
Clinical Topics

The Oxfordshire mental handicap register

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Abstract

A total of 2027 moderately or severely mentally handicapped people in Oxfordshire considered likely to require special services at some time have been identified for the Oxfordshire Mental Handicap Register. Prevalence rates for those aged 5 to 14 years are estimated to be 3.9 per 1000 home population and 4.14 per 1000 total population when hospital residents are included. Entry criteria are less strict than in other registers, however, and people are identified by general practitioners, health visitors, and hospital staff as well as through the more usual sources. The register is already proving useful when planning and providing services to those in need.

Introduction

In Oxfordshire it is likely that nearly all children who are moderately or severely mentally handicapped are identified at an early age and reviewed as necessary through the school health service. Before social workers lost their specialist interests and became "generic" the continuing advice and support for mentally handicapped school-leavers and adults became the statutory responsibility of mental welfare officers. After 1972, though still identified to the social services department, there was little opportunity to review and follow up every person who did not require active help. Various services were provided haphazardly and sometimes inappropriately, and there was often little co-ordination between hospitals, general practitioners, and com-

munity health, education, or social services. More recently, however, in the hopes of improving facilities and care those planning health and local authority services requested better information about the needs of the client population.

It might have been feasible to use prevalence rates from elsewhere and national norms for planning purposes, but as the main aim was to improve the provision of services to individual people a more extensive survey was needed. Consequently a register was started in 1976 under the aegis of the Oxfordshire Area Health Authority's Joint Care Planning Team and has been in use since 1977.

Main aims of the register

- (1) To identify all Oxfordshire residents who are moderately or severely mentally handicapped and who are likely to require supportive services now or in the future.
 - (2) To assess every identified person so as to ascertain the level of support required.
 - (3) To plan and provide such services as might be appropriate.
- Subsidiary aims* include the provision of:
- (4) A central data base and general resource centre.
 - (5) A sampling frame for research into better treatment and prevention possibilities.
 - (6) The means to monitor and evaluate care.

Population and numbers

Oxfordshire has a total population of nearly 550 000. Special schools, hostels, and adult training centres for the mentally handicapped are sited in Oxford, Banbury, and several of the country towns. There are inpatients in two small mental handicap hospitals within the county and a large hospital nearby in Berkshire. Many long-stay hospital patients originally came from outside the county, but when there are no remaining links with relatives or friends living elsewhere these people are now considered to be Oxfordshire residents.

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Method

IDENTIFICATION STAGE

Before any data were collected it was made clear that all information relating to individual people would be treated in strict confidence and that no individuals would be approached except through the doctor, social worker, or other person who first identified them. Most people were already receiving services and were known to one or more agencies so that few were identified for the first time for the register. All health visitors and all but two of the 200 general practitioners contacted agreed to identify people as necessary. One general practitioner refused to allow social workers access to any information about his patients.

Where necessary, after names had been collected present addresses and general practitioners were added from the family practitioner committee records so that the list as it grew could be refined and updated. Every index case was marked on a large map of the county. Sources of data included:

(a) *Community health/school health department*—A card index was set up and became the basis for the whole register.

(b) *Education department*—School lists for the special schools were provided to amplify and amend the index, including some Oxfordshire children educated outside the county or at boarding schools.

(c) *General practitioners and health visitors* were approached individually and agreed to provide names of patients, especially adults.

(d) *Social services department*—Names were added of all those in residential accommodation, in training centres, or who were receiving services such as home helps. Records were also sometimes available of others who had been identified previously but who were receiving no services at present.

(e) *Hospital Activity Analysis*—The Oxford Record Linkage Study holds details about past and present inpatients in the region. Those admitted to any hospital and having relevant diagnoses, such as Down's syndrome, were noted as were all patients admitted to mental handicap hospitals over the past few years.

(f) *Mental handicap hospitals* were visited, and the card index of present inpatients copied in each place.

(g) *Voluntary societies*—Some local members were identified.

(h) *Social security*—Several general practitioners pointed out that information about many handicapped patients had already been supplied to official quarters so that they could receive appropriate allowances and benefits. It proved impossible, however, to gain access to this source of data.

ASSESSMENT STAGE

A questionnaire should have been completed for every person identified. This incorporated sections on family background, education and training, physical history and present state of health, disabilities, incapacities (based on the Wessex "short form"), and services received or required. It was short enough to be completed in about 10 minutes yet comprehensive enough to give a general though superficial picture of each person and his needs. Because it was to be filled in by a wide variety of people (parents, social workers, health visitors, general practitioners, community doctors, teachers, managers of adult training centres, hospital staff, etc) or else details were to be collected from records, the self-coded answers had to be clear-cut and straightforward. Inevitably there was bias in subjective judgments, and some complained that the form was too long, too complicated, or sought too much information. In one mental handicap hospital the nursing staff refused to participate at first, but eventually they used the forms for routine preliminary assessments of patients. In another hospital one consultant undertook almost the whole burden of completing the forms. Overall, there was a remarkable degree of co-operation, and by 1979 86% of those identified had been fully or partially assessed. Data were cleaned and processed, then analysed by computer or by counter-sorter.

PLANNING AND PROVIDING SERVICES

Within a few months of the start of the project statistical evidence was presented to those planning health, education, and social services. Thus, for example, the register was used to support arguments and quantify needs for primary education facilities, a hostel, special care units for training centres, a local voluntary scheme, and a toy library. As the assessments of individual patients accumulated it was found that some hospital inpatients had little or no disability so that use of the

data encouraged a greater emphasis on rehabilitation and resettlement in the community. In order to feed back information to those most concerned with support and care every general practitioner was given a listing of their patients identified, along with a social services booklet on local services available; they were asked to amend details if necessary and return one copy to the co-ordinator of the register; they were also asked if they would agree to share brief details (name, age, address, general practitioner, physical disabilities) of all local patients with their area social services directors as an aid to planning and delivering services.

The computer print-outs will be available every year, and much of the present work of the co-ordinator lies in updating the files, acting as an information source for service provision and planning, initiating local research and small-scale surveys, and analysing the data. New index cases are added and assessed when general practitioners, health visitors, social workers, staff in maternity or paediatric units, and others complete special identification forms. If identified people are assessed as having mild mental handicap with no physical disabilities and are unlikely to require services their names are removed from the register. Those who are mentally ill but not mentally handicapped are also excluded as other service provision is made for them. Though some cases will be missing, it is now likely that the names of a very high proportion of moderately or severely affected adults and children are on the register.

Results

By 1980 2027 adults and children had been identified. Assessment is not yet complete, particularly of adults living at home, but fairly comprehensive data are available for 75% of those on the register and some details (besides basic index information) for 86%. Because of the addition of new cases, withdrawal, etc, the index file will never remain static, but it is unlikely to alter considerably from now on.

Definitions used in the tables include:

(a) *Grade of mental handicap* as assessed clinically or educationally: ESN(S) = severe mental handicap (roughly equivalent to IQ of 50 or less); ESN(M) = moderate mental handicap (IQ about 50-70).

(b) *Incapacity* by Wessex Social and Physical Incapacity Scale: CAN = Continent, Ambulant, No severe behaviour disorders. CANT = one or more severe problem(s) in above—that is, not CAN. A few people with multiple less severe problems were also classified as CANT.

(c) *Physical handicap* (PH)—Severe defect in one or more of vision, hearing, or speech; severe spasticity; frequent epileptic fits.

AGE, SEX, AND PLACE OF RESIDENCE

Overall, 73% of identified people live in the community, a proportion that rises to 89% among those aged under 20 years. Male subjects predominate in hospital and among those under 20, while among adults in the community there are many more women (516) than men (442). The overall sex ratio is 1019 male subjects to 1008 female subjects (table I).

TABLE I—Age, sex, and place of residence

Age group (yr)	Community			Hospital		
	Male	Female	Total	Male	Female	Total
0-4	20	20	40	0	0	0
5-9	70	69	139	2	1	3
10-14	98	76	174	12	9	21
15-19	89	72	161	23	14	37
20-44	310	339	649	124	78	202
45-64	94	111	205	89	67	156
≥65	18	66	84	55	63	118
Not stated	14	22	36	1	1	2
Total	713	775	1488	306	233	539

PREVALENCE OF SEVERE MENTAL HANDICAP

The prevalence varies with different age groups. The Oxfordshire prevalence rates are for people with severe mental handicap and certain other people less severely affected who require services. Rates for those aged 5 to 14 years, however, are due almost exclusively to severe mental handicap (3.9 community and 4.14 total per 1000). Lower rates are found among those under 5 before ascertainment is complete

and in adults over 45. Among children the number of cases has fallen even more steeply than the recent drop in total births, so that two-yearly prevalence rates among children aged 5 to 8 have shown a downward trend again after high rates for those aged 9 to 12 (table II). The rate per 1000 private household population (community cases only) is higher in Oxford City (3.46) than in Cherwell (2.57), South Oxfordshire (2.16), Vale of White Horse (2.26), or West Oxfordshire (2.39) (excluding 203 people out of the county, unknown addresses, etc).

DIAGNOSIS

Assessment is virtually complete for identified children aged 3 to 16 years, nearly all of whom have severe mental handicap. In nearly 40%

TABLE II—Prevalence rates in Oxfordshire by age and local authority district (1980 population estimates)

Age (yr)	In community	In hospital	Total	Rate/1000 private household population (community cases)	Rate/total population (all cases)
0-2	14	0	14	1.19	1.25
3, 4	26	0	26	3.3	3.9
5, 6	49	0	49	3.17	
7, 8	52	3	55	4.52	4.14
9, 10	75	2	77	4.78	
11, 12	79	10	89	3.4	3.3
13, 14	58	9	67	3.9	
15-19	161	37	198	3.5	3.84
20-44	649	202	851	2.47	
45-64	205	156	361	0.96	3.07
≥65	84	118	202	—	
Not known	36	2	38	—	—
All ages	1488	539	2027	2.9	3.71

TABLE III—Diagnosis in 450 children aged 3-16 years (born 1964-77)

Down's syndrome, other chromosomal	26.5
Non-chromosomal abnormalities of central nervous system	9
Cerebral palsy	6.5
Birth injury	2
Infection, postinfective, immunological causes	2
Nutritional, metabolic	2
Psychiatric syndromes	4
Cerebral anoxia	1.5
Cultural-familial	1
Hereditary/familial, degenerative diseases of central nervous system	1.5
Epilepsy	1
Recognised syndromes of unknown aetiology	1.5
Other conditions	3
Subnormality (not elsewhere classified)	4
No known cause	34.5
	100%

TABLE IV—Comparative prevalence rates for severe mental handicap and Down's syndrome

Place	Year	Age group	Prevalence MH per 1000	Down's per 1000	Reference
Wessex Counties	1963	15-19	3.84	1.18	Kushlik and Cox ¹
Edinburgh	1964	7-14	5.0	1.85	Drillien <i>et al</i> ²
Camberwell	1967	7-13	3.57	0.62	Wing ³
Northern Ireland	1975	15-19	4.81	NK	MacDonald and Mackay ⁴
North-east Scotland	1966	{ 15-19 All age	{ 3.70 2.16	NK	Innes <i>et al</i> ⁵
		{ 5-14 15-19	{ 3.9 3.9	1.03	Present study
Oxfordshire	1980	{ All age 3-16	{ 2.9 3.71 (all)	{ 0.66 0.43	

NK = Not known.

TABLE V—Grade of mental handicap and place of residence

Grade	Community			Hospital		
	Age <20	Age ≥20	Total (%)	Age <20	Age ≥20	Total (%)
ESN(M)	102	295	397 (36)	2	71	73 (14)
ESN(S)	318	274	592 (53)	52	314	366 (71)
Other (for example, mental illness and handicap)	9	108	117 (11)	4	77	81 (15)
Total	429	677	1106 (100)	58	462	520 (100)
Not stated	85	297	382	3	16	19

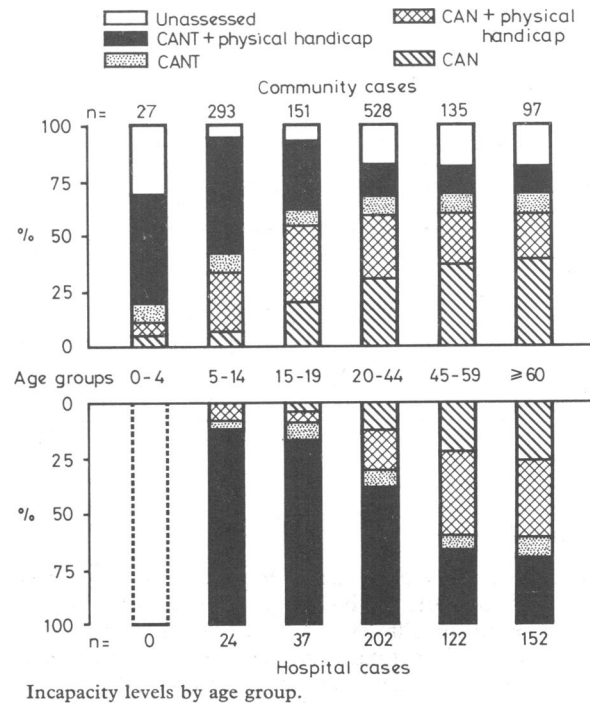
of cases the aetiology is uncertain. About one-quarter have Down's syndrome (table III). The prevalence of this disorder varies with the age group between about 0.6 to 1 per 1000 base population and is similar to findings in surveys elsewhere in Britain (table IV).

GRADE OF MENTAL HANDICAP

Many more people aged under 20 designated as severely handicapped (ESN(S)) live in the community (318) than in hospital (52), but ESN(S) adults are more likely to live in hospital (table V).

INCAPACITY AND PHYSICAL HANDICAP

Of the 1787 people fully assessed, adults living in the community are less likely to have severe incapacities (27% aged 20-64 are CANT) than children in the community (59% of those aged under 20). Almost half the adults living in hospital (46%) are CAN, but a large propor-



tion of them (59%) have severe physical handicaps. Very few children live in hospital and, of these, nearly all are severely affected: 88% of the 24 children aged 5-14 years in hospital are CANT as well as physically handicapped (table VI, figure).

TYPE OF INCAPACITY

Incapacity in adults is probably due to severe behaviour disorders or multiple problems, whether at home or in hospital. Incontinence without locomotor or behaviour problems is found chiefly among young people living at home or adults in hospital (table VI).

TABLE VI—Incapacity by age and place of care (all adults and children)

	Community		Hospital	
	<20 years	≥20 years	<20 years	≥20 years
CAN	195 (41%)	570 (73%)	5 (8%)	221 (46%)
CANT				
Severe incontinence	69	17	8	40
Non-ambulant	65	22	18	48
Severe behaviour	71	80	21	92
Multiple problems	71	90	9	75
Total = (100%)	471	779	61	476
Not known	43	195	0	2

PLACE OF RESIDENCE

Few adults live in hostels or residential homes. Most who are ESN(M) live at home (66%). By contrast over half ESN(S) adults live in hospital. People with severe mental handicap and also severe incapacity (CANT) are more likely to live in hospital while those with moderate mental handicap but severe incapacity are more likely to live at home (table VII).

TABLE VII—Place of residence by incapacity and grade (ESN(M) and ESN(S) adults only)

	Community		Hospital	Total
	At home	Hostel/ residential home		
ESN(M)				
CAN	184	36	43	263
CANT	45	19	28	92
Not known	11	—	—	11
Total ESN(M)	240 (66%)	55 (15%)	71 (19%)	366 = (100%)
ESN(S)				
CAN	148	39	132	319
CANT	56	19	181	256
Not known	11	1	1	13
Total ESN(S)	215 (37%)	59 (10%)	314 (53%)	588 = (100%)

Discussion

The main content of a mental handicap register reflects its main purpose and the method of its development. Many have now been set up in different parts of Britain, some to provide statistical data for planning and a sampling frame for research into aetiology and possibilities for prevention. More recently the emphasis has moved towards providing services and better co-ordination in planning by different agencies. A function that should become increasingly important is the monitoring and evaluation of different forms of treatment and care.

The Wessex register is probably the most comprehensive and effective in Britain at present but is relatively costly in personnel and facilities. It is used in estimating local and national norms for service needs, in the individual provision of care, in monitoring and evaluating services, for research and teaching, and as an information base.

The register developed in Oxfordshire has been designed for a similar variety of uses but is primarily a small and cheap local version to provide better, more co-ordinated, and more appropriate services for mentally handicapped people. The initial work of data collections and collation was done on a part-time basis by a lecturer in community medicine (JJ) and a research assistant (DE), with statistical and computer help later (JG). Without the generous help given in the assessment stage by many different people the register would have been much more expensive to set up, though it might have been functional sooner. The total annual costs remain at about £8000, mainly for the co-ordinator's salary.

The first period of collecting information and providing feedback to service-givers is now complete, and in future there will probably be a greater emphasis on relevant and useful research and review to help the people identified. Access to computer data is controlled by a password held at present by two people. Any research proposals have to be vetted carefully by the area

ethical committee. It has been agreed that registered individuals should not be contacted directly but only through the general practitioner or person(s) who identified them.

This emphasis on confidentiality does not hide the fact that the register was set up without requesting the permission of many affected people or their relatives, albeit that a large number were already identified by different agencies. This was a conscious decision that was regretted in principle but thought necessary at the time. Fortunately, it has caused little difficulty, and when relatives learn more about the register they appreciate the facilities and support offered through it. Those parents and relatives who were asked to complete assessment forms did so in a most co-operative and comprehensive manner, not surprisingly. It will be important to continue on this basis and involve relatives as much as possible in the assessment of individual need and the provision of care. The co-ordinator has interviewed several families in two districts to inquire into any problems of coping in greater depth. She is also circulating a short news bulletin to professional staff and others interested in learning more about the register.

The main findings of the survey have lent greater emphasis to providing homes and hostel places for people who otherwise might have remained in hospital. It has been possible to provide more facilities for the care and treatment of those multiply handicapped, while greater interest in the problems and needs of the disabled and their families has been engendered among primary care teams, social services, and voluntary agencies. There is increased involvement in the assessment and modification of severe behaviour disorders.

At present there is a downward trend in prevalence among younger children, which is probably due mainly to the high quality of care given in pregnancy and early childhood in Oxfordshire along with the availability of alpha-fetoprotein screening and amniocentesis and, where necessary, the offer of early abortion to mothers with severely affected fetuses. Despite these preventive services the number of births of severely mentally handicapped children may well rise during the next few years when the overall birth rate is expected to rise fast. So far most effort has gone into assessing present needs and planning care, but more is needed for clarifying aetiology and for primary and secondary prevention. An important function for which the register is ideally suited because of the in-built updating system will be the evaluation of treatment and care.

It would be difficult to prove that setting up the Oxfordshire Register has been effective and beneficial in providing services to the mentally handicapped although, coincidentally, the planning and delivery of these is becoming more realistic, co-ordinated, and appropriate. Even if other forces have conspired towards these ends a register does appear to be a potent means of stimulating progress in better treatment and care for mentally handicapped people.

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