Tizard, 1962; Drillien, Jameson and Wilkinson, 1966; Birch, Richardson, Baird, Horobin and Illsley, 1970; Wing, 1971). This is the age group most likely to be registered with service providing agencies, particularly educational facilities. This would seem to be a reasonable criterion to adopt, as generally the number of mentally handicapped individuals known to the administrative authorities depends to a large extent on the quality and quantity of the services provided (Penrose, 1963; Kushlick and Cox, 1973). Accordingly, it is not uncommon that cross-sectional studies of age-specific rates of mental handicap show a rising prevalence with age, peaking during later school years and showing a drop of about 50% by the 20's due mainly to people leaving the educational system (Gruenberg, 1964).

Prevalence studies of mental handicap across the entire age range have also been conducted (Kushlick, 1964; Innes, et al, 1968; Midwinter, 1972; Kushlick and Cox, 1973; Akesson, 1974; Russell and Hall, 1980; Martindale, 1980). Only the latter two investigations are directly relevant to this study as they present findings on the differential distribution of occurrences of mental handicap within the districts of a large city. Russell and Hall, (1980) found that areas in which the mental handicap prevalence rate was above average tended to be those wards of the city where housing and social amenities were poorer than average. Thus there is evidence that mentally handicapped people are not distributed uniformly throughout large cities but are found to be concentrated in certain areas. Martindale's (1980) survey of mentally handicapped people in Sheffield also indicated that the poorer residential districts had significantly high referral rates in the age group 5-24 years compared with the low rates for the same age group from the prime residential districts. Although these differences were most marked for those classified as mildly mentally handicapped, the severely mentally handicapped were also unevenly distributed between districts. The numbers of mentally handicapped people identified in the areas comprising the highest proportion of council housing, high-rise flats and older housing lacking basic amenities were twice as great as those referred from prime residential areas.

In respect of these findings Bayley (1973) had earlier concluded that severely mentally handicapped people were not evenly distributed among all social strata, being heavily under-represented in the professional and intermediate groups and over-represented in the unskilled group.

### **AIM OF THE STUDY**

The aim of the present study was to collect information on the administrative prevalence of mental handicap in the various communities of Cardiff, and to select a 'comparison' community, for inclusion in the long term evaluation of the NIMROD service.

## METHOD OF INVESTIGATION

On obtaining official approval for the investigation from the Area Health Authority, the Local Education Authority and the Director of Social Services, a written approach was made to all agencies having contact with mentally handicapped clients. These agencies included:—

—all mental handicap hospitals in Wales

and for Cardiff alone:—

- all Local Authority mental handicap hostels (6)
- ESN(S) schools (2)
- Adult Training Centres (2)
- Social Services Department: all area teams
- Information Co-ordinating Centre for Mental Health in South Glamorgan
- Mental handicap hospital social work team
- Community mental handicap nursing team

The information requested of the above agencies was the name, address and date of birth of the client, the address of the next of kin and, in the case of clients in residential care with no next of kin, the address from which the client was admitted. The information requested did not include the degree of mental handicap (e.g. Intelligence Quotient, diagnosis or severity) because the definition of mental handicap could differ among the various agencies approached.

The following criteria were used to establish the eligibility of clients for inclusion in the survey:—

- i) a client living in a residential mental handicap facility for six or more persons, was included in the investigation if the address of the next of kin was within the city boundary. If the client had no next of kin, then the address from which the client was admitted to residential care needed to be within the city boundary in order to establish eligibility for inclusion in the survey.
- ii) any client living at home or in a small group residential home (less than six persons) within the city boundary, was also included in the survey.

Two groups of clients were excluded from the investigation:—

- clients not on the current caseloads of the Social Services area teams (i.e. not visited or contacted within the last two years).
- clients in mental handicap hospitals outside Wales.

Also, because of the problems of 'labelling' no information was requested from either ESN(M) schools or agencies concerned with pre-school children.

A large scale map (1:10,000) of the city of Cardiff was used to divide the city into 19 communities (15 communities together with the 4 pre-determined NIMROD communities). Naturally occurring communities and electoral wards were used whenever possible to derive each community of approximately 15,000 population, although in many instances, in order to attain the requisite numbers, community boundaries were fairly arbitrary.

The boundary definitions between the 19 communities were clearly marked on the large scale street map of Cardiff, which facilitated classification of clients according to community by means of address. Boundaries between communities were specific and well-defined, frequently following naturally occurring boundaries such as rivers, railway lines or main trunk roads. However, in 30 cases where a client's address coincided with a boundary between two communities, a visit to the locality was necessary in order to ascertain on which side of the boundary line (and hence, in which community), the client's residence was situated.

## RESULTS

### Numbers of Mentally Handicapped People Identified

A total of 761 mentally handicapped individuals were identified in the city of Cardiff, and classified according to community of origin. This gives an overall prevalence rate of 2.58 per 1,000 population. The diagrammatic representation of the city of Cardiff (Figure 1), illustrates the 19 communities, the distribution of mentally handicapped individuals between the communities and the locations of the main mental handicap facilities in the area.

**FIGURE 1.**  
**MAP SHOWING THE DISTRIBUTION OF MENTALLY HANDICAPPED PEOPLE IN THE CITY OF CARDIFF**

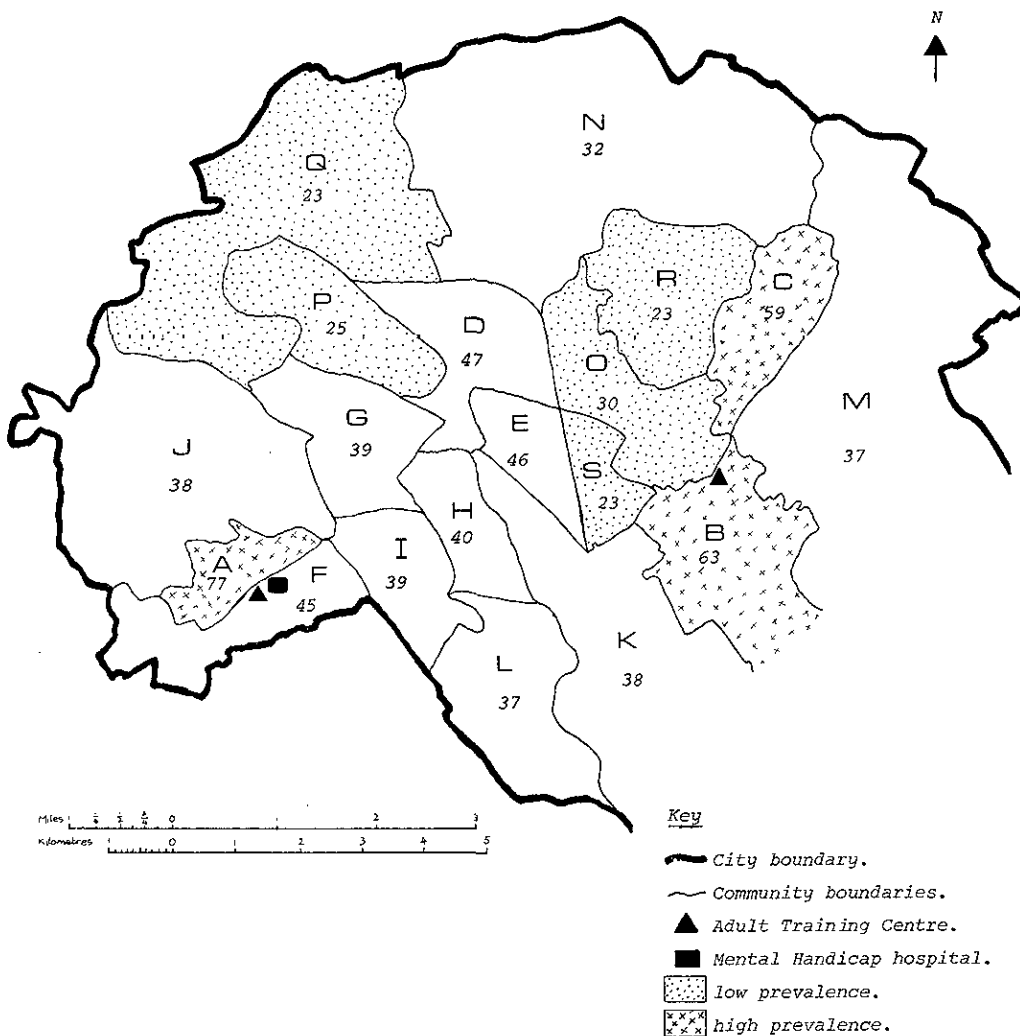


Table 1 presents figures for the total population of each community, together with the prevalence rate for mental handicap in each community. It can be seen that communities A, B and C demonstrate significantly higher rates of mental handicap than would have been expected on examination of the prevalence rate over the entire city. Conversely, occurrence of mental handicap was found to be significantly lower than expectation, in communities O, P, Q, R and S. Consideration is given in the Discussion to possible reasons for the different prevalence rates between communities.

**TABLE 1**  
Prevalence and population figures for each community

Community	Population	Nos.		Significance of Difference*		Prevalence Rate (per 1,000)
		Identified	Expected	$\chi^2$	p	
A	14,367	77	37	38.0	<0.001*	5.36
B	15,341	63	40	12.2	<0.001*	4.11
C	15,931	59	41	6.8	<0.01*	3.70
D	16,894	47	44	0.18	NS	2.78
E	16,100	46	42	0.34	NS	2.86
F	12,878	45	33	3.58	NS	3.49
G	15,294	39	39	—	NS	2.62
H	14,538	40	38	—	NS	2.75
I	14,869	39	41	—	NS	2.46
J	14,760	38	38	—	NS	2.58
K	10,967	38	28	2.83	NS	3.47
L	12,351	37	31	0.63	NS	3.00
M	16,904	37	44	0.82	NS	2.19
N	15,532	32	40	1.38	NS	2.06
O	18,334	30	47	5.76	<0.02*	1.64
P	18,430	25	48	9.93	<0.005*	1.36
Q	16,717	23	43	8.70	<0.005*	1.38
R	18,175	23	47	11.36	<0.001*	1.27
S	15,661	23	40	6.89	<0.01*	1.49
TOTAL	295,043	761	761			2.58

NS=not significant

\*=statistically significant difference

### Characteristics of the Mentally Handicapped Population

Table 2 shows the distribution of the mentally handicapped individuals by community, according to age and sex. It was found that 615 (81%) of clients identified were adults (i.e. 16 years of age or over on 31.12.80) compared with only 146 (19%) children. This was partly a result of the decision not to request information from ESN(M) schools or agencies dealing with pre-school children. As in other prevalence studies, rather more males than females were identified in both age groups, giving an overall ratio of 54% males to 46% females, though the proportion of males to females was somewhat greater among clients under 16 years of age.

Figure 2 shows the age distribution of the mentally handicapped population identified in the survey, and compares the age distribution of those living at home with that of clients in long term care. This shows that a greater percentage of people in the older age groups were in long term care than those in the younger age groups. It was found that only 19% of those under 30 years of age lived in mental handicap residential facilities, compared to 57% of those aged 30 years and over.

**TABLE 2**  
**Numbers of mentally handicapped people divided by age, sex and community**

Community	Adults (>16 yrs. old)			Children (<16 yrs. old)		
	Males	Females	Total	Males	Females	Total
A	39	24	63	7	7	14
B	28	26	54	6	3	9
C	22	24	46	7	6	13
D	17	22	39	5	3	8
E	21	16	37	8	1	9
F	21	18	39	4	2	6
G	16	19	35	3	1	4
H	15	16	31	7	2	9
I	24	9	33	4	2	6
J	13	16	29	4	5	9
K	15	14	29	6	3	9
L	22	9	31	1	5	6
M	13	16	29	6	2	8
N	14	11	25	2	5	7
O	12	11	23	3	4	7
P	9	11	20	3	2	5
Q	5	12	17	4	2	6
R	7	10	17	5	1	6
S	8	10	18	2	3	5
<b>TOTAL</b>	<b>321</b>	<b>294</b>	<b>615</b>	<b>87</b>	<b>59</b>	<b>146</b>

**FIGURE 2**

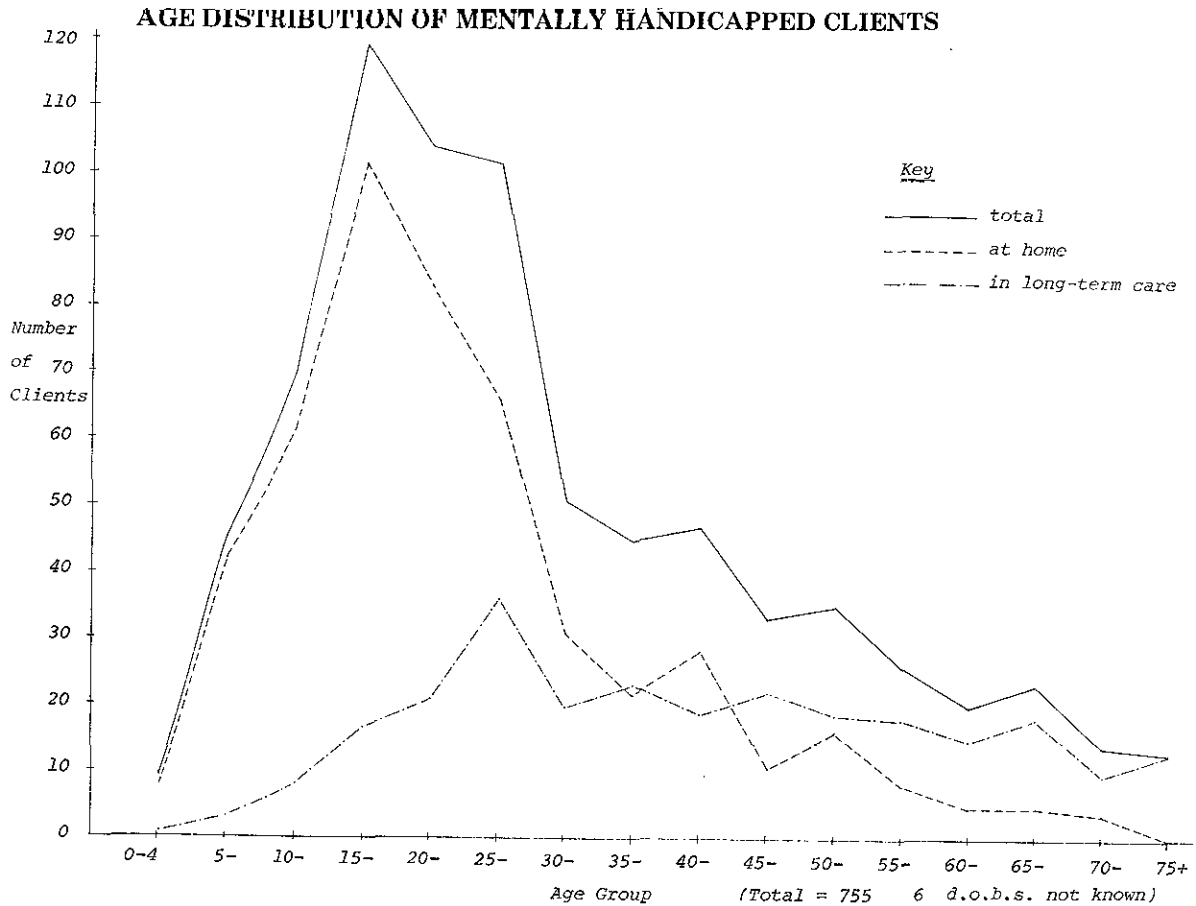


Table 3 indicates the proportions of those identified living at home in the community, in hospitals and in hostels. It can be seen that most people lived at home, only 35% living in a hospital or hostel.

**TABLE 3**  
**Clients' residential placement**

Type of Residence	Adults		Children		Total	
	n	%	n	%	n	%
At Home	363	59.0	129	88.4	492	64.7
In Hospital	218	35.5	12	8.2	230	30.2
In Hostel	34	5.5	5	3.4	39	5.1
<b>TOTALS</b>	<b>615</b>	<b>100</b>	<b>146</b>	<b>100</b>	<b>761</b>	<b>100</b>

#### Use of Mental Handicap Facilities

Table 4 shows the pattern of mental handicap service usage among clients. The nine categories tabled cover the type and combinations of services used. Short and long term care includes use of residential facilities provided by both the Area Health and Local Authorities, and also any provided by voluntary bodies. The categories for short or long term care plus 'other' indicate use of either short or long term care, respectively, plus one other type of service, i.e. day care or community service(s). Day care provision encompasses attendance at Adult Training Centres, ESN(S) schools, Special Needs Unit and other day centres catering for mentally handicapped clients. Included under community services are clients receiving services from social workers (hospital social workers and/or local authority social workers), community mental handicap nurses, and outpatient clinics. Some clients are listed as receiving all three types of services, i.e. residential care, day care and community service(s). A small number of clients, although known to service-providing agencies, were not currently receiving any mental handicap services and so are listed separately.

It was found that 81% of the children identified received day care compared with only 37% of adults. One reason for this, apart from the fact that schooling is compulsory for children, may be that there is a short fall of Adult Training Centre places in Cardiff. Perhaps it should also be mentioned that the overall low percentage of adults and children using short term care facilities (9%) is more a reflection of the shortage of such facilities, rather than non-usage of existing services.

**TABLE 4**  
**Clients' use of mental handicap services**

Type of Service	Adults		Children		Total	
	n	%	n	%	n	%
Short Term Care only	2	0.3	—	—	2	0.3
Short Term Care + other	22	3.6	7	4.8	29	3.8
Long Term Care only	221	36.0	11	7.5	232	30.5
Long Term Care + other	25	4.1	2	1.4	27	3.5
Day Care only	83	13.5	77	52.7	160	21.0
Community Service(s) only	96	15.6	8	5.4	104	13.7
Day Care + Community Services	115	18.7	31	21.2	146	19.2
All of these	28	4.6	10	6.8	38	5.0
None of these	23	3.7	—	—	23	3.0
<b>TOTALS</b>	<b>615</b>	<b>100.1</b>	<b>146</b>	<b>99.8</b>	<b>761</b>	<b>100</b>

## DISCUSSION

The results of this investigation indicate that there are clear differences in rates of administrative prevalence between different areas of the city. The null hypothesis, that prevalence of mental handicap in the various communities would not differ from that observed for the city as a whole must therefore be rejected. The methodology here employed for selection of a 'comparison' community by investigating prevalence of each of the 19 communities would therefore appear to have been justified. The reasons for the varying rates of mental handicap in the different communities cannot be stated definitively, but results of an examination of age structure, housing tenure, and social classification for each community are indicative of certain trends. In those areas where the prevalence of mental handicap is significantly higher than expectation, i.e. communities A, B and C, there is a high proportion of council-rented property (e.g. 89% in A, 65% in C), together with some of the lowest percentages of householders classified in professional or intermediate occupations (e.g. 17% in community A, and 19% in community B). It was found that, conversely, in areas where the numbers of mentally handicapped people were significantly below expectation (Areas O to S) the highest percentages of owner occupied housing (85% in Q; 83% in O; 72% in P) were observed, together with the greatest population of householders in professional and intermediate occupations, (73% in Q; 73% in O; 60% in P).

A second explanation for this finding is however suggested by reference to Figure 1, where it is shown that the two Adult Training Centres in the city are in very close proximity to communities A and B. A similar finding for the city of Bristol was reported by Russell and Hall (1980), where it was suggested that a possible reason for the concentration of the mentally handicapped population in these areas might have been due to the differential migration of families to areas of provision of the main mental handicap facilities in the city. Figure 1 shows that the main mental handicap hospital for the region is also situated on the boundary of community A. It may also be that mentally handicapped people are more readily identified in areas where services are provided.

The significantly low prevalence rates in communities R and S appear to be due to somewhat different reasons. As already mentioned, community S had previously been selected as the 'comparison' community, but was rejected owing to the very low numbers of handicapped clients identified. Some unusual features about this community are that it was found to contain the highest proportion of privately-rented, furnished accommodation (20%) and also to have a higher proportion (26%) than most other communities of people in the 16-29 years age range. The most that can be said concerning these findings is that community S appears to have a fairly mobile population which may explain the low numbers of handicapped persons identified in this area. The low numbers of mentally handicapped people identified in community R, however, would appear to be accounted for by the fact that this is an area of new housing development within the city, accommodating a high proportion of people in the 16-29 years age group (27%) and also the largest proportion (21%) of pre-school children. The numbers in the 30-64 and over 65 age group for this community are the lowest of all the communities (28% and 5% respectively) which tends to confirm the suggestion that this community is primarily composed of young parents with pre-school families. It will be remembered that pre-school children were not especially considered in the investigation—and for community R, this appears to be reflected in the low numbers of handicapped clients identified.

The aim of the investigation was to use the information obtained on administrative prevalence of mental handicap in the different communities to select one 'comparison' community for evaluative research on the NIMROD project. Following detailed examination of the 15 possible communities, it was considered that community E was the most suitable in terms of its central location, its average distribution of housing

types, socio-economic groupings and age composition. In addition, there were rather more handicapped clients in this community than expected, thus providing a sufficient number of clients for evaluative purposes, in the event that some clients or families may not wish to participate in the research.

## CONCLUSION

As with other studies which have found varying numbers of mentally handicapped people in different city areas, it cannot be said whether this reflects a true difference in prevalence rates related to conditions such as poverty, unemployment, social groupings and poor housing conditions, or whether the observed difference could be due to different patterns of referral to service providing agencies or indeed service usage generally. If services for mentally handicapped people are very poor in one area, it may be that families in socio-economic groups 1 or 2 will be in the fortunate position of being able to seek improved services for their handicapped relative elsewhere. This would then be reflected in lowered prevalence rates for this group. It is unlikely however that this possible source of variation in rates of mental handicap can ever be accurately assessed. Since the present study was not designed as an epidemiological survey of mental handicap, it is not possible to state whether the high number of referrals from the socio-economic groups 4 and 5 are comprised mainly of 'mildly' handicapped people as suggested by a survey of the literature (Kushlick, 1968), although the overall prevalence figure for Cardiff of 2.58 cases per 1000 would have been expected to be much higher if in fact, large numbers of 'mildly' handicapped people had been included.

With regard to the overall prevalence rate for mental handicap in Cardiff, the figure of 2.58 cases per thousand is somewhat lower than figures obtained in other areas (e.g. Wessex: 3.09 per 1000, Kushlick, 1963; Bristol: 3.15 per 1000, Russell and Hall, 1980) but direct comparison with other surveys is difficult to make because of differences in age groups and degree of mental handicap considered by different authors.

Nevertheless, the fact that studies of prevalence of mental handicap in three major cities have now indicated that occurrence of mental handicap varies quite dramatically between different districts of cities puts into question the tenability of the concept of an overall prevalence rate for a region, and suggests that national figures calculated for service planning purposes could be quite misleading when the needs of a community are being assessed. With the current move towards the development of community-based mental handicap services, it will become increasingly important to establish local planning norms rather than to rely on centrally calculated prevalence figures to estimate local mental handicap service requirements.

Indeed, on examining the five existing Case Registers of mentally handicapped people, the DHSS found that the registers indicated an average 'prevalence of need' ranging from 2.9 to 3.4 per thousand population and concluded that a single national prevalence rate is not appropriate for the assessment of mental handicap service needs at a local level.

## SUMMARY

A study was conducted to examine geographical variations in the administrative prevalence of mental handicap between various parts of Cardiff. A major aim of the study was to select a 'comparison' community as part of the long term evaluation of a community-based mental handicap service.

Information on known mentally handicapped clients living at home and in residential care was obtained from the local Health Authority and from the Education and Social Services Departments. The city was divided geographically into 19 'communities' each of approximately 15,000 total population and each client allocated to a community.

A total of 761 mentally handicapped individuals were identified, giving an overall prevalence of 2.58 per 1000 population. There were major variations in prevalence between communities ranging from 1.27 to 5.36 per 1000 population. Possible reasons for this variation were examined in terms of housing tenure, socio-economic group, age distribution and the availability of services. A 'comparison' community for use in further research was selected.

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