This is to certify that the

thesis entitled

HEALTH SERVICE USE AMONG ELDERLY PERSONS
WITH DEVELOPMENTAL DISABILITIES

presented by

Teresa Ann Kowalski

has been accepted towards fulfillment
of the requirements for

Master of Science degree in Nursing

Major professor

Date 6/5/91

HEALTH SERVICE USE AMONG ELDERLY PERSONS WITH DEVELOPMENTAL DISABILITIES

By

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE

College of Nursing

1991

ABSTRACT

HEALTH SERVICE USE AMONG ELDERLY PERSONS
WITH DEVELOPMENTAL DISABILITIES

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The purpose of this study was to compare the functional characteristics, service use, unmet service needs, and time elapsed since preventive exams among elderly persons with developmentally disabilities residing in four settings: group homes, adult foster care, nursing homes, and independent living settings. The sample included 67 adults with developmental disabilities who were receiving assistance from a community mental health agency. Residents of group homes were found to have more functional limitations, more communication deficits, and more physician visits than residents of the other types of settings. Needs for equipment were more likely to be fulfilled than needs for services for residents in all types of settings. Implications of the findings for research and practice are offered.

ACKNOWLEDGMENTS

I want to thank the Evaluation Department at Clinton-Eaton-Ingham Community Mental Health Board, specifically Dr. Richard Coelho, for allowing me to use his excellent data set for secondary analysis. Thanks for answering all of the questions of a novice researcher so patiently, Richard!

Thanks so much to all of my committee members. I am very grateful to Clare Collins, committee chair, for making what seemed impossible seem possible. Thanks, Clare, for always finding something positive to comment about before giving constructive criticism. I appreciate Sharon King for her genuine enthusiasm for and interest in my project. Manfred Stommel has my gratitude for his patient help as I stumbled through statistical analysis. I want to thank Barbara Given for adding her perspective and helping me to expand mine. You have all been a pleasure to work with.

Last, but certainly not least, thanks to my husband, Marty, for listening to me whine about this for the last year and for staying anyway.

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Chapter 1

Introduction and Background

Until the late 1960's, the only services available for mentally retarded persons were special education and institutionalization (Wolfensberger, 1985). Health care provided in institutional settings was generally regarded as inferior. Often, physicians who were unable to find employment in other settings, who were isolated from their peers, and who worked with grossly inadequate resources were delivering health care to the institutionalized mentally ill and mentally retarded (McDonald, 1985).

Due to social change, the civil rights movement, and advocacy efforts of family members on behalf of persons with developmental disabilities, there has been a dramatic change over the last twenty years in the delivery of service to this population. Movement to community-based residential and day placements has occurred in an attempt to promote "normalization" of the lives of persons with functional impairments (Seltzer, Seltzer, & Sherwood, 1982). The movement of persons with developmental disabilities into the community has resulted in increased dependence on community health care services (Garrard, 1982; McDonald, 1985; Minihan, 1986). Only in recent years has closer examination of the outcomes of community programs been attempted.

In the past, mentally retarded persons rarely lived to be considered "elderly" (Seltzer et al., 1982). As the percentage of elderly persons in the general population has increased due to improved longevity, so has the number of

aging and elderly persons with developmental disabilities (Jacobson, Sutton, & Janicki, 1985). Over the last 50 years, the life span for persons with Down Syndrome has increased an average of 40 years, while longevity for other persons with developmental disabilities has increased by approximately 30 years (Rubin & Dwyer, 1989). Improved longevity statistics have been attributed to improved medical care (including use of new antibiotics and new anticonvulsants), better diet, and better care environments (Cotten & Spirrison, 1986; Jancar, 1986). Jacobson et al. (1985) estimate that persons over age 55 constitute 6.1 to 15.7 percent of the population receiving state mental retardation services. Cotten and Spirrison (1986) estimate that the number of elderly persons with developmental disabilities in the United States is between 50,000 and 315,000.

Conditions often associated with aging are similar in persons with and without developmental disabilities (Hauber, Rotegard, & Bruininks, 1985; Jacobson et al., 1985). Visual anomalies such as cataracts, glaucoma, and macular degeneration; hearing loss due to cerumen impaction or nerve dysfunction; musculo/skeletal conditions such as osteoporosis and arthropathy; gastrointestinal dysfunction related to decreased nutrient absorption, edentulousness, and constipation; and cardiovascular conditions are noted in both "normal" and developmentally disabled elderly populations (Hauber et al., 1985; Jacobson et al., 1985; MacDonald & Tyson, 1988; Rubin & Dwyer, 1989).

In addition to the "usual" conditions associated with aging, elderly persons with developmental disabilities may have special problems related to institutional placement, such as hepatitis B infection, intestinal parasites, tuberculosis, contractures, or uncontrolled seizures (Rubin & Dwyer, 1989). Janicki and MacEachron (1984) describe members of this population as high consumers of health care services due to their impaired mobility and sensorium, high rate of medication usage, frequency of special diet therapy, and decreased self-care skills.

In summary, it is assumed by most persons familiar with the subject that residing in community settings and receiving health care from generic resources has improved life conditions for the elderly developmentally disabled population. There is a need for further examination and description of this evolving group so that care providers have an accurate perception of their health needs and the most effective methods of meeting identified needs.

Purpose

The purpose of this study is to describe use of medical services, preventive service use, unmet needs, and functional abilities of elderly persons with developmental disabilities who reside in community settings. Elderly developmentally disabled persons are usually classified as high consumers of health care resources (Cotten & Spirrison, 1986; Garrard, 1982; Janicki & MacEachron, 1984; MacDonald& Tyson, 1988; Rubin & Dwyer, 1989), but actual utilization of services has not been examined.

It is important that the Clinical Nurse Specialist in primary care have accurate insight into the actual health service use, functional ability, and unmet needs of the elderly developmentally disabled population in order to plan for their care. Persons from this group may be disqualified as potential patients before they are seen, if stereotypical attitudes about excessive demands for care are accepted.

Knowledge about the likelihood that preventive exams were received can allow for comprehensive planning when the patient presents in the office. The Clinical Nurse Specialist may need to emphasize the importance of preventive exams and assist in scheduling them. Identification of the primary caregiver and familiarity with the type of care provided in various types of residential settings is important in order to plan a therapeutic regimen that can realistically be followed at home. Knowledge of functional ability of the developmentally disabled patient can be helpful in promoting self-care and in assessing the level of instruction that needs to be presented. Unmet needs may include services, such as occupational, speech, and physical therapy, or equipment, such as wheelchairs, dentures, or hearing aids. Knowledge of the most frequent unmet needs is also valuable in planning for comprehensive care. Referral to other community resources can be initiated at the time of the patient contact.

It seems plausible that the effects of aging should be less detrimental if a person is healthy and physically fit. Regular screening for potential health problems is important

for a population whose members may have limited expressive language skills, are unable to monitor their health care independently, and may not communicate symptoms until illness is advanced (Garrard, 1982; Walz, Harper, & Wilson, 1986). Sudden losses of function due to correctable clinical conditions may be mistakenly attributed to the aging process (Jancar, 1986; Rubin & Dwyer, 1989).

Many barriers to health care of persons with disabilities have been identified including financial cost, transportation, ignorance about available services, lack of a primary provider, inaccessible buildings, consent issues, and negative attitudes toward the mentally retarded (Segal, 1977; Garrard, 1982; Gotowka, Johnson, & Gotowka, 1982; Melnyk, 1988). Unfamiliarity of health care providers with members of this population may result in their exclusion as potential clients (Garrard, 1982). Kraus and Seltzer (1986) state that unmet health needs are more common in persons residing in the community than in institutionalized persons.

Janicki and Wisniewski (1985) identify as a main determinant of the type of treatment and programming received by aging persons with developmental disabilities, their type of residence. Janicki, Jacobson, & Ackerman (1985) reported that the degree of debilitation and access to health services of the developmentally disabled elderly varied according to the type of residence they lived in.

Bass and Noelker (1987), after studying service usage by non-developmentally disabled elderly persons, stated that the primary caregiver influenced the use of services both

directly and indirectly. Since developmentally disabled adults are not generally able to monitor health needs independently, an argument could be made that the primary caregiver, or residential provider, is influential in this area. Foster homes and boarding homes are the most common type of non-institutional settings for elderly persons with developmental disabilities (Hauber et al., 1985; Janicki & MacEachron, 1984).

In this retrospective, descriptive study, analysis of cross-sectional data collected by the Clinton-Eaton-Ingham Community Mental Health Board as part of a needs assessment of the population of persons with developmental disabilities aged 55 and over will occur. Data were collected in 1988 using a needs assessment questionnaire to examine future care needs of elderly persons with developmental disabilities who reside in community residential settings. Pertinent demographic data and specific types of health related information were also gathered in the survey questionnaire and will be used to categorize the findings.

Research Questions

The basic research questions for this study are as follows:

1) What is the mean frequency of use of medical services in the last year?
2) How long ago did the last routine preventive dental, physical, vision, hearing, and gynecological exams occur?
3) What are the numbers and types of unmet needs for

services and/or equipment?

4) Are there differences in the functional abilities of residents in different residential settings?

5) Does the use of medical services, mean length of time elapsed since preventive exams were received, and number and type of unmet needs for services and equipment vary across residential settings?

Concept Definitions

Developmental Disability.

A developmental disability may be defined as any chronic mental and/or physical condition that occurs before age 22 and is likely to cause substantial functional limitation in three or more of the following areas: self-care, expressive or receptive language, learning, mobility, self-direction, independent living, and economic self-sufficiency. Inherent in this definition is the assumption that the individual will need individually planned special care services for an extended or lifelong duration. This definition was developed as part of the Developmental Disabilities Act of 1984 and is stated in Public Law 98-527. Persons with mental retardation, cerebral palsy, autism, epilepsy, and debilitating neurological conditions may be categorized developmentally disabled if they have functional limitations in three or more areas (Elder, 1983; Lippman & Loberg, 1985; Thomas, 1986).

Elderly.

MacDonald and Tyson (1988) correctly point out that demarcation as elderly should be individually determined

based on diminishing physical reserves, functional skills, and estimation of oneself as old or elderly. However, many federal agencies set age requirements at 55, 60 or 65 for delineating elderly status (Cotten & Spirrison, 1986). Janicki and Jacobson (1986) found that while onset of old age was highly variable in adults with developmental disabilities, generally, there was a decline in functional motor skills during the mid 50's. No decline in cognitive function was noted until the late 70's. For the purposes of this study, individuals with developmental disabilities aged 55 and over will be considered elderly.

Health Service Use.

Minihan (1986) described the community health care system as "community based physicians and ... loosely affiliated service networks" (p.1202). Health care is delivered by nurses, dentists, audiologists, physical therapists, occupational therapists, counselors, psychologists, optometrists, mental health therapists, geneticists, and nutritionists as well as physicians (Cotten & Spirrison, 1986; Gotowka et al., 1982; Jancar, 1986; Ziring et al., 1988). Medical care may be needed in specialty areas such as orthopedics, internal medicine, neurology, psychiatry, podiatry, urology, gynecology, and cardiology (Janicki & MacEachron, 1984; Minihan, 1986; Rubin & Dwyer, 1989; Segal, 1977; Thomas, 1986). This researcher will examine health service use in three categories: use of medical services, preventive service use, and unmet needs.

1) Use of medical services. The number of physician

visits and hospitalizations in the last year will be examined in an attempt to determine the actual frequency of contact with medical services. Most authors assume this population to consist of frequent users of health services without actually examining utilization patterns. Breakdown by physician specialty and comparison with non-disabled elderly persons is beyond the scope of this study.

2) Preventive service use. For the general population over age 60, Lindberg (1987) recommends annual physical exams, blood pressure measurements, influenza vaccination, and mammography (for women) and biennial visual, hearing, and gynecological exams. Annual physical exams, dental exams, psychological evaluations, audiological evaluations, and visual exams have been recommended for the elderly developmentally disabled population (Jancar, 1986; Rubin & Dwyer; 1989). This author assumes that preventive health exams are as essential for the elderly developmentally disabled as the non-disabled person. Therefore, length of time elapsed since preventive dental, physical, vision, hearing, and gynecological (for women) exams occurred will be examined.

3) Unmet Needs for Services and Equipment. Minihan (1986) points out that medical diagnosis is not as important in identifying health care needs as are current deficits in functioning. Unmet needs identified by other researchers have included services such as medicine, counselling, dental care, audiology, vision care, podiatry, and nutritional consultation and equipment such as wheelchairs, hearing

aids, glasses, dentures, and special diets (Gotowka et al., 1982; Janicki & MacEachron, 1984; Segal, 1977; Stroud & Sutton, 1988). For the purpose of this study, unmet needs are needs for services and equipment that were identified by professionals familiar with individual subjects and that were not being addressed at the time of data collection. Services include occupational therapy, physical therapy, nursing, psychotherapy, and speech/language/hearing therapy. Equipment includes glasses, wheelchairs, helmets, walkers, braces, canes, and hearing aids.

Functional Ability.

Cotten & Spirrison (1986) describe coping and social skills as more important to overall functioning among the developmentally disabled than I.Q. level. Functional ability is often measured by assessing independence in completing activities of daily living, such as bathing toileting, eating, dressing, grooming, and mobility (MacDonald & Tyson, 1988; Walz et al., 1986). Janicki and MacEachron (1984) also include sensory processes such as hearing and vision in their definition of functional ability. A more inclusive definition by Seltzer et al. (1982) covered all community living skills, such as personal care, housekeeping, communication, social skills, community participation, economic management, agency utilization, and individual motivation to perform these skills. For the purpose of this study, functional ability includes activities of daily living (eating, bathing, grooming, dressing, undressing, toileting, mobility), vision, hearing,

expressive and receptive language.

Residential Setting.

Residential setting refers to the place that elderly adults with developmental disabilities live. Four categories of residential options will be discussed: nursing home, group home, adult foster care home, and semi-independent and independent living.

1) Nursing Home: A nursing home is an intermediate care facility or skilled nursing facility (Hauber et al., 1985). They provide shelter, but no training or habilitation of residents (MacDonald & Tyson, 1988). Since nursing homes are "segregated and self-contained health care systems" (Minihan, 1986, p. 1202), they will be considered institutional residential settings. Institutional settings are also considered the most restrictive residential settings (MacDonald & Tyson, 1988). For the purpose of this study, a nursing home is a facility that provides nursing care but no training or habilitation of residents.

2) Group Home: Group homes were developed as a service model to promote entrance into the community of younger deinstitutionalized persons (MacDonald & Tyson, 1988). They are residences with staff who provide care, supervision, and training to one or more person with developmental disabilities (Hauber et al., 1985). Group homes are designed to provide training to promote independence with emphasis on self-help and daily living skills (Cotten & Spirrison, 1986). Seltzer et al. (1982) describe staff as protective of residents and restrictive of

their autonomy. A residence will be considered a group home if it provides training to promote independent functioning of the residents in addition to basic care.

3) Adult Foster Care Home: An AFC is a home or apartment owned or rented by a family that provides care for one or more persons with developmental disabilities who are not related to the homeowners. While help with personal care may be provided, no formal training of the residents is performed (Hauber, et al., 1985). Adult foster care homes are supposed to support community integration while providing a protected family environment and participation in family activities. They must meet state quality assurance guidelines (MacDonald & Tyson, 1988). This type of residence is considered "among the least restrictive of housing options" (Eckert et al., 1987, p.378). For the purpose of this study, an adult foster care home is a home that provides basic care for the residents, with no training in daily living skills.

4) Semi-independent and Independent Living: Supervised and independent apartment living and living with relatives are considered the alternatives that least restrict personal liberty (Cotten & Spirrison, 1986; Janicki & MacEachron, 1984). Supervised apartment complexes may provide minimal supervision of daily activities and some training to refine community living skills. Elderly persons with developmental disabilities who live independently or with their family often receive case-management services (Cotten & Spirrison, 1986). For the purpose of this study,

supervised and independent apartment living and living with relatives will be combined under semi-independent and independent living.

Overview of Chapters

In this chapter, the introduction, background, the purpose, the research questions, and concept definitions have been presented. The conceptual framework that was used to guide the study is presented in chapter 2. The previous work of other researchers is reviewed in chapter 3 and the research methods of this study are described in chapter 4. Results and analyses are presented in chapter 5. Chapter 6 contains a summary and discussion of findings, implications for the Clinical Nurse Specialist, and needs for further research.

Chapter 2

This chapter includes a description of the conceptual framework chosen as the basis from which to examine the utilization of community health services by elderly adults with developmental disabilities. Since members of this population are often dependent on others for their basic needs (Rubin & Dwyer, 1989), their individual characteristics alone cannot be considered significant factors influencing health service utilization. The Behavioral Model of Health Services Utilization was selected for this study because it takes community and individual variables into consideration as controllers of the usage of health care services.

Overview

Andersen introduced the Behavioral Model of Health Services Utilization in 1968. The model has since been expanded by Andersen, Newman, and Aday to take both societal and individual determinants into account in understanding health services utilization behavior (Aday & Shortell, 1988).

Andersen's model depicts individual health services utilization behavior as influenced by **societal determinants** and by the **health service system** (see Figure 1). **Societal determinants** include **technology** and **societal norms**. Continuous technological change is a given in modern health care. The health care system and utilization of the system have been impacted by technological advances in many fields, such as surgery, oncology, hematology, and immunology.

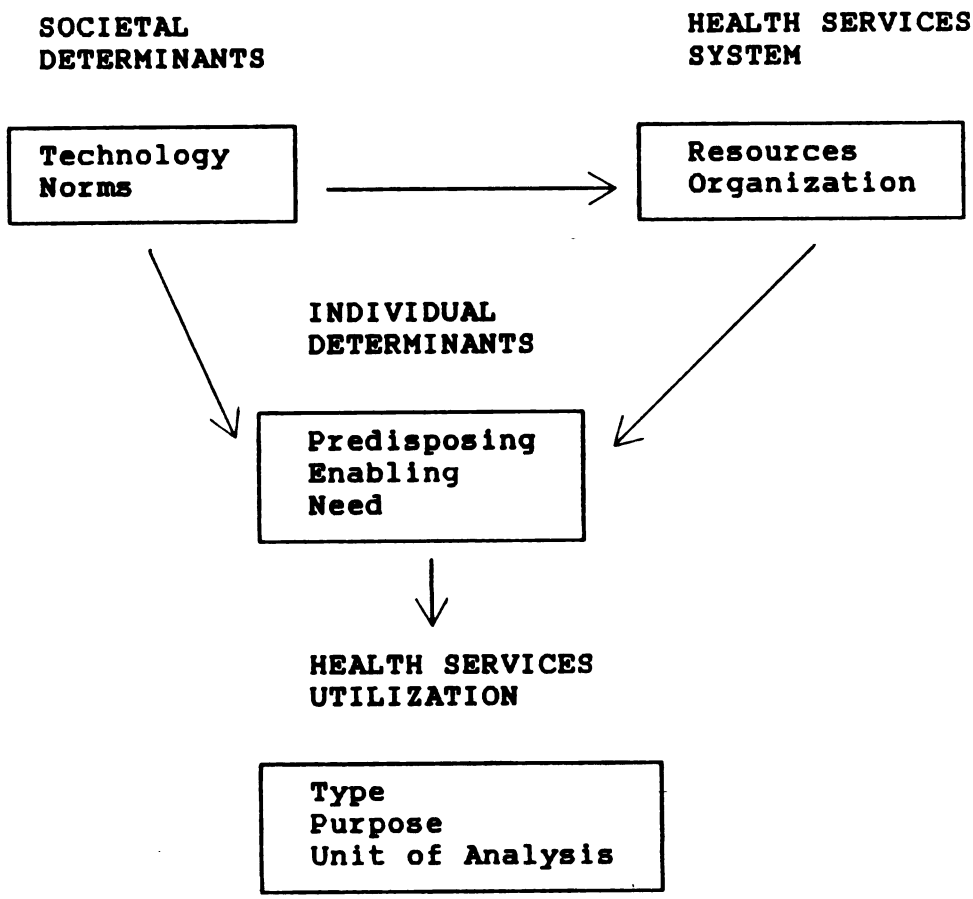

Figure 1. The Behavioral Model of Health Services Utilization.

Legislation affecting the health care system is, in part, influenced by the beliefs and values which are widely held by the population. Examples of social norms include the belief that all persons have a right to health care regardless of their ability to pay and the belief that health care is an important factor in maintaining good health (Andersen & Newman, 1973). Payment for health care is affected by social norms, as is illustrated by the steady increase in third party payment for services in the last thirty years. The normalization and deinstitutionalization

movements are examples of changing societal norms that influenced health service delivery to the mentally ill and developmentally disabled populations. As societal attitudes have changed, community placement and outpatient treatment have become the standard of care.

Societal determinants influence the health service system as well as individual behavior. The **health service system** is defined as "arrangements for the potential rendering of care to consumers" (Aday & Shortell, p. 53), and consists of two major divisions, **resources** and **organization**. Health care deliverers and capital, such as facilities, equipment, and materials are considered **resources**. **Organization** refers to the way in which health resources are distributed and includes factors that affect entry into the system and characteristics that determine movement through the system. Health service delivery for the developmentally disabled population is influenced by the type of and proportion of health care expenses paid for by the government (Cotten & Spirrison, 1981; Garrard, 1982; Gotowka, Johnson, & Gotowka, 1982; Yankaur, 1986; Ziring, et al., 1988). When discussing societal determinants and the health care system, the unit of analysis is the community, not the individual.

The **individual determinants** of health services utilization behavior include three components; each person's predisposition to use services, ability to access services, and need for services. **Predisposing variables** include attributes that exist prior to service usage that affect the

propensity to use services. These pre-existing characteristics may identify persons more likely to use services, although the characteristics may not be directly responsible for the use of services. Included are demographic characteristics, such as age, sex, family; social structural variables, such as race, ethnicity, educational level, employment status, and occupation, which reflect the status of the individual in society; and individual beliefs about the value of health care, which partially regulate utilization behavior.

Resources that promote or inhibit health service usage by the individual are **enabling variables** (Noelker & Bass, 1989). Andersen and Newman (1973) define enabling conditions as those that "permit a family to act on a value or satisfy a need regarding health service use" (p. 109). Resources of the individual, the family, or the community are included. Examples are income, insurance coverage, transportation, the cost of services, the amount of health facilities and personnel in a community, and whether or not there is identified a regular source of care.

The most important and immediate variables affecting health service usage refer to health or illness status and are called **need variables**. Health or illness status may be based on perceptions of the patient and/or family or on actual clinical evaluation by the health care provider. The perceived state of general health or illness, number of disability days, and actual symptoms are all examples of need variables. Noelker and Bass (1989) identified illness

or impairment features, mental impairment, chronic health conditions, and the presence of paralysis as need variables that may be identified in elderly populations.

Predisposing, enabling, and need variables are categorized as mutable or immutable, depending on whether or not they can be altered by health policy. Variables considered biological or social givens, such as age, sex, race, or place of residence, are considered immutable. While they define groups of interest, they cannot be directly altered by health policy. Characteristics that may be influenced by health policy are called mutable. Attitudes, beliefs, and insurance coverage are all variables that may be affected by changing health policy.

Health service utilization behavior may be characterized by type, purpose, and unit of analysis. Different types of services may have varying predictive variables. Physician, dental, hospital admissions, and prescriptions are examples of different types of services.

Determinants may also vary based on whether the reason for seeking care is primary, secondary, tertiary, or custodial. The purpose of primary prevention is "health maintenance in the absence of symptoms" (Aday & Shortell, 1988, p.52) The diagnosis and treatment of illness in order to return to a previous state of well-being is considered secondary prevention. Management of persons with long-term, irreversible conditions is considered tertiary prevention. Custodial care refers to the provision of care that meets the medical and personal needs of dependent adults or

children.

The unit of analysis, or time interval, may measure whether contact occurred, volume of service usage, or episodic patterns of service usage. Measurement of contact would assess whether contact occurred within a certain time period, for example, whether physician contact occurred within the last year. Volume of service usage would measure the number of contacts during that time period. Episodic patterns would describe the patterns of care prescribed for an episode of a specific condition, such as breast cancer or myocardial infarction.

Integration of Variables Within the Behavioral Model

Residential setting, functional ability, the utilization of preventive health services and medical services, and the type and number of unfulfilled needs for services or equipment of elderly persons with developmental disabilities are examined in this study. Residential setting and functional ability are discussed in the framework of enabling and need variables (see Figure 2).

Enabling variables are the resources which allow individuals to access and use health services (Aday & Shortell, 1988). The support and assistance with transportation and accessing the health service system received by developmentally disabled persons in the residential setting is likely to affect health service utilization behavior.

Health status or illness are categorized as need variables in the Behavioral Model. Functional ability as

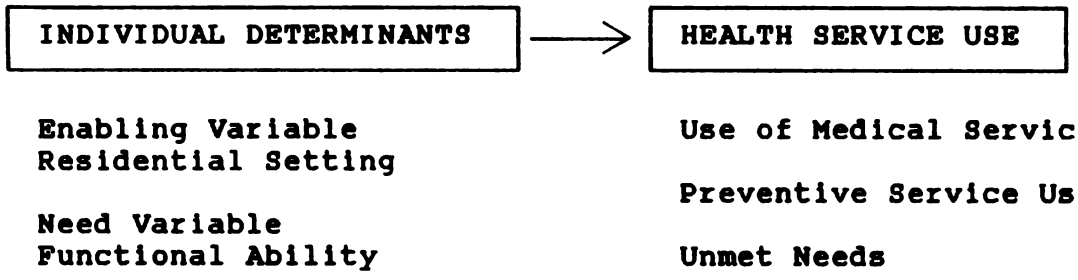

Figure 2. Integration of variables within the Behavioral Model.

measured by ability to complete activities of daily living, sensory impairments, and communication impairments may affect the perceptions of the caretakers of developmentally disabled persons in assessing health status. Health problems perceived by caretakers may be related to visual and auditory deficits or inability to communicate symptoms of illness.

Use of medical services, preventive service usage, and unmet needs are described as parts of the dependent variable, utilization behavior. The volume of medical services (physician visits and hospitalizations) are measured, while preventive service usage is examined to determine whether contact occurred. Type and volume of unmet needs are identified.

Limitations

Although widely used in literature, the Andersen Behavioral Model of Health Services Utilization is not extensively developed and described (Bass & Noelker, 1987). Criteria for classifying characteristics as enabling,

predisposing, and need variables are not universally agreed upon (Harel, et al., 1985) The impact of informal support systems, such as caregivers, on utilization behavior is absent from the model (Bass & Noelker, 1987).

While variables that comprise some components of the model are described, it is beyond the scope of this study to exhaustively describe every element of the model. These outcomes are not necessarily representative of all of the possible utilization behaviors that may be significant for elderly adults with developmental disabilities. Other outcomes, such as emergency room visits, number of visits to dentists and other specialists, number of prescription medications used, and admissions to nursing homes are beyond the scope of this study. All possible factors that influence health service utilization behaviors of elderly adults with developmental disabilities could not be included. No attempt is made to provide cause and effect explanations for noted patterns of utilization behavior in this study. While types and frequency of health care contact are described, there is no attempt to measure quality of the services.

Summary

Presented in this chapter was an overview of the conceptual framework that is the basis for the research questions generated in this study. The Behavioral Model of Health Services Utilization was described, and the variables of residential setting, functional ability, use of medical services, use of preventive services, and unmet needs were

integrated into the model. A review of the literature pertinent to the concepts involved in this study is the focus of chapter 3.

Chapter 3

Historically, the emphasis has been on children and young adults when research and development of programs for the developmentally disabled population has occurred. Only since the mid-1970's have the needs of the aging and elderly developmentally disabled population emerged as important issues (Segal, 1977). When reviewing the small body of literature available about this population, it is generally assumed that older adults with developmental disabilities have more health impairments and functional limitations than younger disabled adults (Cotten & Spirrison, 1986; Garrard, 1982; Janicki & MacEachron, 1984; MacDonald & Tyson, 1988; Rubin & Dwyer, 1989). The literature that describes health status, functional status, residential settings, and health service usage of this group is reviewed in this chapter.

Health Status

While it is assumed that elderly adults with developmental disabilities have more chronic health problems and functional limitations than younger adults, few researchers have investigated this assumption. The few researchers that have studied the developmentally disabled have obtained conflicting results, but there is general agreement that certain health conditions occur more frequently in this group than in the general population.

Medical records of 610 adults (aged 18-64) were examined by Buehler, Smith, and Fifield (1985) in order to explore medical issues involved in serving them. Individual records of adults receiving services from a single large

mid-western agency were reviewed. Primary health problems identified by the reviewers included seizures (52% of the group), hearing problems (15%), vision problems (12%), major motor involvement (9%), and other non-specific medical problems (12%). The main diagnoses included in hearing difficulties were chronic otitis media with secondary deafness and congenital deafness. Visual difficulties included esotropia, severe acuity problems, and blindness. The major motor difficulty was a diagnosis of cerebral palsy.

Secondary medical problems identified by Buehler et al. (1985) included obesity and chronic skin problems such as acne, eczema, and severe dermatitis. A small percentage of individuals with diabetes mellitus and hypothyroidism were identified. No significant differences were noted between the health status of institutionalized adults and those living in community settings.

Minihan (1986) examined the medical care needs of 229 institutionalized developmentally disabled persons aged 15 and older in an attempt to prepare for their movement into the community. Questionnaires were completed by the primary care physician and nurse practitioner who cared for each client in the institution. Each condition identified by these care providers was then classified as Level 1, 2, or 3 by an Advisory Committee that consisted of a Medical Director, Community Nurse, Director of Community Services, and a representative from the Department of Community Health of Tufts University School of Medicine. Level 1 conditions

were defined as those that could be managed solely by the primary care physician. Level 2 conditions would be managed mainly by the primary care physician with occasional back-up by a specialist. Level 3 conditions would be managed solely by a specialist. The researcher considered the presenting problem and functional deficits more important than medical diagnoses.

Minihan (1986) found that 227 of the 229 persons had at least one chronic condition requiring care from a physician. In addition, 46% of the sample population were taking medication for a seizure disorder and an extra 6% had histories of seizures even though not currently taking medication for the problem. Also frequently noted were visual cataracts (17%) which were related to phenothiazine medication usage.

The usage of community health care services and the medical needs of developmentally disabled persons were also of interest to McDonald (1985). Assumptions that this group had high medical needs and were high users of medical services were cited as the basis for this study of 27 severely impaired persons aged 14-33 who lived in community intermediate care facilities in New York City. Data were obtained from the records of the subjects with assistance from the professional most familiar with the subject. Consistent with the findings of Buehler et al. (1985) and Minihan (1986), McDonald noted a high prevalence of seizure disorders, orthopedic problems, visual impairments, upper respiratory infections, and otitis. The small sample and

the type of community intermediate care facility residences which were managed by registered nurses and often provided around-the-clock care by licensed practical nurses limit the representativeness of the study. The extremely high prevalence of orthopedic problems could be speculated to be related to the type of intensive nursing care available in this type of facility. Similar prevalence of orthopedic problems may not occur in other types of community residential settings.

Gotowka, Johnson, and Gotowka (1982) described the dental status of 106 developmentally disabled persons aged 17 to 77 who lived in community residences in a study designed to examine the costs associated with providing dental care to this population over the period of one year. Data were gathered by the dentists and dental hygienists as they provided comprehensive care to the 106 adults enrolled in the program.

Eighty-seven patients had some teeth, however only four had complete dentition. Each patient had an average of 14.5 missing teeth. Of the patients who had some teeth, there were an average of five cavities or defective restorations each. Edentulous patients numbered 19. Dentures were not provided to 25 per cent of the patients without teeth and half of the edentulous patients had dentures that did not fit properly. No previous dental records were available. Poor oral hygiene was universal. The dentists noted gross amounts of plaque and tartar, gingival inflammation, and accumulation of food debris in nearly 100% of the patients.

The studies previously described have not focused specifically on the elderly person with developmental disabilities. However, a case can be made for their inclusion since the problems identified (epilepsy, cerebral palsy, vision and hearing deficits, poor dentition, skin disorders) are likely to be chronic and, with the exception of upper respiratory infections, are not likely to contribute to increased mortality or shortened life span.

Stroud and Sutton (1987) are the only researchers who collected data through actual interviews with 149 elderly (aged 55 and over) developmentally disabled subjects. The subjects were enrolled in their county boards for the mentally retarded/developmentally disabled and lived in community group homes or nursing homes. The researchers concluded that there are no significant differences in the health status of disabled and non-disabled elderly adults, but were not clear about how they reached that conclusion. Frequently occurring health problems identified by Stroud and Sutton (1987) included obesity (33%), visual deficiencies requiring glasses (54%), poor dentition, hearing deficits (15%), cardiovascular disorders (31%), and seizure disorders (19%).

The prevalence of chronic disease conditions, decline in sensory abilities, and decline in behavioral abilities among elderly persons with developmental disabilities were examined by Janicki and Jacobson (1986). Data obtained annually as part of the New York Developmental Disabilities Information System needs assessment compiled by program

staff who were trained in the use of the instrument and who work with 10,532 developmentally disabled persons aged 45 to 89 were analyzed. Completed forms were checked for completeness of information by regional coordinators before processing.

The distribution of degree of mental retardation (mild/moderate, severe/profound) remained stable across age groups. As age increased, more chronic disease conditions affecting the cardiovascular, musculoskeletal, digestive, and respiratory systems were noted. Hearing and visual impairments were also evident with increased age.

The previously described studies confirm that seizure disorders, poor dentition, hearing and visual impairments, and obesity are prevalent conditions among elderly persons with developmental disabilities. There is a wide range of reported prevalence of orthopedic and motor disorders. Specific information on prevalence of chronic conditions is not as readily available when reviewing pertinent literature about this population. Ongoing research is needed to examine whether the types of health conditions related to persons with developmental disabilities change as the composition of the population changes and as community living rather than institutionalization becomes the norm.

Functional Ability

Functional abilities of elderly (aged 55 and over) and adult (aged 22-54) persons with mental retardation were compared in a study by Krauss and Seltzer (1986). The Massachusetts Service Coordination Battery was completed by

community residence staff members, ward attendants, or social workers familiar with 8,232 mentally retarded persons in the state who received services from the Department of Mental Health. Data were collected about individual characteristics, medical history, cognitive and functional status, educational history, and service needs and programming. The investigators selected random samples of subjects in two age groups: adult (22-54, n=530) and elderly (55-91, n=555).

Five variables were used to measure functional ability. One score from the Minnesota Developmental Programming System (a subscale of the Battery which contains 12 scales to measure areas from gross-motor to independent living scales) was used as an overall measure of activity of daily living skills and independent living skills. The four other scores measured visual impairment, hearing impairment, the presence of significant behavior problems, and self-preservation (the ability to evacuate from a building independently in 2.5 minutes). Using scores on these five variables, the researchers concluded that the elderly mentally retarded persons were less functionally impaired than the younger mentally retarded persons in all areas with the exception of hearing. The elderly mentally retarded persons were more likely to have a hearing impairment than the subjects in the younger group.

Janicki and Jacobson (1986) also examined functional ability in their previously described study of the records of 10,532 developmentally disabled adults aged 45 and older.

Impairments in vision, hearing, and mobility were noted to increase with advancing age. The researchers also noted that the persons with the greatest life-long skills and capabilities showed the most decline in functional ability as they aged. It is interesting that decreases in skills involving motor activity were noted to begin at age 50, whereas decreases in skills involving cognitive function did not begin until the late 70's. However, Janicki and Jacobson (1986) point out that decline in ability is highly variable for each individual.

The relationship between age and community adjustment was studied by Seltzer, Seltzer, and Sherwood (1982). A sample of 153 adults who had been released from a single institution in Massachusetts was studied. The investigators compared mentally retarded persons aged 18 to 54 (n=128) with those aged 55 and over (n=25) with regard to community living skills (activities of daily living skills and independent living skills), the extent to which each subject performed these skills regularly and independently, the degree of autonomy allowed at each subject's residence, and the motivation of each subject to perform community living skills. Data were collected using a tested instrument, the Community Adjustment Scale, through structured interviews with social workers, house managers, parents, or other unspecified persons who knew the subjects well.

In examining the results, the authors found no significant differences in I.Q. scores or level of mental retardation between the two groups. However, the older

group was found to function less independently than the younger group. The older group had fewer community living skills, performed these tasks less often, and scored lower on motivation to perform these skills. The authors attribute the lower level of functioning of the older group to living in more restrictive settings and receiving fewer support services as well as advancing age. Not mentioned as a possible reason for the noted differences is the fact that the subjects in the older group had spent an average of 36 years in an institution while the younger subjects were released from the institution after an average of 18 years.

Buehler, Smith, and Fifield (1985), in their analysis of the records of 610 developmentally disabled adults mentioned that hygiene difficulties were noted in nearly half of the subjects and "several secondary medical problems were observed related to chronic hygiene problems" (p.8). That observation highlights the need for basic activities of daily living skills in the developmentally disabled population.

In summary, information available about the functional abilities of elderly persons with developmental disabilities is conflicting, possibly because researchers defined and measured functional ability if differing ways. While Seltzer, Seltzer, and Sherwood (1982) found elderly subjects to function at a lower level than younger subjects, Krauss and Seltzer (1986) came to the opposite conclusion. Janicki and Jacobson found functional decline began at about age 50 for motor skills and in the late 70's for cognitive

functioning. More research is needed on this subject, with more universal agreement of how to define and measure functional ability.

Residential Settings

Janicki and MacEachron (1984) used the same data set (the New York Developmental Disabilities Information Survey) as Janicki and Jacobson (1986) in their examination of the demographic characteristics, types of living arrangements and day activity, functional ability, and health and social service needs of 7823 developmentally disabled adults aged 53 and older. Use of group homes, independent living settings, and family homes was noted to decrease and use of adult foster care homes to increase as age of the persons with developmental disabilities increased.

While examining the relationship between age and community adjustment, Seltzer et al. (1982) noted that subjects in the group aged 55 and over were more likely to live in adult foster care homes and in environments that were restrictive of personal autonomy than subjects in the group aged 18 to 54. While 18% of the persons in the younger group lived independently, not a single member of the older group did. Sixty-eight percent of the older subjects lived in adult foster care homes compared to only 15% of the younger group. A larger number of the younger subjects (41%) lived in group homes than the older subjects (8%).

The New York Developmental Disabilities Information System was again the database for Janicki, Jacobson, and

Ackerman (1985) to compare elderly developmentally disabled persons living in group homes and adult foster care homes and to compare service needs and usage. The Developmental Disabilities Information System includes descriptions of physical disabilities, mobility, hearing, and visual impairments. Also included in the instrument is an 80-item Minnesota Developmental Programming System Behavior Scale. This subscale contains questions in eight domains covering gross motor, toileting, dressing/grooming, eating, language, reading/writing, quantitative, and independent living abilities. Records of 3,763 developmentally disabled persons aged 50 and over were examined. The subjects were divided into three age cohorts: aged (73 and over), aging (63-72), and late middle age (53-62).

These researchers reported that group homes and adult foster care homes in the state of New York were inhabited with equal frequency by developmentally disabled persons aged 50 and over. However, residents of group homes were more likely to be aged 50 to 59 (61.6%) and residents of adult foster care homes were more likely to be aged 60 and over (62.8%). Only one out of eight older adults with developmental disabilities was found to be living with family. Family living was found to occur mainly in the group aged 50 to 59 (80%) and rarely for persons aged 60 and over (20%).

Examination of residential settings utilized by elderly adults with developmental disabilities consistently reveals increased utilization of adult foster care homes and

decreased usage of independent living and group home options as age increases. The reasons for this trend are not clear.

Examination of types of living arrangements utilized by persons with developmental disabilities has not been attempted very often. Future research focusing on the characteristics of residents as well as caregivers is needed to describe the strengths and needs of the existing residential care system.

Health Service Use

Janicki, Jacobson, and Ackerman (1985) randomly selected 30 group and adult foster care homes from the New York Developmental Disabilities Information System and used a specially designed form, the Community Residence Health Care Utilization Survey, to examine health service utilization patterns of the residents of different homes. Access to health services was found to vary according to type of residential placement. Receipt of services was found to decrease as comparison moved from group home to adult foster care home to family home. A greater number of subjects living in adult foster care than group homes reported one or more unmet needs for clinical or community generic services due to unavailability of the service or difficulty in securing the service. Older residents of all types of homes were noted to have contact with a physician less often than younger residents.

Janicki et al. (1985) noted that while persons living in adult foster care homes were more likely to have physical disabilities, they were also more independent in basic

activities of daily living skills than residents of group homes. Persons residing in group homes were described as having more limited cognitive skills and more limited mobility than persons living in adult foster care homes. Therefore, it seems unlikely that initiative of the individual subjects is a factor in the greater prevalence of services available for group home residents.

While comparing adult and elderly persons with mental retardation, Krauss and Seltzer (1986) noted that the younger institutionalized mentally retarded subjects in their study received significantly more therapeutic and medical services than the older institutionalized subjects. The younger persons in community-based settings were likely to have the greatest number of unmet needs. No significant differences were noted between the number of services received or unmet needs of the younger and older community groups.

Older mentally retarded adults living in the community were purported to receive fewer support services than younger mentally retarded persons in community residences by Seltzer et al. (1982), although there was no explanation as to the exact type of support services examined in their study. This finding is in conflict with the report of Janicki and MacEachron (1984) that as age of developmentally disabled persons increased, more audiological, nursing, physical therapy, specialized medical care, and recreational services were provided, while unmet needs for audiologists, physical and occupational therapy, and recreational

activities remained apparent. Janicki and MacEachron (1984) report that there was no change in frequency of medical, speech, occupational therapy, and psychological services with increasing age, although needs for these services may increase.

Once again, there are conflicting results from studies that have examined the utilization of health services by elderly adults with developmental disabilities. Janicki, Jacobson, and Ackerman (1985) reported the persons residing in group homes are most likely to receive services, followed by persons living in adult foster care homes and family homes. No significant differences in services received by younger and older subjects were detected by Krauss and Seltzer (1986). Services were described as consistently provided by Janicki and MacEachron (1984), but the amount of available services did not increase as need for services increased with age.

More specific information regarding the types and numbers of unmet needs for health related services and equipment is needed. Transportation, accessible buildings, insurance coverage, and attitudes of care providers toward persons with developmental disabilities and elderly persons are all factors which may be examined in relation to the health care delivery system.

Summary

The small body of literature pertinent to the health status, functional status, residential setting, and health service usage has been reviewed in this chapter. Ongoing

examination of health conditions of generational cohorts of persons with developmental disabilities is needed in order to provide appropriate health care. More accurate information about the functional abilities of members of this population throughout the lifespan is needed by health care providers. The current system of residential options available for persons with developmental disabilities needs to be examined to determine if the objectives of the deinstitutionalization movement are being achieved. Not much is known about health service use patterns and barriers to health care access of this population. Additional information about the characteristics and service needs of persons with developmental disabilities is needed for system modification as well as for care of individuals.

Methods utilized in this investigation are described in the following chapter. Research questions, data collection procedure, operational definitions of concepts, human subjects protection, and statistical analysis of data are included in chapter 4.

Chapter 4

This retrospective, descriptive study was designed to describe use of medical services, preventive service use, unmet needs, and functional abilities of elderly persons with developmental disabilities who reside in community settings. This author analyzed cross-sectional data collected by Richard J. Coelho and Norma F. Dillon, Evaluation Specialists at Clinton-Eaton-Ingham Community Mental Health Board (CEI-CMHB), for a study of service needs of the population of persons with developmental disabilities aged 55 and over. The original study met requirements for the utilization review process of CEI-CMHB. Data were collected in 1988 using a needs assessment questionnaire to examine future programming needs of elderly persons with developmental disabilities who reside in community residential settings. Pertinent demographic data and specific types of health related information were also gathered in the survey questionnaire and will be used to categorize the findings. There was no attempt to analyze the effects of aging using cross-sectional data.

Operational definitions for the concepts are developed in this chapter. In addition, methods of instrument development, sample selection, and human rights protection are described.

Research Questions

The basic research questions for this study are as follows:

1) What is the mean frequency of use of medical

services in the last year?

2) How long ago was the last routine preventive dental, physical, vision, hearing, and gynecological exam?
3) What are the numbers and types of unmet needs for services and/or equipment?
4) Are there differences in the functional abilities of residents in different residential settings?
5) Does the use of medical services, mean length of time elapsed since preventive exams were received, and number and type of unmet needs for services and equipment vary by residential settings?

Sample

The target population of the original study was aging and elderly persons (aged 55 and over) with developmental disabilities who reside in the community. The study participants were persons receiving services from a tri-county community mental health agency in Michigan. The entire population of persons aged 55 and over with developmental disabilities who resided in the community and received services from the mental health agency was surveyed. The total number of participants was 67.

Instrument

The majority of persons with developmental disabilities are unreliable informants and historians when discussing complex information such as medications taken and medical diagnoses. Services at Clinton-Eaton-Ingham Community Mental Health Board are provided by an interdisciplinary

team comprised of professionals such as social workers, day program clinicians, nurses, occupational therapists, speech and language pathologists, nutritionists, psychologists, psychiatrists, behavior treatment specialists, rehabilitation counselors, and residential specialists. In order to obtain more accurate and reliable data while reducing the burden on individual respondents, the investigators decided to obtain information from several persons. Drs. Coelho and Dillon chose to base the needs assessment on information obtained from professionals most familiar with their area of clinical specialty and with the developmentally disabled subjects.

Pertinent literature and existing instruments for measuring the needs of persons with developmental disabilities were reviewed. Some questions from previously tested instruments were considered appropriate for assessing the needs of the population receiving services from the agency, but the primary investigators did not use existing instruments because they were too lengthy and were designed for one person to complete. A needs assessment survey questionnaire (see Appendix A) was developed by Drs. Coelho and Dillon in conjunction with an interdisciplinary clinical team. Forced choice, Likert type, and short answer questions similar to questions standard in existing instruments with good reliability and validity scores were included in the survey instrument, as were questions that were designed to collect information of specific interest to the quality assurance committee. The survey was designed to

collect information from four service areas: 1) Case Management, 2) Day Program, 3) Residential, and 4) Nursing. A pilot test was conducted by the CEI-CMHB quality assurance committee, which consisted of members from the disciplines that would be required to fill out the questionnaires.

Data Collection Procedure

The final instrument (see Appendix A) was separated into four sections and each section was completed by a different person. Each section was distributed by the appropriate supervisor to the elderly individual's case manager, residential home provider, day program team leader, and assigned nurse for completion. The community mental health agency supported the data collection for the purpose of needs assessment, resulting in 100% participation. Respondents were case managers, nurses, day program team leaders, and residential providers who were knowledgeable about their areas of expertise and about individual elderly persons receiving services.

Finished surveys were reviewed for completeness, accuracy, and conflicting information by Dr. Coelho. Less than five percent of the surveys were noted to have incomplete information. Incomplete surveys were returned to the raters for completion before they were included in the data base. Data obtained from the needs assessment was coded for use with SPSS-X software and stored in ASCII language on computer diskettes by Jo Benson, data specialist and keypunch operator.

Operationalization of Study Concepts

Health Service Use.

Health service use was examined in three categories: use of medical services, preventive service use, and unmet needs.

1) Use of medical services: The number of physician visits and the number of hospitalizations in the last year were examined in an attempt to determine what the actual frequency of contact with medical services. Respondents were asked to provide the actual number of physician visits and hospitalizations in the last year.

2) Preventive service use: The length of time elapsed since preventive dental, physical, vision, hearing, and gynecological (for women) exams occurred was examined. Respondents were asked to provide the number of months elapsed since these exams were performed for the elderly developmentally disabled subjects.

3) Unmet Needs for Services and Equipment: Unmet needs are defined as needs for services and equipment that were identified by professionals familiar with individual subjects and that were not being addressed at the time of data collection. These needs were identified during the annual individual program planning meeting that is mandated by the Department of Mental Health for each person receiving mental health services in the state of Michigan. The interdisciplinary team process is the same regardless of the residential setting of the developmentally disabled person. Disciplines represented on the interdisciplinary team may

include social workers, day program clinicians, nurses, occupational therapists, speech and language pathologists, nutritionists, psychologists, psychiatrists, behavior treatment specialists, rehabilitation counselors, and residential specialists.

Assessments completed by the team members before the annual meeting provide the data needed by the team members to plan for service delivery for the next year. If services by a discipline not represented on the interdisciplinary team appear to be needed based on the evaluations of other professionals, a referral to the appropriate discipline is completed. An expert in that discipline then evaluates whether there is a legitimate need for their services. Unmet needs may occur when there is an inadequate number of professionals to provide services to all persons with confirmed needs for the services.

Data describing unmet needs were obtained by comparing recommendations of the interdisciplinary team with actual services received by the subjects. Services needs that were likely to be unmet included occupational therapy, physical therapy, nursing, psychotherapy, and speech/language/hearing therapy. Equipment needs included glasses, wheelchairs, helmets, walkers, braces, canes, and hearing aids.

In identifying unmet needs for services, each category of service was listed and respondents were required to indicate whether or not the service was identified as needed by the interdisciplinary team during development of the latest individual program plan. For needed services,

response categories for indicating whether or not the service was received in the last month were provided.

Needs for equipment were assessed by listing the equipment and providing five categories of responses, including "has no need", "needs, has, and uses", "needs, has, cannot or will not use", "needs, but does not have", and "unknown".

Functional Ability.

Functional ability includes activities of daily living (eating, bathing, grooming, dressing, undressing, toileting, mobility), vision, hearing, expressive and receptive language. Three categories of functional ability were examined: activities of daily living, sensory impairments, and communication impairments.

The amount of assistance needed for activities of daily living was measured through a series of questions about self-care activities with Likert-type responses ranging from "does not receive help or supervision" to "does not participate (i.e. is dressed)". Independent activities of daily living, such as cooking, cleaning, and laundry skills were not included because of prior knowledge of this author of limited opportunity to participate in independent activities of daily living in many of the residences included in the study.

Measurement of the amount of visual and auditory impairment was accomplished through the use of questions with responses ranging from "normal or minimal loss" to "total blindness" or "total deafness".

A Likert-type scale for measurement of receptive and expressive communication impairment included five responses ranging from "speaks and is usually understood" to "does not convey needs" and "usually understands oral communication" to "does not understand". Use of sign language, lip reading, symbol boards, facial expressions, primitive gestures, and grunts were included in the choice of responses.

Residential Setting.

Residential setting refers to the type of place that elderly adults with developmental disabilities live. Category of residence was elicited at the beginning of the questionnaire along with demographic information such as age, sex, and race. Respondents were asked an open-ended question about type of residence. Dr. Coelho then placed each response into categories according to previously established CEI-CMHB criteria for categorizing homes based on the amount of care and training provided for residents. Categories identified by Dr. Coelho included Community Services for the Developmentally Disabled, contract, group, adult foster care, Alternative Intermediate Services, family, supported apartment, independent living, and nursing home.

For the purpose of this study, types of homes were consolidated into four categories of residential options: nursing home, group home, adult foster care home, and semi-independent and independent living.

1) Nursing Home: A nursing home is a facility that

provides nursing care but no training or habilitation of residents. Only the response "nursing home" applied to this type of living situation.

2) Group Home: A residence is considered a group home if it provides training to promote independent functioning of the residents in addition to basic care. CSDD, group, AIS, and contract categories were combined and recategorized as group homes, because they all provide training in activities of daily living as well as basic care. The main difference in these homes is the amount and source of funding.

3) Adult Foster Care Home: An adult foster care home is a home that provides basic care for the residents, with no training in daily living skills. Adult foster care homes are denoted by the AFC acronym.

4) Semi-independent and Independent Living: Supported apartment, independent living, and family categories were combined under the category of semi-independent and independent living. All of these residential options are considered the least restrictive and most independent types of living arrangements.

Statistical Analysis of Data

Demographic data, like sex and residence, are presented using descriptive statistics, with categorical variables displayed in frequency tables, and continuous variables (age) summarized through means, standard deviations, and ranges. Oneway analysis of variance was used to test for significant differences in the mean ages of males and

females and of residents of the four types of settings.

Two categories of responses were examined to determine frequency of use of medical services in the last year. The mean, standard deviation, and range for the number of physician visits and the number of hospitalizations were computed.

Likewise, the same statistics were computed for the number of months since routine preventive dental, vision, physical, hearing, and gynecological (for women) exams were received. This was done for each type of preventive exam separately. Correlation coefficients were employed to explore relationships between the amounts of time elapsed since the various exams occurred. Finally, oneway analysis of variance was used to determine whether the use of medical services and mean length of time elapsed since preventive exams were received varied across residential settings.

Unmet needs for services and unmet needs for equipment were examined separately. A frequency table is used to show the numbers and percentages of identified needs not met in each category of equipment variables such as glasses, hearing aid, helmet, walker, braces, canes, and wheelchair and of services such as nursing, speech/language/hearing therapy, physical therapy, psychotherapy, and occupational therapy. Factor analysis was used to explore groupings of unmet needs.

Functional ability of the subjects was examined in three areas; activities of daily living, sensory impairments, and communication impairments after performing

factor analysis to support the three subscales. Correlations between the three subscales were performed to explore whether impairment in one category is related to impairment in other categories.

The scale used to evaluate ability to complete activities of daily living independently included responses arranged so that a higher score indicates less ability to complete each activity. Scores in the areas of eating, bathing, grooming, dressing, undressing, toileting, and mobility were combined to create a total activity of daily living score. Lower scores reflect more independence of the subjects in activities of daily living, while higher scores reflect less independence.

Visual and auditory scores were examined separately since they were not highly correlated. Expressive and receptive communication scores were combined to form the communication subscale after performing correlations to certify that the individual variables measure the same dimensions. Frequencies of each response category for the two subscales are presented in table form. After each of the three areas of functional impairment were examined, oneway analysis of variance was used to determine whether or not significant differences in ability exist between subjects living in different types of residential settings.

Methodological Assumptions and Limitations

The original investigators assumed that the potential for measurement error inherent in utilizing different raters for different subjects was outweighed by the advantage of

having raters who were familiar with the characteristics of the individual elderly developmentally disabled subjects. The primary investigators also assumed that all raters had an understanding of terminology used in the instrument and would interpret the questions in similar ways.

As mentioned above, measurement error was introduced by having a variety of case managers, home providers, day program team leaders, and nurses complete the survey instrument. The fact that different persons collected data from different subjects may have resulted in variations that have nothing to do with variations in the attributes of subjects.

Although all of the professional data collectors (nurses, case managers, and day program team leaders) possessed college degrees, the home providers had varying levels of educational preparation. Differences in educational preparation may have influenced the raters interpretation of survey questions.

The wording of some of the questions, for example the inquiries about doctor and specialist visits, may have been confusing to the case managers who completed that section of the survey. Some questions relevant to the population of elderly persons with developmental disabilities were not included on the survey instrument (see Appendix A). The instrument did not differentiate between physician visits for routine preventive care and acute care. Information about use of emergency room or urgent care facilities was not solicited. Questions concerning the occurrence and

frequency of mammography for female subjects were not included. Need for the services of a dietician was not included in the service need section. The amount of description possible about health services utilized by the subjects is limited to the available information.

Findings of the study cannot be generalized to the entire population of elderly adults with developmental disabilities residing in community setting in Michigan, since only "approximately 40 per cent of Michigan's 5400 older adults (60 years and older) with developmental disabilities are served by the public mental health system" (Michigan Office of Services to the Aging, 1990). And furthermore, the subjects from the tri-county area may not be representative of the Michigan population served by the public mental health system.

Elderly persons with developmental disabilities who are residing in family homes, Department of Social Service licensed adult foster care homes, and homes for the aged are not always known to or served by the mental health system. The number of members of this population is estimated, since persons who have mild impairments may not be diagnosed as developmentally disabled (Michigan Office of Services to the Aging, 1990).

Protection of Human Subjects

The proposal for the original study performed by Richard Coelho and Norma Dillon was reviewed and approved by the CEI-CMHB Research Review Committee. Because it was part of the utilization review process, it was also approved by

the boardwide quality assurance committee. This author secured the permission of the Research Review Committee and the Executive Director of the Community Mental Health Board to perform secondary data analysis for the purpose of this study of use of medical services, preventive service use, unmet needs, and functional abilities of elderly persons with developmental disabilities who reside in community settings. Expedited approval for secondary analysis of the data was obtained from the University Committee on Research Involving Human Subjects of Michigan State University (see Appendix B) prior to analysis of data.

Confidentiality was maintained by converting questionnaire answers to a code sheet and performing analysis by computer. Results were reported in group form. Because the data were collected using surveys completed by service providers, participation of the actual elderly persons was not involved and informed consent was not deemed necessary by the Community Mental Health Board. Confidentiality was be maintained by this researcher through group reporting of results.

Summary

This chapter outlined the methods that were used for this study. Reviewed were the research questions, instrument development, data collection procedure, operational definitions of concepts, protection of human subjects, and statistical analysis of data.

Chapter 5

A description of the sample and interpretation of the research findings are presented in this chapter. Data relevant to the research questions are examined and findings are discussed.

Sample Characteristics

The target population of the original study was aging and elderly persons (aged 55 and over) with developmental disabilities who reside in the community. The study participants constituted a sample of persons receiving services from a tri-county community mental health agency in Michigan. The entire population of persons aged 55 and over with developmental disabilities who resided in the community and received services from the mental health agency was surveyed (n=67).

Demographic Characteristics of the Sample

Demographic variables examined in this study include age, sex, and type of residential setting of individual subjects. Frequency distributions of these variables are presented in Table 1. The mean age for the entire sample of elderly developmentally disabled subjects is 62.1 years (S.D.=5.8) with a range from 55 to 75 years. There are no significant differences between the mean ages of males and females (f=.18: p.<.68). The majority (74.6%) of subjects are aged 55 to 64. There are 29 male subjects and 38 female subjects. The proportion of men and women is essentially the same in all age groups.

Table 1

Demographic Characteristics of the Sample

Age by Sex

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	1	6.04	6.04	.18	.68
Within Groups	65	2232.23	34.34		
Total	66	2238.27			

Total Sample	$\bar{X}$=62.1 years	S.D.=5.8	Range=55-75 years
Male	$\bar{X}$=62.5 years	S.D.=6.0	Range=55-75 years
Female	$\bar{X}$=61.8 years	S.D.=5.8	Range=55-75 years

Sex by Residence

	Male	Female	Total
Nursing Home	2	0	2 (3.0%)
Group home	17	17	34 (50.7%)
AFC	9	14	23 (34.3%)
Semi-ind, Ind	1	7	8 (11.9%)
	29	38	67

Age by Residence

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	167.44	55.81	1.70	.18
Within Groups	63	2070.83	32.87		
Total	66	2238.27			

Total Sample	$\bar{X}$=62.1 years	S.D.=5.8	Range=55-75 years
Nursing Home	$\bar{X}$=56.5 years	S.D.=0.7	Range=56-57 years
Group Home	$\bar{X}$=62.5 years	S.D.=5.9	Range=55-75 years
AFC	$\bar{X}$=63.1 years	S.D.=6.2	Range=55-75 years
Semi-ind, Ind	$\bar{X}$=59.0 years	S.D.=3.0	Range=55-63 years

The residential setting with the largest number of subjects is group home (n=34), followed by adult foster care home (n=23), semi-independent and independent living (n=8), and nursing home (n=2). The only two nursing home residents are males aged 56 and 57. Men and women are equally likely to live in group homes, but more women than men live in adult foster care homes and semi-independent or independent living situations. The results of a oneway analysis of variance of the age of residents in the four settings indicated that no significant differences exist in the mean ages of residents across settings ($f=1.7$: $p<.18$). However, given the small number of cases living semi-independently or in nursing homes, it is not clear whether their apparent younger age is typical for all such individuals living in those settings.

Use of Medical Services

Summary data for the use of medical service items of the number of physician visits and the number of hospitalizations in the last year is presented in Table 2.

Table 2

Use of Medical Services in the Last Year (n=67)

Physician Visits	$\bar{X}$=5.8	S.D.=5.7	Range=0-24 visits
Hospitalizations	$\bar{X}$=.254	S.D.=.636	Range=0-3

Considerable variation is noted in the number of physician visits per subject. There is little variation in

the number of hospitalizations, with a mean significantly less than one hospitalization per subject. However, information on the number of hospitalizations per subject does not reflect the amount of time spent in the hospital. Thus, a large variation in the number of days hospitalized is possible. Knowledge of the number of days hospitalized in the last year would have perhaps provided more meaningful data.

Since the number of hospitalizations has a very narrow range and does not provide information about the number of hospital days, only the number of physician visits was employed in testing for differences among residences. Oneway analysis of variance revealed significant variation in the number of visits to the physician by persons in the four types of residences (p.<.00, Table 3).

Table 3

Oneway Analysis of Variance and Mean Number of Physician Visits by Residential Setting

		Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	719.76	239.92	10.58	.00
Within Groups	63	1428.09	22.67		
Total	66	2147.85			

Total Sample	$\bar{X}$=5.82	S.D.=5.70	Range=0-24
Nursing Home	$\bar{X}$=18.00	S.D.=8.49	Range=12-24
Group Home	$\bar{X}$=7.85	S.D.=5.54	Range=0-24
AFC	$\bar{X}$=2.91	S.D.=3.26	Range=0-12
Semi-Ind, Ind	$\bar{X}$=2.50	S.D.=3.93	Range=0-12

The Scheffé multiple comparison procedure was employed to determine which residential means accounted for the differences. Interpretation of the Scheffé test revealed that the nursing home residents (n.=2) varied significantly from residents ofthe three other types of homes ($p.<.05$). There were also significant differences between the mean number of physician visits of residents of AFC and group homes ($p.<.05$), with subjects residing in group homes reporting a high mean number of physician visits.

Preventive Health Examinations

Frequency distributions representing the number of months elapsed since preventive physical, gynecological, dental, vision, and hearing exams occurred are presented in Table 4.

Table 4

Mean Number of Months Since Preventive Health Exams

Physical (n=66)	$\bar{X}$=7.4	S.D.=6.2	Range=0-31 months
Gynecological (n=12)	$\bar{X}$=14.3	S.D.=11.0	Range=0-31 months
Dental (n=40)	$\bar{X}$=9.9	S.D.=10.0	Range=0-60 months
Vision (n=45)	$\bar{X}$=12.6	S.D.=13.3	Range=0-84 months
Hearing (n=48)	$\bar{X}$=19.2	S.D.=22.0	Range=0-96 months

The value of this information is diminished because of

the large number of missing values noted for several of the variables. The number of months since gynecological examination occurred is known for only 12 of the 38 female subjects. No information is available concerning the time elapsed since dental, vision, and hearing exams for 19 to 27 of the 67 subjects.

Correlation coefficients were calculated in order to judge whether the variables of number of months since physical, gynecological, dental, vision, and hearing exams were related to each other. Only months since vision and hearing exams were strongly correlated ($r=.65$, $p.<.01$). Since the majority of the correlation coefficients indicated no correlation between the variables and since the percents of missing responses to these variables ranged from 1.5 to 68.4 percent, no attempt was made to combine the variables into a single scale to measure the length of time elapsed since the preventive exams occurred. Analysis of variance, using residence as the independent variable was performed separately for each exam (physical, gynecological, dental, vision, and hearing). Only months since physical exam showed a statistically significant difference between the residential groups (Table 5). When the Scheffé multiple comparison procedure was performed to determine which groups were different at the .05 significance level, no two residential groups were identified as significantly different.

Table 5

Oneway Analysis of Variance and Mean Number of Months Since Physical Exam by Residential Setting

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	292.13	97.38	2.74	.05
Within Groups	62	2203.62	35.54		
Total	65	2495.76			

Total Sample	$\bar{X}$=7.39	S.D.=6.20	Range=0-31
Nursing Home	$\bar{X}$=1.00	S.D.=1.41	Range=0-2
Group Home	$\bar{X}$=6.21	S.D.=5.33	Range=0-25
AFC	$\bar{X}$=8.13	S.D.=5.02	Range=0-19
Semi-Ind, Ind	$\bar{X}$=11.75	S.D.=10.28	Range=0-31

Number and Type of Unmet Needs

In previous chapters, this investigator separated unmet needs into the categories of service and equipment. Factor analysis (using two, three, and four factor solutions) of the ten categories in which unfulfilled needs exist did not support the division of the needs into service and equipment categories or into other meaningful groups. When discussing unmet needs, the categories of equipment and services will be used to differentiate the needs for tangible, physical objects (equipment) and intangible benefits provided by other persons (services).

When examining unmet needs, simply listing the numbers of unmet needs did not provide accurate comparisons, since the number of identified needs varied considerably. Therefore the numbers of unmet needs are presented as the proportions and percentages of identified needs that were

not fulfilled (Table 6).

Table 6

Proportions and Percentages of Unmet Needs for Services and Equipment

Equipment	Proportion	Percentage
Glasses	1/36	2.8%
Wheelchair	1/9	11.1%
Helmet	0/1	0%
Walker	2/5	40.0%
Braces	0/2	0%
Cane	0/2	0%
Hearing Aid	6/16	37.5%
Other	5/16	31.3%
	15/87	17.2%
Services		
Physical Therapy	5/8	62.5%
Occup. Therapy	7/25	28.0%
Speech/Hearing	27/43	62.8%
Nursing	1/45	2.2%
Psychotherapy	3/4	75.0%
	43/125	34.4%

The needs for equipment which are unfulfilled most frequently are for walker (40% unmet), hearing aid (37.5 % unmet), and other (31.3% unmet). A smaller percentage of unmet needs for glasses and wheelchairs is noted. Braces, canes, and helmets are the most frequently provided. The service with the highest proportion of unmet need is for psychotherapy, which is not received 75 percent of the time. Speech and hearing therapy and physical therapy needs are unmet approximately 62 percent of the time. Occupational

therapy and nursing are the services most likely to be provided when identified as needs. Overall needed equipment is likely to be provided over 80% of the time, while needed services are provided only two-thirds of the time (the exception being nursing services).

The proportion of unmet needs for equipment is based on the number of identified needs that are not fulfilled. It seems logical that a speech/hearing evaluation is necessary in order to identify the need for a hearing aid and that evaluation by a physical or occupational therapist is needed to identify the need for a wheelchair or walker. Since there is a large percentage of unmet need for these services, the needs for related equipment may be greater than reflected by the data.

Proportions of unmet needs categorized by residential setting are presented in Table 7. Of the needs identified for nursing home and semi-independent/independent residents, needs for glasses, wheelchairs, walkers, nursing, physical therapy, and occupational therapy are met 100 percent of the time, while needs for speech and hearing therapy and hearing aids are unfulfilled 100 percent of the time. The nursing home and semi-independent living groups are quite similar in number and percentages of overall unmet need.

The group home and AFC residents have similar numbers of unmet needs for all categories of services. Unmet needs in these settings appear to be greater by more than 10% compared to nursing home and independent residences. Wheelchairs, walkers, and glasses were needed more often by

Table 7

Proportions and Percentages of Unmet Needs by Residential Setting

Need	Nursing Home	Semi-ind, Ind Living
Glasses	0/1 (0%)	0/6 (0%)
Wheelchair	0/2 (0%)	
Walker		0/1 (0%)
Hearing Aid		1/1 (100%)
Braces		
Cane		
Other	1/1 (100%)	0/2 (0%)
Phys. Ther.		0/1 (0%)
Occup. Ther.	0/2 (0%)	0/1 (0%)
Speech/Hear.	1/1 (100%)	2/2 (100%)
Nursing	0/2 (0%)	0/2 (0%)
Psychother.		
	2/9 22.2%	3/16 18.8%

Need	AFC Home	Group Home
Glasses	0/14 (0%)	1/15 (6.7%)
Wheelchair		1/7 (14.3%)
Walker		2/4 (50.0%)
Hearing Aid	4/9 (44.4%)	1/6 (16.7%)
Braces		0/2 (0%)
Cane	0/1 (0%)	0/1 (0%)
Other	2/6 (33.3%)	2/7 (28.6%)
Phys. Ther.	2/3 (66.7%)	3/4 (75.0%)
Occup. Ther.	4/9 (44.4%)	3/13 (23.0%)
Speech/Hear.	9/13 (69.2%)	15/27 (55.6%)
Nursing	0/13 (0%)	1/28 (3.6%)
Psychother.	2/3 (66.7%)	1/1 (100%)
	23/71 32.4%	30/101 29.7%

group home residents, while hearing aids were less likely to be provided to AFC residents. No information is available concerning the specific types of unfulfilled needs

designated as "other".

Functional Ability

Variations in the functional ability indicators were satisfactorily accounted for through a three-factor solution that explained 75.2 percent of the variance among items. The factor loadings support separation of the functional ability variables into three subscales: activities of daily living skills, sensory ability, and communication ability. Therefore, no attempt was made to combine the three subscales into a single measure of functional ability.

Table 8

Oneway Analysis of Variance of Mean ADL Deficits by Residential Setting

Scale	Alpha Value	Mean Inter-item Correlation
ADL	.92	.63

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	15.87	5.29	15.26	.00
Within Groups	63	21.85	.35		
Total	66	37.72			

Total Sample	$\bar{X}$=1.94	S.D.=.76	Range=1.00-4.00
Nursing Home	$\bar{X}$=3.43	S.D.=.81	Range=2.86-4.00
Group Home	$\bar{X}$=2.29	S.D.=.70	Range=1.00-3.71
AFC	$\bar{X}$=1.50	S.D.=.35	Range=1.14-2.43
Semi-Ind, Ind	$\bar{X}$=1.34	S.D.=.58	Range=1.00-2.71

The activities of daily living (ADL) subscale includes the variables bathing, dressing, undressing, toileting, eating, mobility, and grooming. Reliability analysis using

coefficient alpha indicated that the seven ADL variables formed a highly reliable scale (Table 8). The mean of the seven variables constitute each subject's ADL score. Lower ADL scores indicate less need for assistance with activities of daily living, while higher scores indicate the need for more assistance.

Analysis of variance was used to test whether significant differences in functional ability exist among the residents of various settings. Significant variation in the mean ADL scores of residents of the four types of homes is noted (sig.=.00). The Scheffé multiple comparison procedure was used to determine that the mean ADL scores of AFC and semi-independent/independent living residents were significantly lower than the scores of subjects who reside in group and nursing homes ($p.<.05$). Scores of subjects residing in nursing homes indicate the highest need for assistance with personal care even though the nursing home residents have the lowest mean age of any of the residential groups. Persons in semi-independent/independent living and AFCs have the most similar mean scores indicating the lowest need for assistance with activities of daily living, although there is greater variation in the scores of persons living in semi-independent and independent settings. AFC residents score low in need for assistance even though they have the highest mean age.

Although the vision and hearing variables were grouped during factor analysis, there is no logical reason to believe that hearing impairment is necessarily related to

visual impairment. Performance of correlations between the two variables confirmed that they were not related. Frequency of responses in each category of sensory impairment is presented in Table 9.

Table 9

Frequency of Sensory Impairment (n-67)

Visual Acuity	Frequency	Percent
1=Normal/Min Loss	57	85.1
2=Mild/Mod Loss	7	10.4
3=Severe Loss	3	4.5
4=Blind	0	0
Hearing Acuity		
1=Normal/Min Loss	47	70.1
2=Mild/Mod Loss	13	19.4
3=Severe Loss	3	4.5
4=Profound Loss/Deaf	4	6.0

Since less than 15% of subjects displayed a visual loss, analysis of variance for sensory loss related to residential settings was performed only for the hearing acuity data (Table 10).

Table 10

Oneway Analysis of Variance of Hearing Deficits by Residential Setting

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	1.42	.47	.66	.58
Within Groups	63	45.24	.72		
Total	66	46.66			

The communication subscale is composed of the expressive and receptive language variables. The mean of these two variables was calculated for individual subject scores. Higher scores are indicative of greater communication impairment and lower scores less impairment. Frequency of responses in each category of communication impairment is presented in Table 11.

Table 11

Frequency of Communication Impairment

Expressive Communication	Frequency	Percent
1=Speaks, is understood	32	47.8
2=Speaks, diff to understand	17	25.4
3=Uses signs, symbol, writes	5	7.5
4=Uses gestures, grunts, symb.	12	17.9
5=Does not convey needs	1	1.5
Receptive Communication		
1=Understands speech	40	59.7
2=Limited Comprehension	18	26.9
3=Signs, lipreads, writes	3	4.5
4=Gestures, environ cues	6	9.0
5=Does not understand	0	0

Significant differences exist in the communication scores of subjects across various residences. The Scheffé multiple comparison procedure was used to identify group home and AFC residents as the groups that are significantly different at the .05 significance level. Mean scores of subjects residing in group homes denote more communication impairments in this group (Table 12).

Table 12

Oneway Analysis of Variance and Mean Communication Deficits by Residential Setting

Scale	Alpha Value	Mean Inter-item Correlation
Communication	.79	.67

Source	D.F.	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	3	9.11	3.04	3.59	.02
Within Groups	63	53.31	.85		
Total	66	62.42			

Total Sample	$\bar{X}$=1.81	S.D.=.97	Range=1.00-4.50
Nursing Home	$\bar{X}$=1.50	S.D.=.00	
Group Home	$\bar{X}$=2.18	S.D.=1.07	Range=1.00-4.50
AFC	$\bar{X}$=1.43	S.D.=.76	Range=1.00-4.00
Semi-Ind, Ind	$\bar{X}$=1.44	S.D.=.68	Range=1.00-2.50

Summary of Findings

Data relevant to the research questions were examined and interpreted in this chapter. There are no significant differences in the mean ages of males and females or of residents of various settings. Women are more likely than men to live in semi-independent/independent living and adult foster care settings.

The average number of physician visits per year for the total sample is six. Residents of group homes see their physicians more frequently than residents of AFC settings. There are no significant differences in the length of time since preventive exams occurred for residents of the four types of settings when the scant amount of available information is examined.

Overall, the percentage of unmet needs for services are greater than the unmet needs for equipment. Identified needs for equipment such as walkers, hearing aids, and others are unfulfilled approximately one third of the time. Needed services such as psychotherapy, speech and hearing therapy, and physical therapy are not provided about two thirds of the time for the members of the elderly developmentally disabled population examined. Group home residents are less likely to receive wheelchairs, walkers, and glasses, while AFC residents have more unmet need for hearing aids.

Residents of AFC and semi-independent/independent living settings have less need for assistance with activities of daily living than residents of group and nursing homes. No significant differences in auditory acuity is noted between residents of the four settings. Residents of group homes have significantly more expressive and receptive communication impairments than AFC residents.

Implications for future research along with a nursing framework for working with elderly persons with developmental disabilities in primary care practice are discussed in chapter 6.

Chapter 6

A retrospective, descriptive study using secondary data analysis was performed to describe use of medical services, preventive service use, unmet needs, and functional abilities of elderly persons with developmental disabilities who reside in community settings. Data for the study were collected by Richard J. Coelho and Norma F. Dillon, Evaluation Specialists at Clinton-Eaton-Ingham Community Mental Health Board (CEI-CMHB), for a study of service needs of the population of persons with developmental disabilities aged 55 and over.

Andersen's Behavioral Model of Health Services Utilization was used as a framework for the investigation. The study participants constituted a sample of 67 persons (aged 55 and over) with developmental disabilities receiving services from a tri-county community mental health agency in Michigan. The survey instrument (see Appendix A) was separated into four sections and each section was completed by the case manager, residential home provider, day program team leader, and assigned nurse most familiar with each subject.

Conclusions and implications for future research along with a nursing framework for working with elderly persons with developmental disabilities in primary care settings are presented in this chapter.

Conclusions

Functional Status.

When examining functional status, no conclusions may be

drawn about functional ability of the subjects over time or in comparison to younger adults with developmental disabilities due to the lack of longitudinal data and a comparison group. The finding that residents of AFC and semi-independent/independent living settings have less need for assistance with activities of daily living than residents of group and nursing homes is consistent with the findings of Janicki, Jacobson, and Ackerman (1985). The mean ADL scores ranged from 1.34 to 3.43 for the various residents, with the lowest possible score (1) indicating no need for assistance or supervision with activities of daily living. The fact that some degree of assistance or supervision is necessary for all residential groups supports the contention of Buehler et al. (1985) that health conditions related to hygiene may occur in this population.

Many confounding variables may explain the less independent functioning ability of group home residents. Implicit entrance and exit criteria for the various residences may dictate the level of dependence deemed acceptable in individual settings. Unsystematic variation in the level of functioning and type of behavior tolerated in the home may influence the composition of residents.

No significant differences in auditory acuity are noted between residents of the four settings. The fact that approximately 30 percent of the subjects experience some degree of hearing loss is consistent with existing literature (Buehler et al., 1985; Janicki & Jacobson, 1986; Stroud & Sutton, 1987). Given cross-sectional data, no

distinction between life-long and age-related hearing loss is possible. Residents of group homes have significantly more expressive and receptive communication impairments than AFC residents. Communication and activity of daily living impairments are more likely to influence residential placement than hearing or visual impairment.

Residence.

The subjects living in adult foster care homes have the highest mean age, but the difference is not statistically significant due to the small numbers of subjects residing in nursing homes and semi-independent/independent living settings. The fact that there are no statistically significant differences in the mean ages of residents across settings conflicts with the findings of Janicki and MacEachron (1984) and Janicki, Jacobson, and Ackerman (1985) that utilization of AFC homes increases with age. However, findings from this study must be viewed with caution given the very small number of subjects in two settings.

Health Service Use.

The average number of physician visits per year for the total sample is six. As previously reported by Janicki et al. (1985), residents of group homes see their physicians more frequently than residents of AFC settings. This finding is not unexpected given the lower functional ability of group home residents.

There are no significant differences in the mean length of time since preventive exams occurred for residents of the four types of settings. However, due to the large number of

missing responses, this result must be treated with caution. It is beyond the scope of this study to provide the reasons for the missing information. However, previous researchers have documented the lack of accurate health records for adults with developmental disabilities (Gotowka et al., 1982). Inadequacy of previous medical records, frequent changes in residence, and lack of an identified person responsible for monitoring health care are all areas that could be explored in future investigations. Persons familiar with the developmentally disabled would not be surprised to learn that these examinations have never been performed in some cases. Walz et al. (1986) postulate that lack of "routine health management for persons with developmental disabilities may have contributed in subtle ways to the overall issue of premature aging in this group" (p. 624).

When information about length of time since preventive exams occurred is available, the average time elapsed falls within one year for physical and dental examinations and within two years for vision, hearing, and gynecological exams. However, there is wide variation in the elapsed time, ranging from zero to eight years for hearing exams, zero to five years for dental exams, and zero to seven years for vision exams. These findings do not support one of the main assumptions of the deinstitutionalization movement, that residing in community settings and receiving care from generic providers results in improved life conditions for persons with developmental disabilities. It is the opinion

of this author that needed services are available in the community, but improved methods of coordinating access to the existing services is needed.

Unmet Needs.

Overall, the percentage of unmet needs for services are greater than the needs for equipment. Identified needs for equipment such as walkers, hearing aids, and others are unfulfilled approximately one third of the time. Needed services such as psychotherapy, speech and hearing therapy, and physical therapy are not provided about two thirds of the time for the members of the elderly developmentally disabled population examined. The unavailability of physical therapy and audiological services is consistent with the findings of Janicki and MacEachron (1984), but subjects of this study received occupational therapy services more consistently. The number of unmet needs for walkers, braces, and hearing aids may be artificially low since physical therapy and audiological examinations are not consistently received.

Of the needs identified for the residents of semi-independent/independent living and nursing homes settings, needs for hearing aids and speech and hearing therapy are unfulfilled 100 percent of the time. The contention of Janicki et al., (1985) that AFC residents have more unmet needs than group home residents is not supported by the data. Needed services are provided with about equal frequency for residents of AFC and group homes. Group home residents are less likely to receive wheelchairs, walkers,

and glasses, while AFC residents have more unmet need for hearing aids.

Conceptual Model.

When evaluating the study findings in the context of the Andersen Behavioral Model of Health Services Utilization, the enabling variable residential setting was a significant predictor of the number of physician visits, but not independent of the functional status of residents. The fact that functional ability for ADL and communication varied with type of residence may account for the relationship between residence and number of physician visits. It is also possible that some unexamined variable is responsible.

Since functional ability is related to type of residence, it may also partially predict number of physician visits, and is therefore correctly categorized as a need variable. However, functional ability is not likely to be related to unmet needs or preventive service use.

Residence was not useful in predicting the number and type of unmet needs or use of preventive services. When the model was developed in 1968, it was meant to be applied as a predictor of acute care service use. When using the model to explain the use of preventive services, need variables are not likely to be influential, but enabling variables such as community resources, income, transportation, and insurance coverage may partially predict utilization behaviors.

Further research examining possible enabling, need, and

predisposing variables is needed to determine which characteristics of elderly persons with developmental disabilities are predictors of health service usage. Perceived and actual health status, individual and provider beliefs about health care, type of insurance, family involvement, cost, degree of cooperation of the disabled patient, transportation, and proximity to health facilities are all areas which need further exploration. In addition, the predictive value of the variables may vary according to the type of health service investigated.

The Andersen model is a useful framework for the Clinical Nurse Specialist. In addition to using the model to predict individual health service utilization behaviors, the Clinical Nurse Specialist can use the model to influence care at a societal or health care system level. Input from Clinical Nurse Specialists familiar with persons with developmental disabilities is needed to guide political and health care policy. Evaluation of the outcomes of the current delivery system and development of more effective models for health care of members of this population are sorely needed, and Clinical Nurse Specialists could be a valuable resource in the process.

Recommendations for Future Research.

Many recommendations for further research can be derived from the results of this study. Findings of the study cannot be generalized to the entire population of elderly adults with developmental disabilities residing in the community, since only approximately 40 per cent of the

estimated 200,000 to 500,000 older adults with developmental disabilities are served by the public mental health system (Ansello & Rose, 1989). Elderly persons with developmental disabilities who are residing in family homes, Department of Social Service licensed adult foster care homes, and homes for the aged are not always known to or served by the mental health system. Further study of elderly persons with disabilities who are not receiving mental health services is needed, since existing information is only relevant to the "well-served" members of the population. Examination of unserved members of the developmentally disabled population may aid in the development of more effective service patterns.

Examination of generational cohorts of persons with developmental disabilities over time is needed. For the current cohort, mental retardation and developmental disability are terms that are used synonymously (Buehler et al., 1985; Cotten & Spirrison, 1986; Janicki & Jacobson, 1986; Janicki & Wisniewski, 1985; Krauss & Seltzer, 1986; Stroud & Sutton, 1988). Rarely have non-retarded persons with diagnoses of epilepsy, cerebral palsy, autism, and learning disability been examined in research. If the current cohort of elderly persons with developmental disabilities is a heterogeneous group with a wide range of functional abilities, future cohorts are likely to be characterized by greater diversity as persons with more severe impairments and a variety of disabling conditions live longer. Disparities in data reported in previous

studies of this population may be the result of generational differences (Janicki & Jacobson, 1986). Longitudinal studies are needed to observe trends over time.

The study data were collected as part of a needs assessment survey designed by the primary researchers to identify demographic and functional characteristics, and clinical and rehabilitative service needs of elderly adults with developmental disabilities. The data analyzed in this study were very complete with the exception of information relating to the time elapsed since preventive health examinations occurred.

Further examination of the health needs of members of this population utilizing more specific health-related questions is indicated. The instrument did not differentiate between physician visits for routine preventive care and acute care or between number of hospitalizations and number of hospital days. Information about use of emergency room or urgent care facilities was not solicited. Questions concerning the occurrence and frequency of mammography for female subjects were not included. Need for the services of a dietician was not included in the service need section. More specific information describing existing health conditions and medication usage in this population would add to existing knowledge.

Methodological changes could also improve the accuracy and usefulness of future studies. As mentioned in chapter 4, measurement error may have been introduced by having

varying case managers, home providers, day program team leaders, and nurses complete the survey instrument. The comparisons within and between settings may have been weakened by having different raters complete the surveys. Stricter control of the number of persons completing the surveys, as well as expansion and clarification of the wording of the surveys could provide more useful information.

The literature specific to the characteristics of elderly persons with developmental disabilities is scarce. The existing literature often reports conflicting information. Further investigation of this population is needed in order to provide effective service in the future.

Implications for Nursing Interventions

Implications for care of the individual with developmental disabilities by the Clinical Nurse Specialist in primary care will be presented in the context of first and level assessment described in the Roy Adaptation Model. While the Andersen model provides a framework for identifying factors which may predict health service utilization behaviors, the Roy Adaptation Model guides the Clinical Nurse Specialist in assessing whether need, enabling, and predisposing variables are mutable or immutable and in planning nursing interventions using the nursing process. The Roy model is appropriate for working with persons with developmental disabilities, because of the emphasis on altering the patient's coping behavior or the environment to promote adaptation. This philosophy is

congruent with the normalization movement for persons with disabilities, which basically promotes participation of individuals to the best of their ability and alteration of the environment to compensate for their limitations.

The goal of nursing is to promote adaptation in four modes through modification of the stimuli or adaptation zone. The three psychosocial modes related to adaptation are the self-concept mode, the role function mode, and the interdependence mode. The physiological mode is the label given to physiological responses to environmental stimuli. The basic needs of the physiological mode are oxygenation, nutrition, elimination, activity and rest, and protection. Four processes modulate regulator activity: the senses, fluid and electrolytes, neurological function, and endocrine function. The purpose of physician visits and preventive health exams is to promote physiological adaptation through early detection of health problems. The importance of these screenings is considerable in persons whose ability to report symptoms of illness is impaired. Assessment of unmet needs for equipment and services also promotes physiological adaptation.

Roy uses the nursing process to assess, diagnose, plan, intervene, and evaluate behavior in each of the four modes. First level assessment examines coping behaviors in each of the four modes. If behavior is evaluated as adaptive, that behavior is reinforced and maintained. If behavior is assessed as ineffective, interventions are planned to improve response. Interventions planned as a result of

first level assessment involve the client more than the environment. The functional ability of the person with disabilities must be assessed realistically in order to estimate coping behavior effectiveness and potential for improvement.

Second level assessment investigates focal, conceptual, and residual stimuli which influence coping behavior. A focal stimulus is the one receiving the person's immediate attention. All other stimuli that are evident in the situation are termed contextual stimuli. Unmet needs for services and equipment as well as type of residence and caregivers that assist the elderly person with developmental disabilities would be considered contextual stimuli. These factors would affect the situation no matter what the focal stimulus was. Residual stimuli are factors that may be affecting the situation, but are not confirmed as influences. Interventions planned as a result of second level assessment would more likely involve the environment than the client.

The remaining four steps of the nursing process are diagnosis, goal setting, intervention, and evaluation. Roy stresses patient involvement to the extent of his/her ability in the identification and confirmation of accuracy of information gleaned in each step of the process. Adaptive responses to constantly changing environmental stimuli free energy to deal with new stimuli.

First level assessment of the developmentally disabled person's functional ability allows identification of

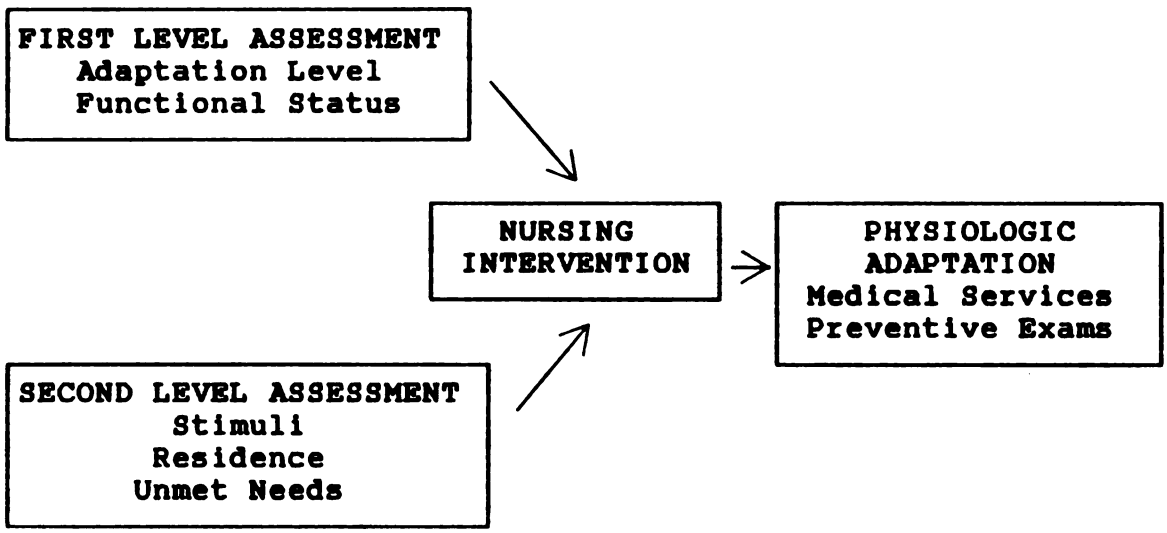

Figure 3. Integration of variables within the Roy Adaptation Model.

strengths and need areas of coping behavior and development of nursing interventions aimed at increasing individual adaptation. The Clinical Nurse Specialist in primary care must be aware that there is considerable variation in the characteristics and needs of elderly persons living in different types of residential settings in order to better serve individuals with disabilities. Significant differences in communication and functional abilities have been previously demonstrated, so the CNS should be sure avoid patronization of the person with disabilities by directing questions to the person rather than making an assumption about his/her ability and communicating directly with the care giver (Thomas, 1986). The disabled person needs to be involved in making decisions about health care as much as possible.

Knowledge of functional ability of the developmentally

disabled patient can be helpful in promoting self-care and in assessing the level of instruction that needs to be presented. Independent behavior should be encouraged. Patient teaching methods may need to be modified to the person's level of comprehension, as when dolls or models are used to provide concrete visual information.

Second level assessment of contextual stimuli such as type of residence and prevalence of unmet needs for services and equipment provides the Clinical Nurse Specialist with information that may affect the plan for nursing intervention. Interventions may be geared to altering the setting to promote adaptation. Awareness that the type of residence used by the elderly person with developmental disabilities is related to the number of health visits allows the CNS to anticipate and emphasize the importance of needed return visits when the patient and care giver present for care.

Identification of the primary caregiver and familiarity with the type of care provided in various types of residential settings is important in order to plan a therapeutic regimen that can realistically be followed at home. When the health of the disabled person deteriorates, alternative placement in a more medically oriented residence often occurs. Identification of health care needs and provision of in-home support services such as visiting nurse may allow continued placement and prevent the disruption of main sources of support (Rinck, Cohen, & Griggs, 1990).

The Clinical Nurse Specialist may need to emphasize the

importance of preventive exams and assist in scheduling them in order to promote physiologic adaptation. For the general population over age 60, Lindberg (1987) recommends annual physical exams, blood pressure measurements, influenza vaccination, and mammography (for women) and biennial visual, hearing, and gynecological exams. Annual physical exams, dental exams, psychological evaluations, audiological evaluations, and visual exams have been recommended for the elderly developmentally disabled population (Jancar, 1986; Rubin & Dwyer; 1989). Since information about the physical exam was the most frequently available, the CNS needs to be aware of the importance of the opportunity to assess hearing, vision, dental, and gynecological status when older adults with developmental disabilities present for physical examination.

Knowledge of the most frequent unmet needs of the members of this population is also valuable in planning comprehensive care. The CNS who cares for elderly persons with developmental disabilities may explore the means available for obtaining needed equipment and services rather than simply writing a prescription. Referral to other community resources can be initiated at the time of the patient contact.

Summary

Significant variation in the functional abilities and impact of residential setting on health service utilization provide clues to the heterogeneous nature of the elderly developmentally disabled population. The Clinical Nurse

Specialist in primary care may use first level assessment to judge effectiveness of coping behaviors and second level assessment to evaluate the focal, contextual, and residual stimuli confronted by the elderly person with disabilities. Familiarity with common characteristics along with an awareness of individual abilities are important when planning and implementing comprehensive, participatory care for persons with developmental disabilities.

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APPENDIX A

Appendix A

ELDERLY DD SURVEY ---- CSDD/UR COMMITTEE

CASE MANAGER SECTION:

(1) Name: _____ (2) Case #: _ _ _ _ _ _ _

(3) D.O.B.: _ _ / _ _ (4) Age: _ _ (5) Sex: _ 1. Male _ 2. Female
Month Year Years

(6) Race: _ 1. White _ 3 Hispanic
_ 2. Black _ 4. Other (Specify): _____

(7) Type of Residence: _____ (8) Initial Source of Referral: _____
1=Institution 2=Community

(9) Guardian Status: _ 1. Plenary _ 2. Partial _ 3. Own Guardian

(10) Level of Retardation:

_1. Not Retarded
_2. Mildly Retarded
_3. Moderately Retarded
_4. Severely Retarded
_5. Profoundly Retarded

(11) Most Recent IQ Score:

_ 1. 70 or above
_ 2. 55-69
_ 3. 40-54
_ 4. 25-39
_ 5. 0-24
_ 6. Unmeasureable

(12) Primary Diagnosis: _____
(13) Secondary Diagnosis: _____

(Circle Only One Number) **ADAPTIVE BEHAVIOR**

(14) VISION (With glasses - if used)
4 Normal vision or minimal loss
3 Mild/Moderate loss
2 Severe loss: Cannot find way around without feeling or or using a cane; can tell light from dark
1 Total blindness: No vision at all, i.e., cannot tell light from dark

(15) HEARING (With hearing aid - if used)
4 Normal hearing or minimal loss
3 Mild/Moderate loss: Hears adequately only in special situations (i.e., one-to-one, raised volume, etc.)
2 Severe loss: Hears with difficulty even in special situations (i.e., conversation restricted, many misunderstandings, or frequently fails to respond, etc.)
1 Profound hearing loss, deaf

(16) EXPRESSIVE COMMUNICATION

1 Speaks and is usually understood
2 Speaks but is only understood with difficulty
3 Uses only structured sign language, symbol board, or writes to communicate
4 Uses only gestures, grunts, or primitive symbols to communicate
5 Does not convey needs

(17) RECEPTIVE COMMUNICATION

1 Usually understands oral communication
2 Has limited comprehension of oral communication
3 Understands by depending on lip reading, written materials, or structured sign language
4 Understands only primitive gestures, facial expressions, simple pictorgrams, and/or recognizes environmental cues
5 Does not understand

RESTRAINTS: Does this person's program include any of the following?

1=No
2=Yes, in written plan
3=yes, but not in written plan

(18) __ Time out or exclusion over 5 minutes
(19) __ Overcorrection (restoring situation to better than normal state)
(20) __ Mechanical restraint
(21) __ Physical restraint
(22) __ Isolation (in room with door closed)
(23) __ Chemical restraint (any medication given in emergencies or prn to control behavior)

I-TEAM

(24) NEEDS IDENTIFIED (LIST)

a. _____
b. _____
c. _____
d. _____
e. _____
f. _____
g. _____
h. _____
i. _____
j. _____
k. _____
l. _____
m. _____
n. _____

(25) LONG TERM PROGRAMMING (LIST)

a. _____
b. _____
c. _____
d. _____
e. _____
f. _____
g. _____
h. _____
i. _____
j. _____
k. _____
l. _____

(CHECK RESPONSE) FAMILY/ADVOCATE INFORMATION

(26) In the past year, how often has the family contacted the person or program staff by phone?

__ 1. No Family
__ 2. Never
__ 3. Twice a year or less
__ 4. About every three months
__ 5. About once a month
__ 6. About once a week or more

(27) How often did family members visit the person (in past year)?

__ 1. No Family
__ 2. Never
__ 3. Twice a year or less
__ 4. About every three months
__ 5. About once a month
__ 6. About once a week or more

(28) How often did this person visit with the family at their home or on outings (in past year)?

__ 1. No Family
__ 2. Never
__ 3. Twice a year or less
__ 4. About every three months
__ 5. About once a month
__ 6. About once a week or more

(29) How often did a friend or advocate make contact by phone or visit (in past year)?

__ 1. No Family
__ 2. Never
__ 3. Twice a year or less
__ 4. About every three months
__ 5. About once a month
__ 6. About once a week or more

(30) Does family attend medical appointments? __ 1. No __ 2. Yes
(31) Does family attend IPP meetings? __ 1. No __ 2. Yes

(32) In general, how would you describe family involvement with this person?

__ 1. Not Involved __ 2. Involved __ 3. No Family

MEDICAL STATUS: (Please CIRCLE either Month or Year)

(33) Visits to doctor (average)____times per Month/Year.
(34) Visits to other specialists (average)____times per Month/Year.
(35) Has person seizured within the last 6-months? __ 1. No __ 2. Yes
(36) Does person have a Nursing M.O.S. __ 1. No __ 2. Yes
(37) Does person have a Nutrition M.O.S. __ 1. No __ 2. Yes
(38) Current Psychological Assessment __ 1. No __ 2. Yes
(39) Current Speech Assessment (per policy) __ 1. No __ 2. Yes
(40) Current Hearing Assessment (per policy) __ 1. No __ 2. Yes
(41) Past year, how many times has person been hospitalized? ____
(42) What were the reasons: _____

SERVICES

1=Need identified on IPP; has received this service in past month.
2=Need identified on IPP; has not received this service in past month.
3=Need not identified on IPP.

(43) __ A. Physical Therapy
(44) __ B. Occupational Therapy
(45) __ C. Nursing Care (other than administration of routine medications.)
(46) __ D. Psychotherapy
(psychological therapy performed by a trained therapist)
(47) __ E. Behavior Modification (to reduce maladaptive behavior)
(48) __ F. Dressing Skills Training (teaching, not just helping)
(49) __ G. Eating Skills
(50) __ H. Social Interaction Training (e.g. interpersonal skills, manners)
(51) __ I. Hygiene and Grooming Skills Development (including toileting)
(52) __ J. Speech/Language and Hearing Therapy
(services to improve receptive/perception of speech/language)
(53) __ K. Special Diet (please explain): _____
(54) __ L. Recreational Activities
(55) __ M. Transportation
(56) __ N. Visiting Nurse
(57) __ O. Other (Specify): _____

BEHAVIOR TREATMENT PLANS IN EFFECT: Total Number: _____

	Intervention	Target Behavior
Level I:	_____	_____
(58)	_____	_____
Level II:	_____	_____
(59)	_____	_____
Level III:	_____	_____
(60)	_____	_____
Emergency	_____	_____
Techniques:	_____	_____

	RESPONDENT NAME	JOB TITLE	DATE
1. Case Manager:	_____	_____	_____

CLIENT'S NAME:_____ CASE#:_____

DAY PROGRAM SECTION

(62) Day Program (Enter number):_____

1=Day Activities At Residence	4=No Day Program
2=ADL/TTS Type Program	5=Work Activity Program (TCDI/BSI/PVI)
3=Enclave	6=Competitive Employment
7=Half Time WAC Placement	8=Senior Day

(63) How does this person normally travel to the day program?
__1. Walks
__2. Uses public transportation, escorted
__3. Uses public transportation, independent
__4. Residence provides transportation
__5. Special Transportation/Etran
__6. Other (specify):_____

(64) How many days per week does person go to day program?
(Enter 1 to 5). If two day programs, record total days: ____

(65) How many hours per day? ____ (Exclude travel time).
(Enter number, 1-8). If two day programs, record average.

(66) On an average, how long does it take for person to get to day program using their source of transportation? ____ minutes

(67) Over the last programming year, how many days was person absent from day program due to illness, hospitalization, doctor appointments? ____

WITHIN THIS PERSON'S DAY PROGRAM TEAM:

(68) a. Total number of clients in team currently: ____
(69) b. Total number of males in team: ____
(70) c. List team members ages: _____

(71) SENSE OF DIRECTION (Include visually impaired also)
1 Goes several blocks from Day Program or home, without getting lost
2 Goes around Day Program grounds or a couple of blocks without getting lost
3 Goes around Day Program facility or house
4 Gets lost whenever s/he leaves own living area

(72) ABILITY TO AVOID SIMPLE DANGERS
1 Not exhibited by individual
2 Presents a minimal problem
3 Presents a moderate problem
4 Presents a serious problem
9 Not determined

(73) Is person able to give personal information (e.g., phone number, home address):__ (1) No __ (2) Yes

(74) Has this person shown an inability to remember previously known routines?__ (1) No __ (2) Yes

(75) ABILITY TO REMEMBER DATES
1 Not exhibited by individual
2 Presents a minimal problem
3 Presents a moderate problem
4 Presents a serious problem
9 Not determined

BEHAVIOR PROBLEMS:

4=Never observed
3=Not observed within last 4 weeks
2=Occasionally (5 times or less per week) within last 4 weeks
1=Frequently (more than 5 times per week) within last 4 weeks

(76) __ a. PROPERTY DAMAGE (whether client damages property, e.g. breaking windows, tearing clothing).

(77) __ b. SELF-ABUSE (whether client causes physical injury, e.g. biting or hitting self, head banging).

(78) __ c. TEMPER TANTRUMS (whether client shouts or yells at others and has emotional outbursts, e.g. episodes of rage, throwing self on floor, verbal abuse).

(79) __ d. INAPPROPRIATE SEXUAL BEHAVIOR (whether client is inappropriate in public, e.g. undresses or masturbates).

(80) __ e. PICA (Whether client compulsively consumes non-food items, e.g. glass, metal).

(81) __ f. WANDERS AWAY (whether client will walk away in confusion from a site).

(82) __ g. FUNCTIONING INTERFERENCE (whether client exhibits behaviors which interfere with daily functioning, e.g. hallucinations, anxiety).

(83) __ h. THREATENS OR DOES PHYSICAL VIOLENCE TO OTHERS

(84) __ i. REQUIRES RESTRAINT OR TIME-OUT

(85) __ j. OTHER (please specify): _____

_____

_____

	RESPONDENT NAME	JOB TITLE	DATE
1. **Day Program:**	_____	_____	_____

CLIENT'S NAME:_____ CASE#:_____

RESIDENTIAL SECTION

BEHAVIOR PROBLEMS:

4=Never observed
3=Not observed within last 4 weeks
2=Occasionally (5 times or less per week) within last 4 weeks
1=Frequently (more than 5 times per week) within last 4 weeks

(86) __ a. PROPERTY DAMAGE (whether client damages property, e.g. breaking windows, tearing clothing).

(87) __ b. SELF-ABUSE (whether client causes physical injury, e.g. biting or hitting self, head banging).

(88) __ c. TEMPER TANTRUMS (whether client shouts or yells at others and has emotional outbursts, e.g. episodes of rage, throwing self on floor, verbal abuse).

(89) __ d. INAPPROPRIATE SEXUAL BEHAVIOR (whether client is inappropriate in public, e.g. undresses or masturbates).

(90) __ e. PICA (Whether client compulsively consumes non-food items, e.g. glass, metal).

(91) __ f. WANDERS AWAY (whether client will walk away in confusion from a site).

(92) __ g. FUNCTIONING INTERFERENCE (whether client exhibits behaviors which interfere with daily functioning, e.g. hallucinations, anxiety).

(93) __ h. THREATENS OR DOES PHYSICAL VIOLENCE TO OTHERS

(94) __ i. REQUIRES RESTRAINT OR TIME-OUT

(95) __ j. OTHER (please specify): _____
_____
_____

(96) BATHING OR SHOWERING
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Is bathed (does not participate)

(97) DRESSING (Circle Number)
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Is dressed (does not participate) or remains undressed

(98) UNDRESSING
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Is undressed (does not participate) or remains undressed

(99) USING TOILET
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Does not use toilet room

(100) TRANSFERRING IN AND OUT OF BED OR CHAIR
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Is transferred (does not participate) or remain in bed

(101) Number of persons needed to do a transfer:
__ (1) None __ (2) One __ (3) Two

(102) EATING (Excludes help in cutting meat)
1 Does not receive personal help or supervision except as above
2 Receives supervision but no help except as above
3 Receives personal help in addition to that above
4 Is fed totally by another person

(103) Uses adaptive equipment to eat: __ (1) No __ (2) Yes

(104) WALKING/AMBULATION (with mechanical aid(s) if customarily used)
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Does not walk, if unassisted

(105) GROOMING AND HYGIENE (e.g., Hair care, shaving, toothbrushing)
1 Does not receive personal help or supervision
2 Receives supervision only
3 Receives personal help
4 Does not participate

(106) BOWEL CONTINENCE
- 1 Is continent & does not have accidents or takes care of ostomy, diapers, or related device by self
- 2 Receives personal help or supervision in care of continence device
- 3 Receives personal help or supervision in using toilet room (includes reminders, making decisions, and assistance in toilet use)
- 4 Individual does not participate in continence care which is provided entirely by staff

(107) BLADDER CONTINENCE
- 1 Is continent & does not have accidents or takes care of catheter, diapers, or related device by self
- 2 Receives personal help or supervision in care of continence device
- 3 Receives personal help or supervision in using toilet room (includes reminders, making decisions, and assistance in using toilet)
- 4 Individual does not participate in continence care which is provided entirely by staff

(108) SENSE OF DIRECTION (Include visually impaired also)
- 1 Goes several blocks from Day Program or home, without getting lost
- 2 Goes around Day Program grounds or a couple of blocks without getting lost
- 3 Goes around Day Program facility or house
- 4 Gets lost whenever s/he leaves own living area

(109) ABILITY TO AVOID SIMPLE DANGERS
- 1 Not exhibited by individual
- 2 Presents a minimal problem
- 3 Presents a moderate problem
- 4 Presents a serious problem
- 9 Not determined

(110) Is person able to give personal information (e.g., phone number, home address):__ (1) No __ (2) Yes

(111) Has this person shown an inability to remember previously known routines?__ (1) No __ (2) Yes

(112) ABILITY TO REMEMBER DATES
- 1 Not exhibited by individual
- 2 Presents a minimal problem
- 3 Presents a moderate problem
- 4 Presents a serious problem
- 9 Not determined

(113) On an average, how long does it take to transport this person to their physician and back (i.e. physician seen most often)? ____

	RESPONDENT NAME	JOB TITLE	DATE
1. **Residential:**	_____	_____	_____

CLIENT'S NAME: _____ CASE#: _____

NURSING SECTION

(114) Seizure Frequency (Check One)

__ 1. Continuous one per day
__ 2. Approximately one per day
__ 3. Approximately one per week
__ 4. Approximately one per month
__ 5. 7-11 seizures per year
__ 6. 1-6 seizures per year
__ 7. Documented history, none currently
__ 8. Does not have seizures

(115) Epilepsy (Check all that apply):

__ A. Recorded History
__ B. Medicated for Epilepsy
__ C. Seizure observed within last year
__ D. Does not apply

(116) Any other physical/medical impairments (e.g., hemipelega, congestive heart failure), please list: _____

_____

_____

_____

(117) CURRENT MEDICATION: How many different prescribed medications (**exclude vitamins and topical ointments**) are administered daily? (Enter number. If none, enter 0. If greater than nine, enter 9):____
What is the medication(s) and its dosage?

NAME	DOSAGE	TIMES PER DAY

Physical Aids: 4 Needs, but does not have
3 Needs and has, but doe not or cannot use
2 Needs, has, and uses
1 Has no need

(118) Glasses:___ (119) Wheelchair:___ (120) Helmet:___
(121) Walker:___ (122) Braces:___ (123) Cane:___
(124) Hearing Aid:___ (125) Other (Specify): _____

NEXT 8 ITEMS: 00=This month 98=Never 99=N/A

(126) How many months since general medical checkup? ____
(127) How many months since exam by gynecologist? (Enter 99 if male)____
(128) How many months since exam by a dentist? ____
(129) How many months since eyes were examined? ____
(130) How many months since hearing was tested? ____
(131) How many months since last speech assessment? ____
(132) How many days in the past 4 weeks has this person required hospital care (inpatient, outpatient, emergency room)? (Enter number of days, 00-30) _____
(133) How many days in the past 4 weeks have this person's normal activities been restricted because of health problems? (Enter number of days, 00-30) _____

	RESPONDENT NAME	JOB TITLE	DATE
1. Nursing:	_____	_____	_____

APPENDIX B

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

January 25, 1991

Ms. Teresa Kowalski
6388 S. St. Clair Road
St. Johns, MI 48879

RE: CHARACTERISTICS OF ELDERLY PERSONS WITH DEVELOPMENTAL DISABILITIES RELATED TO HEALTH SERVICE UTILIZATION BEHAVIORS, IRB#90-532

Dear Ms. Kowalski:

I am pleased to advise that because of the nature of the proposed research, it was eligible for expedited review. This process has been completed, the rights and welfare of the human subjects appear to be adequately protected, and your project is therefore approved.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to December 21, 1991.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

David E. Wright, Ph.D., Chair
University Committee on Research
Involving Human Subjects (UCRIHS)

DEW/deo

cc: Dr. Clare Collins