OLDER MENTALLY HANDICAPPED PERSONS RESIDING AT HOME AND INSTITUTIONS*

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INTRODUCTION

There are concerns that the aging process may ultimately lead aging/aged persons to be institutionalized, an action often related to loss of various functions and ability for self-care, and a general greater severity of disablement (Branch & Jette, 1982; Ikegamie, 1982). Little has been written about the characteristics and need of older mentally handicapped people and whether they suffer a higher or lower rate of institutionalization during old age (Cotton, Sison & Starr, 1981; Digiovanni, 1978; Janicki & MacEachron, 1984). What is known about this population is usually drawn from small group studies conducted in institutional settings among individuals already institutionalized as they enter old age (Ballinger, 1978; O'Connor, Justice & Warren, 1970; Reid & Aungle, 1974; Tait, 1983). These data may offer a biased picture of what older mentally handicapped people are like because, in general, institutionalized disabled populations presumably are more severely impaired (Cocks & Ng, 1983; Janicki & MacEachron, 1984; Sutton, 1983).

Many older mentally handicapped persons have been in institutional settings for a good portion of their lives. However, many mentally handicapped people also have lived in the community all their lives; in many instances, these persons may be as mentally or physically disabled as their age peers who reside in institutions. Little has been written specifically comparing such individuals with age peers in institutional settings, so an important question is to what degree are elderly mentally handicapped persons in institutional settings the same or different from their counterparts in the community? An attempt to answer this question was the point of a study in which the known older mentally handicapped population in one American state was examined to determine whether mentally handicapped persons residing in institutions did in fact differ from those residing in the community.

The Study. The study population was drawn from 9,066 mentally handicapped individuals age 50 or older registered with the State of New York's Office of Mental Retardation and Developmental Disabilities. The Office, responsible for the provision of specialized services for persons with such mental handicaps as mental retardation, maintains an extensive client registry system. Begun in 1978, the system currently contains information on some 55,000 individuals drawn from all over the state. This older mentally handicapped population represents 0.31% of the 17.5 million persons residing in the state, and 16.5% of the overall case registry's 55,000 mentally handicapped persons.

Information on this population was collected during a statewide needs assessment project using the state agency's client information system, the Developmental Disabilities Information System (DDIS). The DDIS uses an 8-page optically scannable computer form that asks information on demographics, disability characteristics, functional abilities, residential situation, and services received and needed. Forms are completed periodically by agencies, parents, and a variety of caregivers. For more information on the DDIS and the state's needs assessment project see Janicki & Jacobson (1982).

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Data were analyzed by comparing all older mentally handicapped individuals age 50 and above, who resided in either institutional settings or in the community. Three age cohorts were considered: (a) persons age 50-59, (b) persons age 60-74, and (c) persons age 75 and older. Mental handicap includes disabilities such as mental retardation, autism, epilepsy, and cerebral palsy.

The Results. What did these data reveal about the characteristics of this older mentally handicapped population? The registry data revealed that of the 9,066 individuals age 50 or older identified, 4,132 or 45.6% resided in an institutional setting and 4,934 or 54.4% resided at home or other community setting. TABLE 1 indicates the number of individuals who were either in institutional or community environments by the three age groups; it also indicates the variations within community settings. These data indicate that a sizable portion of the known older mentally handicapped population is institutionalized, and proportionately that the rate of those institutionalized tends to increase as age increases. Further, when just the community group is considered, the data show that a greater number are in alternate care settings than at home.

Given what has been observed about the age distribution between individuals in institutional and community settings, what were the other observable differences in characteristics or capabilities? TABLE 2 illustrates the sex and intellectual level data, within age groups, between these two populations. Generally, in terms of the distribution by sex, the two groups are identical. However, when settings and age groups combined are considered, the rate of being institutionalized increases with age and is greater for males than for females.

In terms of intellectual level, the differences are striking. Institutionalized older mentally handicapped individuals are much more intellectually handicapped. Some 23% of the institutional population are profoundly intellectually handicapped, in contrast to only 7% of the community group. What is more telling is that the relative intellectual handicap distribution patterns remain fairly constant across age groups for the community group, but not so for the institutional group. There are less profoundly intellectually handicapped individuals among the institutional group as age increases, most probably attributable to a greater mortality rate among profoundly intellectually handicapped individuals with increasing age.

TABLE 3 shows the distribution of various body system impairments by setting and age cohort. In general, no major differences are observed when the two setting groups are compared by presence of physical impairment. It is clear, nonetheless, that the institutional group has a greater overall rate of disability (87% of the institutional residents had some type of physical impairment). However, when the within-setting age-cohort patterns are examined, certain conditions show up with a greater frequency with increasing age. For example, in both groups, the rates of musculo-skeletal and cardio-vascular conditions, as well as sensory impairments (i.e., vision, hearing), increase with age. What is different between the two setting groups is the rate of cardio-vascular and endocrine system involvement. Although cardio-vascular condition increases were related to increasing age in both groups, there was a higher reported rate of cardio-vascular conditions already present among those older mentally handicapped individuals residing in the community. There was a decrease with age in the rate of occurrence of endocrine disorders in the community group.

TABLE 1: Number and Percentage of Older Mentally Handicapped Persons by Residential Setting

AGE N %		50 + (9,066) --	AGE GROUP 50-59 (4,359) (48.1)	60-74 (3,683) (40.6)	75 + (1,023) (11.3)
Setting:					
Institutional	N (ROW %)	4,131	1,774 (42.9)	1,713 (41.5)	644 (15.6)
	COL %	45.6	40.7	46.5	63.0
Community	N (ROW %)	4,934	2,585 (52.3)	1,970 (40.0)	379 (7.7)
	COL %	54.4	59.3	53.5	37.0
Community Settings[a]					
With Relatives		926	674 (72.8)	219 (23.6)	35 (3.8)
	COL %	18.8	26.1	11.1	9.2
Foster Families		1,812	693 (38.2)	907 (50.1)	212 (11.7)
	COL %	36.7	26.8	46.1	56.0
Group Homes		1,258	758 (60.3)	446 (35.5)	54 (4.2)
	COL %	25.5	29.3	22.6	14.2
Adult Homes		291	99 (34.0)	149 (51.2)	43 (4.8)
	COL %	5.9	3.8	7.6	11.3
Other[b]		577	324 (56.2)	228 (39.5)	25 (4.3)
	COL %	11.7	12.5	11.6	6.6

[a] Column percentage (COL %) are taken from the total community group.

[b] Other includes small "intermediate care facilities."

TABLE 2: Comparison of Sex and Intellectual Level of Older Mentally Handicapped Persons by Residential Setting and Age

SETTING	ALL SETTINGS	INSTITUTIONAL				COMMUNITY			
AGE	50 +	50 +	50-59	60-74	75 +	50 +	50-59	60-74	75 +
N	(9,066)	(4,131)	(1,774)	(1,713)	(644)	(4,934)	(2,585)	(1,970)	(379)
SEX									
Male	50[a]	50	54	49	39	49	53	48	35
Female	50	50	46	51	61	51	47	52	65
IQ									
Normal +	7	4	2	4	6	11	11	9	14
RETARDATION									
Mild	23	11	10	11	14	33	32	35	32
Moderate	22	16	15	17	18	27	27	27	28
Severe	25	28	25	31	32	23	23	23	22
Profound	23	41	49	38	30	7	7	6	4

[a] percent

TABLE 3: Comparison of Physical Disabilities of Older Mentally Handicapped Persons by Residential Setting and Age

SETTINGS	ALL SETTINGS	INSTITUTIONAL				COMMUNITY			
AGE	50 +	50 +	50-59	60-74	75 +	50 +	50-59	60-74	75 +
N	(9,066)	(4,131)	(1,774)	(1,713)	(644)	(4,934)	(2,585)	(1,970)	(379)
PHYSICAL DISABILITY									
Musculo-Skeletal	12[a]	14	11	14	18	11	11	10	13
Sensory	17	18	17	17	22	16	14	18	23
Respiratory	3	3	2	4	4	2	2	2	5
Cardiovascular	16	15	8	16	27	17	13	21	31
Digestive	3	3	3	4	4	3	3	3	3
Genito-Urinary	2	2	2	3	2	1	1	1	1
Hemic/Lymphatic	1	1	1	0	1	0	1	0	0
Endocrine	5	5	4	6	8	5	5	6	3
Neoplastic Disease	2	2	2	2	3	1	1	2	2
None	22	13	18	12	6	31	35	27	15

In terms of basic activities of daily living skills and ambulation abilities, it is evident that the community group had a greater overall level of capability. TABLE 4 shows the percentage of individuals reported to be independent in these functions. Although basic activity function losses are not marked across the two groups, it is evident that there were some notable differences (e.g., the institutional group showed an increase in eating skills). Further, losses in ambulation independence clearly demonstrate that this capability becomes more problematic with increasing age.

Commentary

What these data show is that there are differences, in general, between older mentally handicapped persons who are institutionalized and those who reside in the community. Older mentally handicapped persons in community settings generally are more capable and less impaired than their institutionalized age peers and presumably their relative patterns of skill maintenance and decline vary as much as do those of the general population. Although these data are drawn from a known population (and therefore limited in application), it can be assumed that those unknown persons would only add to the relative differences since those unknown would presumably be less impaired.

Whether age-associated debilitation leads to institutionalization or it's just that more severely disabled persons are institutionalized at a younger age is an interesting question. A review of the length of stay (LOS) data on the older institutionalized group indicates that some 90% have been institutionalized for at least 15 years or more (TABLE 5); indeed, relatively few have been admitted within the past few years. This would seem to indicate that age-associated debilitation is not the primary factor in having to be institutionalized for the first time, or being re-institutionalized, for older mentally handicapped persons. For some, however, it may be a factor in terms of continued stay, since institutions are less inclined to release older individuals who, due to aging, require significant health or other care services (Richards & Siddiqui, 1980).

What do these findings mean in terms of services? There is no reason to believe that older mildly handicapped persons residing in the community would need significantly different types of sources than other older persons. Perhaps the exception would be with aid in housing or provision of sheltered residential care; older mentally handicapped persons would be expected to need sheltered housing at a much greater rate than their non-mentally handicapped age-peers. The assumption is that non-mentally handicapped older persons have spouses, children, or younger family members who they can rely on in old age and consequently remain at home. Mentally handicapped older people generally do not have the same informal support systems to rely on.

The similarity of service needs for community elders would extend to availability of health and nutrition services; social supports such as old age, insurance/social security income, access of social activities, transportation, and other social services; and continued employment, as applicable. However, the variability in loss of skill or greater impairment patterns observed with increasing age, means that individual capability, not necessarily chronological age, should be the major determinant of what services are to be provided, and in what manner. Further, because of a greater rate of physical impairment among institutional residents, special consideration must be given to the more complex health care

TABLE 4: Comparison of Basic Daily Living Skills of Older Mentally Handicapped Persons by Residential Setting and Age Group

SETTING	ALL SETTINGS	INSTITUTIONAL				COMMUNITY			
AGE N	50 + (9,066)	50 + (4,131)	50-59 (1,774)	60-74 (1,713)	75 + (644)	50 + (4,934)	50-59 (2,585)	60-74 (1,970)	75 + (379)
MOBILITY	75[a]	59	65	58	45	88	88	88	80
ACTIVITY OF DAILY LIVING SKILL									
Toilet	68[a]	47	46	49	43	86	85	87	84
Eating	67	48	43	52	53	83	82	83	84
Dressing/Grooming	44	23	22	25	22	61	61	63	58

[a] Percent independent in this skill

TABLE 5: Length of Stay of Older Mentally Handicapped Persons in New York's Developmental Centres

YEARS SINCE ADMISSION

AGE	N	LTE 5 n	LTE 5 %	5 - 9 n	5 - 9 %	10 - 14 n	10 - 14 %	15 - 19 n	15 - 19 %	20 - 29 n	20 - 29 %	30 - 39 n	30 - 39 %	GTE 39 n	GTE 39 %
45 - 64	(2568)	133	5	216	8	74	3	205	8	223	9	524	20	1193	46
over 64	(1059)	23	2	63	6	27	6	68	6	85	8	117	11	676	64

needs of these individuals. Additionally, since debilitation and age appear to be associated with institutionalization in general, special services (to address diminished capacity for self-care and increasingly prevalent health problems) among community residents should be made more readily available to preclude institutionalization.

What is the most important aspect of these findings? That studies of older mentally handicapped individuals based solely upon institutional populations fail to adequately represent the overall aging/aged mentally handicapped population. If the results of these studies are used to develop public policy for care and services to mentally handicapped people, then potential inadequacies in community service systems may be the result.

SUMMARY

Most reports in the literature related to older mentally handicapped persons are derived from studies conducted with institutionalized populations. These studies, while valid as descriptions of the populations studied, may skew general descriptions of older mentally handicapped persons. This report compared one large older mentally handicapped population by place of residence: institution or community. The results revealed substantial differences between those older mentally handicapped persons who are institutionalized and those who reside in the community. Comments were offered related to programme and policy implications of the findings.

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