THE UNIVERSITY OF CALGARY

A PROFILE OF OLDER DEVELOPMENTALLY DISABLED PERSONS IN THE PROVINCE OF ALBERTA

BY

DOROTHY ELEANOR BADRY

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "A Profile of Older Developmentally Disabled Persons in the Province of Alberta," submitted by Dorothy Badry, in partial fulfillment of the requirements for the degree of Master of Social Work.

L. McDonald

Lynn McDonald, Ph.D., Chairman
Assistant Professor
Faculty of Social Welfare

J. P. Hornick

Joseph P. Hornick, Ph.D
Associate Professor
Director of Research
Faculty of Social Welfare

G. Groeneweg

Gerrit Groeneweg, Ph.D.
Senior Research Associate
Vocational and Rehabilitation
Research Institute

Dated: April 28/86

ABSTRACT

The major purpose of this study was to assess the needs of older mentally retarded persons in the province of Alberta. The focus of the major research questions was on the identification of this population; their use of services; and an assessment of differences between community based and institutionalized populations.

This study utilized a survey approach and was carried out in two stages. The first stage was a survey of Michener Centre, an institution for the mentally retarded located in Red Deer, Alberta. The second stage involved a survey of programs, agencies and facilities that were associationed with the mentally retarded throughout the province of Alberta. A modified version of the Developmental Disabilities Information Survey (Janicki & Jacobson, 1979) was utilized to identify 742 persons.

Major findings indicated that the majority of persons resided in institutional settings, and for the most part lacked meaningful daytime activities. Those persons aged 65+ were reported to have the lowest level of independence capacity skills and the highest level of health impairments. Physical disabilities were more prevalent for those residing in congregate care settings as compared to community based settings. Activity/leisure programs were primarily reported as the most important service required.

This paper presents the major findings of this study and a profile of older mentally retarded persons in the province of Alberta.

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CHAPTER 1.0

INTRODUCTION AND REVIEW OF THE LITERATURE

1.1 Introduction

The area of aging and developmental disabilities remains relatively unexplored in Canada. Aging and developmental disability falls into a grey area between two highly specialized and recognized fields; gerontology and rehabilitation. Boundaires for responsibility for service provision to this population have not been established. One of the major reasons for this is that we are dealing with a 'new' population. Prior to the mid 1950's the mentally retarded/developmentally disabled were primarily institutionalized. The other major factor was that they did not live long lives. This is no longer the case. The developmentally disabled are aging along with the rest of society and there are a number of issues regarding this population which must be addressed.

This paper presents a profile of older developmentally disabled persons in the province of Alberta. As there has only been one major study of this population in Canada (Delaney, 1984), this project was considered exploratory in nature. Using a modified version of the Developmental Disabilities Information Survey (DDIS)(Janicki & Jacobson, 1979) data was collected in four major areas: identifying information; disability and functional status; program information; and service needs.

The first section of this paper is a review of the literature in the area of aging and developmental disabilities. Section 2.0 presents the methodology utilized in this research, as well as a discussion of the limitations of the study. Section 3.0 presents an analysis of the results. Section 4.0 presents a discussion of the major findings of this study. Section 5.0 presents conclusions and specific and specific recommendations regarding service delivery to this population.

1.1 Introduction to Review of the Literature

The body of literature in the area of aging and mental retardation/developmental disability is steadily growing. However, because it is relatively new, there are very few major research studies on this population. The majority of research in this area has been carried out by the New York State Office on Mental Retardation and Developmental Disabilities where major demographic studies are currently underway on the older mentally retarded population. The following literature review will consider six major areas: (1) the nature of mental retardation/developmental disability; (2) an aging society; (3) lifespan and the developmentally disabled; (4) needs and services; and, (5) the aging developmentally disabled person in the province of Alberta. The review will conclude with an outline of research questions which were derived from the literature review.

1.3 The Nature of Mental Retardation/Developmental Disability

A definition of developmental disability includes five major categories: mental retardation, cerebral palsy, autism, seizure disorders, and other neurological impairments. The signs or symptoms of these disabilities occur on four levels: mild, moderate, severe, and profound (Wisniewski, 1985).

Developmental disability refers to a disability which has an early onset (before age 18) and is lifelong. It is attributed to physical and mental impairment, or a combination of both. It results in functional limitations and "reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are lifelong or of extended duration and are individually planned and coordinated" (Ross, 1983, p. 4). It should be noted that the major focus for this study was on the mentally retarded; however, the terms developmental disability and mental retardation have been used interchangeably as so much of the available literature use these terms synonymously.

Mental retardation has traditionally been measured in terms of IQ. Recently, there has been a shift towards the use of a more functional definition of mental retardation to reflect a person's abilities as opposed to a stereotype of disability. "Mental retardation is a descriptive term applied to those individuals who develop intellectually at

below average rates and experience unusual difficulty in learning, social adjustment and economic productivity (Wiegerink & Pelosi, 1979, p. 7).

The developmental disabilities field has progressed at a remarkable rate over the last few decades. A movement from institutionalization to self help is indicative of a societal trend towards integration of the disabled into the many facets of life in the community. This trend has been strongly rooted in the human rights movement. "Historically, handicapped people have been badges of shame and objects of pity and embarrassment to families and communities. They were often hidden from public view...they became candidates for poor houses and mental institutions" (Enns, in Freeman & Trute, 1981, p. 175). In Canada the history of the disabled living in the community is shorter than their history of institutionalization.

Service trends in Canada as they relate to the developmentally disabled can be categorized into four major areas: (1) The Development of Asylums, (2) The Mental Hygiene and Eugenics Movement, (3) The Growth of the Modern Institution, and (4) The Return to the Community (Wight-Felske, 1984).

The first stage "The Development of Asylums" occurred in the late 1800's and was related to the protection of the individual who could not survive in society without assistance or from whom society was to be protected. The second stage "The Mental Hygiene and Eugenics Movement"

ushered in the 1900's and dominated for 50 years in a time which has been historically referred to as "The Dark Decades of Developmental Disabilities" (Neufeld, 1984). A custodial approach based on a medical model was the predominant force operating in the lives of the developmentally disabled. There was a belief that handicaps were caused by genetic inferiority and retardation was linked to societal ills and social problems. "The Growth of the Modern Institution" dominated from 1920 to 1970. There was a feeling of obligation towards the disabled by the state during the depression and war years. At that time in history the development of institutions was viewed as a progressive movement by many parents, professionals, service planners and politicians. "The Return to the Community" was largely due to the growth of parent's organizations which questioned the rights of 'professionals' to institutionalize their children. Steady progress has been made since the 1950's in terms of integrating the disabled into the community. The present directions are positive, but also indicate the need for research on the needs of disabled persons living in the community, particularly older persons who face reinstitutionalization because of a lack of community residential alternatives (Jacobson, Sutton & Janicki, 1985).

1.4 An Aging Society

We live in an aging society. The average life expectancy today for men is 70.2 years, and 77.5 years for

women (National Council of Welfare, 1983). This is an increase of 25 years over the average life expectancy in 1900. The proportion of persons over age 65 is increasing and the average life expectancy has shown a marked increase over the last century. These developments can be attributed to an overall lowered birthrate, lowered infant mortality rates and increased longevity due to significantly improved health and social conditions over the last century (Norton & Vitalis, 1984).

Persons who are elderly represent a large proportion of the citizens of Canada. As of June, 1983, 10% of the Canadian population was 65 years of age and over (National Council of Welfare, 1983). Population trends in the United States indicate that by the end of the century the total population age 65 and over will equal the entire population of Canada (Norton & Vitalis, 1984). In 1981, there were 163,390 persons 65 years of age and over in Alberta. It is predicted that this number will more than double by the year 2006 (Alberta Senior Citizens Bureau, 1984). In 1981, the average life expectancy for men was 72.4 years and for women 78.6 years (Alberta Bureau of Statistics).

1.5 Lifespan and the Developmentally Disabled

The lifespan of the mentally retarded "is increasing because of improvements in medical care received by them" (Seltzer & Seltzer, 1985). There is evidence, however, that in developmental disability the degree of disability, living

conditions, and quality of care are considered to affect life expectancy (Thomae and Fryers, 1982). Several studies have indicated that the more severe the disability, the shorter the lifespan, and those with a more severe or profound handicap and motor dysfunction have a reduced life expectancy in comparison to the normal population (Spencer, 1979). Blair and Leland (1966) stated that the institutionalized mentally retarded appeared to age more rapidly than other individuals.

Kriger (1976) argues that the aging process in the developmentally disabled has an onset at a much earlier age than for normal persons, as early as the fifth decade. She further states that "...two ages have been used as the lower limit of old age for the retarded, 40 and 55 years, both of which have been arbitrarily chose" (Driger, p. 108). One study done in Edmonton, Alberta in 1979 defined a developmentally disabled senior citizen as one who is over the age of 50 (Wachowich and Zalasky, 1979). A recent study done across the United States showed the variability in the age criterion of the older
developmentally disabled population to range from 55 to 65 years (Janicki, Ackerman, Jacobson, 1984). In an examination of aging and mental handicap, the official position paper of the International League of Societies for Persons with Mental Handicap states "it is worth giving special attention to those reaching the age of 45, especially in cases of severe handicap" (Thomae & Fryers,

1982). The elderly mentally retarded were previously not a concern to society because they were institutionalized and they did not live long lives. For example, the average lifespan of a person with Down's Syndrome in the 1930's was 11 years. The present life expectancy for these persons is now well into the 50's (Aging/Developmental Disabilities Report, 1984).

There appears to be no clear empirical evidence towards a definition of aging for the developmentally disabled. The clearest definitions found in the literature to date are as follows:

> Aging Developmentally Disabled Persons: "those individuals within the larger developmentally disabled population who are between the ages of 55 and 75 and are experiencing a constellation of losses of ability relative to their individual, previous level of functioning and life situation as a function of the normal process of aging
>
> AND
>
> "those individuals, of any chronological age, within the larger developmentally disabled population, who are experiencing a constellation of losses of ability relative to their individual, previous level of functioning and life situation as a function of an abnormal, anomalous, or pathogenic process of aging." (Puccio, Janicki, Otis, and Rettig, 1983, p. 11)

Recent studies have categorized aging among the mentally retarded as follows: "late middle-age (ages 53 to 62); the aging (ages 63-72); and the aged (ages 73 and older) (Janicki & MacEachron, 1984; & Seltzer, 1985).

A definition of aging for this population is important because it has implications for funding sources, and policy and planning issues for this population. If, indeed, the

developmentally disabled age sooner than the non-disabled the question is raised as to whether 65 is an appropriate age at which they might become eligible for programs available to senior citizens.

1.6 Needs and Services

Services for the elderly mentally retarded are limited, and providing effective, lifelong support services is difficult to accomplish" (Dickerson, Hamilton, Huber and Segal, 1979; Kriger, 1975; Sweeney & Wilson, 1979).

A 1975 conference in Ann Arbor, Michigan entitled "Gerontological Aspects of Mental Retardation", identified the following needs in order of priority: "health related services; social and emotional needs; housing programs; vocational services; recreation and leisure time activities; information and referral services; and support for families of the elderly" (Segal, 1977). Needs identified in other publications include: legal services (Tymchuk, 1979); education for aging (Mental Retardation Journal, 1982); and interpersonal relationships and crisis management (Cohen and Dickerson, 1983).

Supportive networks for the developmentally disabled grow increasingly tenuous as the person ages. "The loss of significant persons in their lives is frequent. Family members die or become incapable of a supportive relationship" (Thurman, 1986, p. 107). Synor (1985) identified a number of concerns expressed by older

developmentally disabled persons. These concerns included questions such as; "What will happen to me when my parents die? Where will I live? Who will love me?" These are very real questions of significant consequence. They highlight the need for planning and developing "social supports that help prepare the aging developmentally disabled person for life's losses..." (Thurman, 1986, p. 107). The death of parents of elderly mentally retarded persons is considered to be a major problem insofar as siblings cannot always be relied upon to provide the emotional support, or even financial support required by the elderly retarded person. The elderly mentally retarded are at risk of becoming socially isolated with the loss of their parents and require permanency planning in three major areas: residential security, legal protection, and financial security (Seltzer & Seltzer, 1985).

Mentally retarded persons are often not considered as possible clients by generic service programs; or even by programs for the retarded as they generally provide service to a younger population (Segal, 1977; Seltzer & Seltzer, 1985). There are many obstacles which appear to limit the provision of services to the elderly developmentally disabled. The 1975 Ann Arbour conference mentioned earlier included the following: lack of trained professionals; services not easily accessible to transportation; discrimination and negative community attitudes; limited opportunities, eg., housing alternatives; lack of awareness

of the problems of the elderly retarded; lack of funding; and difficulty in locating the elderly retarded (Segal, 1977). In relation to the use of generic services, it was found in Edmonton that of all the services available to senior citizens, only 24% of these services were offered to developmentally disabled seniors (Wachowich & Zalasky, 1979). Notably deficit were services in the areas of social/emotional counselling, financial guidance, housing and independent living services, and general information and referral services.

In New York, there exists a Commissioners Committee on Aging and Developmental Disabilities which consists of a number of professionals, advocates and consumers. In a recent report of this committee, it was estimated that 5% of the elderly (over age 65) persons of New York reside in institutions, whereas 50-60% of the elderly developmentally disabled lived in institutional settings. This report further stated that there was not a great difference in the needs of the elderly and the elderly developmentally disabled with the exception of four special services:

(1) "a full range of residential care options, primarily located in community care settings;
(2) in-home supports both to elders and the families that care for them;
(3) health care services that are fully available and accessible; and
(4) social and recreational services that can substitute

for vocational and activity programs." (Puccio et al., 1983; p. 14).

It would appear that many of the services identified here can be found within the realm of generic services. Willer and Intagliata (1984) noted that the elderly retarded were best served within the generic service system. They stated that as a result of aging, many elderly non-retarded persons suffer losses such as mental capacity and social roles and they become dependent; "...the distinction between them and mentally disabled individuals begins to blur." (P.113) Their argument in support of this is that the mentally retarded have lived with a lowered mental capacity all their lives and have not functioned in many of the social roles in which the non-retarded have participated. It is expected however that strong social, political and economical roots that have traditionally segregated the mentally retarded may continue to play a role in the denial of appropriate generic services to this aging population.

One recent study deserving attention highlights the difficulty in planning for the elderly developmentally disabled because of a lack of a clear definition of this population. The New York State Office of Mental Retardation and Developmental Disabilities recently carried out a "Survey of State Developmental Disabilities and Aging Plans Relative to States' Older Developmentally Disabled Population" (Janicki, Ackerman & Jacobson, 1984). Only 6% of the states involved in the survey (N = 46) had a working

definition of the older developmentally disabled population. Fifty percent of the states had an estimate of the size of their older developmentally disabled population while 48% had specific reference to the "elderly developmentally disabled in the developmental disabilities state plan."

Another study of particular importance is entitled "Residential, Health and Social Service Needs of Elderly Developmentally Disabled Persons" (Janicki & MacEachron, 1984). This report resulted from a statewide needs assessment carried out by the New York Office of Mental Retardation and Developmental Disabilities from 1978 to 1982. Of the 49,954 individuals identified as developmentally disabled, 7,823 were 53 years of age and older. The instrument used in this study was the "Developmental Disabilities Information Survey" (DDIS); and it addressed "demographics, categorical disability conditions, functional skills, program/service status and needs, and adaptive behaviour skills" (Janicki & Jacobson, 1979, p. 15). The significance of this study is that identification of the elderly developmentally disabled population is essential to the planning of services. The data suggested that many of the elderly developmentally disabled currently institutionalized would be able to reside in less restrictive community alternatives which are less expensive and allow for the elderly to maintain links with the community. The importance of maintaining community

links has been supported further in the literature by Thurman (1986) and Seltzer & Seltzer (1985).

The needs of elderly mentally retarded persons surface consistently in the literature. The major themes emerging are that the elderly developmentally disabled population is increasing; that their support network often diminishes; that there is a need for permanency planning; and that there is a lack of integration in the generic service system.

1.7 The Aging Developmentally Disabled Person in the Province of Alberta

In reviewing the situation of the aging developmentally disabled population in the province of Alberta, it is evidenced that there is some involvement of this population within our social service system. For example, in 1985, 543 mentally retarded persons between the ages of 45 and 65 were receiving benefits from the Alberta Assured Income for the Severely Handicapped (ASSCH Management Information & Systems Services, 1985).

Michener Centre, an institutional care facility for the mentally retarded located in Red Deer, Alberta was a primary source of data for this study.A brief history of Michener Centre reveals that it opened in 1923 as a residential facility with 108 residents. The population increased over the years and in 1969, there were approximately 2200 persons residing at Michener. A gradual decrease in the population of this institution has been occuring for the past 10 years

as a result of efforts to relocate residents to their home communities; and to afford opportunities for community living to the less severely disabled (Michener Centre: A History, 1923 - 1983, 1983). In 1983 there were 146 persons 65 years of age and over in this institution. The statistics for January of 1985 show that there were also 146 persons age 65 and over; the majority (101 persons) were 70 years plus (Monthly Statistics Report, Michener Centre, January, 1985).

Within Alberta there have been no major studies regarding the older mentally retarded population with the exception of a survey in Edmonton of service usage by aging developmentally disabled persons (Wachowich and Zalasky, 1979). This was a preliminary report for the Task Force on Older Persons located in Michener Centre.

The Disability Information System of Calgary (Marlett, 1983) provides information regarding the levels of disability and the number of disabled persons under age 65 in Calgary. The data from the Disability Information System of Calgary (DISC) indicates that as a person grows older, the likelihood of institutionalization (24 hour staffing model) increases greatly while the number of persons living in community environments decreases substantially (Calgary Community Horizons '84, December, 1984). This, in and of itself, is not surprising since a decline in the health of older persons often leads to institutionalization. However, older mentally retarded

persons are particularly vulnerable to being institutionalized despite their health condition due to a lack of community options in Alberta.

There is currently one community group home operating in Alberta located in Red Deer which serves only the elderly mentally retarded. This group home is run through the Central Alberta Residential Society. A similar group home is scheduled to open in Medicine Hat in 1986.

Considering that there has only been one minor study on the elderly mentally retarded in the Province of Alberta, it is assumed very little if any attention has been devoted to developing policy for this population.

In summary, a survey of the literature indicates that there is a deficiency of service delivery to the older developmentally disabled population (Panitch, 1983; Tymchuk, 1979; and Segal, 1977). The need for demographic studies has been indicated in terms of identifying the number of older developmentally disabled who may be residing in either institutional or community settings (Janicki & MacEachron, 1984; Tymchuk, 1979; and Segal, 1977). Identification of this population is directly related to the establishment of needed services.

In Canada, there are few reports in the literature that suggest that special services are required for this group. There are few empirical studies on the needs of this population and none about the forces operating in the

delivery of service. Based on the lack of available evidence, it is expected that the elderly developmentally disabled are not receiving the required professional support services that they need. It is anticipated that major studies in this area are on the horizon as this segment of the population ages along with the rest of society. The body of literature is growing and serious examination of the needs of this population is not only timely, but necessary.

1.8 Purpose of the Study and Major Research Questions

In light of the paucity of research, the purpose of this study was to carry out a demographic and needs analysis of the older mentally retarded population. The following were identified as major research questions:

(1) How many mentally retarded persons within identified service systems aged 45 and over are residing in the province of Alberta?

(2) What are the needs of this population?

(3) What services currently exist and what services should be developed to meet the needs of this population?

(4) Are there major differences between older mentally retarded institutionalized and community based populations?

CHAPTER 2.0

METHODOLOGY

This chapter provides a discussion of the methods and procedures utilized in the collection of data for this study.

2.1 Study Design

A survey approach was utilized in this study which was carried out in two stages. The first stage was a survey of the older mentally retarded population in Michener Centre, an institution for the mentally retarded located in Red Deer, Alberta. The second stage involved a mailout survey to programs, agencies and facilities that were associated with mentally retarded persons aged 45 and over in the province of Alberta. Descriptive statistics were used to assess the needs of the aging mentally retarded population, their utilization of services, and to compare and contrast community based and institutionalized populations.

2.1 Sampling

Individuals involved in this study were involved in three major settings; (1) community based; (2) congregate care; and (3) an institution for the mentally retarded.

Overall, there were 197 agencies, programs and facilities involved in this study. This included vocational programs, group homes, approved homes, independent

living services, Client Service Coordination Units, associations for the mentally handicapped, lodges, nursing homes, extended care centres, and health services.

The final sample included 742 subjects. The following criteria were employed for inclusion of subjects:

(1) Residency at Michener Centre.

(2) Mental retardation had to be reported as a major developmental disability.

(3) If mental retardation was not reported as a major developmental disability, a functional level of retardation had to be reported.

A summary of basic sociodemographic characteristics of this sample of 742 subjects can be found in Table 1. The mean age of the sample was 60.13 years and the majority were single (91.2%). The Census Canada Urban/Rural Code (1981) was utilized for location and it was evident that the majority of subjects (99.2%) resided in urban settings. A more comprehensive description of the sample is presented in the results section.

2.3 Definitions of Major Variables

This section presents definitions of the major variables included in this study.

Developmental Disability: A disability that has an early onset (before age 18) and is lifelong. It is attributed to physical or mental impairment, or a combination of both (Ross, 1983, p.4).

Mental Retardation: Heber (1959) provides the following definition: "subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following; (1)maturation (2) learning, and (3) social adjustment" (p. 3).

Level of Retardation: The American Association on Mental Deficiency defines retardation on four levels; mild (IQ: 56 - 70); moderate (IQ: 41 - 55); severe (IQ: 26-40); and profound (IQ: 25 and below.

Community Based Settings: Included in this category are vocational programs; residential programs, ie. group homes; associations for the mentally handicapped, client service coordination units of Alberta Social Services and Community Health, and independent living services.

Congregate Care Settings: Included in this category are nursing homes, lodges, extended care centres, and auxiliary hospitals.

Institition for the Mentally Retarded: Michener Centre is an institution located in Red Deer Alberta. This institution opened in 1923 and approximately 1500 persons currently reside there; the majority of whom are severely and profoundly retarded.

The terms developmental disability and mental retardation have been used synonymously throughout this paper as the majority of the available literature reflects both terms. A glossary of terms was developed for this

project and includes definitions for Residential Services, Day Programs, Professional Services and Support Services (Appendix A).

2.4 Instrument/Materials

The Developmental Disabilities Information Survey (DDIS)(Janicki & Jacobson, 1979) is a comprehensive assessment instrument specifically designed for use with the developmentally disabled. The stability of this instrument has been tested. In the DDIS User's Guide (Janicki & Jacobson, 1979) a number of quality assurance checks for this instrument have been listed. These include: trained respondents, standardized training, computer edit, face edit, profile error edits and error feedback. The rejection rate for failure to complete the survey forms properly in the first 1200 forms used in a 1979 New York study was .025.

A User's Guide and Technical Report is available for researchers using the DDIS. A description of checks for reliability and validity of the DDIS are listed. Therefore, the DDIS was considered an appropriate, if not the only model on which to develop a comprehensive assessment instrument for the older (aged 45 and over) mentally retarded population in the province of Alberta.

The DDIS was modified over a three month period prior to its implementation. A pilot study involving 20 mentally retarded individuals was conducted at The Vocational and Rehabilitation Research Institute (VRRI), and resulted in

major changes to the original instrument in the areas of: source of income; and health and social services benefits. Minor changes were made in the following areas: languages spoken, health impairments, sensory-motor/ language skills, independence capacity skills, residential services, day programs, professional services, and support services. The instrument included a service needs index similar to the one found in the DDIS in order to identify the most important services currently received and presently required by the individuals involved in the study. The service needs index was considered as the primary indicator of the service needs of this population. As such, it was considered as a useful tool for planning purposes.

The form used during the first stage of the study differed slightly from the form used in the second stage. For example, social contact was assessed over the past year at Michener Centre, and over the past three months in community based settings.

The instrument is entitled "A Demographic and Needs Analysis of Older Developmentally Disabled Persons in the Province of Alberta" (Appendix B). The cover page of the instrument includes a description of the project and a set of instructions. A glossary of terms was included in the mailout under separate cover providing a set of definitions to be used in completing the instrument. This glossary was developed as there was a broad range of specialized and generic services involved in the study and

it could not be assumed that those completing the forms were familiar with the mentally retarded population. Definitions were derived from three major sources; the DDIS (1979); the Disability Information System of Calgary (DISC); and the Assessment Department of Calgary and Auxiliary Hospital District #7 (1985).

2.5 Procedures for Data Collection

In the first stage of this study, which involved a survey at Michener Centre, the collection of data began in July of 1985 and was completed in early September, 1985. Data was collected from secondary sources only; staff members and client files. At no time were subjects directly involved. Initially, a letter of permission from the Director of Social Services at Michener Centre was obtained in order to facilitate access to staff members and client files in order to carry out this research.

A Research Assistant was hired on a full time basis for two months in collaboration with the Client Service Coordination Unit of Alberta Social Services and Community Health, Calgary, Alberta to assist in data collection. The survey form took between ten minutes to one hour to complete, depending upon the availability of information in client files and knowledge of the client by appropriate staff members.

Problems encountered in the data collection process centred around staff resistance in providing information for the completion of survey forms. The major reason given for

not wanting to participate in the survey was that of time constraints. However, of the estimated 475 persons aged 45 and over at this institution data was collected on 460 persons.

The second stage of this study involved a provincial mailout to agencies, programs, and facilities that were associated with mentally retarded persons. A comprehensive mailing list was developed from a number of sources including associations for the handicapped, vocational training centres, Client Service Coordination Units, and auxiliary and hospital district lists. Overall, 197 agencies, programs and facilities were represented on the mailing list. A condition for participation in this study was that the researchers would not make public the names of participating agencies, programs and facilities in order to ensure confidentiality. Therefore, this list has not been included in an appendix.

Approximately 1500 survey forms were mailed. The number of forms sent out to each agency was arbitrarily determined by the researcher. Those agencies known to be involved with the mentally retarded such as associations for the handicapped received more forms than settings such as nursing homes or lodges. As the associations for the mentally handicapped were considered potentially valuable sources of information for this study, a letter of support for this research was obtained from the President of the Board of the Alberta Association of the Alberta Association

for the Mentally Handicapped. This was included in the mailout to the associations (Appendix C). Agencies, facilities and programs in rural areas received fewer forms due to lower population ratios in these locations.

A complete mailout package included the following: a letter of introduction to the study from the Senior Research Associate at the VRRI (Appendix D); a letter of consent of which two copies were included and agency, program, and facility directors were asked to sign both, retain one copy for their files and return the other copy with the completed forms (Appendix E); the modified version of the DDIS (Appendix B); a glossary of terms (Appendix A); and a self-addressed, stamped envelope.

Returns were monitored over a six week period at which point a follow-up letter was mailed to those agencies from which there was no response. Data collection was completed approximately four and a half months after the initial mailout. There was an overall response rate of 64% with 127 agencies responding. Sixty-eight agencies identified a total of 742 persons. The other 59 responding agencies reported that they did not serve any persons aged 45 and over who were mentally retarded. There was no response from 65 agencies. It should be mentioned that problems were reported with the postal service for at least 10 agencies. Upon follow-up, these agencies reported that they had not received the original mailout package. Survey

forms were sent for a second time to these agencies. One agency reported having returned 22 completed forms which were never received by the researchers.

As a large amount of data was requested on each individual, and as forms were completed by respondents from secondary sources such as client files and personal knowledge of the client, it was expected that the total data requested might not be available. As expected, a number of forms with missing data were returned. In addition, the question of accuracy of completed forms was raised when 52 forms were returned on persons who were not mentally retarded but suffered from a variety of impairments such as Alzheimer's Disease and Organic Brain Syndrome. These forms were primarily returned from facilities such as nursing homes and extended care centres. These forms were not analysed in the present study but could provide the basis for a comparison between institutionalized non-retarded and retarded persons. It is suggested in the literature that these types of comparisons, particularly in longitudinal studies, are useful as it is currently not known whether aging developmentally disabled persons decline at a rate similar to, faster than or slower than aging non-developmentally disabled persons (Seltzer, 1985, p. 169).

2.6 Data Analysis

After the data was collected, it was coded onto data

forms for optic scanning. Four data forms were required for each individual as there was a maximum of 221 variables. It took approximately four months to complete the coding process. The raw data was analysed using descriptive statistics to provide frequencies, means and standard deviations for major variables for the entire population. Further analyses included the use of crosstabulation procedures from the Statistical Package for the Social Sciences (SPSS) (Nie, Hull, Jenkins, Steinbrenner, & Bent, 1975). For the purpose of these analyses, a significance level of $<.01$ was adopted and maintained for all tests of significance.

The types of agencies included in this study could be collapsed into three major categories: community based, congregate care, and an institution for the mentally retarded. The types of agencies included in each of these major categories has been included in the definition of major variables.

2.7 Limitations of the Study

The findings of this study should be interpreted with some caution. As the agency staff were able to choose who would be reported on in the study, it is a possibility that some persons were not included and therefore the sampling in this study is neither exhaustive nor random. Additionally, although as comprehensive a mailing list as possible was developed from a variety of sources, it is possible that

some agencies serving the mentally retarded were unintentionally excluded. As this study utilized a survey approach and focused on a specific population. The results do not represent a true random sample and the results are therefore not generalizable. This study was cross-sectional and although certain results may indicate major differences across age groups, this is only implied and can only be stated as such.

A number of problems are typically encountered in a mailout survey, particularly a low response rate. In this study however with follow-up, a satisfactory response rate was achieved. It is unknown as to whether respondents filled out the forms accurately and completely on all older mentally retarded persons in their agency. Eleven agencies identified 77 persons but refused to complete survey forms for reasons such as time constraints and confidentiality. Missing data was evident on a number of survey forms and whether this was due to respondents lack of knowledge on subjects or other reasons is unknown.

A major limitation reported by the research assistant hired to carry out the survey at Michener Centre was that client records were either incomplete or out of date and time constraints on the part of staff forced a rushed completion of survey forms at times. In addition, it was reported that many staff at Michener Centre had difficulty in stating what needs outside of current programs were appropriate for individuals in their care. Staff were

especially reluctant to make recommendations for individuals to move from their current residential placement within the institution.

It is undoubtedly safe to conclude that this study does not represent the entire mentally retarded population in the province of Alberta. A number of factors including missing data and various problems associated with the mailout indicate potential problems in validity and reliability. However, the major contribution of this research is that it provides a general profile and description of a substantial number of older mentally retarded persons in the province of Alberta.

CHAPTER 3.0

ANALYSIS OF RESULTS

3.1 Introduction

This chapter will present the results and major findings of this study.

In order to determine major variables for analysis, the studies conducted by the New York State Office on Mental Retardation and Developmental Disabilities (NYOMRDD) in relation to the aging developmentally disabled population were carefully considered. There is evidence in the literature that few reports have presented contemporary data on the demography, morbidity and residential situations of aging or elderly mentally retarded persons (Jacobson, Sutton, & Janicki, 1985, P. 116).

Seltzer (1985) outlines a number of areas where research is required in aging and developmental disabilities. These areas include information on basic sociodemographic data; studies on younger developmentally disabled persons (age 35-55) in order to project future aging populations; studies on severity of disability as it related to life expectancy; studies on major causes of morbidity and mortality; and distributions on gender, disability, and type of residential setting. One study indicated that the "elderly (63 or older) mentally retarded person was more likely to be

female", particularly those in public facilities (Hauber, Rotegard, and Bruininks, 1985, p. 347). Studies on younger and older mentally retarded persons to assess age related differences are also considered to be useful for the area of program planning. If both populations are basically similar, perhaps specialized programming may not be required. A final area where major research is required is on informal support systems for aging developmentally disabled persons.

A major research focus of this study was to examine needs and services as they relate to the older mentally retarded population. It was, therefore, necessary to determine which variables were related to service delivery. Based on the available literature, it was evident that age, gender, and the location of persons in various types of settings were considered important variables related to service deliver for this population; and these were therefore selected from a number of choices as primary variables for analysis in this research.

Gender was considered as an important variable as it is a well known fact in gerontological literature that females live longer lives and generally constitute the majority of the elderly population (National Council of Welfare, 1983). This variable was included, therefore, to assess differences between older mentally retarded males and females.

Another major focus for this study was a comparison of older mentally retarded individuals involved in

institutional and community based settings. The type of setting an individual was involved in was considered to have an important relationship to a number of characteristics of the older mentally retarded population. For example, profoundly retarded persons were considered more likely to reside in institutional settings as compared to mildly retarded persons; and converely,.persons residing in community settings were considered more likely to have greater independence capacity skills than persons residing in institutional settings. As well, type of setting is generally a major determinant of the types of services provided.

Seltzer (1985) and Janicki (1984) report that, for reasons unknown, the aging mentally retarded are at particular risk of institutionalization and that studies of community based and institutional populations are useful. The types of agencies involved in this study were broken down into three major categories as previously defined: community based settings, congregate care settings, and an institution for the mentally retarded (Michener Centre).

Basic frequencies were generated on all variables for the entire population. An analysis was then conducted which indicated that gender, age and type of setting were significant on a number of variables. A crosstabulation of age, gender and type of setting agency with major developmental disability, level of retardation, health impairment, independence capacity and self care

skills and professional services followed. Chi square analyses were conducted to determine levels of significance. A note will be provided on tables in which multiple response categories were reported.

3.2 Sample

Individuals involved in this study were generally referred to as the 'sample' since data was collected from secondary sources. The actual respondents in this study are the staff persons who completed the survey forms.

An almost equal distribution of males (49.9%) and females (47.2%) was noted in this study.. Data on gender was missing for 22 subjects (2.9%). The mean age of the sample was 60.13 years. The primary sources of income were the Assured Income for the Severely Handicapped, Old Age Security and Other which was reported primarily as an institutional allowance for residents of Michener Centre (Table 3.1). The mean monthly income reported was $626.85 per month. In Table 3.1 it was reported that 54.0% of the sample received an income from sources other than the Assured Income for the Severely Handicapped and Old Age Security. Other income was primarily reported as an institutional allownace and was received by the majority of the subjects residing in Michener Centre. Individuals resided in a variety of settings as reported in Table 3.1. It is evident that institutional and congregate care facilities dominate as the primary type of residential setting for this older developmentally disabled population.

TABLE 3.1

Percentages for Sociodemographic Characteristics of Developmentally Disabled Persons Aged 45 and Over in the Province of Alberta

Characteristics	Mean or Percentage
Marital Status	
Single	91.2%
Other	7.2%
Missing Cases	1.6%
Location	
Urban	99.2%
Rural	0.8%
Gender	
Male	49.9%
Female	47.2%
Missing Cases	2.9%
Source of Income ****	
Assured Income for the Severely Handicapped	24.1%
Old Age Security	23.3%
*Other	54.0%
Residential Program	
Active Treatment Hospital	0.5%
Adult Foster Care	0.1%
Approved Home	3.6%
Auxiliary Hospital	2.6%
Cooperative Living	0.3%
Extended Care Centre	3.8%
Group Home	8.0%
Group Residence at Institution	5.3%
Independent Living	4.2%
Institution for the Handicapped	56.5%
Living with Parents/ Relatives	3.2%
Minimally Supervised Apartment	0.4%
Nursing Home	9.3%
Lodge	0.9%
Other	0.8%

N of Cases =742

**** Income was a multiple response item, therefore percentages do not sum to 100.

TABLE 3.2

Percentages of Major and Significant Disabilities for Older Developmentally Disabled Persons in the Province of Alberta

Major Developmental Disability	Percentages
Autism	2.1%
Cerebral Palsy	3.1%
Epilepsy	25.1%
Mental Retardation	95.4%
Down's Syndrome	7.7%
Other Syndrome	1.1%
Neurological Impairment	3.1%
Other Significant Disability	
Brain Injury	3.0%
Drug Dependence	0.1%
Functional Learning Disability	3.4%
Organic Brain Syndrome	1.0%
Alzheimer's Disease	0.3%
Senile Dementia	0.4%
Psychiatric Disability	12.1%
Other Disability	2.2%

N of Cases = 742

**** Major Developmental Disability and Other Significant Disability are multiple response categories, therefore percentages do not sum to 100.

As indicated in Table 3.2, the majority of the sample were mentally retarded (95.4%). Other significant disabilities were also reported in this table and it is evident that psychiatric disabilities were reported most frequently.

3.3 Gender

Data on gender was analysed to ascertain differences between males and females. A crosstabulation of gender by level of retardation indicated that mild retardation was most prevalent among males while moderate retardation was most prevalent among females. Similar frequencies on severe and profound retardation were reported for males and females (Table 3.3).

The relationships between gender by major developmental disabilities and health impairments are reported in Table 3.4. Utilizing Chi Square as test for statistical significance, it was noted that there were significant differences ($p < .01$) between females and males in the areas of epilepsy, endocrine disorders, musculoskeletal disorders and obesity. Females had the highest frequencies of these health impairments..

An analysis of gender by professional services indicated significant differences ($p < .01$) between females and males in the areas of nursing services, nutritional services and religious/ pastoral services. Females were reported to receive these services more frequently than males (Table 3.5).

TABLE 3.3

Level of Retardation by Gender

Gender	Level of Retardation				
	Mild	Moderate	Severe	Profound	Total
Male	30.1%	24.7%	25.3%	19.9%	52.7
Female	26.5%	29.1%	24.2%	20.2%	47.3
Total	28.4%	26.8%	24.8%	20.1%	100.0

N of Cases = 638

Missing Cases = 104

TABLE 3.4

Percentages on Major Developmental Disability and Health Impairments Reported for Males and Females

Major Developmental Disability	Males	Females
Autism	1.4%	2.6%
Cerebral Palsy	2.7%	3.5%
Epilepsy	19.7%*	30.2%*
Mental Retardation	95.3%	95.6%
Down's Syndrome	6.8%	9.0%
Other Syndrome	1.1%	1.2%
Neurological Impairment	2.2%	2.9%
Health Impairments		
Cardiovascular	15.7%	18.3%
Digestive	7.9%	6.6%
Edema	4.1%	7.5%
Endocrine	5.1%*	14.1%*
Genito Urinary	3.0%	3.8%
Growth Impairment	1.4%	1.4%
Hemic Lymphatic	0.5%	2.0%
Musculoskeletal	17.6%*	27.5%*
Neoplastic Disease	1.6%	1.4%
Neurological	4.9%	6.6%
Obesity	9.2%*	22.8%*
Paralysis	6.0%	6.1%
Other	15.3%	13.3%

N of Cases = 720

* Indicates a significant difference at <.01 was reported between males and females.

****Major Developmental Disability and Health Impairments are multiple response categoreis, therefore percentages do not sum to 100.

Note: Data on gender was missing for 22 cases.

TABLE 3.5

Percentages on Professional Services Received by Males and Females

Professional Services	Males	Females
Audiology	3.5%	2.6%
Behavioral Intervention	4.1%	4.7%
Communication Therapy	1.1%	0.6%
Client Service Coordination	75.3%	72.1%
Dental	81.0%	81.5%
Guardianship - Private	29.8%	31.6%
Guardianship - Public	51.9%	47.1%
Legal	1.1%	2.0%
Nursing	25.8%*	39.2%*
Nutritional	25.3%*	36.7%*
Occupational Therapy	7.6%	11.4%
Physical Therapy	6.0%	7.7%
Psychologist	3.0%	5.3%
Psychiatrist	4.1%	5.6%
Recreation Therapy	8.4%	12.4%
Rehabilitation Counseling	75.3	68.3%
Religous/Pastoral	28.5%*	39.3%*
Routine Medical	84.3%	84.5%
Social Worker	76.2%	77.7%
Specialized Medical	13.2%	12.3%
Trusteeship	77.0%	79.8%

N of Cases = 720

* Indicates a significant difference at <.01 was reported between males and females.

**** Professional services are a multiple response category, therefore, percentages do not sum to 100.

Note: Data on gender was missing for 22 cases.

In summary then, it would appear that females have a higher frequency of health impairments relative to males. However, females were also reported to appropriately receive significantly more health related services such as nursing care and nutritional services. The professional services most frequently received for both males and females include routine medical care, dental services and trusteeship.

3.4 AGE

Age was analyzed to assess differences between three age groups: 45 - 54, 55 - 64, and 65+. A crosstabulation of age and major developmental disability yielded a significant difference ($p < .01$) for Down's Syndrome for the older age group compared to the two younger age groups. A significant decrease in population size for subjects with Down's Syndrome aged 65+ was evident (Table 3.6). This finding is consistent with the literature where it is reported that the average life expectancy for the Down's Syndrome population decreases with age and typically reaches only into the fifties (Lubin & Kiely, 1985). In an examination of health impairments, age was also reported to be significantly related to cardiovascular disorders and musculoskeletal disorders for the older age group as compared to the two younger age groups (Table 3.6). Musculoskeletal disorders are reported in the literature as " the third leading cause of incapacity" for elderly persons (Rudelli, 1985). Catapano, Levy, and Levy (1985) also report an increase in cardiovascular and musculoskeltal disorders for elderly

developmentally disabled persons.

In the area of independence capacity skills, a consistent decrease in the ability to perform these skills is noted for older subjects (Table 3.7). Those aged 45 - 54 were reported to have the highest level of independence capacity skills. Age was significant for the older age group compared to the two younger age groups related to banking skills ; laundry skills ; and meal preparation skills. This finding is not surprising given that increasing age is often associated with increasing dependence. In the area of self care skills which included dressing/grooming, eating and toileting, only toileting was reported to yield a significant difference. Again, this was noted for the 65+ age group (Table 3.7).

In a crosstabulation of age by day programs significant differences were evident in the areas of activity leisure programs, vocational programs and senior citizens' activities. An increase was reported for activity/leisure programs and senior citizens' activities with age. This is appropriate given the significant decrease in formal day programs for the older age groups. For example, vocational training was reported to be received by 41.2% of the subjects aged 45 to 54 , and only 3.5% of the subjects aged 65+. Slightly more than 60% of those aged 65+ were reported to have no formal day program (Table 3.7).

TABLE 3.6

Percentages for Major Developmental Disability and Health Impairments Across Three Age Groups (45-54; 55-64; & 65+)

	Percentages		
Major Developmental Disability	45 - 54	55 - 64	65+
Autism	1.9%	2.1%	2.2%
Cerebral Palsy	4.5%	3.3%	1.3%
Epilepsy	26.1%	26.1%	23.0%
Mental Retardation	97.3%	93.6%	95.2%
Down's Syndrome	13.1%	7.9%	0.9%**
Neurological Impairment	1.9%	2.9%	3.1%
Health Impairments			
Cardiovascular	12.8%	14.9%	24.5%**
Digestive	6.0%	8.3%	7.5%
Edema	3.0%	5.8%	8.8%
Endocrine	6.3%	11.6%	12.3%
Genito-Urinary	2.2%	3.8%	4.4%
Growth Impairment	1.9%	1.7%	0.4%
Hemic Lymphatic	1.1%	2.1%	0.4%
Musculoskeletal	15.7%	19.8%	32.0%**
Neoplastic Disease	0.4%	1.2%	3.1%
Neurological	5.2%	5.4%	7.4%
Obesity	18.3%	15.3%	13.6%
Paralysis	8.3%	6.3%	3.1%
Other	14.6%	15.0%	13.2%
N of Cases = 742			

**** Major Developmental Disability and Health Impairments are multiple response categories, therefore percentages do not sum to 100.

** Indicates that significant differences were reported for that age group in relation to both other age groups.

TABLE 3.7

Percentages on Independence Capacity Skills, Self Care Skills and Day Programs Across Three Age Groups (45-54; 55-64; & 65+)

Independence Capacity Skills	45 - 54	55 - 64	65+
Banking	10.8%	6.3%	1.8%**
Laundry	23.1%	22.9%	8.8%**
Meal Preparation	11.5%	7.1%	3.5%**
Public Transportation	21.4%*	13.9%	6.3%*
Shopping	45.4%*	39.7%	27.4%*
Telephone	26.8%*	21.1%	13.2%*
Self Care Skills			
Dressing/Grooming	53.0%	49.8%	43.6%
Eating	88.0%	86.7%	82.8%
Toileting	77.8%	77.5%	65.3%**
Day Programs****			
Activity/Leisure	9.8%**	24.4%	26.3%
Adult Education	7.1%	2.5%	0.0%
Senior Citizen's Activity	1.5%*	6.6%	6.1%*
Sheltered Workshop	11.6%*	9.1%	4.4%*
Vocational Training	41.2%**	19.8%**	3.5%**
No Formal Day Program	31.2%	42.5%	60.9%**

N of Cases of = 742

* Indicates a significant difference at < .01 between groups.

** Indicates that a significant difference was reported for that age group compared to both other age groups.

**** Day Programs are a multiple response category, therefore percentages do not sum to 100.

Note: In the areas of Independence Capacity and Self Care Skills the ability to perform these skills independently is reflected.

Table 3.8 summarizes the relationship between age and receipt of professional services. It demonstrates that age was an important factor in terms of a number of variables. For example, the receipt of custodial services such as public guardianship was more in evidence in the older age groups. Private guardianship services were reported to increase for those aged 55 to 64 (42.7%) and to decrease substantially for those aged 65+ (28.1%). It has been reported in the literature by Thurman (1986) that supportive relationships for older developmentally disabled persons grow increasingly tenuous with age.

In summary, age has been found to be significantly related to a number of variables. It would appear there are significant differences between the different age groups. There is a decrease in independence capacity skills in the older age groups. The receipt of many professional services shows a consistent increase with age including dental care, public guardianship, nursing care, nutritional therapy, occupational therapy, recreation therapy, religous/pastoral services, routine medical care, social work, specialized medical care and trusteeship. The increase in all these services appear to indicate that a higher levels of professional care are required as a person grows older.

TABLE 3.8

Percentages on Professional Services Received Across Three Age Cohorts (45 - 54; 55 - 64; & 65+)

Professional Services	45 - 54	55 - 64	65+
Audiology	3.0%	4.6%	1.3%
Behavior Intervention	6.0%	3.8%	3.5%
Communication Therapy	0.8%	0.4%	1.3%
Client Service Coordination	69.8%	77.0%	70.2%
Dental	76.2%	79.5%	88.9%**
Guardianship - Private	33.6%	31.4%	27.0%
Guardianship - Public	41.9%	46.7%	60.0%**
Legal	1.5%	1.3%	1.8%
Nursing Care	18.9%**	30.8%**	51.8%**
Nutritional	25.4%	27.5%	42.8%**
Occupational Therapy	6.4%	8.8%	14.9%
Palliative Care	0.0%	0.8%	1.3%
Peer Support	9.5%	8.4%	3.5%
Physical Therapy	7.2%	7.1%	6.2%
Psychologist	5.7%	4.2%	1.7%
Psychiatrist	5.3%	6.3%	3.9%
Recreation Therapy	6.1%	9.2%	18.1%**
Rehabilitation Counsellor	73.5%	69.9%	68.3%
Religous/Pastoral	21.6%**	35.0%	46.7%
Routine Medical	79.8%	84.1%	88.1%
Social Worker	73.5%	76.4%	77.2%
Specialized Medical	10.6%	12.6%	15.5%
Trusteeship	75.4%	78.7%	82.4%

N of Cases = 742

** Indicates that a significant difference at < .01 was reported for that age group compared to both other age groups.

**** Professional services are a multiple response category, therefore percentages do not sum to 100.

3.5 Type of Setting

Data on type of agency was analyzed to ascertain differences between three major types of locations: community based settings (vocational programs, residential programs, associations for the mentally handicapped, independent living services and Client Service Coordination Units); congregate care settings (lodges, extended care centres, nursing homes and auxiliary hospitals); and Michener Centre, an institution for the mentally retarded located in Red Deer, Alberta. These distinctions were made for the purpose of comparison between community based and institutional settings. Table 3.9 reports findings of an analysis between setting and major developmental disability. In this analysis, significant differences were reported for cerebral palsy, epilepsy, neurological impairment, and brain injury. It was evident that those in congregate care settings had higher percentages of cerebral palsy, mental retardation and neurological impairments.

An examination of health impairments indicated that those in congregate care settings were reported to have the highest frequencies of health impairments relative to Michener Centre and community based settings (Table 3.9). Edema, paralysis, musculoskeletal and neurological impairments were reported to be significantly different between all settings. Obesity differed significantly between congregate care settings and Michener Centre. Those in congregate care settings were more likely to suffer this

impairment.

In the area of independence capacity skills significant differences were reported between all settings agency types for banking, laundry, public transportation, shopping and telephone skills (Figures 3.1, 3.2, 3.3, 3.4, & 3.5). Meal preparation skills were also reported to differ significantly for community based settings compared to congregate care settings and Michener Centre (Figure 3.6). It is consistently apparent that the percentage of those with no skills in all independence capacity skill areas is much greater in congregate care settings and Michener Centre, than in community based settings.

Table 3.10 reports percentages on normal functioning in relation to sensori-motor/language skills. Significant differences were noted across all settings in the areas of mobility and expressive language. Vision (normal) differed significantly between those in congregate care settings and Michener Centre. Those in Michener Centre were reported to have a higher level of normal vision. Receptive language (normal understanding) differed significantly for those in community based settings compared to congregate care settings and Michener Centre.

An analysis of self care skills between all agency types indicated significant differences in all skill areas (Table 3.10). Dressing/grooming skills were found to be displayed significantly more often in community based settings than in congregate care settings and Michener Centre. Overall,

TABLE 3.9

Percentages on Major Developmental Disabilities and Health Impairments by Type of Setting
(1-Community Based;2-Congregate Care; & 3-Michener Centre)

Major Developmental Disability	Setting Community	Congregate	Michener
Cerebral Palsy	2.9%	11.2%*	1.5%*
Epilepsy	12.2%*	27.5%*	29.0%
Mental Retardation	93.4%	98.9%	95.9%
Down's Syndrome	10.5%	4.5%	7.4%
Neurological Impairment	4.1%	7.4%*	0.2%*
Health Impairments			
Edema	4.0%	16.5%**	3.5%
Genito-Urinary	0.6%*	6.5%*	3.5%
Musculoskeltal	13.5%**	30.5%	23.0%
Neurological	4.7%	27.4%**	1.5%
Obesity	21.5%	27.7%*	10.6%*
Paralysis	0.6%	7.7%	7.4%**

N of Cases = 742

* Indicates a significant difference at <.01 between groups.

** Indicates that a significant difference at <.01 was reported for that agency compared to both other agencies.

**** Major Developmental Disability and Health Impairments are multiple response categories, therefore percentages do not sum to 100.

FIGURE 1

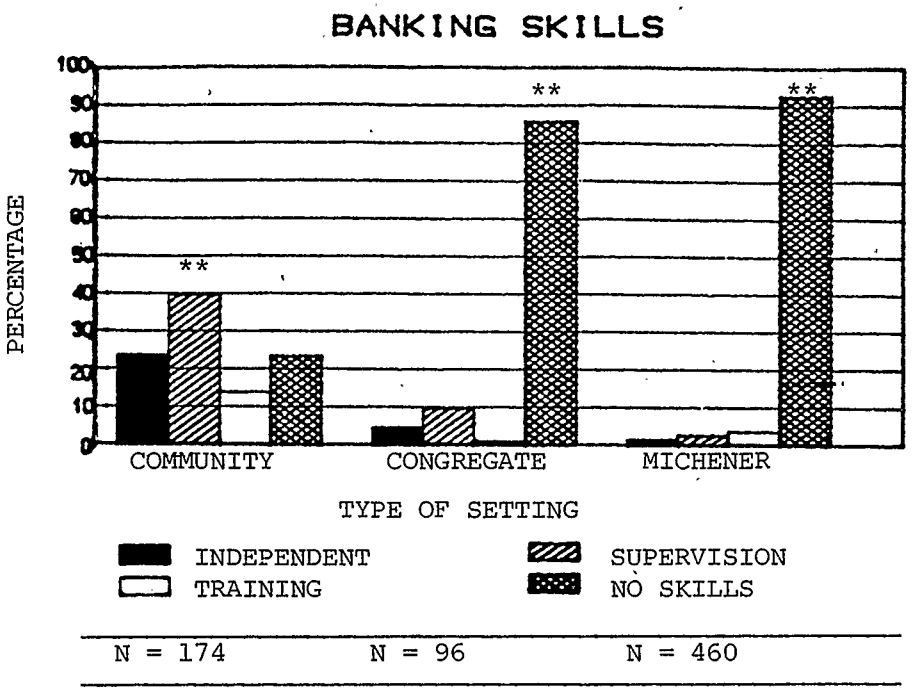
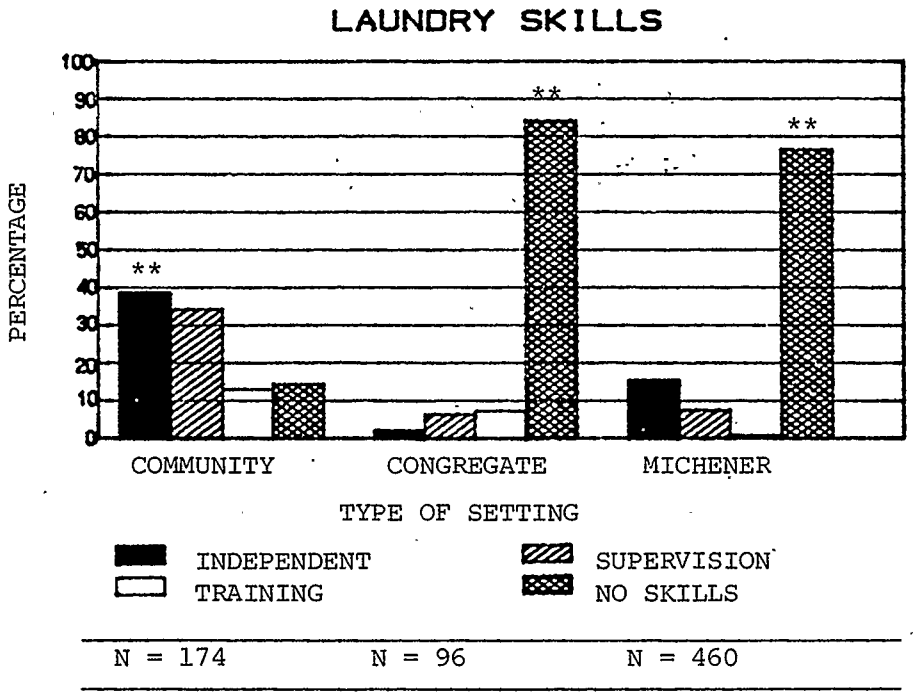


FIGURE 2



** Indicates that a significant difference at $< .01$ was reported for that setting compared to both other settings.

FIGURE 3

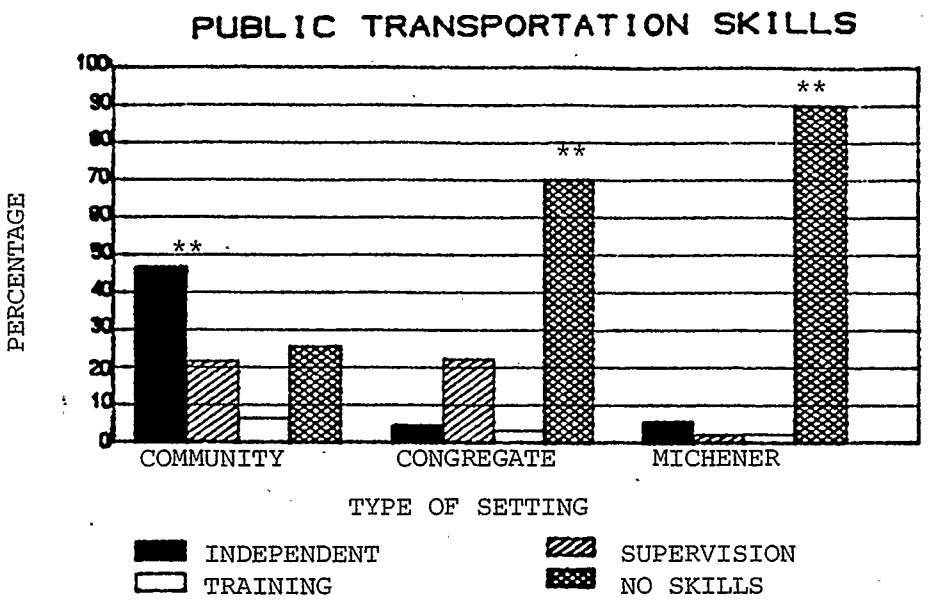
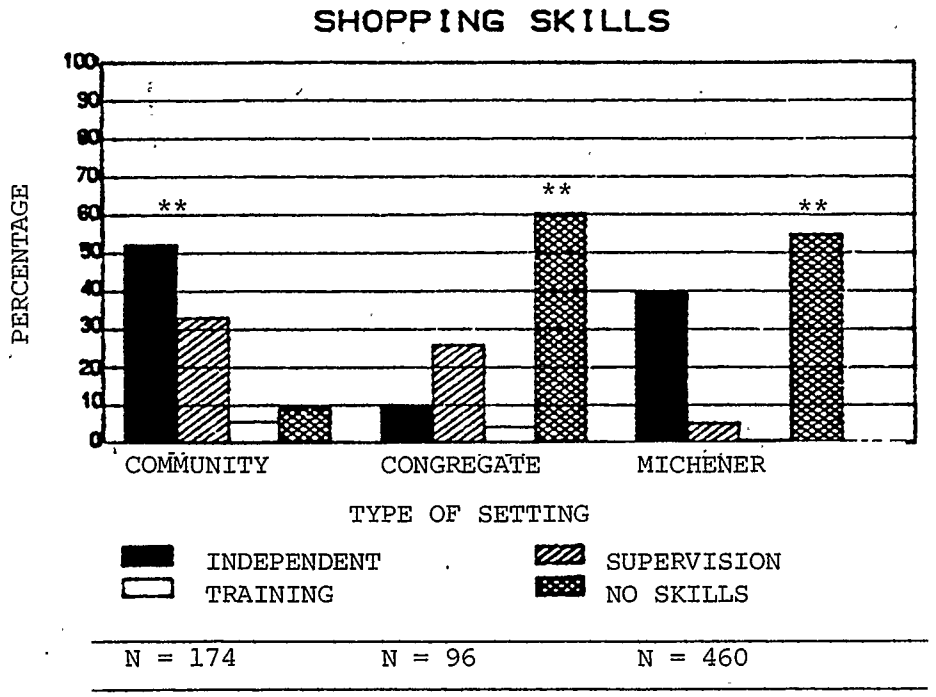


FIGURE 4



** Indicates that a significant difference at $< .01$ was reported for that setting compared to both other settings.

FIGURE 5

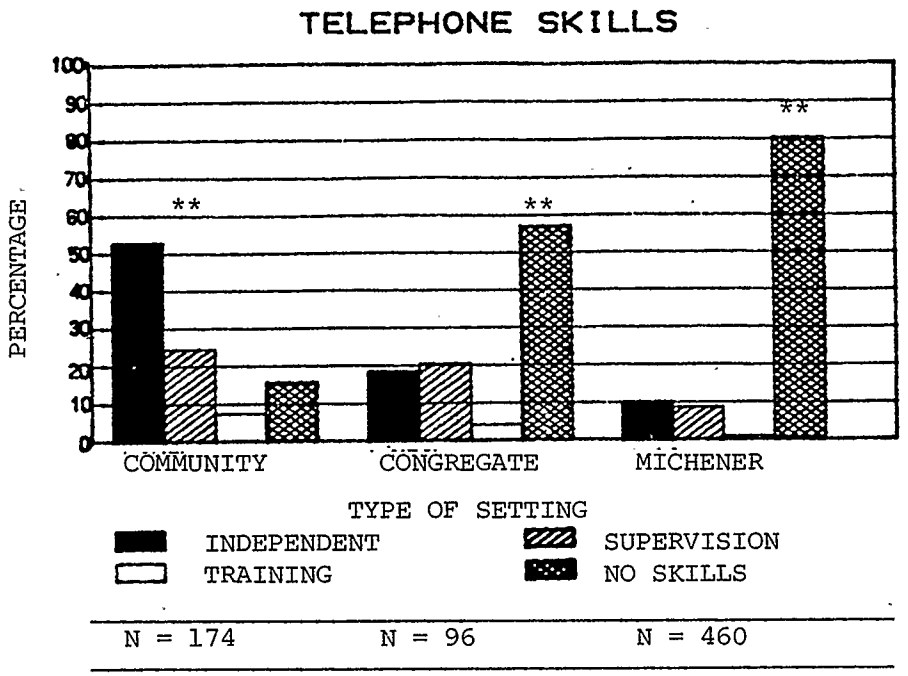
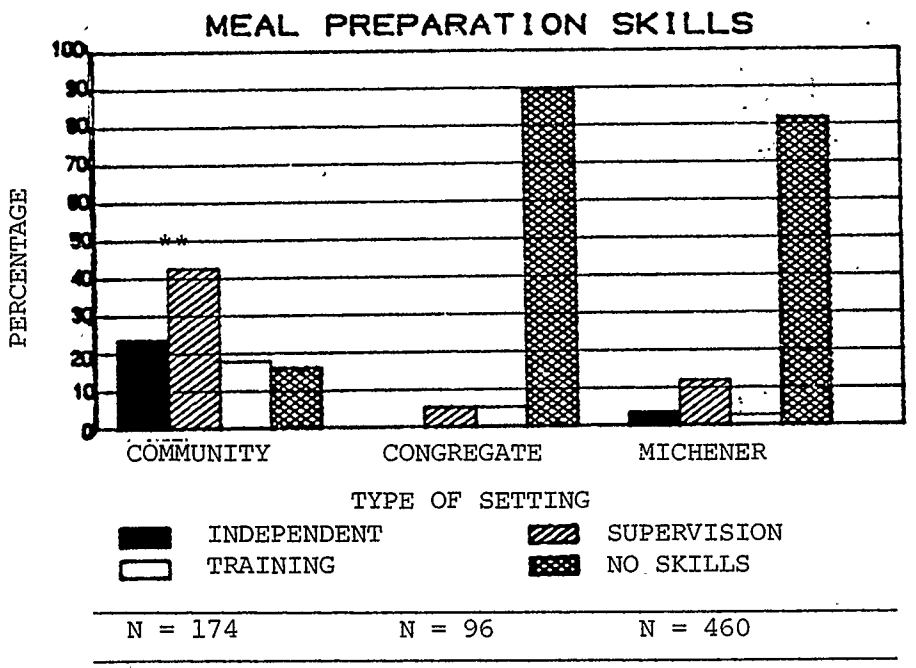


FIGURE 6



** Indicates that a significant difference at $< .01$ was reported for that setting compared to both other settings.

those in community based settings had the highest frequencies of independent functioning in the area of self care. An the analysis of type of setting by day programs demonstrated that those in community based settings and Michener Centre received fewer activity/leisure programs compared to those in congregate care settings. There were significant differences in the area of no formal day programs between all settings (Table 3.11). Those in Michener Centre had the highest frequencies reported in the area of no day programs (60.6%).

An analysis of setting by professional services indicated significant differences across all settings for client service coordination, public guardianship, nursing services, nutritional services, occupational therapy, recreation thereapy, rehabilitation counselling, and religous/pastoral services. Health related services such as nursing care, nutritional and recreational atherapy were reported most frequently for those in congregate care settings. Given the custodial nature of institutional environments, it was not surprising that public guardianship was reported most frequently for those at Michener Centre. Other service areas where significant differences were indicated between congregate care settings and Michener Centre were behavioral intervention; private guardianship; palliative care; and psychiatric services. Those in congregate care settings received these services more frequently than those at Michener Centre.

TABLE 3.10

Percentages of Sensori-Motor/Language Skills and Self Care Skills by Type of Setting
(1-Community Based; 2-Congregate Care; and 3-Michener Centre

Setting Sensori-Motor/Language	Community	Congregate	Michener
Mobility	85.1%**	49.4%**	67.0%**
Vision	85.1%	78.0%*	87.4%*
Hearing	85.9%	88.4%	84.8%
Expressive Language	63.3%**	36.2%**	33.9%**
Receptive Language	81.8%**	58.0%	48.8%
Self Care Skills			
Dressing/Grooming	79.2%**	32.3%	41.8%
Eating	94.6%	68.8%**	87.1%
Toileting	93.4%**	54.7%**	71.5%**

N of Cases = 742

* Indicates a significant difference at <.01 between groups.

** Indicates that a significant difference at <.01 was reported for that age group compared to both other age groups.

Note: The figures reported for Sensori-Motor/Language Skills reflects 'normal' ability in all areas. The figures reported for Self Care Skill reflect the ability to perform these skills independently.

TABLE 3.11

Percentages of Day Programs and Professional Services Received by Type of Agency
(1-Community Based; 2-Congregate Care; and 3-Michener Centre)

	Setting		
Day Programs	Community	Congregate	Michener
Activity/Leisure	15.2%	53.2%**	13.9%
Adult Education	2.9%	2.2%	3.9%
Sheltered Workshop	21.6%**	5.3%	4.6%
Sr. Citizen's Activity	8.8%*	4.2%	3.3%*
Vocational Training	53.8%**	2.1%**	15.7%**
Volunteer Work	3.5%	7.4%	0.4%**
No Formal Day Program	8.8%**	25.5%**	60.6%**
Professional Services			
Behavioral Intervention	8.4%	8.3%*	2.2%*
Client Service Coordination	41.0%**	0.0%**	99.6%**
Guardianship - Private	29.9%	42.7%*	28.1%*
Guardianship - Public	15.0%**	33.7%**	65.9%**
Nursing Care	14.45**	96.8%**	25.1%**
Nutritional	9.0%**	80.2%**	28.5%**
Occupational Therapy	8.4%	39.8%**	3.5%
Palliative Care	0.6%	3.2%*	0.0%*
Physical Therapy	2.4%*	13.0%*	6.8%
Psychiatrist	13.8%	10.5%*	1.1%*
Recreation Therapy	5.4%**	65.6%**	0.9%**
Rehabilitation Counseling	33.5%**	8.9%**	98.0%**
Religous/Pastoral	14.5%**	52.7%**	36.7**
Social Worker	43.4%	22.8%*	98.9%*
Trusteeship	45.8%	55.3%	96.7%**

N of Cases = 742

* Indicates a significant difference at <.01 between groups.

** Indicates that a significant difference at <.01 was reported for that agency compared to both other agencies.

**** Day Programs and Professional Services are multiple response categories, therefore percentages do not sum to 100.

3.6 Social Relationships

The social relationships of individuals were analyzed to ascertain the degree of involvement these individuals had with family and friends. Relationships with significant others generally decreased across the age groups. It is expected that this would be particularly true for a population of which the majority is single and childless. An examination of family social contact for this sample indicated that those persons involved in community based settings had an average of 14 face to face visits with immediate family members over the past three months while those residing in congregate care settings had an average of five face to face visits over the past three months (Table 3.12). Those persons residing at Michener Centre were reported to have an average of two face to face visits with immediate family over the past year (Table 3.13).

3.7 Service Needs

A major research focus for this research was to determine the most important services currently received and presently required for the older mentally retarded population of Alberta. As the three major types of agencies involved in this study are diversified in nature, the results of the service needs index were reported separately for each setting. Each agency was requested to report the five most important services received and required for each subject. The service needs index is presented in Tables 3.14, 3.15 & 3.16.

Table 3.12

MEANS AND PERCENTAGES FOR SOCIAL CONTACT OVER THE PAST 3 MONTHS FOR OLDER MENTALLY RETARDED PERSONS INVOLVED IN COMMUNITY BASED AND CONGREGATE CARE SETTINGS

	Mean	No Contact Percentage
Community Based Settings		
Immediate Family		
Face to Face Visit	14.24	23.6%
Other (Telephone/Letter)	5.6	26.3%
Relatives		
Face to Face Visit	2.3	47.9%
Other	1.6	41.4%
Friends		
Face to Face Visit	17.8	22.6%
Other	10.9	29.8
Congregate Care Settings		
Immediate Family		
Face to Face Visit	6	28.4%
Other	4.9	13.4%
Relatives		
Face to Face Visit	1	52.8%
Other	0.075	16.9%
Friends		
Face to Face Visit	2.4	34.5%
Other	0.3	18.5%

N of Cases = 282

Table 3.13

MEANS, RANGES, STANDARD DEVIATIONS AND PERCENTAGES FOR SOCIAL CONTACT OVER THE PAST YEAR FOR RESIDENTS OF THE MICHENER CENTRE

	Mean	Range	SD	No Contact Percentage
Immediate Family				
Face to Face Visit	2.2	0-53	6.3	58.3%
Other(Telephone/Letter)	3.6	0-75	8.4	48.5%
Relatives				
Face to Face Visit	0.2	0-48	2.4	94.8%
Other	0.2	0-12	1.2	94.8%
Friends				
Face to Face Visit	0.2	0-52	2.9	96.7%
Other	0.2	0-52	2.5	95.0%

N of Cases = 460

3.8 Community Based Settings

Table 3.14 presents the most important services received and required for those individuals involved in community based settings (vocational programs, residential programs, independent living services, associations for the handicapped and Client Service Coordination Units). The services reported most frequently in the category of services received are vocational programs and routine medical care. The services reported most frequently as required include activity/leisure programs; adult education programs; and senior citizens' activities.

3.9 Congregate Care Settings

Table 3.15 presents the most important services received and required for those individuals involved in congregate care settings (lodges, extended care centres, nursing homes and auxiliary hospitals). The services reported most frequently in the category of services received were nursing home services, activity/leisure programs and nursing care. For those in congregate care settings there was was a low response rate in the category of services required as is evidenced by the low frequencies reported in the table. However, activity/leisure programs and psychological services were reported most frequently as services required by residents of congregate care settings.

3.10 Michener Centre

For those individuals residing at Michener Centre, routine medical care; rehabilitation counselling ; and

vocational/sheltered workshop activities were reported most frequently as the most important services received (Table 3.16). In the category of most important services required, group home placements and activity/leisure programs were reported as the most important services required.

Table 3.14

FREQUENCIES FOR THE MOST IMPORTANT SERVICES RECEIVED AND REQUIRED IN COMMUNITY BASED SETTINGS

Services Priority	1	2	3	4	5
Services Received					
Vocational	21	22	--	--	--
Routine Medical	2	--	12	3	6
Peer Support	--	--	11	--	--
Rehabilitation Counseling	--	--	9	--	--
Dental	--	--	--	8	--
Guardianship - Private	--	--	2	6	--
Sheltered Workshop	--	8	--	--	--
Religous/Pastoral	--	--	--	6	--
Social Work	--	--	--	--	6
Approved Home	6	--	--	--	--
Group Home	5	--	--	--	--
Client Service Coordination	--	2	--	2	--
Audiology	--	--	--	--	1
Services Required					
Activity/Leisure	5	13	1	4	--
Adult Education	--	8	10	--	--
Senior Citizens Activity	5	2	4	2	--
Group Home	8	--	--	--	--
Full Time Employment	--	--	4	--	--
Guardianship - Public	2	--	1	1	--
Shopping Assistance	2	--	--	1	--
Communication Therapy	2	--	--	--	--
Approved Home	2	--	--	--	--
Volunteer Work	--	--	--	2	--
Supervised Apartment	2	--	--	--	--
Trusteeship	--	--	1	--	--
Psychologist	--	--	1	--	--
Recreation Therapy	--	--	1	--	--

N of Cases = 174

Table 3.15

FREQUENCIES FOR THE MOST IMPORTANT SERVICES RECEIVED AND REQUIRED IN CONGREGATE CARE SETTINGS

Services / Priority	1	2	3	4	5
Services Received					
Nursing Home	36	--	--	--	--
Activity/Leisure	--	15	--	--	3
Nursing Care	--	4	9	4	--
Extended Care Centre	14	--	--	--	--
Nutritional	--	--	4	4	6
Routine Medical	--	--	3	7	4
Occupational Therapy	--	--	--	4	--
Guardianship - Private	--	--	--	--	4
Services Required					
Activity/Leisure	3	--	1	--	--
Psychologist	--	2	1	--	1
Occupational Therapy	2	--	1	--	--
Communication Therapy	2	--	--	1	--
Volunteer Work	2	--	--	--	--
Vocational Training	2	--	--	--	--
Trusteeship	1	--	--	--	--
Legal	--	--	1	--	--

N of Cases = 96

Table 3.16

FREQUENCIES FOR THE MOST IMPORTANT SERVICES RECEIVED AND REQUIRED AT MICHENER CENTRE

	Priority				
	1	2	3	4	5
Services Received					
Group Home	69	19	--	--	--
Activity/Leisure	32	9	2	--	--
Physical Therapy	14	--	--	--	--
Occupational Therapy	6	5	--	--	--
Intensive Program Residence	5	--	--	--	--
Vocational Training	--	3	--	--	--
Communication Therapy	--	3	3	--	--
Legal	--	--	1	--	--
Services Required					
Routine Medical	163	139	17	3	--
Rehab. Counselling	105	44	31	--	--
Vocational/Sheltered Workshop	19	38	8	--	--
Activity/Leisure	26	29	4	1	2
Nursing	53	--	--	--	--
Group Home	--	--	5	--	--
Legal	--	--	--	2	--
Adult Education	--	--	--	1	1
Sr. Citizen Activity	--	--	--	1	--

N of Cases = 460

CHAPTER 4.0

DISCUSSION OF THE RESULTS

4.1 Discussion of Findings

The major variables selected for analysis; gender, age and setting yielded interesting results. Although gender was reported to be an important variable to include in studies on the older mentally retarded population (Seltzer, 1985); there is very little evidence in the available literature on aging and developmental disabilities that suggests differences between males and females. Our findings indicated that there were only major differences in the area of health impairments. Females were reported overall, to have more health impairments than males.

It was interesting to note an almost equal distribution of males (49.9%); and females (47.2%) in our study. Generally speaking, females constitute the highest proportion of the aging population (National Council of Welfare, 1983; Gibson & Rowland, 1984). However, as we included persons aged 45 and over; and the mean age of our sample was only 60.13 years, comparisons between the general aging population and the aging mentally retarded population cannot be inferred from our data.

Age was found to be related to lowered ability in the area of independence capacity skills. The oldest age group was reported to have the lowest level of independent functioning in these skill areas. Those in community based settings had varying degrees of ability to perform

independence capacity skills. However, a significant decrease in the ability to perform these skills was noted for those in congregate care settings and Michener Centre. This finding is not surprising given that increasing age is often associated with increasing dependence. For a population who is mentally retarded; particularly those who are institutionalized, and not expected or required to be independent, this finding may be particularly true. Given the characteristics of increasing age and institutional placements for approximately 75% of the sample, it would not be expected that services promoting independence capacity would be forthcoming. However, in more progressive gerontological facilities, the promotion or maintenance of independence is usually an important part of the program (Singer-Edelson & Lyons; 1985).

It was evident in our study that those in congregate care settings were more physically disabled than those in community based settings and Michener Centre. The congregate care settings included in our study primarily provide nursing and medical care and therefore it would make sense that this would be a more physically disabled group. Although differences in health conditions are indicated generally between community based and institutionalized settings; it must be noted that differences are also evident between various types of institutional placements. Gibson and Rowland (1984) have reported that the "disabilities most likely to lead to institutionalization in later life are

limitations on use of feet and legs, mental disabilities and blindness" (1984: p. 999). In our study, those in congregate care settings were reported to have the lowest levels of mobility (totally ambulatory), and vision (normal). Previous studies have indicated that persons who are institutionalized are the more seriously disabled of the mentally retarded population (Jancar & Carter, 1983). For at least one segment of the institutionalized population in our study, this was found to be true.

An examination of age as it relates to day programs indicated a significant decrease in formal day programs for the older age groups. Given that retirement age among the general aging population is 65, this decrease in vocational programs would be considered consistent with trends for the population at large. Similarily, the increase noted in activity/leisure programs for the two older age groups would be considered appropriate. It has been reported in the literature that activity/leisure are among the most important services required by the aging mentally retarded (Segal, 1977). Involvement in senior citizen's activities was only noted for approximately 6% of the population in both of the older age groups. It was noted in a previous study by Wachowich and Zalasky (1979) that many generic programs do not see the elderly retarded as potential candidates and this may be reflected in the low level of involvement in senior citizen's activities.

An increase in services related to health care such as nursing care were noted for the population aged 65+. This finding would be consistent with the significant increases very debilitating health conditions such as cardiovascular and musculoskeletal disorders which were noted for this age group. The increase in these conditions is consistent with findings in previous studies (Rudelli, 1985; & Catapano, Levy, & Levy, 1985).

In relation to the service domain, there is strong evidence that the setting in which a mentally retarded person is involved is a major factor in the types of services received by that individual. For example, therapeutic services such as nutritional, occupational and recreation therapy were received significantly more often for those in congregate care settings. As this type of setting is geared towards providing these types of services characteristic of the medical model, and given the fact that they are utilized by a high percentage of individuals; it is not inappropriate to suggest that aging mentally retarded persons in other settings may be in need of these services. However, it is evidenced that these services are utilized at much lower level for those in Michener Centre and community based settings. It would appear to be self evident that services such as recreation therapy would be a definite requirement for this population given the lower levels of physical disabilites presented and the lack of day programs.

Guardianship was a major presence in the lives of many of the individuals involved in this study. For example, approximately 66% of the residents at Michener Centre received public guardianship services while approximately 28% received private guardianship. Given the lack of social contact indicated for this population, i.e. a mean of 2.2 face to face visits over the past year for those at Michener Centre; it is not surprising that guardianship was reported at such a high level for this sample.

This lack of social contact leads to the conclusion that those who are institutionalized are less likely to have family contact relative to those involved in community based settings. A decrease in social relationships for the aging mentally retarded has been reported on in the literature by Thurman, 1986; and Seltzer, 1985. The previously reported increases in custodial services such as guardianship and trusteeship would certainly appear to support this. It would appear therefore that both age, and institutional placement affect social contact with family members for the elderly retarded. These factors combined with increasing health impairments, decreased independence capacity skills, and a lack of formal day programs appear to dictate a fairly isolated existence for the aging mentally retarded person.

Although formal day programs in the sense of formal training programs are not necessarily required by the older mentally retarded population there is strong evidence in the service needs index that at least some form of daytime

activity is important and required by this population. For example, activity/leisure programs were consistently reported across all settings as a definite need for this population. It should be noted that programs such as vocational and sheltered workshops which involve daytime activity were among the most frequently reported in the category of most important services received for those in community based settings. Leisure, adult education and senior citizens' activities were reported as the most important services required for those in community settings. Again, it is noted that an element of daytime activity is involved in all these services.

The responses in the service needs index were very representative of the types of setting involved in this study (community based, congregate care and Michener Centre). For example, the most important service reported to be received for those individuals in congregate care settings was nursing home care. It was interesting to note that those in institutional environments barely responded in the category of services required. Perhaps this reflects the medical model in which institutional care is viewed as meeting the total needs of the persons, therefore relatively few additional support services are required. The sample in congregate care settings was clearly more physically disabled having the lowest level of mobility and self care skills, and the highest overall level of health impairments. Nursing home/care services were reported as the most

important services required by this population. Routine medical care was reported as the most important service received by residents of Michener Centre. Group homes and approved homes were reported as priority needs for at least ten individuals in community based settings.

Although the majority of the sample (75%) were residing in institutional types of environments; there is an indication of the need for community based services for a substantial amount of the sample. In particular, community residential placements appear to be a priority need, especially for those at Michener Centre. Previous studies have suggested the importance of community based settings for aging mentally retarded persons (Janicki & Jacobson, 1979; Thurman, 1986; and Seltzer & Seltzer, 1985); and have also indicated that institutionalized mentally retarded persons are often capable of living in less restrictive environments (Janicki and MacEachron, 1984).

There appears to be no clear policy as yet on service provision for older mentally retarded persons in the province of Alberta. Turning again to the United States the New York State Office on Mental Retardation and Developmental Disabilities approached policy development for this population from the following orientation:

"- maintain and enhance those aspects of policy which are perceived as meeting the needs of older persons,

- reject those aspects of policy which do not contribute to the well-being of older disabled persons, and
- develop new policy recommendations for the yet to be resolved issues/solutions which are both programmatically sound and attainable with realistically available resources" (Puccio, Janicki, Otis & Rettig, 1983, p. 53).

It is important to note that there are many similarities between the normal aging and the developmentally disabled aging poulation and these should be taken into consideration when developing policy for this population. They are both affected by the normal changes of aging; there is a need for adequate and appropriate housing, for health and nutritional services, and for appropriate support services.

Turning to the final chapter, we will address the major research questions and make recommendations based on the findings of this study.

CHAPTER 5.0

CONCLUSIONS AND RECOMMENDATIONS

In this chapter we will restate the major research questions and attempt to provide answers to them based on information gathered through the survey. In addition, based on those answers, recommendations for future action will be made.

5.1 Restatement of the Major Research Questions

1) How many mentally retarded persons within identified service systems are residing in the Province of Alberta?

In the study, 742 persons were identified. This does not represent the entire population for reasons such as refusal to participate or respond by some agencies, and data lost in the mail. However, it is considered to represent a large cross-section of the population from a variety of service systems. It is the view of this writer that the data collected provides a representative profile of older mentally retarded/developmentally disabled persons in the province of Alberta.

2. What are the needs of this population?

Based on the data medical types of services are a need for this population, particularly for the older subjects involved in this study. This was evidenced by the increased proportions of these types of services received by the older age groups, and the importance ascribed to routine medical

care in the category of most important services received. In the gerontological literature the plea is the same - more routine medical care is required for the elderly (Marshall, 1980).

Looking at the service needs index, it was very clear that activity/leisure programs are also required by this sample. Given the lack of formal day programs, these types of services would at least provide some form of meaningful daytime activity. The types of services required varied with the type of setting in which the subject was involved. Group home placements were not received by a large proportion of individuals in this study (8.0%). Institutional settings were clearly the predominant type of living environment. It has been suggested in the literature that institutionalized persons could reside in less restrictive environments (Janicki & MacEachron, 1984). Although very few group homes exist for this population in Alberta, a system which takes into consideration the medical requirements of this population could provide a viable alternative to institutionalization and possible reinstitutionalization as mentally retarded persons grows older.

The lack of social contact, particularly for residents of Michener Centre indicated that this population is, in many ways, very isolated. Community living placements, an increase in activity/leisure and senior citizen's activities would be viewed as a positive step towards increased

socialization. Overall, some type of meaningful daytime activity is required. This was reported consistently across all settings.

As this study is exploratory, there may be other areas in which this population may be lacking appropriate support or professional services. Further research specifically focusing on the needs of the older mentally retarded person within specific types of programs is required to determine the most appropriate types of services in relation to different settings.

3. What services currently exist and what services should be developed to meet the needs of this population?

Many of the professional services reported to be received by this sample can generally be found within the generic service system; eg. social work, and psychology. However, programs such as group homes and vocational services are found within a specialized system which provides services to the disabled. Funding, within this system is provided for specific services and current policy may exclude many older persons not able to participate fully in day programs such as those offered in vocational training centres and sheltered workshops. For example, most agencies providing community residenctial programs for the mentally retarded have as part of the entrance criteria into residential programs a requirement that a person must have a day program. This policy was a fairly standard one among residential programs in this study with few exceptions.

This type of policy however, excludes persons who may not be able to participate in a formal full-time day program for reasons such as health or other conditions associated with aging. Additionally, an older person may not want to enter into a full time vocational training program at age 45 or beyond. Therefore, the only alternative in many cases for the older mentally retarded person is placement in facilities such as nursing homes and extended care centres.

Current policy should be directed towards the types of programs that would provide appropriate age related activities to the older mentally retarded population. Health conditions, the need for community based settings and activity/leisure programs should be considered as important needs for this population in the establishment of programs.

It would be appropriate for staff working with the mentally retarded to receive some training in the field of aging. Given that this is really a new population it is suggested that service delivery to this population has not been a priority until recently. Policy makers and social planners must become informed of the characteristics and needs of this population before program planning for this population can become a reality.

It is evident that a cross-disciplinary approach which applies concepts and approaches related to both gerontology and rehabilitation is required for the older mentally retarded persons. Each discipline has expertise to provide

to enhance the lives of this population. Our findings indicate that there are many implications for both the gerontological and rehabilitation fields in relation to service provision. A number of different kinds of programs serve to maintain the general aging population in the community and these services should not be overlooked in the case of the elderly mentally retarded.

Certainly, the social work profession has a contribution to make in service provision to this population. An examination of Table 3.11 indicated that social work was one of the most frequently received services for those in community based settings and Michener Centre. Given the relatively high involvement of the social work profession with this population, it is not inappropriate to suggest that training in both the areas of aging and developmental disability would be an important component of social work education programs. Given the overall increase in the aging population in general, it is certain that the level of involvement with aging persons will increase for social workers.

4. Are there major differences between institutionalized and community based populations?

The major differences that were evident between community based and institutionalized populations were in the areas of skill levels attained, health impairments, day programs and types of professional services received. It was evident that those in community based settings had

higher skill levels in the area of sensori-motor/language skills, and self care skills, and received more day programs such as vocational programs and sheltered workshops relative to congregate care settings and Michener Centre. Only 8.8% of those in community based settings had no formal day program compared to 25.5% in congregate care settings and 60.6% in Michener Centre. There appears to be a strong relationship between type of setting and a lack of day programs; particularly for institutionalized populations. However, it is evident that community based and congregate care settings place a higher value on day programs relative to Michener Centre. The rehabilitation field has traditionally not served aging persons and it is appropriate to suggest that the experience of the gerontological field would be a tremendous asset in facilitating the development of appropriate services to this population.

It was interesting to note that despite long term institutionalization of the residents at Michener Centre, health impairments did not differ a great deal between Michener and community based settings. Those in congregate care settings required medical and nursing care more frequently than those in other settings.

Generally speaking, those in community based settings were less disabled and more frequently involved in a variety of programs and activities. Those in institutional settings were more disabled, had less family contact and more health impairments. Despite these conditions, community placement

would probably be beneficial for a number of the institutionalized persons in this study. In Canada, the Province of Alberta has the highest rate of institutionalization for its elderly population (9.3%) (Schwenger & Gross, 1980). It would appear that this trend is impacting the aging developmentally disabled given the high rates of placements in institutional types of environments. It is self evident that community placement provides a wider range of options and should be considered as priority need for the older mentally retarded person in Alberta.

5.1 Recommendations

Recommendations are suggested in several areas.

1. It is recommended that community based residential placements be considered as a viable option for older mentally retarded persons in Alberta.
2. It is recommended that community supports that take into consideration the various health imapairments of the older mentally retarded person be developed in order to facilitate residency in the community as long as possible.
3. It is recommended that the rehabilitation and gerontological fields consider joint planning in the establishment of services required to meet the needs of this population.
4. It is recommended that training programs in the area of aging be developed for staff working with the mentally retarded; and concurrently, that training programs in the

area of mental retardation be developed for staff working with this aging population.

5. It is recommended that studies in aging be considered a mandatory part of social work education programs.

6. It is recommended that day programs be developed for this population, particularly activity/leisure programs. These programs are not suggested as replacements for full time vocational programs, but rather as optional, creative alternatives for older mentally retarded persons who require meaningful daytime activities.

7. It is recommended that policy be developed that takes into consideration the special needs of aging mentally retarded persons and that this policy provide a planning base for age appropriate programs and activities.

8. It is recommended that further research be implemented in the area of aging and developmental disabilities. Areas for further exploration include: demographics and characteristics of aging mentally retarded persons across Canada; medical research which studies the aging process in this population; family studies; pilot project which consider the special needs of this population in the areas of activity/leisure, residential and social programs.

In conclusion; the intention of this research project was to provide a profile of the older mentally retarded population in the province of Alberta. This has been achieved and provides the groundwork for future studies on this population. There are tremendous implications for both

the gerontological and rehabilitation fields in relation to this aging population and a cross-disciplinary approach is suggested as the best approach in the development of services to this population. It is hoped that this study and future studies will be influential towards a goal of providing quality of life programs to the aging mentally retarded person.

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APPENDIX A

APPENDIX A

A DEMOGRAPHIC AND NEEDS ANALYSIS OF OLDER DEVELOPMENTALLY DISABLED PERSONS IN THE PROVINCE OF ALBERTA

GLOSSARY OF TERMS

B. DISABILITY AND FUNCTIONAL STATUS

1. Major Developmental Disability

Please apply the following set of definitions:

AUTISM: This disability refers to a syndrome characterized by severe disorders which began in early childhood and interfere with learning, developmental rate and sequences, responses to environmental events, communication, and interpersonal relations.

CEREBRAL PALSY: This disability is a group of dysfunctions characterized by difficulty in muscular control as well as sensory functions, with mobility affected in most cases in addition to speech and hand movements.

EPILEPSY: This disability involves a number of disorders of the nervous system, centered in the brain, which are characterized by sudden seizures, muscular convulsions, and partial or total loss of consciousness due to the abnormal electrical discharges of brain cells.

MENTAL RETARDATION: This disability is characterized by significantly sub-average intellectual functioning and deficits in adapative behavior. Mental retardation is a condition, not an illness or disease.

NEUROLOGICAL IMPAIRMENT: This disability is a group of disorders of the central nervous system characterized by dysfunction in one of more, but not all, skills affecting communicative, perceptual, cognitive, memory, attentional, motor control, and appropriate social behavior.

C. PROGRAM INFORMATION

1. Residential Services

1 Active Treatment Hospital-Rehabilitative Facility: acute medical intervention or psychiatric behavioral treatment
2 Adult Foster Care: complete care within a family setting
3 Approved Home: room and board as well as some training and supervision in living skills
4 Auxiliary Hospital: facility for person who require elements of hospital care at a less intensive level than is provided in general hospitals
5 Cooperative Living Arrangement: independent living with regular supervision
6 Corrections Facility: minimum or maximum security facility
7 Extended Care Centre: 24 hours nursing and medical care as well as rehabilitative services
8 Group Home (Adult Community Residence): personal and community living skills supervision and training
9 Group Residence on Grounds of Institutional Setting: group home on the campus of larger residential facility
10 Independent Living: independent accommodation. may have some supports or assistance in maintaining independent status
11 Institution for the Mentally Handicapped: congregate facility for mentally handicapped persons removed from the community
12 Intensive Program Residence: behavioral management or medical adaptation in a home setting
13 Living with Parents/Relatives
14 Minimally Supervised Apartment - independent living arrangement with some drop in supervision
15 Nursing Home: supervised personal care for persons who are not ill enough to require hospitalization, but require assistance with activities of daily living
16 Senior Citizens' Apartment: self contained housing program at an affordable rent
17 Senior Citizens' Lodge: low rental accommodation for elderly persons not suffering from any chronic disease or disability that requires specialized care
18 Single Men's Hostel
19 Women's Emergency Shelter
20 YMCA-YWCA
21 Other (specify)

2. Day Programs

1 Activity-Leisure Programs: organized leisure activities. sports. crafts. hobbies. drop-in centres or other social events as alternative to day program
2 Adult Education: day or evening education program in areas such as lifeskills. upgrading. trades training and general education
3 Competitive Employment - full time: f.t. work at competitive wage
4 Competitive Employment - part time: p.t. work at competitive wage
5 Day Hospital: day program providing medical and rehabilitation therapy as well as social and recreational opportunities on a daily basis. Psychogeriatric day hospital programs provide assessment and therapeutic treatment to mentally disordered elderly persons
6 No Formal Day Time Program
7 Senior Citizens' Activities: ie. Drop In Centre. Golden Age Club
8 Sheltered Workshop - a sheltered work setting in which an individual is paid for work and or receives other vocational rehabilitation services
9 Vocational Training: preparation for employment through development of basic and specific work skills
10 Volunteer Work: unpaid free time donated to the community
11 Other (specify)

3. Professional Services

1 Adaptive Aids: therapeutic and specialized equipment, ie. wheelchair, mobility aids. etc.
2 Audiology Services: screening or evaluation services, and services undertaken to obtain a hearing aid for an individual
3 Behavioral Intervention: specialized program or specialist support for behavior problems
4 Communication Therapy: assessment, consultation and treatment of communication/speech disorders
5 Client Service Coordination: identification and promotion of joint planning for service needs
6 Dental Services: includes both routine and specialized dental services
7-8 Guardianship: legal substitute decision maker acting on behalf of client in the least restrictive manner
9 Legal Services: services provided by a lawyer. ie. constructing a will, transfer of property
10 Nursing Services: medical/physical care, administration of medication, health education and assessment
11 Nutritional Services: those services provided by a dietician above and beyond regular meal planning, ie. specialized diet for medical condition
12 Occupational Therapy: services provided by a certified specialist in the areas of evaluation, assessment and therapy
13 Palliative Care: services provided to the terminally ill to improve quality of life
14 Peer Support: information and person support provided by peer(s) having a similiar disability
15 Physical Therapy: services provided by a certified specialist in the areas of evaluation, assessment and therapy
16 Psychologist: specific psychometric evaluation, behavioral assessment and individual counselling provided by a certified psychologist
17 Psychiatrist: prescription and supervision of medication and psychiatric treatment
18 Recreational Therapy: services provided by a certified specialist in the areas of evaluation, assessment and therapy
19 Rehabilitation Counsellor: services provided by a certified specialist in the areas of lifeskills, residential and vocational programs
20 Religious·Pastoral Services: individual pastoral counselling or participation in religious services and related activitives
21 Respiratory Services: specialized technical services
22 Respite Care: full range of temporary and relief services ie. vacation relief
23 Routine Medical: services provided by the more generic medical specialities, ie. family practitioner. internists
24 Social Worker: services provided by a social work practitioner in major life areas. ie. psychosocial emotional counselling
25 Specialized Medical: ie. podiatrist, eye specialist. gynecologist. ear. nose and throat specialist. etc.
26 Trusteeship: legal substitute decision maker in financial matters pertaining to the disabled person
27 Other (specify)

4. Support Services

1 HomeMaker Services: in-home services to assist with household maintenance, skilled childsitting, or care for a disabled individual
2 Meals on Wheels: home delivered hot meals at low cost
3 Personal Care Attendance: health maintenance and assistance in personal care needs, ie. bathing
4 Seniors' Surveillance Program: daily or weekly phone calls to monitor well being of seniors in their own homes
5 Shopping Assistance: actual assistance with shopping and/or home delivery services
6 Transportation: subsidized services that provide vehicles equipped to carry and aid passengers with special transportation needs
7 Other (specify)

NOTE: The definitions listed in this glossary are from three primary sources: The Developmental Disabilities Information Survey, New York (1979); The Disability Information System of Calgary (1984); and Calgary Auxiliary and Hospital District #7 (1985).

APPENDIX B

A DEMOGRAPHIC AND NEEDS ANALYSIS OF OLDER DEVELOPMENTALLY DISABLED PERSONS IN THE PROVINCE OF ALBERTA

Description of the Project

The purpose of this research project is to identify and assess the needs of older developmentally disabled persons within identified service systems in the province of Alberta. The needs of older developmentally disabled persons have remained relatively unexplored in Canada and it is anticipated that there will be a need to plan and develop services for this population.

A modified version of the Developmental Disabilities Information Survey (DDIS) developed by the New York State Office of Mental Retardation and Developmental Disabilities (1979) has been utilized. We anticipate that the results of this research project will not only provide a planning base for this population. but may also influence future policy development regarding the aging developmentally disabled.

Instructions

This form is intended to be self instructing. The items have been listed in alphabetical order. A glossary of terms for Section B -1. Major Developmental Disability and Section C-1. Residential Services. 2. Day Programs. 3. Professional Services and 4. Community Services has been included under separate cover to assist you in completing the form. **PLEASE FILL OUT ONE FORM ON EACH MENTALLY HANDICAPPED PERSON IN YOUR AGENCY/FACILITY AGE 45 AND OVER AS OF AUGUST 1, 1985.** It is suggested that someone familiar with the client is the most appropriate person to complete the form as some of the required information may not be available on client records.

Your participation in this project is appreciated. If you have any questions please contact Dorothy Badry at 284-1121 for assistance. Thank you for your help.

A VOCATIONAL AND REHABILITATION RESEARCH INSTITUTE PROJECT
May 1985 - April 1986

OFFICE USE ONLY

CARD 1

1-4 IDENTIFICATION NUMBER: ☐☐☐☐

5-12 TODAY'S DATE: ☐☐ day ☐☐ month ☐☐☐☐ year

AGENCY NAME: _____

13-15 ☐☐☐ LOCATION: (city, town, village) _____

16-18 ☐☐☐

A. IDENTIFYING INFORMATION

1. CLIENT INITIALS:

19-21 ☐ first ☐ middle ☐ last

2. BIRTHDATE:

22-29 ☐☐ day ☐☐ month ☐☐☐☐ year

3. GENDER: Write the appropriate number in the box below.

30 ☐
1 Male
2 Female

4. LENGTH OF TIME IN CURRENT AGENCY: Please list the client's date of admission below.

31-38 ☐☐ day ☐☐ month ☐☐☐☐ year

5. MARITAL STATUS: Write the appropriate number in the box below.

1 Single
2 Common-law
3 Married
4 Widowed
39 ☐ 5 Separated
6 Divorced

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6. LANGUAGE(S) SPOKEN: Please indicate the primary and secondary language(s) spoken by writing the appropriate number(s) in the boxes below.

40-41 ☐☐ PRIMARY

42-43 ☐☐ SECONDARY

01 Chinese
02 Dutch
03 English
04 French
05 German
06 Italian
07 Japanese
08 Native Languages
09 Polish
10 Russian
11 Scandinavian
12 Ukranian
13 Other (specify): _____

7. FINANCIAL STATUS

a. **SOURCE OF INCOME:** Please check all that apply.

44 ☐ Alberta Assured Income Plan (AAIP)
45 ☐ Assured Income for the Severely Handicapped (AISH)
46 ☐ Canada Pension Plan (CPP)
47 ☐ Family Support
48 ☐ Guaranteed Income Supplement (GIS)
49 ☐ Old Age Security (OAS)
50 ☐ Self Supporting
51 ☐ Social Allowance (SA)
52 ☐ Social Assistance (SA)
53 ☐ Spouses Allowance (SA)
54 ☐ Unemployment Insurance (UIC)
55 ☐ War Veterans Allowance (WPP)
56 ☐ Widows Pension Plan (WPP)
57 ☐ Other (specify): _____

b. APPROXIMATE MONTHLY INCOME: Total combined income from any of the above sources of income.

58-61 $ ☐☐☐☐.00

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c. HEALTH AND SOCIAL SERVICES BENEFITS: Please check all that apply.

62 ☐ Alberta Blue Cross Plan
63 ☐ Alberta Extended Health Benefits Plan
64 ☐ Alberta Health Care Insurance Plan

B. DISABILITY AND FUNCTIONAL STATUS

1. MAJOR DEVELOPMENTAL DISABILITY(S): Please check all that apply. Please see glossary for definitions of terms.

65 ☐ Autism
66 ☐ Cerebral Palsy
67 ☐ Epilepsy
68 ☐ Mental Retardation
69 ☐ Down's Syndrome
70 ☐ Other Syndrome if known: _____
71 ☐ Neurological Impairment

2. OTHER SIGNIFICANT DISABILITIES: Please check all that apply.

Do not check these categories unless they have been assessed and reported on by an appropriate professional.

72 ☐ Alcohol Dependence or Abuse
73 ☐ Brain Injury
74 ☐ Drug Dependence or Abuse
75 ☐ Functional Learning Disability
76 ☐ Organic Brain Syndrome
77 ☐ Alzheimer's Disease
78 ☐ Senile Dementia
79 ☐ Psychiatric Disability
80 ☐ Other (specify): _____

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CARD 2

3. LEVEL OF INTELLECTUAL FUNCTIONING

a. **Most recent IQ score:**

1-3 ☐☐☐

b. **Name of Test:** _____

4-6 ☐☐☐

c. **Date of Test:** ☐☐ ☐☐ ☐☐☐☐

7-14 day month year

d. **Level of Retardation:** (AAMD Classification) Please indicate the level of retardation by writing the appropriate number in the box below.

1 Mild
2 Moderate
3 Severe
4 Profound

15 ☐

4. HEALTH IMPAIRMENTS: Please check all that apply.

16 ☐ Cardiovascular (heart disease, high blood pressure)
17 ☐ Digestive (liver and bowel deficiencies, ulcers, colitis)
18 ☐ Edema (swelling, water retention)
19 ☐ Endocrine (thyroid disorders, diabetes)
20 ☐ Genito-Urinary (kidney disease)
21 ☐ Growth Impairment (weight and height deficiency)
22 ☐ Hemic Lymphatic (sickle cell disease, leukemia)
23 ☐ Multiple Body Systems (immunity deficiencies, Tay Sachs disease)
24 ☐ Musculoskeletal (arthritis, scoliosis, spinal cord injury, amputations, muscle weakness, osteoporosis)
25 ☐ Neoplastic Disease (cancer, tumors)
26 ☐ Neurological (motor dysfunction, brain tumors, communication impairment)
27 ☐ Obesity (20 lbs. over appropriate weight for height & build)
28 ☐ Paralysis
29 ☐ Other: (specify) _____

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5. a. SEIZURE DISORDER AND FREQUENCY: Please check appropriate category. If response is Number 1 move onto Question 6.

☐ 1 None
☐ 2 Seizures controlled (No seizures in past 2 years)
☐ 3 Seizures in past 2 years but none for 6 months
30 ☐ 4 Currently has seizures

b. Types of seizures: Please check appropriate category.

☐ 1 Petit Mal (absence)
☐ 2 Grand Mal (major motor)
☐ 3 Psychomotor (temporal lobe)
31 ☐ 4 Other (akinetic drop, ataxic episodes, Jacksonian [focal])

6. SPECIAL DIETARY NEEDS: Please check appropriate category(s).

☐ 1 None
☐ 2 Yes, nutritional reasons
32 ☐ 3 Yes, diet control/planning
33 ☐ 4 Yes, other reasons (specify): _____

7. a. TYPES OF MEDICATION: Please check appropriate category(s). If response is Number 1 move onto Question 8.

☐ 1 No medication
34 ☐ 2 Prescription
35 ☐ 3 Non prescription medication

b. MEDICATION ADMINISTRATION: Using the following scale indicate beside the appropriate medication category who administers drugs to the client.

1 - Self administered
2 - Self administered with support
3 - Administered by others

MEDICATIONS

36 ☐ 1 Anticonvulsant
37 ☐ 2 Cardiac
38 ☐ 3 Diabetic
39 ☐ 4 Non prescription
40 ☐ 5 Other Prescription Medication
41 ☐ 6 Psychotropic: If known check the drug type:
42 ☐ Anxiolytic (decreases anxiety)
43 ☐ Neuroleptic (decreases psychotic behavior)
44 ☐ 7 Other (specify): _____

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8. SENSORI-MOTOR/LANGUAGE SKILLS: Please check the most appropriate category according to the *current status* of the client. Check only one category.

a. MOBILITY

- ☐ 1 AMBULATORY WITHIN NORMAL LIMITS - fully independent walking
- ☐ 2 PARTIALLY AMBULATORY - fully independent walking on flat surfaces. may use wall or rail for support, may have poor gait, can walk unassisted for short distances.
- ☐ 3 WHEELCHAIR or EQUIVALENT (cane, walker) WITHOUT ASSISTANCE - does not require assistance to transfer or to be mobile
- ☐ 4 WHEELCHAIR OR EQUIVALENT WITH ASSISTANCE - resident spends most of the day in wheelchair, needs transfer assistance
- ☐ 5 NOT AMBULATORY - confined to bed, needs transfer assistance

45

b. HEARING

- ☐ 1 HEARING IS NORMAL (includes hearing corrected by hearing aid)
- ☐ 2 HEARING IS IMPAIRED
- ☐ 3 NO FUNCTIONAL HEARING
- ☐ 4 UNKNOWN OR NOT DETERMINED AT THIS TIME

46

c. VISION

- ☐ 1 VISION IS NORMAL (includes vision corrected by glasses)
- ☐ 2 VISION IS IMPAIRED
- ☐ 3 LEGALLY BLIND
- ☐ 4 NO FUNCTIONAL VISION
- ☐ 5 UNKNOWN OR NOT DETERMINED AT THIS TIME

47

d. EXPRESSIVE LANGUAGE

- ☐ 1 USES APPROPRIATE SPEECH SKILLS (normal speech patterns)
- ☐ 2 USES SIMPLE SPEECH (can indicate needs)
- ☐ 3 USES ONLY MANUAL LANGUAGE (ie. form of sign language)
- ☐ 4 USES ONLY WRITTEN SYMBOL LANGUAGE (ie. Bliss)
- ☐ 5 USES ONLY WRITTEN LANGUAGE
- ☐ 6 NO EXPRESSIVE SKILLS OR USES NONSENSICAL SPEECH

48

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e. RECEPTIVE LANGUAGE

49

- ☐ 1 UNDERSTANDS NORMAL CONVERSATION IN SPEECH, SIGNS, OR SYMBOLS
- ☐ 2 UNDERSTANDS PHRASES AND SIMPLE SENTENCES (speech, signs or Bliss)
- ☐ 3 LIMITED UNDERSTANDING WITHOUT GESTURES (shows understanding of one and two word statements in speech, signs or Bliss)
- ☐ 4 LIMITED UNDERSTANDING WITH GESTURES (shows understanding of simple gestures, ie. stop or come)
- ☐ 5 NO UNDERSTANDING OF LANGUAGE OR GESTURE (does not respond to attempts at communication)

9. BEHAVIOR PROBLEMS

If NO behavior problems are present please check the following box and move onto Question 10.

50 ☐ No Behavior Problem(s)

Please identify the major behavior problems which have been observed. Using the following frequency scale mark the appropriate number beside the appropriate category below.
CHOOSE ONLY 3.

FREQUENCY
1 - daily
2 - weekly
3 - monthly
4 - has occured in the past

a. BEHAVIOR PROBLEMS

- 51 ☐ 01 Actively resists supervision
- 52 ☐ 02 Crying temper tantrums
- 53 ☐ 03 Delusions
- 54 ☐ 04 Depression
- 55 ☐ 05 Disorientation to time or place
- 56 ☐ 06 Disruptive to others, constantly noisy
- 57 ☐ 07 Echolalia
- 58 ☐ 08 Extreme mood changes

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59 ☐ 09 Fire-setting or attempts at fire-setting
60 ☐ 10 Inappropriate affect
61 ☐ 11 Inappropriate sexual behavior
62 ☐ 12 Lack of social or interpersonal responsiveness
63 ☐ 13 Perseveration
64 ☐ 14 Physical assaults on others
65 ☐ 15 Property destruction
66 ☐ 16 Property thefts
67 ☐ 17 Self-injurious behavior
68 ☐ 18 Stereotypic repetitive movements
69 ☐ 19 Suicide threats or attempts
70 ☐ 20 Verbally abusive to others
71 ☐ 21 Wandering, roaming or running away
72 ☐ 22 Other (specify): _____

b. **MAJOR BEHAVIOR PROBLEMS:** Please list *in order of severity* the three major behavior problems by code number as by specific problem.

73-74 1st ☐☐

75-76 2nd ☐☐

77-78 3rd ☐☐

CARD 3

10. INDEPENDENCE CAPACITY SKILLS: Using the following scale mark the appropriate number beside *each* category below.

1 - Completely independent
2 - Can perform with direct supervision or assistance
3 - Needs training
4 - Cannot presently do

1 ☐ Banking (checking, savings account)
2 ☐ Laundry
3 ☐ Meal preparation
4 ☐ Uses public transportation
5 ☐ Uses shopping centres/corner stores
6 ☐ Uses telephone

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11. SELF CARE SKILLS: Using the following scale mark the appropriate number beside *each* category below.

1 - Completely independent
2 - Can perform with direct assistance or supervision
3 - Needs training
4 - Completely dependent

7 ☐ Dressing/Grooming
8 ☐ Eating
9 ☐ Toileting

C. PROGRAM INFORMATION

Please see glossary for definitions of terms.

1. **RESIDENTIAL SERVICES:** Please check services which are currently received.

10 ☐ 1 Active Treatment Hospital/Rehabilitation Facility
11 ☐ 2 Adult Foster Care
12 ☐ 3 Approved Home
13 ☐ 4 Auxiliary Hospital
14 ☐ 5 Cooperative Living Arrangement
15 ☐ 6 Corrections Facility
16 ☐ 7 Extended Care Centre
17 ☐ 8 Group Home (Adult Community Residence)
18 ☐ 9 Group Residence on Grounds of Institutional Setting
19 ☐ 10 Independent Living
20 ☐ 11 Institution for the Mentally Handicapped
21 ☐ 12 Intensive Program Residence (Specialized Group Home)
22 ☐ 13 Living with Parents/Relatives
23 ☐ 14 Minimally Supervised Apartment
24 ☐ 15 Nursing Home
25 ☐ 16 Senior Citizens' Apartment
26 ☐ 17 Senior Citizens' Lodge
27 ☐ 18 Single Men's Hostel
28 ☐ 19 Women's Emergency Shelter
29 ☐ 20 YMCA/YWCA
30 ☐ 21 Other: (specify) _____

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2. **DAY PROGRAMS** (Adult Alternatives): Please check all that apply as primary day time activity(s).

31 ☐ 1 Activity/Leisure Programs
32 ☐ 2 Adult Education
33 ☐ 3 Competitive Employment - full-time
34 ☐ 4 Competitive Employment - part-time
35 ☐ 5 Day Hospital (including psychogeriatric day hospital)
36 ☐ 6 No Formal Day Time Program
37 ☐ 7 Senior Citizens' Activities (ie. Golden Age Club)
38 ☐ 8 Sheltered Workshop
39 ☐ 9 Vocational Training
40 ☐ 10 Volunteer Work
41 ☐ 11 Other (specify): _____

3. **PROFESSIONAL SERVICES:** Please check services which are currently received.

42 ☐ 1 Adaptive Aids
43 ☐ 2 Audiology Services
44 ☐ 3 Behavioral Intervention
45 ☐ 4 Communication Therapy (Speech Therapy)
46 ☐ 5 Client Service Coordination
47 ☐ 6 Dental Services
48 ☐ 7 Guardianship private
49 ☐ 8 Guardianship public
50 ☐ 9 Legal Services
51 ☐ 10 Nursing Services
52 ☐ 11 Nutritional Services
53 ☐ 12 Occupational Therapy
54 ☐ 13 Palliative Care

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55 ☐ 14 Peer Support
56 ☐ 15 Physical Therapy
57 ☐ 16 Psychologist
58 ☐ 17 Psychiatrist
59 ☐ 18 Recreational Therapy
60 ☐ 19 Rehabilitation Counsellor
61 ☐ 20 Religious Pastoral Services
62 ☐ 21 Respiratory Services
63 ☐ 22 Respite Care
64 ☐ 23 Routine Medical
65 ☐ 24 Social Worker
66 ☐ 25 Specialized Medical
67 ☐ 26 Trusteeship
68 ☐ 27 Other: (specify) _____

4. SUPPORT SERVICES: Please check all that apply.

69 ☐ 1 Homemaker Services
70 ☐ 2 Meals on Wheels
71 ☐ 3 Personal Care Attendance
72 ☐ 4 Seniors' Surveillance Program
73 ☐ 5 Shopping Assistance
74 ☐ 6 Transportation (Handibus, Handitaxi, etc.)
75 ☐ 7 Other (specify): _____

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5. CLIENT SOCIAL CONTACT: Please list below the number of face to face and other (ie. telephone and mail) contact the client has had **over the past 3 months** for the different support groups.

Number of Contacts by Immediate Family

76 - 77 ☐☐ Face to Face

78 - 79 ☐☐ Other

CARD 4

Number of Contacts by Other Relatives

1 - 2 ☐☐ Face to Face

3 - 4 ☐☐ Other

Number of Contacts by Friends Outside of the Agency

5 - 6 ☐☐ Face to Face

7 - 8 ☐☐ Other

6. STAFF CONTACT WITH CLIENT'S SUPPORT NETWORK: Please list below the number of face to face and other (i.e. telephone and mail) contact the staff have had **over the past 3 months** with the different support groups.

Number of Contacts by Immediate Family

9 - 10 ☐☐ Face to Face

11 - 12 ☐☐ Other

Number of Contacts by Other Relatives

13 - 14 ☐☐ Face to Face

15 - 16 ☐☐ Other

Number of Contacts by Friends Outside of the Agency

17 - 18 ☐☐ Face to Face

19 - 20 ☐☐ Other

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7. **RESIDENTIAL GOAL AND READINESS TO MOVE:** Indicate any changes in residential setting which may be anticipated in the future. Using the following scale write the appropriate number beside the category which is seen as a realistic goal. If no change is anticipated please check the following box and move onto Section D.

21 ☐ No Change

1 - Immediately
2 - 3 - 6 months
3 - 1 year
4 - more than 1 year

22 ☐ 1 Apartment with Supervision
23 ☐ 2 Approved Home
24 ☐ 3 Foster Home
25 ☐ 4 Group Home
26 ☐ 5 Independent Living
27 ☐ 6 Live with Family or Relatives
28 ☐ 7 Nursing Home
29 ☐ 8 Special Support Home for Physical Disability
30 ☐ 9 Special Support Home for Psychosocial Disability
31 ☐ 10 Unknown
32 ☐ 11 Other (specify): _____

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D. SERVICE NEEDS INDEX

Received and Required Services
From all the services listed in the glossary for Section C, PROGRAM INFORMATION, Numbers 1 - 4; list in order of priority the most important services currently received by the client and most important services presently required by the client.

RECEIVED

33-35 ☐☐☐ _____

36-38 ☐☐☐ _____

39-41 ☐☐☐ _____

42-44 ☐☐☐ _____

45-47 ☐☐☐ _____

REQUIRED

48-50 ☐☐☐ _____

51-53 ☐☐☐ _____

54-56 ☐☐☐ _____

57-59 ☐☐☐ _____

60-62 ☐☐☐ _____

APPENDIX C

ALBERTA ASSOCIATION FOR THE MENTALLY HANDICAPPED
11728 KINGSWAY AVE., EDMONTON, ALBERTA. T5G 0X5 PHONE (403) 451-3055

August 23, 1985

To Whom it May Concern:

Please accept this letter as a recommendation with regard to the study entitled, "A Demographic and Needs Analysis of Persons Who are Older and Developmentally Disabled in the Province of Alberta", currently being carried out by the Vocational and Rehabilitation Research Institute based in Calgary.

The Alberta Association for the Mentally Handicapped has recently examined the proposal and is aware of the need for this particular project as well as the professionalism of the group conducting it. AAMH believes that the information which will result from this effort has the potential to be of considerable value to the population it is ultimately intended to benefit, aging people who are developmentally disabled. Therefore your cooperation would be much appreciated in assisting for planning for their futures.

Yours sincerely,

THE ALBERTA ASSOCIATION
FOR THE MENTALLY HANDICAPPED

Berta B. Fisher
President

HBF:bmf

c.c. Mr. Reg Peters, Executive Director - AAMH
Mr. William N. McLellan, Resource Assistant - AAMH

APPENDIX D

THE VOCATIONAL AND REHABILITATION RESEARCH INSTITUTE
3304 - 33rd Street N.W., Calgary, Alberta T2L 2A6 • Telephone (403) 284-1121
Charitable Institute #0305847-20-24

November 1, 1985

Dear

The Vocational and Rehabilitation Research Institute (VRRI), in collaboration with Dr. Lynn McDonald and Dr. Joe Hornick, Faculty of Social Welfare, The University of Calgary, is undertaking a provincial study on the needs of older developmentally disabled persons. Developmental disability refers to those whose disability has been present since birth or generally before the age of 18 years. This study is entitled "A Demographic and Needs Analysis of Older Developmentally Disabled Persons in the Province of Alberta" and is supported and funded by Alberta Social Services and Community Health.

The focus of the study is on persons who are mentally handicapped and are 45 years of age and older. A number of concerns have been raised by parents, professionals, services and agencies serving the mentally handicapped about the future of this aging population. The purpose of our study is to address the following questions:

1. How many developmentally disabled persons within identified service systems over age 45 are living in the province of Alberta?

2. Are there major differences between older developmentally disabled persons living in community and institutional settings?

3. What are the needs of older developmentally disabled persons in the province of Alberta?

4. What services currently exist and should be developed to serve the needs of the older developmentally disabled population?

.../2

A consent form has been included which ensures the confidentiality of the information your agency/facility provides to the project. This form should be signed by the agency director prior to completion of the survey forms by yourself or designated staff members. A direct interview format for gathering information will not be used in this study. Rather, the information you provide to the study should be able to be taken directly from the files and/or staff knowledge of the clients.

Each survey form has been assigned an identification number in the event you require specific feedback on the information you have sent to us. This will also assist us in data entry and validation procedures. Each agency/ facility participating in the study will receive a copy of the final report.

We have enclosed a short answer questionniare related to planning issues for the service coordinators throughout the province. Please note that we do not require information on any clients you may have that are living in Michener Centre. We are interested in clients living within your region.

We would very much appreciate your input into this project and have enclosed survey forms for completion by your agency. Please refer to the cover page of the form for specific instructions. We have targeted November 30, 1985 as the date for return of the survey forms and would ask that you return any that are not used. If there is any problem with the target date please let us know.

If you have any questions or comments regarding this project please contact Dorothy Badry, our research assistant coordinating the project, or myself at the above number. Looking forward to hearing from you.

Sincerely,

Gerrit Groeneweg, Ph.D.
Senior Research Associate

GG:ev

APPENDIX E

CONSENT FORM FOR AGENCY/FACILITY REPRESENTATIVE

A Demographic and Needs Analysis of Older Developmentally Disabled Persons in the Province of Alberta

The Vocational and Rehabilitation Research Institute (VRRI) has undertaken this research project in order to identify the developmentally disabled population in Alberta over age 45. The identification of older developmentally disabled persons will be useful in planning services for this growing population.

This project is being carried out by Lynn McDonald, Ph.D., Joe Hornick, Ph.D., Faculty of Social Welfare, The University of Calgary; Gerrit Groeneweg, Ph.D., and Dorothy Badry, B.S.W., VRRI.

The survey form will take approximately 15 minutes to complete for each individual. We would ask that you, or your designate identify each individual by their birthdate and first, middle, and last initials. We require this information to avoid duplication of data. This information will be kept confidential and will not be used to identify individual clients, professionals and agencies/facilities. Data will be used for scholarly reporting of the research findings and service planning for the older developmentally disabled population.

Your agency will receive feedback in the form of the final research report.

We hope that your agency/facility will be willing to help in this project but wish to assure you that your participation is entirely voluntary and you have the option to withdraw at any time. Thank you for your assistance and cooperation.

Lynn McDonald, Ph.D.
INVESTIGATOR

INVESTIGATOR (signature)

DATE: _____

I voluntarily agree to complete this questionnaire and give permission for the agency/facility I represent to participate in this project.

_____ _____

AGENCY DIRECTOR (print) AGENCY DIRECTOR (signature)

Date: _____

NOTE: Two consent forms have been included. Please sign both, keep one for your records and return the other with the completed survey forms.