

A SURVEY OF MENTAL RETARDATION IN VICTORIA (Australia)

1. FAMILIES' PERCEPTIONS OF THE NEEDS OF MENTALLY RETARDED IN THE COMMUNITY

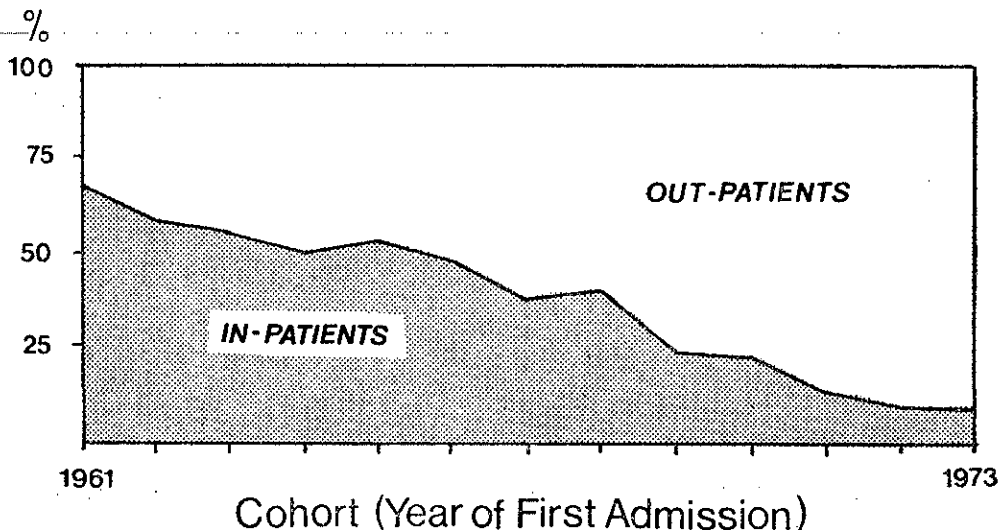
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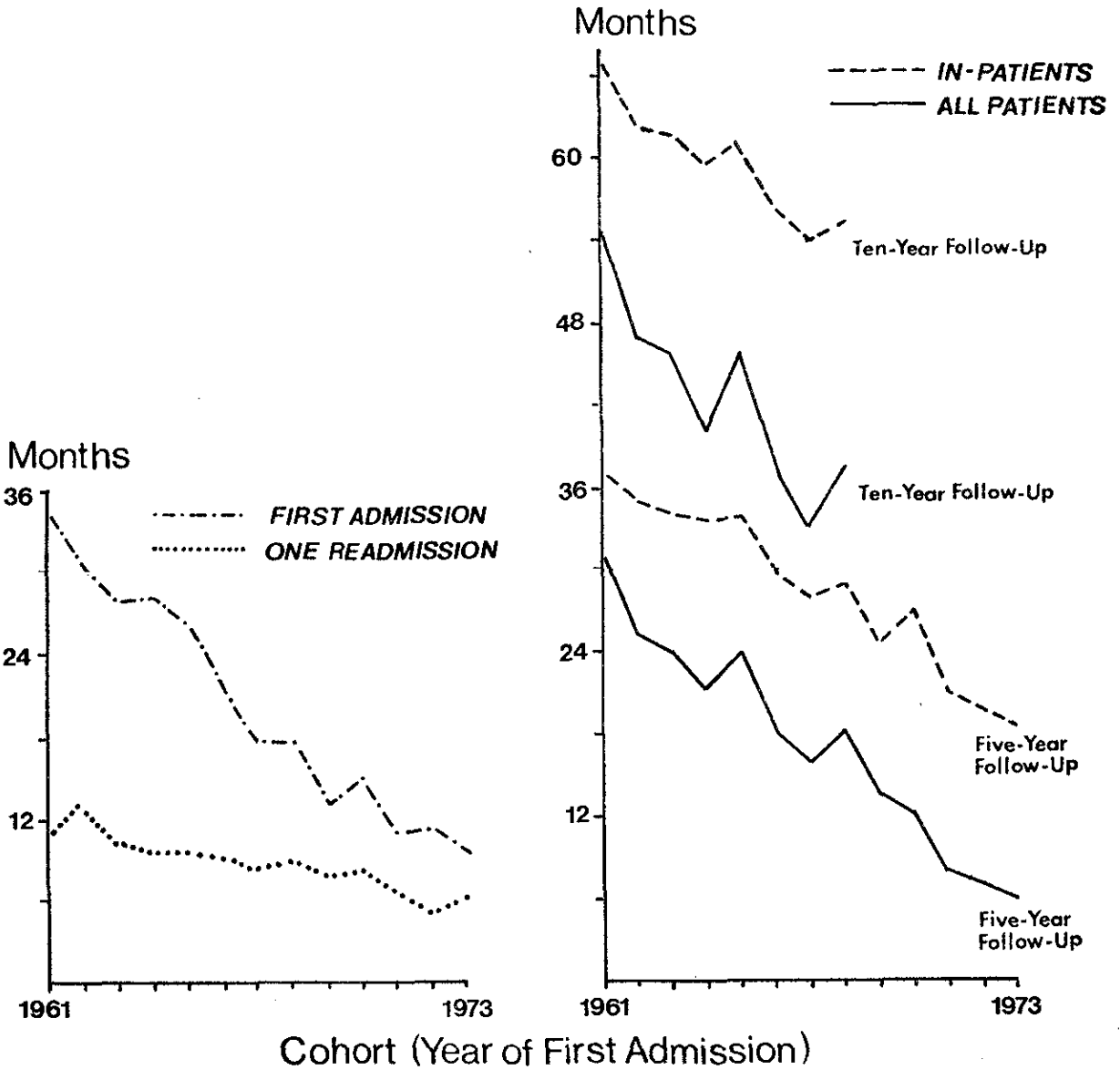
INTRODUCTION

The types of appropriate services for mentally retarded have been the subject of a heated debate in the last ten or more years (Gunzburg, 1972; Rosen and Kiwitz, 1973; Smokoski, 1971). All persons working in the field of mental-retardation are in agreement that large, old-style institutions have outlived their usefulness, and their environment is often more harmful than helpful to the habilitation of the mentally handicapped. The concept of 'normalisation' has been developed by Nirje (1969) and Wolfensberger (1972) assuming not only a move from institutions to the community, but also from specialised to general community service.

A longitudinal study of the Victorian computerized register (Krupinski et al. 1982) has shown a significant shift in the care of the mentally retarded in Victoria from institutions to out-patient facilities (Figure 1) and a significant decrease in the total length of stay in residential care during the last twenty years (Figure 2).



1. Percentages of in-patient and out-patient first admissions by year, 1961-1973.



2. Time spent in institutions on one admission and during the follow-up periods by year of first admission.

There is, however, a paucity of data on the mentally retarded in the community, a paucity which prevents the objective assessment of their needs, and the gearing of services to their particular requirements. To fill this gap, the Mental Health Research Institute of Victoria, Australia, recently carried out a study of the "Needs of the Mentally Retarded in the Community" (Krupinski et al., 1981). A stratified sample of 718 families was drawn from the 5770 mentally retarded persons known to the Victorian Mental Retardation Services. A comprehensive semi-structured interview schedule was devised to record information on health, physical disabilities, educational achievements and social functioning of subjects. Gunzburg's Progress Assessment Charts (Gunzburg, 1974) were used to assess their social competence. The methodology applied is described elsewhere (Krupinski and O'Connell, 1983.) Details of social and familial background, relationships with other family members, and effects upon the family were also recorded. Information on the type of care and use of counselling and welfare services, since retardation was diagnosed, was noted along with the family's expressed current and future needs in respect of the retarded member. The interviews were carried out by qualified social workers and senior social work students specially trained for the task. Interviewers also attempted to assess the current and future needs of the studied subjects and their families.

Successful interviews were obtained for 529 subjects, the response rate being 73.7%. Only 29 families (4.0%) refused to participate in the survey with a further 45 (6.3%) apparently avoiding the interviewer by being absent from home at the arranged appointment time. In 78 instances (10.9%) the address recorded in the departmental files was no longer current and we were unable to locate the family's present whereabouts. In another 25 cases there was no address recorded at all in the files. Thus our sample is representative of only those mentally retarded living in the Victorian community who were known to the Mental Retardation Services. Of the 5770, however, 432 (7.5%) had already been placed in residential care at the time of the study.

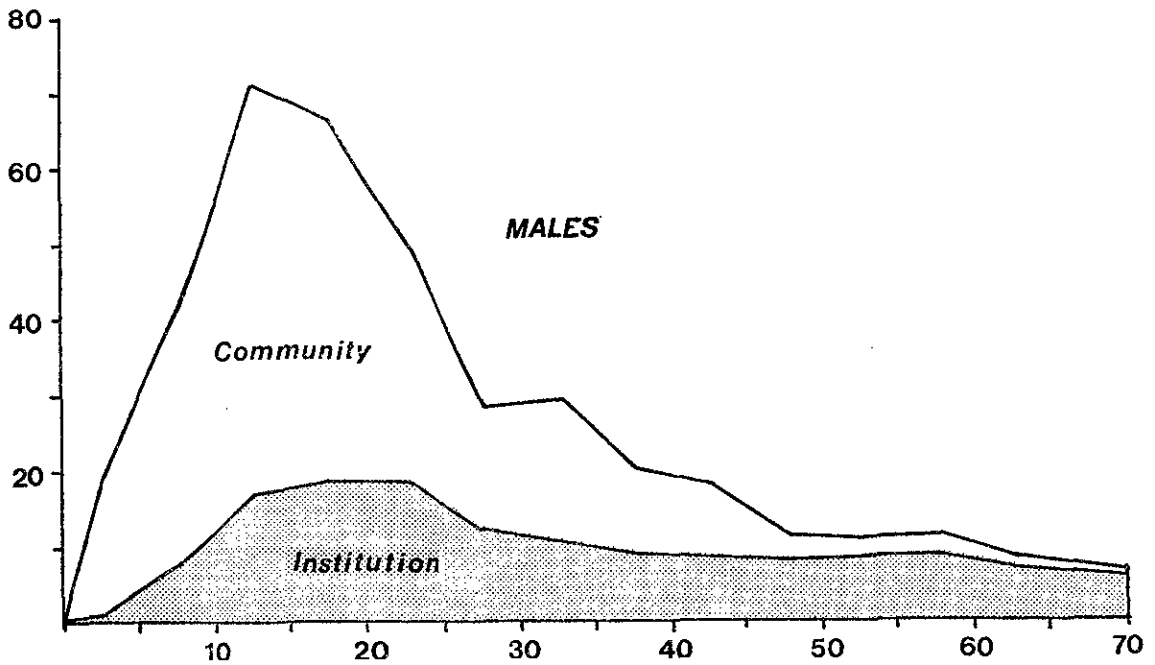
The Mentally Retarded

Figures 3 and 4 compare the age-specific prevalence of all retarded known to the Service with those under residential care in departmental facilities. The greatest gap appears in adolescence and young adulthood, when the majority of the retarded are still living in the community. Forty-nine per cent of subjects had already passed their seventeenth birthday, and only eight per cent were in the under six year age group. The level of retardation was obtained from the latest diagnosis made. Almost two-thirds of the retarded in the community were found to be mildly or moderately retarded, with only a relatively small proportion (13%) recorded as either severely or profoundly retarded. The remainder were either borderline (6%) or else the level of retardation was not known. The Progress Assessment Charts were used to determine the level of impairment of their social competence and an age-related index of the latter¹. Index scores of physical and sensory impairments and behavioural problems were calculated on the basis of the types of existing impairments, and the frequency and severity of specific behavioural problems. Table 1 characterises the subjects in terms of these variables.

One-quarter of the retarded experienced very severe impairment of social competence, and this proportion exceeded even one-third when the age related index of social competence was calculated. Additional physical and sensory impairments were fairly common, but tended to be of a minor degree or else limited in nature. One-half of all persons were described as having some form of additional handicap of a minor nature. In a small group (4%), interviewers reported that subjects were either severely handicapped or else had multiple handicaps. Most families reported some form of problem behaviour in the retarded child/adult. A few (9%) regarded the problem as severe, or else reported multiple behavioural problems.

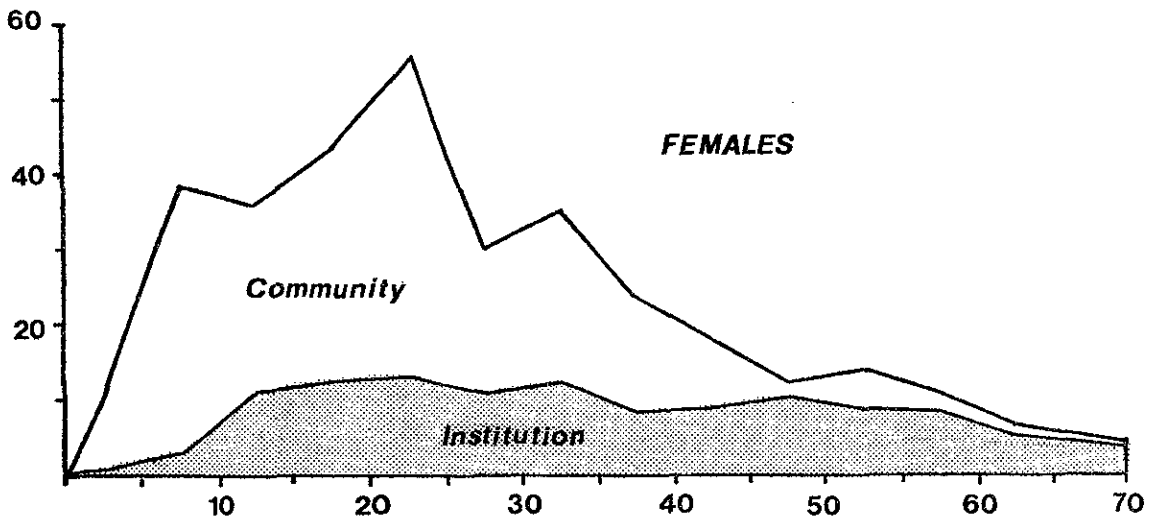
1. For details see p.40.

RATE PER 10,000 POPULATION



3. Age-specific prevalence rates per 10,000 of male population in terms of type of care.

RATE PER 10,000 POPULATION



4. Age-specific prevalence rates per 10,000 of female population in terms of type of care.

Table 1
Mentally Retarded in the Community: Levels of Retardation, Social Competence, Physical Impairments and Behavioural Problems (Percentages).

Level of Retardation	Level of Impairment (Modified Scale of Social Competence)		Index of Social Competence		Physical and Sensory Impairment Index		Behavioural Problems (Behavioural Problems Index)	
	%	%	%	%	%	%	%	%
Borderline	6.0	Mild 16.2	70%+	15.5	Nil	43.6	Nil	14.5
Mild	18.9	Moderate (high) 19.4	50<70%	26.8	Minor	29.5	Minor	27.6
Moderate	47.4	Moderate (low) 14.1	35<50%	14.4	Moderate	16.2	Moderate	26.5
Severe	9.0	Severe 26.9	20<35%	8.9	Major	7.0	Major	22.8
Profound	3.8	Very Severe 23.4	<20%	34.4	Multiple/severe	3.7	Multiple/severe	8.6
Not known	14.9							
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

As expected, the strongest correlation (0.7) was found between the P-A-C Index and the level of mental retardation. The Impairment Index Score was also markedly correlated with the above two variables (0.47 and 0.51, respectively), whilst the correlation of the Behaviour Index Score with any of the three characteristics was rather low.

Translating the percentages into absolute figures, one can expect the following numbers in each category from the total population of 5770 (Table 2).

Table 2
Mentally Retarded in the Community: Levels of Retardation, Social Competence, Physical Impairments and Behaviour Problems (Numbers)

Level of Retardation	Level of Impairment (Modified Scale of Social Competence)		Index of Social Competence		Physical and Sensory Impairment Index		Behavioural Problems (Behavioural Problems Index)	
	N	N	N	N	N	N	N	N
Borderline	346	Mild 935	70% +	894	Nil	2516	Nil	837
Mild	1091	Moderate (high) 1119	50<70%	1546	Minor	1702	Minor	1592
Moderate	2735	Moderate (low) 814	35<50%	831	Moderate	935	Moderate	1529
Severe	519	Severe 1552	20<35%	514	Major	404	Major	1316
Profound	219	Very Severe 1350	<20%	1985	Multiple/severe	213	Multiple/severe	496
Not known	860							
	5770	5770	5770	5770	5770	5770	5770	5770

EFFECTS ON THE FAMILIES

Almost all (88.9%) subjects in the study were living with one or both parents. The remainder were either with other relatives (usually siblings) or else were already permanently institutionalised (7.5%) at the time of the study. The location of the subject was related to the type of family of origin, although this relationship was not absolute. Where the subject was living within the family of origin, the family unit usually included both parents (82.8%). However, more than one-half of those who were already institutionalised, and one-third of those living with other relatives, were from intact families where both parents were living together. In almost two-thirds of cases (64.3%), one of the parents was responsible for the care of the subject, and this was predominantly the mother (54.5%). Only in one in nine cases (10.9%) was the subject, or the subject's spouse, recorded as the caring person. Many subjects (15.6%) were being cared for by elderly parents aged sixty years or over. One in four of the subjects (23.7%) had parents aged from fifty to fifty-nine years. In most of these cases the subjects had already reached adolescence or even adulthood.

Interviewers asked informants to describe what effects (if any) the presence of the retarded member had had upon the family in respect of family relationships and cohesion. In most cases informants felt that any effects had been predominantly negative. Only 16.4% of families described their experiences as positive. About one-half of all families (54.3%) stated that the care of the retarded child had resulted in restrictions on other members of the family.

The specific area of family life most often reported as being restricted was social activity (41.5%) followed by the inability to take family holidays (35.7%) or engage in leisure pursuits (34.6%). Parents of children aged between six and sixteen years were more likely than others to report restrictions on family activities. In terms of social competence (as might be expected), the subjects with the highest levels of impairment presented the greatest restrictions upon family members and activities. Restriction upon family life was significantly correlated with behaviour problems (0.51), social competence (0.41), physical impairments (0.32) and the level of retardation (0.31).

USE OF COMMUNITY SERVICES

The use of community-based services — both specialised facilities for the mentally retarded and general services designed primarily for the non-retarded — were analysed in several ways. We considered past and present use of specific services, use during three different age periods, and an overall rating in which both the number of services used and the frequency of use were taken into account.

Overall, almost two-thirds (65%) of the families were currently using specialised facilities or services. This percentage was slightly higher in the school age group (68%) and the post-school age group (67%), but was much lower for the pre-school children (24%). As expected, when the rates of past and current use of specialised services were combined the percentages were much higher for the older subjects. Whilst only a small proportion (25%) of families had ever used specialised services during the child's pre-school years, the corresponding figures for school and post-school years were considerably higher (72% and 87% respectively).

In contrast, over half (58%) of the children under six years were currently attending kindergartens, play centres or other services for the non-retarded. The corresponding rates for school age children (12%) and post-school subjects (2%) were very much lower. This extensive use of services for the non-retarded by pre-school children is a recent phenomenon. When the older subjects were included, the percentage of combined past and current use of general pre-school services dropped markedly to twenty-three per cent.

The low rate of use of specialised services during pre-school age years was due to both a lack of suitable services (in 32% of cases) and a high number (20%) of parents who chose not to use such services, even though they were available to them.

Day Training Centres were the most frequently used of the specialised services. Almost two-thirds of our subjects had attended in the past or were currently enrolled at day centres. One in six were attending sheltered workshops and adult training groups. The out-patient section of the Mental Retardation Service had been used at some time by one-quarter of the families (27%), with a group about half this size (17%) reporting that they were involved with organizations of parents of the retarded.

Of the general community services, the most frequently used were home help (30%) and infant welfare centres (29%). The rate for infant welfare centres was extremely low in comparison with the general rate of enrolment which exceeds ninety percent of reported births.

In order to assess the overall extent of use of community services by families, a Service-Use Index was devised. This Index took account of both the number of different services used and the frequency of use. A rather large number of families (23%) reported having used only a few services; a small group (1%) stated that they had never used any community service. Frequent use of services was recorded for a number of families (12%). The remainder (64%) used these community facilities at a level somewhere between 'occasionally' and 'frequently'. Community based services were used least by subjects with lower grades of retardation and lower levels of social competence.

SERVICES NEEDED

Residential Care

To assess the needs for residential care, parents were asked if they considered residential care desirable, and if so, what were the specific reasons for placement. In addition, interviewers were asked to assess the need for permanent placement on the basis of the family's wishes and circumstances, taking into account the level of dependence of the subject, the demands of other members of the family upon parents, accommodation and any other factors considered to be relevant. The families were almost evenly divided with slightly more (50.9%) seeing no need for a current placement. Over one-quarter (26.4%) felt that residential care was required now, whilst an additional 22.7% foreshadowed the possibility of a future request for placement. The most commonly given reasons by those requiring placement now were the subject's need for specialised treatment (19.3%), age or ill-health of parents (17.4%), inability to cope (13.6%) and other family demands and responsibilities (12.9%). However, 35.3% of those requiring placement now did not give any reason for their request.

The interviewers found nearly one-half (41.5%) of the subjects as being unlikely to ever require permanent institutionalisation. Of the 5770 persons represented by the sample, only 263 were considered to be in need of immediate placement. An additional 432 had already been institutionalised at the time of interviewing. Thus 12.1% were either already placed or required placement as soon as possible. Another nine per cent would require placement in the future, whilst such a likelihood of placement exists for a further 28.7%. It seems that parents tended to consider early placement as necessary much more than interviewers felt was appropriate. The latter were more likely to see placement needs emerging in the future. Immediate placement was more often requested by the six to sixteen years age group, whereas the need for future placement was lowest in the youngest age group and highest among those aged seventeen years or over.

Similarly, the need for placement was strongly related to the level of social competence. The higher the latter, the greater the percentage of those not requiring

placement, or at most, assessed as only likely to require it in the future. On the other hand, the percentage of those definitely requiring placement now or in the future increased along with the diminishing level of social competence. The one exception to this trend was the high percentage of persons already in residential care in the group with the least impairment of social competence. As well as assessing the needs for residential care, the interviewers were asked to specify reasons why they assessed placement as being necessary. The questionnaire distinguished between family-related and child-related reasons for placement. Behavioural problems of the subject were the most common child-related reasons offered for immediate institutionalisation. It was recorded in two-thirds of cases where immediate placement was necessary, and in one-third of cases where placement was required as soon as possible. Need of care was the main reason offered where future placement was assessed as either likely or necessary. Ill-health of parents was the most common family-centred reason for placement. Similarly to behavioural problems of the subject, ill-health was recorded in two-thirds of cases where immediate placement was needed and in one-third where placement was required as soon as possible. Inability to cope physically was the main reason offered where future placement was considered necessary, and the second most important reason in cases where placement was needed as soon as possible. It is interesting to note that restriction on family activities was seen as a pressing reason for immediate placement whilst marital or family discord only merited an assessment of placement as soon as possible.

The combination of parental ill-health and behavioural problems in the subject accounted for 57.6% of cases where placement was necessary now, and for 16.4% of cases where it was required as soon as possible. In a further 16.4% of cases in the latter group parental ill-health was combined with a need for care and protection of the child. The family's inability to cope physically together with a possible lack of care in the future were the most common combined reasons in the group assessed as requiring placement in future (18.2%).

Approximately one-half of the parents interviewed expressed opinions as to the type of residential facility they would prefer if their child was to go into care. The general preference was for small units rather than large specialised institutions.

The most frequently mentioned facility was hostel accommodation, which was nominated by one-quarter (25.3%) of the parents. As expected, the preference for hostels increased with the greater social competence. In terms of age, 33.0% of the seventeen years and over age group preferred hostels, as compared with 19.2% of the six to sixteen years age group, and only 4.5% of those under six years of age. Less than seven per cent expressed a preference for family group homes — with no differences in this regard in terms of age or social competence. However, 15.7% of parents with children under six years of age mentioned foster care in contrast to the overall figure of 1.6%.

The variable most related to the assessed need for placement was the subject's P-A-C Index, closely followed by the diagnosed level of retardation. The higher the P-A-C Index, the lower was the need for institutional care. Need of institutional care was greatest where the level of retardation was the most severe. Other variables found to be strongly associated with the need for placement were the subject's Impairment Index score, the extent of restrictions upon the family's social activities, and the subject's Behaviour Problem Index Score.

Restriction upon family activities was the only family variable found to be strongly associated with the level of urgency — parent age, family income and the parental marital relationship were not directly related to the assessed need for placement.

Community Services

To determine the needs for community services at different chronological ages, we asked respondents to nominate the types of services they considered would have been the most helpful at different periods, had they been available.

Special schools and special pre-schools were the most frequently desired facilities which parents found lacking during school and pre-school years. During the same periods, the second most often desired service was home help. It will be noted that as well as being the second most desired service, home help was the second most often used of the counselling and welfare services. During post-school years, accommodation facilities (family-type hostels) were the services most needed. Where the retarded member could no longer remain within his own family, the most popular alternative was a family-type hostel. With the older teenagers and adult retarded recreational services were found to be lacking by a number of families.

Community services were seen as a source of emergency assistance by 30.2% of parents. They were cited by parents of 45.4% of pre-school children, as compared with 36.8% of those of school age, and only 22.2% of the older subjects.

DISCUSSION AND CONCLUSIONS

The survey provided useful information from parents and others responsible for the care of mentally retarded. This information is reliable when it provides objective data on the subjects and their families. However, responses to questions about satisfaction with existing services, and types of services requested, have to be taken with caution. This applies especially to the discrepancy between the parents and the interviewers in their assessment of the need for residential placement. The responses have to be evaluated in the context of the current Victorian situation where residential services are provided predominantly within large institutions (nearly three and a half thousand people in 12 centres). From one side parents have shown a lack of knowledge and understanding of the wide range of options including adoption and fostering, short-term relief, family interchange, group homes, hostels and other family support services (particularly for the younger handicapped person) which could provide alternatives for institutionalisation. In a context in which few of these alternatives exist and certainly in which no "system" or "service" exists, the responses of parents when asked for preferences will reflect a limited understanding of options. In a similar vein, the knowledge that large institutions are the primary residential alternative to keeping the child at home may lead to an underestimation of the perceived need for residential services.

The survey showed clearly that there is an ageing population in Victoria both in terms of handicapped people and their families. The current unmet demand for residential services is considerable and will be overwhelming in the future.

The factors which were most significant in determining need for residential care were those related to the retarded individual himself, rather than those associated with the family. The individual's level of social competence, the level of retardation and the extent of other sensory and physical handicaps were the most important criteria in determination of the urgency for residential placement. The only family-related factor that was relevant to any marked degree was the extent to which the family's social and leisure activities were restricted by the presence of the retarded member. However, it is intriguing that interviewers felt that parents considered the need for early placement more than was "appropriate". If residential services are viewed from the perspective of *developmental needs*, that is as required throughout the life of the handicapped person, taking a variety of forms as he grows older and ultimately involving the person leaving home, the question becomes either at what age should such services first be available or at what age should

the handicapped person leave home. Where services are inadequate reasons for perceived need for residential services will reflect "crisis-type" reasons which outweigh consideration of developmental needs. It is also apparent that "placement" was considered a primary (perhaps only) solution to their problems.

The survey has shown a general lack of specialised community services providing for the needs of pre-school age children. As a consequence of this, a significant number of parents of younger children were using general services designed specifically for the non-retarded. Even where parents of pre-school age children were able to use specialised services, there was a marked degree of non-acceptance of these facilities. In contrast, parents of school age children and (especially) older adolescents or adults mainly used services for the mentally retarded. The uneven distribution of community services was clearly reflected in regional variations in the level of use. Many families, particularly those living in western regions of either the Melbourne metropolitan area or the State, were poorly serviced by specialised facilities (as compared with the rest of the State.) The level of use of community services varied considerably from region to region in both metropolitan and rural areas, although the range of mean Service-Use Index scores did not show any overall marked difference between metropolitan and country areas.

The conclusions the service provider can draw from the survey are two-fold. Firstly, similar to all need surveys, the survey indicated a need for new "beds", more places in the sheltered workshops and residentials. The economics of this purely quantitative approach, particularly now and in the foreseeable future, are such that the service provided may well fail to meet the future needs of the retarded and their families.

Another solution is the development of a new conceptual base upon which services are planned. Residential care has to be redefined to include different options throughout the life of the handicapped persons provided within a service system. Such a system should aim to reduce dependency and may take forms which appear to be remote from traditional notions of residential care (e.g. family support options, recreational services) recognizing the developmental needs of handicapped persons.

The survey data suggests that convincing parents of the efficacy of alternative services may be difficult if their experience is predominantly of institutional services. Until they are prepared to utilize the alternative services it will be necessary to continue to provide the existing types of services for families of handicapped persons.

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