

THE WIMMERA SURVEY OF HANDI CAPPED CHILDREN

by

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Introduction

The Wimmera Survey was conducted by Miss Brown and four social work students from the University of Melbourne, during February 1973. All were resident at the Wimmera Base Hospital for the duration of the survey (3½ weeks). Without the four students who assisted as part of their field work training, the survey would not have been possible.

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Aims

The aims and purpose of the pilot survey, which was conducted under the auspices of the Hospitals and Charities Commission, were:

1. To ascertain the number of persons in the area under 21 years with a handicap.
2. To describe facilities currently available for handicapped children and young adults.
3. To assess the need for additional services.

The definition of handicapped was taken as 'a disability which is more than temporary which restricts or handicaps that person in normal daily living, education or employment'. This definition is very much a functional one, stressing permanency and is used for the State Register of handicapped young people. It is only secondarily a medical one.

Contact

Preliminary contact with relevant personnel was made from Melbourne, but the actual interviewing and collection of data was carried out from Horsham on a daily basis, the area being divided into five regions, one for each member of the Team. We were assisted by members of the Red Cross Society who provided voluntary transport, travelling as much as 140 miles per day. In fact over 1850 miles was covered in the 3½ weeks, in visits to Dimboola, Nhill, Kaniva, Stawell, Goroke and Warracknabeal.

Guidelines

Five sets of guidelines for the interviewers were drawn up to cover areas of interest — health, education, employment, welfare and family services. One hundred and eighty four informants were consulted by face to face interviews, letters and telephone contacts were also made to outlying centres and small country schools. Discussions were sought with knowledgeable

Region Surveyed

An area with a population of 47,000, the majority living in Horsham (11,045), was selected for study. It is interesting to note that in 12,000 square miles the density of population outside Horsham is .275 per square mile. (Shires of Donald, Avoca and St. Arnaud were not included). All the other major towns have a negative growth rate, according to 1971 Census. This is important in planning services, especially in rural areas. Expansion of services does not need to increase parallel with the rise in the State's overall population increase. The percentage of those under 21 in the Wimmera is similar to the remainder of the State, indicating that whole families are leaving the area.

(See map next page)



Miss B. Brown

For the past six years Miss Brown has held the position of Registrar of the Handicapped Persons Information Bureau of Victoria. Prior to 1970 Miss Brown worked as a Medical Social Worker at the Royal Children's Hospital in the Neurosurgical, Neurological and Spina Bifida Units, and has spent some time working in the General Hospital in London and teaching physically handicapped children.

and experienced people e.g. medical practitioners, infant welfare sisters, school principals, hospital personnel, paramedical staff, and welfare officer in Horsham. In addition, voluntary organisations and service clubs were consulted. Co-operation was excellent and we were also able to meet 26 families each having a handicapped child.

Basically we were interested in how parents obtained medical treatment and other services, such as education, for their children, the problems they faced and also the referral patterns used by them and Doctors to obtain Specialist treatment necessary. It should be noted that no names and address were sought although many were given voluntarily, only age, sex, disability and place of residence and sufficient details to prevent duplication.

Findings

The data collected, we believe is a reasonable picture of the situation in the survey area at the time of the pilot study. Certain bias did occur; for example, information regarding speech problems was an underestimation of the situation as the therapist had only just begun an assessment program; and some variation in the amount of information obtained from each area occurred according to the skill of the interviewer and the co-operation of the personnel interviewed. It became apparent that the definition of 'handicapped' might have to be modified or a better selection of the 'handicapped' should need to be made. The definition was being stretched to include 'social problem', 'behaviour difficulties' and even 'mother working'.

Time was in short supply as the whole project was to be completed in six weeks, distances to be covered proved further than anticipated and in addition many of the voluntary drivers had family commitments.

The child population (i.e. under 21 years) of the area surveyed was 19,152. The number of handicapped children or young adults was ascertained at 283 i.e. 1.48% of the total.

HANDICAPPED CHILDREN 0-20 YEARS

	Number	Rate per 1000 children
Mental Retardation	155	8.10
Sense Organs	46	2.40
Nervous System	26	1.35
Asthma	25	1.30
Others	31	1.62
	283	14.77

A summary can be shown —

HANDICAPPED CHILDREN 0-20 YEARS (283)

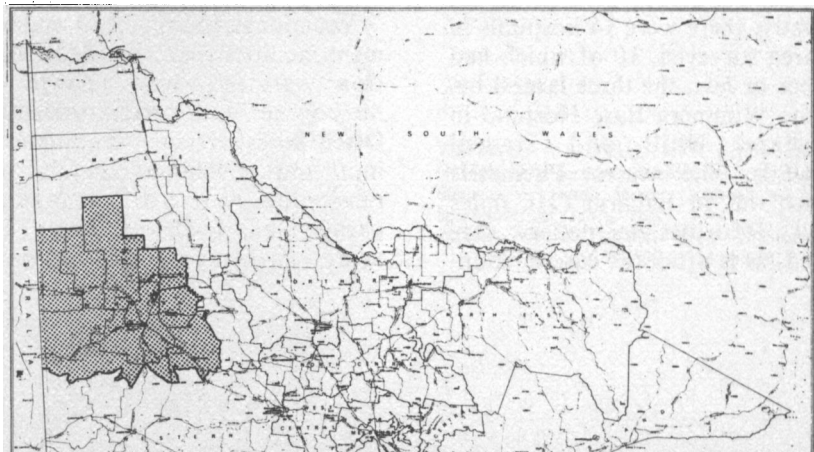
Mental Handicaps* i.e. M.R.	172 (61%)
Sensory Handicap only	45 (16%)
Physical Handicap only	66 (23%)
	283

* With or without physical handicap

(1) Specific learning difficulties

In addition there were 124 children, including 17 classed as having 'specific learning difficulties', where the degree of handicap was uncertain and where it was uncertain whether special facilities would be required. Of the total number assessed as in need for some special service 12% were multi-handicapped — an important factor when considering the establishment of special services.

(2) Map of Victoria depicting Wimmera district.



HANDICAPPED CHILDREN 0-20 YEARS NERVOUS SYSTEM

Cerebral Palsy	10
Epilepsy	9
Polio	4
Spina Bifida and Paraplegia	3
	—
	26

The major handicap was of course mental retardation, followed by sensory defects (especially deafness), asthma, and neurological conditions such as epilepsy. The figures for epilepsy and cerebral palsy are probably underestimated because when they have been combined with mental retardation they have been generally classified under the latter, because this is the dominant condition governing the services required. Only 23% of the children had physical handicaps alone. Thus mental retardation and sensory defects made up 77% of all handicaps ascertained.

HANDICAPPED CHILDREN 0-20 YEARS MENTAL RETARDATION

Borderline	94 (61%)
Moderate	30 (19%)
Severe	8 (5%)
Unspecified	23 (15%)
	—
	155

HANDICAPPED CHILDREN 0-20 YEARS

Sense Organs	Number	Rate per 1000 children
Deafness	32	1.67
Blindness	14	0.73
	—	—
Total:	46	2.40

Although we were not including psychotic children and adults in our study, at least 23 children and a minimum of 2 of the 36 adults were variously described as emotionally or psychologically disturbed, or had behaviour problems which were considered to be severe enough to handicap them in their performance at school or in employment. (The adults in question were unemployed and attending O.T. at the Base Hospital for want of something better to do, or were at home doing nothing).

The 31 children described in 'other diseases' had conditions which were considered handicapping but perhaps would not fit into another group diagnostically for the purpose of establishing new services.

HANDICAPPED CHILDREN 0-20 YEARS OTHER DISEASES

C.H.D.	5
Orthopaedic	4
Diabetes	4
Emotional	4
Coeliac	3
Speech Defect	3
Autism	2
Head injury	2
Encorpresis	1
Oesophageal Problem	1
Cleft Palate	1

Lacks

As far as services already available to the family with a handicapped member were concerned, a few brief comments follow. The main problems of the Health Services were:

1. Lack of specialists
2. Lack of access to diagnostic and treatment facilities
3. Lack of paramedical personnel

Firstly, there were 14 hospitals in the area surveyed, 10 of which had 20 beds or less, the three largest being the Wimmera Base Hospital in Horsham, Nhill and Stawell Hospitals. The nearest Paediatric Service was in Ballarat (116 miles away). Priorities in patient care tended, as is often the case in coun-

try areas, to be geared to the geriatric age group. Of the 22 doctors in the area, all specialist personnel were in Horsham e.g. obstetrician, ophthalmologist, radiologist, and orthopaedic, psychiatric and T.B. Clinics were conducted regularly (2 weekly — 3 monthly) in the city too. Assessment of children generally meant a trip to Melbourne (188 miles). Paramedical personnel were in short supply, a common fact in country areas.

It seemed that the main deficiencies in the educational services were:

1. Lack of adequately trained personnel.
2. Lack of remedial services.
3. Lack of close liaison between specialist services e.g. Clinical Guidance and Counselling Service, School Medical Service; to ensure better screening of children.

Services

Services for the handicapped children within the education system consisted of one speech therapist, one district inspector, a visual education and remedial centre, all based in Horsham. Visiting teachers for deaf and blind children attended regularly from Melbourne. Counselling services for children leaving school and their families were nil!

A problem, specific to the Wimmera was the existence of the residential Day Training Centre for mentally retarded at Warracknabeal, and of Stawell Special School and residential facilities in Stawell. Being residential, children (mainly Wards of State) from other parts of Victoria are placed in these institutions thus depriving local residents of places.

Vocational training

Vocational training and employment facilities were few. Rehabilitation services were based in Melbourne and were residential. Often these services were unknown in the area, and individuals were reluctant to 'come off the land' to participate in the scheme. The nearest sheltered workshops for the

mildly retarded were in Bendigo and Ballarat. However since the survey, Horsham and Nhill have established Day Training Centres and will develop workshops, and Ballarat has started a Rehabilitation Centre. There is still a need however for hostel accommodation for persons attending these facilities.

There were a paucity of professional welfare personnel to provide much needed 'support' for families. The voluntary agencies however provided an invaluable grass roots service.

Conclusions and Comments

This was not a medical survey. We were interested in total numbers and prevalence. It was a general survey concerning the whole child population and the whole range of handicaps. This is more difficult than a single disease survey, but much more valuable as a guide to community service requirements.

The definition of 'handicapped' stressed its permanency, the presence of some residual disability, the need for prolonged observation and care and the requirements of special services.

Chronic diseases

This was the first survey of its kind in Victoria though many surveys have been carried out in other countries. Most surveys are based on administrative prevalence i.e. number known to hospital, clinics, institutions, and agencies; or with specific diagnostic groups.

The figure of 1.48% of children is a common figure for those handicapped children who require special services. The number of children with chronic diseases is much larger, most studies indicating 13-17%; interpolating those figures from Western countries and from the Wimmera survey, we can expect about 20,000 such children in Victoria and 70,000 in Australia.

One of the major handicaps in children is deafness, and although there is the problem of assessing when does the degree of impaired hearing become a real handicap; most surveys of school age children

reveal about 2-3% have impaired hearing to some degree. (For the incidence of permanent deafness in Australian children please refer to M.J.A. July 4th, 1973). Incidence of children requiring a hearing aid is 2:1000 live births varying from 1.7 in N.S.W. to 2.9 in South Australia. Asthma produced the largest group of children with physical handicaps — a finding not uncommon to surveys. The children in the Wimmera were coping with school but the number of episodes and loss of education days was not recorded.

The dominant position of mental retardation and multiplicity of handicaps complicates provision of services and many services in rural areas may well have to be multi-diagnostic as there are not sufficient members in single groups to justify the establishment of separate facilities. Another important implication of this dominance is public education. The public tend to equate 'handicapped child' with 'crippled child', considering mental retardation, sensory defects and other conditions apart.

Implications for the Development of Services

In summary, the main problems facing families with handicapped members particularly children, in the Region (and presumably in other country areas) were:

1. Lack of access and availability of diagnostic and treatment facilities.
2. Lack of personnel (reasonably distributed).

3. Lack of 'support' services, both on a practical and emotional level.

4. Inadequate transport system affecting accessibility of services, and delays in treatment.

The problems of distance, in addition to the predominance of mental retardation and multi-handicapping conditions, must inevitably have an effect on the planning and provision of services in a country area such as the Wimmera.

It would appear that, with the centralisation of essential specialists in Horsham, a system of itinerant physiotherapists, occupational therapists and speech therapists, even social workers, would go a long way to alleviating the inadequacies of specialist services.

Inadequate knowledge of facts concerning the handicapped and their needs increases difficulties in planning, damage to public confidence and adverse consequences to the handicapped themselves. The availability of accurate information would lead to:

1. Relief, and possible cure of many ills.
2. Substantial economic gains to the community (Griffith) ⁴.

Start

This survey was a start in the gathering of information. Many others of a general 'need' nature have been carried out, particularly since the establishment of the Regional Councils for Social Development in the State. This is

encouraging and should lead to valuable resource material being available to the planners and coordinators of services in the future.

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The survey found that 1.48% needed special services. The number of children with chronic diseases is much larger, around 13-17%. Interpolating from this — "we can expect around 20,000 such children in Victoria and 70,000 in Australia."