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Older Developmentally Disabled Adults and the Ecological Theory of Aging

Michelle Blenkush

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College of Social Sciences

Department of Interdisciplinary Studies

St. Cloud, Minnesota 56301

612/255-2248

OLDER DEVELOPMENTALLY DISABLED ADULTS
AND THE ECOLOGICAL THEORY OF AGING

The thesis submitted by Michelle Blenkush represents scholarship that is both creative and sensitive. Her research and analysis regarding aging persons who are developmentally disabled offers fresh insights into an emerging field in gerontology. Ms. Blenkush's respect for the "subjects" comes through in this study; it reflects both the knowledge and values she brings to her professional activity.

Submitted to

Eleanor Stokes

Chairperson

St. Cloud State University

in Partial Fulfillment for the Requirements

for the degree

Master of Science

St. Cloud, Minnesota

February, 1992

Department Programs: American Studies • East Asian Studies • Futures Studies • Gerontology •
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OLDER DEVELOPMENTALLY DISABLED ADULTS
AND THE ECOLOGICAL THEORY OF AGING

by
Michelle L. Blenkush
B.S., St. Cloud State University, 1990

A Thesis
Submitted to the Graduate Faculty
of
St. Cloud State University
in Partial Fulfillment for the Requirements
for the degree
Master of Science

St. Cloud, Minnesota

February, 1992

Dean
School of Graduate and Continuing Studies

St. Cloud, MN 56301

OLDER DEVELOPMENTALLY DISABLED ADULTS
AND THE ECOLOGICAL THEORY OF AGING

This thesis, submitted by Michelle L. Blenkush in partial fulfillment of the requirements for the Degree of Master of Science at St. Cloud State University, is hereby approved by the final evaluation committee.

Literature regarding the provision of service to elderly persons with developmental disabilities is reviewed with an emphasis on policy issues that affect day programs. A typology of service options is presented in order to consider the factors involved in each alternative. The ecological theory of aging is outlined as the organizing framework for considering the fit between person and environment.

A case study compares two programs for seniors with developmental disabilities coordinated by a Day Activity Center (DAC) in central Minnesota. Eight seniors remain in-house for services while fifteen attend a local senior center on a daily basis. Results from ten weeks of participant observation which alternated between the two settings are presented. Information obtained from informal interviews conducted with staff members from each settings supplements the participant observation.

Clarence M. Stokes
Chairperson

Each environment is presented as a "typical day." A selection of activities are described and analyzed within the framework of the ecological theory of aging. An alternative setting for the in-house group provides an interesting contrast. The in-house group visits a local senior nutrition site once per week and participates in bingo prior to the meal. These experiences are compared to the normal "bingo and meals" routines for both groups.

Beverly Stodum
Michelle Blenkush

The ecological theory of aging is then further explored in a review of the DAC staff roles in each environment and the issues involved in determining which clients participate in each setting. Transitions between the two settings, retirement as an issue, and declines and increases in competency are illustrated in a presentation of six client profiles. Proactivity is introduced as an emerging issue in ecological theory.

Dennis Nunns
Dean
School of Graduate and Continuing Studies

St. Cloud, MN 56301

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Michelle L. Blenkush

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A case study compares two programs for seniors with developmental disabilities coordinated by a Day Activity Center (DAC) in central Minnesota. Eight seniors remain in-house for services while fifteen attend a local senior center on a daily basis. Results from ten weeks of participant observation which alternated between the two settings are presented. Information obtained from informal interviews conducted with staff members from both settings supplements the researcher's observations.

Each environment is presented as an ethnography of the "typical day." Arrivals, orientation, and the selection of activities are compared and assessed within the framework of the ecological theory of aging. An alternative setting for one of the groups then provides an interesting means for comparison. The in-house group visits a local senior nutrition site once per week and participates in bingo prior to the meal. These experiences are compared to the normal "bingo and meals" routines for both groups.

The ecological theory of aging is then further explored in a review of the DAC staff roles in each environment and the issues involved in determining which clients participate in each setting. Transitions between the two settings, retirement as an issue, and declines and increases in competency are illustrated in a presentation of six client profiles. Proactivity is introduced as an emerging issue in ecological theory.

The discussion emphasizes the need for further research in light of the complexity involved in providing supportive day program environments to elderly people with developmental disabilities. Issues in program development across the two domains, "choice" as a new reality for people with developmental disabilities, integration into generic settings, and the changing nature of service are presented. A vision of the "ideal setting" as imagined by staff concludes with the contention that the provision of services for elderly people with developmental disabilities must be taken in the context of the person/environment fit.

This gratitude is also extended to Eleanore Stokes, my advisor, for the hours of consultation and sincere interest in this study. I would like to thank my family

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Eleanore Stokes
Eleanore Stokes, Chairperson

the coat. And finally, I thank my pal, Sam Richards, whose warmth, faith, and humor have been a source of comfort and inspiration from the beginning.

M.L.S.

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Herbert Otto
M.L.B.

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CHAPTER I

INTRODUCTION

The population of U.S. citizens above the age of sixty with developmental disabilities is estimated to be between 200,000 and 500,000, or as many as ten out of every 1000 elderly persons (Ansello & Rose, 1989). As in the rest of the American population, the percentage of developmentally disabled seniors is expected to rise sharply; it may well double before the year 2000 (Ibid).

People with developmental disabilities have historically had a relatively short lifespan, had little contact with community service systems, and have lived primarily in public institutions or with their parents at home (Wilhite, Keller, & Nicholson, 1990). Recently, however, "shifts in treatment philosophy, improvements in medical and habitualization technology, and progress in community based service delivery systems have contributed to a longer lifespan and better quality of life" (Coelho & Dillon, 1990, p. 10).

While the general elderly population's social support systems and activities revolve around informal

caregivers and the aging services network, the developmentally disabled elderly's social relationships consist of "coresidents in congregate residential facilities, friends at work or day activity centers, and paid caregivers" (Hawkins & Kultgen, 1990, p. 9). In contrast with the younger cohort of people with developmental disabilities, the elderly in this population have had dramatically less control over their lives. Both routine and crucial life decisions have typically been made for them as they experienced much of their lives within institutions or under the care of family members (Edgerton, 1988). Thus, seniors with developmental disabilities encounter a more comprehensive set of limitations in personal choice and autonomy than either the general elderly population or younger people with developmental disabilities.

Statement of the Problem

Day programs for seniors with developmental disabilities are now emerging in facilities which traditionally served either younger people with developmental disabilities or the general aging population. A coordinated effort which focuses on each individual's skills, needs, and desires is needed so that each will be able to strengthen his or her support networks and autonomy in selecting appropriate services. The provision of service to any group of people requires

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an understanding of how one's environment shapes his or her adaptation level in any given setting. More exploration is needed in order to determine which "model" provides the most appropriate service to this specialized yet heterogeneous population.

The ecological theory of aging maintains that adaptation is determined through interaction of the individual and the environment. Social expectations which are either too low or too high for a person's level of competence are detrimental and result in maladaptive behavior within the context of that setting. However, the adaptation level may increase if an individual is provided with an environment that continues to challenge while allowing for variations in independent functioning.

This study explores the fit between person and environment in a presentation of two day programs designed for seniors with developmental disabilities. One which provides programming to eight people who attend in-house at a day activity center is compared to another which serves fifteen who visit a local senior center on a daily basis. A general overview of the involved dimensions including profiles of six seniors with developmental disabilities experiencing transitions in service is then presented. The study concludes with a call for further descriptive studies which will provide

researchers with a more complete understanding of the needs of this population as they move through the later years of the life course.

CHAPTER 11

LITERATURE REVIEW

Historically, people with mental retardation, cerebral palsy, or any other lifelong disability were given labels such as mentally deficient, idiots, and morons. Those who would not be considered "mentally deficient" today were routinely placed in large institutions by a society which held many fears and misconceptions (Wolfensberger, 1975).

The concept of developmental disabilities was first introduced with the passage of the Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-517). This Act defined any condition such as mental retardation, cerebral palsy, autism, or epilepsy, originating before the age of 22, constituting a substantial disability, and expected to continue indefinitely as a developmental disability (Wilbite et al., 1990). It was amended in order to further describe functional limitations and to reemphasize the chronic or lifelong nature of disability and the need for ongoing assistance (Ibid). Physical

CHAPTER II

LITERATURE REVIEW

Historically, people with mental retardation, cerebral palsy, or any other lifelong disability were given labels such as mentally deficient, idiots, and morons. Those who would not be considered "mentally deficient" today were routinely placed in large institutions by a society which held many fears and misconceptions (Wolfensberger, 1975).

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and mental disabilities which arise in late life do not meet this definition.

A 1987 provision (PL 100-146) established a linkage between the developmental disabilities and aging networks. It required the appointment of the State Aging Agency Administrator to the State Developmental Disabilities Council. This created better networking between the sectors while requiring the council to consider aging related issues (Janicki, 1988, p. 177). Likewise, the addition of a number of special provisions for individuals with disabilities to the Older Americans Act also recognized special needs coordination: "They set the expectation that mainstream aging network services will be accessible to all elderly persons, irrespective of the nature of their disability" (Ibid, p. 178).

Related definitional and policy issues combine to create a confusing maze of paths for service providers. The shift from institutionalization to care within the community has introduced a relatively new need for habilitative or vocational training in sheltered workshops or day programs (Catapano, Levy, & Levy, 1985). This becomes even more challenging when applied to those seniors with developmental disabilities who may no longer be willing or able to work on a full time basis.

Difficulties in creating a cooperative delivery system arise partly due to the different beliefs and practices between the two systems. The developmental disabilities field is based on a medical model of total care with an emphasis on cognitive development, a high staff to client ratio, and is client driven with funding based on individual care needs (Tedrick, 1990). However, the aging field is program driven and tends to focus on serving groups in need of service (Ibid). At the same time, those employed in the developmental disabilities field practice the principles of a developmental model; they promote the acquisition of skills while the aging field has traditionally focused on the maintenance of skills (Seltzer & Krauss, 1987b).

Recent treatment issues within the field of developmental disabilities become even more complex when applied to the elderly. Active treatment is a program model of activities designed to maximize the physical, intellectual, social, and vocational functioning of each person (Janicki, Ottis, Puccio, Rettig, & Jacobson, 1985). It is based in part on Wolfensberger's concept of normalization (1972) which refers to the process of developing culturally normative social roles through the creation of culturally appropriate activities and services (Wilhite et. al., 1990).

The issue of age-appropriate programming emerges when one considers that some activities are not considered to be culturally normative for seniors. Children's items such as crayons, dolls, and toy telephones are not to be used in an adult setting. However, some clients will respond only to familiar activities and dismiss as not enjoyable those traditionally considered appropriate for retirement (i.e., reading, bingo, latchhook, cards). Service providers must incorporate the principles of normalization and active treatment in order to determine just what is appropriate for each individual. Given the diversity in images, roles, individual abilities, and energy levels that even those in the general aging population display, this process is understandably quite difficult (Herr, 1985).

Flexibility and individualization have become even more necessary as both fields acknowledge that:

. . . for some older developmentally disabled populations, an intervention that is directed at minimizing debilitation due to injury or illness will be more critical to their well-being and quality of life than an objective that specifies measurable growth and improvement. (Catapano et al., 1985, p. 309)

The awareness of changing needs and capabilities as one ages has introduced the possibility of "retirement" for those who choose to do so (Stroud & Sutton, 1988).

Supplemental retirement programs designed for

developmentally disabled people focus on recreational rather than vocational services in response to a "reduced capacity of clients to participate in a full day program" (Seltzer & Krauss, 1987a, p. 85).

Day services, which are defined as "any focused and purposeful activity of a full-day duration that involves work or habilitative tasks, or sociorecreational, avocational, and stimulatory activities" (Janicki et. al., 1985, p. 295) now lean more toward recreation and leisure as their clientele ages. As in the general population, work settings are now focusing on preretirement and activity planning. This trend helps to negate stereotypes that old age is a time of "nothing to do" (Hawkins & Kultgen, 1990, p. 14).

While some states require a minimum number of weekly day programming hours in order to maintain financial support, recreation services are not legally mandated. At the same time, the principles and methods used by those agencies and communities that have accepted the responsibility of providing these services are still being explored and developed (Riddick & Keller, 1990).

Typology of Service

Service modes are currently in a state of flux due to a variety of factors. While there is pressure from external forces such as advocacy organizations and

federal and state governments, no uniform agreement in approaches, funding requirements, and program standards exists. Meanwhile, the increasing sophistication of service providers and the need to create more economical methods of service delivery has led to the formation of three developing service options. The following typology has been outlined by Seltzer and Krauss (1987):

Age integrated programs, such as those in group homes and sheltered workshops within the developmental disabilities network, encourage clients to continue building vocational and habilitative skills with the contention that "age integration is normalizing" (Seltzer, 1988, p. 184).

Drawbacks include that they are sometimes seen as inflexible, not age-appropriate, or insensitive to the client's health needs. "These programs were seen as particularly important for clients who do not identify themselves as old" (Ibid).

Generic aging services such as senior centers and nutrition sites are considered to be age-appropriate and flexible, yet staff often have little experience in developmental disabilities. At times, there is a hostility on the part of the host elders directed toward seniors with developmental disabilities who may be seen as "taking over" as they use the generic facility (Ibid).

Age specialized programs are those designed for "elderly persons with lifelong disabilities which includes services designed exclusively and primarily to meet their needs" (Ansello & Rose, 1989, p. 2). Because these services are "specialized both with respect to age and disability, they have the potential to be more flexible, individualized, and appropriate for the clients served" (Seltzer, 1988, p. 184). However, while they do tend to offer more retirement options and foster better peer relationships, they are also viewed as stigmatizing, isolating, less stimulating, and with a lower level of expectations (Ibid).

Selecting an appropriate model depends upon the individual client and the availability of local services. Service providers must consider the health, abilities, and desires of the client as well as the geographic availability of options. Factors in service provision also include attitudinal readjustment, staff training, program design, and adequate funding (Tedrick, 1990, p. 142). A need for balance between integrated and specialized services exists. There is:

concern that such services are too specialized and have the effect of isolating MR/DD [mentally retarded/developmentally disabled] elders from both the age integrated MR/DD service sector and the generic aging service sector. (Seltzer, 1989, p. 26)
Elderly persons with developmental disabilities

have recently begun to utilize senior centers rather than day programs offered under the umbrella of

developmental disabilities (i.e., vocational day activity, day activity, supplemental retirement, leisure and outreach). Generic senior centers have been seen as "the most unique in organizational context, program characteristics, and client characteristics, because they [are] a part of the aging services network" (Seltzer & Krauss, 1987a, p. 94).

While the utilization of generic aging services such as senior centers can provide a rewarding integrated experience for some developmentally disabled seniors, individualization remains the key in service provision. "Not all activities are suitable for the frail. Their social participation will actually be enhanced if they are offered differential programs that take account of their limitations" (Monk & Cox, 1989, p. 25). Segregated programs may better meet the needs and abilities of certain individuals who are not ready to participate fully in general society due to certain limitations such as an "inability to read, follow complex instructions, and share materials with others" (Riddick & Keller, 1990, p. 21).

Person in Environment

As the literature indicates, the need to examine the fit between the individual's needs and the service settings must be taken into consideration in choosing appropriate day services for developmentally disabled

elderly. Zimrig, Carpman, and Michelson state that, at any given moment, people have a range of needs. "All of these must be satisfied within a permissive physical setting Viewed from the perspective of an individual wishing to fulfill a need, not every environment provides an adequate fit . . ." (1987, p. 20). If the "fit" is found to be inappropriate, modifications may be made to individual needs and/or the environment (Ibid).

Nahemow, Stokes, and Granfield point out that "older people with mental retardation may take a longer time to adapt to new environments than others" (1988, p. 4). They explain that while the highly competent can adapt to a wide range of expectations, "lower functioning individuals are more vulnerable to the environment and can be dragged down by more environmental misfit" (Ibid, p. 3).

Inappropriate environmental expectations can be highly detrimental. As Wolfensberger asserts:

It is a well-established fact that a person's behavior tends to be profoundly affected by the role expectations that are placed upon him [sic]. Generally, people will play the roles that they have been assigned. This permits those who define social roles to make self-fulfilling prophecies by predicting that someone cast into a certain role will emit behavior consistent with that role. Unfortunately, role-appropriate behavior will then often be interpreted to be a person's "natural" rather than elicited model of acting. (1975, p. 2)

The ecological theory of aging (Lawton & Nahemow, 1973) maintains that behavior is determined by both the individual and the environment. This adaptation level theory is based on the work of Helson, who explained that "adaptation is a mechanism for acquainting us with changes in the environment" (1964, p. 43). He argued that people are normally at an adaptation level with respect to their environment, and that it is only those changes in our competence or in the environment itself which defines our behavior as "maladaptive" (Ibid).

Lawton and Nahemow extended Helson's model of biological adaptation to the psycho-social sphere of the aging individual. As seen in Figure 1, the person will generally gravitate along the adaptation level between the comfort and the challenge zones. The theory holds that expectations which are either too low or too high for the individual's competence will move him or her into a maladaptive zone. This zone is defined specifically within the framework of expectations for that particular environment. Therefore, a behavior that may be considered maladaptive in one setting may be perfectly acceptable in another.

In this study, Environmental Press is defined as the cultural expectations which govern behavior and Competence is defined as the ability to conform to those expectations. Following the direction anticipated by

Nahemow, Stokes, and Greenapan (1988). Individuals are expected to change their levels of social competence according to the environmental press and eventually move within the adaptive range.

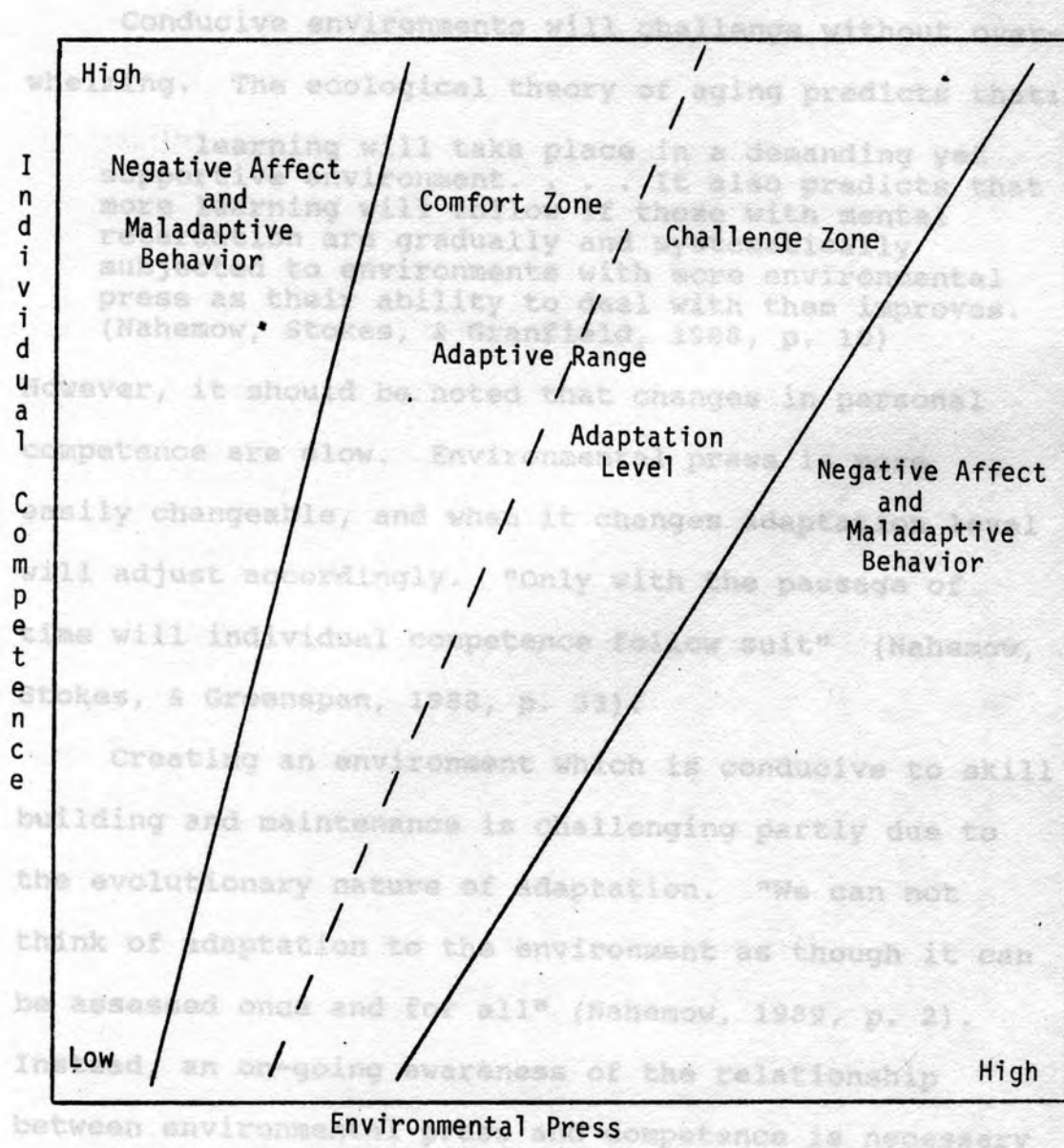


Figure 1. The ecological theory of aging (Lawton & Nahemow, 1973).

The design of the physical environment provides or eliminates training opportunities; it allows mentally retarded people to operate independently or only with help, and it establishes mentally retarded

Nahemow, Stokes, and Greenspan (1988), individuals are expected to change their levels of social competence according to the environmental press and eventually move within the adaptive range.

Conducive environments will challenge without overwhelming. The ecological theory of aging predicts that:

learning will take place in a demanding yet supportive environment. . . . It also predicts that more learning will follow if those with mental retardation are gradually and systematically subjected to environments with more environmental press as their ability to deal with them improves. (Nahemow, Stokes, & Granfield, 1988, p. 10)

However, it should be noted that changes in personal competence are slow. Environmental press is more easily changeable, and when it changes adaptation level will adjust accordingly. "Only with the passage of time will individual competence follow suit" (Nahemow, Stokes, & Greenspan, 1988, p. 33).

Creating an environment which is conducive to skill building and maintenance is challenging partly due to the evolutionary nature of adaptation. "We can not think of adaptation to the environment as though it can be assessed once and for all" (Nahemow, 1989, p. 2). Instead, an on-going awareness of the relationship between environmental press and competence is necessary in providing service to this population:

The design of the physical environment provides or eliminates training opportunities; it allows mentally retarded people to operate independently or only with help, and it establishes mentally retarded

people as equals or inferiors. (Zimrig et al., 1987, p. 933)

CHAPTER III

METHODS

This study explored the environmental expectations of two day programs for developmentally disabled seniors. Each of the 23 subjects are contracted for service through the West Lake Day Activity Center (DAC). West Lake is located in a suburb of a small city and is licensed to serve up to 136 clients with developmental disabilities. About 50% of the clients are employed on crews within the city or perform contracted work in-house.

Although West Lake has a strong vocational emphasis, focus groups have been created to provide more individualized services to clients not geared toward employment training. Two of these groups are specifically designed for seniors. Fifteen of the 23 senior clients attend the Miller Senior Center on a daily basis and eight receive in-house programming.

Terms Used

For purposes of this study, each of the two groups is labeled according to its setting and the differentiating characteristics that set it apart from

CHAPTER III

METHODS

This study explored the environmental expectations of two day programs for developmentally disabled seniors. Each of the 23 subjects are contracted for service through the West Lake¹ Day Activity Center (DAC). West Lake is located in a suburb of a small city and is licensed to serve up to 130 clients² with developmental disabilities. About 50% of the clients are employed on crews within the city or perform contracted work in-house.

Although West Lake has a strong vocational emphasis, focus groups have been created to provide more individualized service to clients not geared toward employment training. Two of these groups are specifically designed for seniors.³ Fifteen of the 23 senior clients attend the Miller Senior Center on a daily basis and eight receive in-house programming.

Terms Used

For purposes of this study, each of the two groups is labeled according to its setting and the differentiating characteristics that set it apart from

that setting. Those who attend the Miller Senior Center for programming are termed the Miller Clients, and those who receive in-house services at West Lake are termed the West Lake Seniors. The general population of seniors participating at the Miller Senior Center are referred to as the General Miller Seniors. The general population of clients at the West Lake DAC are termed the West Lake Clients.

The West Lake DAC has an administrative director, two program directors, and a fourteen member board of directors. One program director is responsible for both senior groups and is referred to as such throughout this study. The word "staff," in the context of this discussion, refers to the person or persons employed by West Lake to work with the clients.

Subjects and Settings

The Miller Clients: Fifteen developmentally disabled seniors attend the Miller Senior Center for an average of 5.5 hours per day. However, because about 25% of the clients have specified "days off," no more than fourteen are present at any given time. They are accompanied by two West Lake staff and a worker from the area Green Thumb⁴ program. Clients work toward the development of leisure and recreation skills and focus on integration both within the Center and the community.

While the Miller Clients are organizationally part of West Lake and just visit the senior center daily, this activity is an example of integration into generic aging services. Only a relatively small percent of the total programming is conducted at the DAC itself. As seen in Figure 2, the group does overlap into West Lake and the Miller Senior Center, but is also an entity of its own.

The West Lake Seniors: In the Spring of 1991 the closing of another local DAC in a nearby community resulted in the merging of those clients into the West Lake facility. This increased the number of seniors whose mandatory goal plans called for a nonvocational day activity program. At the same time, the space limitations ⁵ at the Miller Senior Center resulted in the development of an in-house option for seniors.

One staff member works with eight clients in an area that also houses the younger Life Skills group. Both groups are nonvocational in nature and have similar goals of building skills in hygiene and self care, recreation and leisure, and community integration.

The program is difficult to define according to the Seltzer and Krauss typology. While the service is specifically geared toward older adults with developmental disabilities and may be classified as age specialized, it is also part of a larger age integrated

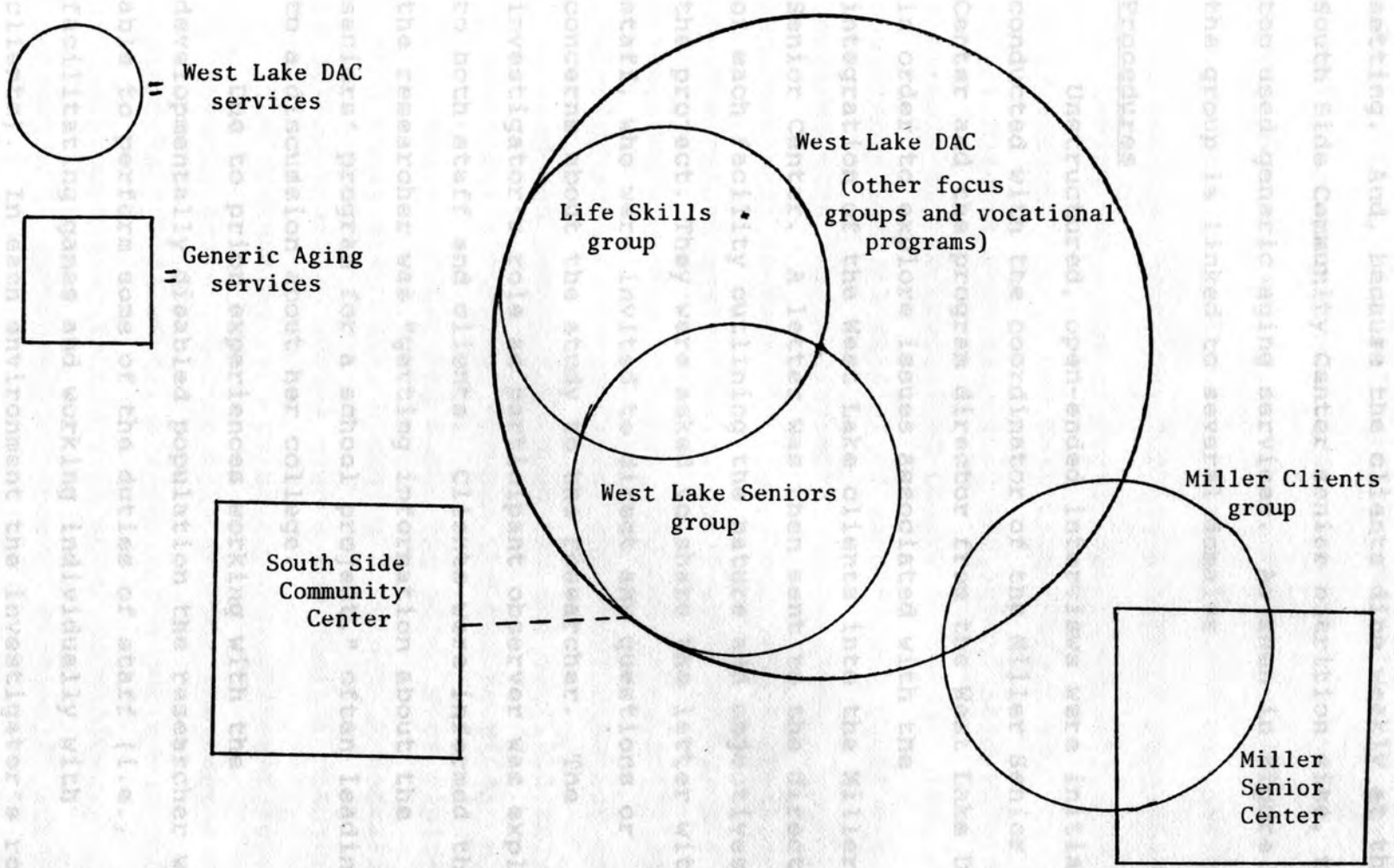


Figure 2. Arenas of activity for older persons with developmental disabilities, West Lake DAC.

setting. And, because the clients dine weekly at the South Side Community Center senior nutrition site, they too used generic aging services. As seen in Figure 2, the group is linked to several domains.

Procedures

Unstructured, open-ended interviews were initially conducted with the coordinator of the Miller Senior Center and the program director from the West Lake DAC in order to explore issues associated with the integration of the West Lake clients into the Miller Senior Center. A letter was then sent to the director of each facility outlining the nature and objectives of the project. They were asked to share the letter with staff, who were invited to direct any questions or concerns about the study to the researcher. The investigator's role as participant observer was explained to both staff and clients. Clients were informed that the researcher was "getting information about the seniors' program for a school project," often leading to a discussion about her college.

Due to prior experiences working with the developmentally disabled population the researcher was able to perform some of the duties of staff (i.e., facilitating games and working individually with clients). In each environment the investigator's role ranged from quietly observing to actual participation

in activities. It is interesting to note that, even when the researcher was merely observing, she was perceived as "staff." In the West Lake facility itself clients from other focus groups and vocational areas would ask the researcher for assistance or permission.

During ten weeks of participant observation the daily experiences of the West Lake Seniors and the Miller Clients were described and interpreted within the framework of the ecological theory on aging. The competency (social skills) of each client group was compared with the environmental press (social expectations) in each setting. Detailed observations about physical environments, daily experiences, use of space, conversation patterns, the nature of activities, community outings, meal times, and staff behavior were monitored and recorded through the use of field notes. Observations alternated between the two settings on a weekly basis. After six weeks the sites were visited 2 to 3 times each week, changing settings as necessary to attend specific social events and monitor change.

The fieldnotes were compiled and cross-referenced on a weekly basis. During this process the researcher decided to "profile" clients who had experienced changes in day programming settings in order to monitor adaptation to environmental press. Particular attention

was then paid to the daily experiences and behavior patterns of those individuals.

During the final week of the participant observation separate unstructured interviews were conducted with the following key informants: the two West Lake staff and the Green Thumb employee who work with the Miller Clients at the Senior Center, the West Lake program director, the staff who works with the West Lake Seniors at the West Lake DAC, one of the two staff working with the Life Skills group, and a West Lake substitute employee who has worked with both seniors groups as well as other vocational and focus groups at the West Lake facility.

All of the informants were asked similar questions, but each was also encouraged to discuss other concerns related to her role at West Lake. Those who had contact with the profiled clients were asked their impressions of each in order to develop a comparison of perspectives between each respondent's and the researcher's observations.

An interview was also conducted with the director of the South Side Community Center, where the West Lake Seniors ate lunch once per week, in order to gain a better understanding of that center and their impressions of the West Lake Seniors.

Confidentiality

Permission was obtained from the West Lake program director to observe the clients in both settings provided that actual names would not be used. Confidentiality was maintained at all times. Actual names were not recorded in the fieldnotes, and pseudonyms have been used throughout this report. Basic demographic information was also provided by the program director with the understanding that names would not be revealed.

Due to the difficulty associated with obtaining informed consent, interviews were not conducted with the clients themselves. All staff respondents were informed of their rights not to answer any and all questions prior to conducting each interview, and each was assured that actual names would not be used in connection with her comments.

Ethnographic Method

Ethnographic studies are highly valuable in uncovering the richness and complexity of social interactions among people with developmental disabilities in a variety of institutional and community settings (Edgerton, 1984; 1988). Participant observation seeks to preserve the integrity of the culture in question as well as the values and attitudes which influence policy (ibid). As Ansello and Rose assert, the needs of seniors with developmental

disabilities have often either been over- or under-estimated, and there is a definite need for descriptive studies in this area (1989).

Edgerton, an innovator in research on the cultural dimensions of developmental disabilities, argues:

The emphasis on verification rather than on the generation of theory, with the attendant constraints of operationalism, has led many researchers into ever more objective and precise exercises in the measurement of variables that are nowhere demonstrated to be the most relevant for prediction or understanding. (Edgerton, 1984, p. 2)

The findings of this study are rich with seeds of further exploration, but due to the small sample size and other limitations, generalizations are not attempted. In light of ethical considerations, complete information about client backgrounds was not available. And, because they were not interviewed, interpretations by the developmentally disabled seniors themselves were not obtained. Nevertheless, this study does provide a detailed account of day to day activities, interactions, behaviors and responses, and conflicts and successes as they happened. Exploratory studies such as this are necessary in order to approach the developing issues. Many questions remain unanswered and, in fact, have yet to be asked.

POPULATIONS

Total Subject Population

As indicated in Table 1, 23 subjects in this

study range in age from 55-86 with a mean age of 68.5.

ETHNOGRAPHY

Eleven of the 23 are male. They live at a variety of

residences. In order to assess the relationship between social expectations and competency for these populations it is necessary to portray and compare their routine experiences. Descriptions of the involved subjects and settings, morning routines, and methods of activity planning are presented and assessed in a comparison of the typical daily experiences of both groups.

The relationship between person and environment is then further considered in the following chapter. A review of two features common to both groups--mealtimes and bingo--provides an added dimension of an alternative setting for the West Lake Seniors.

It should be noted that much of this report is written in the ethnographic present in order to convey a sense of presence to the reader. However, settings, populations, and experiences, are constantly changing. Therefore, it should be understood that all events occurred during the period of research (October through December, 1991) and cannot be generalized outside of that time.

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POPULATIONS

Total Subject Population

As indicated in Table 1, the 23 subjects in this study range in age from 55-86 with a mean age of 66.5. Eleven of the 23 are male. They live in a variety of residential settings, with slightly over 50% (12) living in group homes.

Individual histories were not always known as the researcher did not have permission to read complete client files. For this reason, combined diagnosis and social history information is not tabulated. However, information did emerge revealing that at least nine of the 23 were institutionalized for much of their early lives and another eight clients were raised at home--some until quite recently when their parents were no longer able to care for them.

It may also be noted that of the 23 subjects, at least two have suspected Alzheimer's disease,⁶ four have some form of mental illness, and one has cerebral palsy. Some display one or more "behavior problems" such as verbal or physical aggression, failure to respond to direction, and wandering. During this study the incidence of each behavior problem was greater among the West Lake Seniors than in those clients at the Miller Senior Center.

This higher incidence of behavior problems becomes important in exploring the fit between person and environment. One might consider whether the behavior problems are heightened. Table 1 lists which is more likely to expect Client Characteristics other explored in

	Miller Clients N=15	West Lake Seniors N=8	Total Clients N=23
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and forth between the two. It is also interesting to note the differences in the Miller Senior Center setting. One wonders if the more "socially competent" clients work longer and are therefore more likely to be involved in a retirement program until they are older.

Demographics:

	Miller Clients N=15	West Lake Seniors N=8	Total Clients N=23
Age Range	57-86	55-69	55-86
Mean Age	70	63	66.5
# Males	6	5	11

Current Residence:

	Miller Clients N=15	West Lake Seniors N=8	Total Clients N=23
Foster Care Home	3	2	5
Board and Care	3	0	3
Nursing Home	2	0	2
With Family	1	0	1
Group Home	6	6	12

of 70. Six of the fifteen are male (see Table 1).

Seven of the fifteen have attended the center since the initiation of the project in the fall of 1989. Since then, one client has died and four have been transferred to the in house West Lake seniors group. One of these four, Robert, returned to the Miller Senior Center during the course of this research and is profiled in this study.

At least five of the fifteen have been institutionalized for a large part of their lives, and at least six of the fifteen have lived at home. Presently, six

This higher incidence of behavior problems becomes important in exploring the fit between person and environment. One might consider whether the behavior problems are heightened in a setting which is more likely to expect them. This idea is further explored in Chapter VI, with profiles of clients who have moved back and forth between the two settings.

It is also interesting to note the higher mean age in the Miller Senior Center setting. One wonders if the more "socially competent" clients work longer and are therefore less likely to become involved in a retirement program until they are older.

Miller Clients

The fifteen West Lake seniors who attend the Miller Senior Center range in age from 57-86, with a mean age of 70. Six of the fifteen are male (see Table 1). Seven of the fifteen have attended the center since the initiation of the project in the fall of 1989. Since then, one client has died and four have been transferred to the in house West Lake seniors group. One of these four, Robert, returned to the Miller Senior Center during the course of this research and is profiled in this study.

At least five of the fifteen have been institutionalized for a large part of their lives, and at least six of the fifteen have lived at home. Presently, six

live in group homes, three live in board and care facilities, three live in foster care, two live in nursing homes, and one lives at home with her mother.

At first glance they appear similar to any other group of seniors in that many have hearing aides, glasses, and graying hair. However, one may soon notice the classic Down syndrome features of one of the participants and the distinguishing characteristics (i.e., appearance, dress, speech patterns) of others. Ambulatory abilities also vary within the group. A woman has cerebral palsy and uses either a cane or assistance in walking. One man has special shoes and uses a walker. One woman spends most of her time in a wheelchair, and another has leg braces and an unsteady gait.

Although two of the women have diabetes, the group is generally physically healthy. Some attend exercise group regularly. One man has gone three times a week since the fall of 1989 and has lost weight due to a combination of that and changes in diet.

The Miller Clients are generally referred to as "higher functioning" or "more socially competent" than the West Lake Seniors. However, they vary greatly in their skills within the group. In greeting behavior alone the clients ranged from inappropriately hugging unfamiliar people to an ability to engage in pleasant

conversation with new acquaintances. Some need reminders to not interrupt, to lock the bathroom door, and to otherwise comply with the customary norms of the Center.⁷

West Lake Seniors

The West Lake Seniors, who receive in-house programming, range in age from 55-69, with a mean age of 63. Five of the eight are male. At the time of this study six of the eight lived in group homes and two lived in foster care (see Table 1). These clients also have a varied background. Four of the eight have a known history of institutionalization, while two lived at home for much of their lives. Three of these seniors have participated at the Miller Senior Center at one time, but were moved to the "in house" group for a variety of reasons as outlined in Chapter VI.

These clients have many of the same "aging" characteristics as the above group--glasses, hearing aides, and graying hair. Yet one might be quicker to guess that these seniors are different from the general population due to a greater proportion of idiosyncrasies in behavior and dress. For example, one man often wears mismatched clothes and a bandanna around his neck, and one woman must routinely be asked to roll her pants legs down.

They are generally physically healthy. One woman has had hip surgery and still uses a walker although she can also walk quite well on her own. One man has frequent grand mal seizures. Although he seems to be quite socially competent, it appears that his incontinence during seizures and the expected reactions of the general Miller Senior Center participants to the seizure itself are factors in keeping him in-house.

The West Lake Seniors are perceived as needing greater assistance in developing social skills than those who attend the Miller Senior Center. However, like the Miller Clients, there is great variation within the group. A man who is generally friendly and enjoys making small talk with anyone also has episodes of delusion and will at times claim to have been shot or poisoned. Another man will often wave his arm at staff or new acquaintances and exclaim, "Mamamamama" repeatedly. One woman with manic depression will either fail to acknowledge another's presence or excitedly share any and all details of her life. In general, this group of clients receives many reminders to comply with staff direction and their own personal objectives.⁸

While a few West Lake clients participate in some classes and groups, the group generally retains the main room as a "hangout." This room, like much of the center, is decorated in mauve and has a "warm" feel to

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PRIMARY SETTINGS

The Miller Senior Center

The Miller Senior Center is located in a small central Minnesota city. The Center is one of the largest in the nation and hosts a large variety of activities seven days a week. Community education and exercise classes, support groups, meetings, and entertainment programs geared toward older adults are often held simultaneously in one of the six meeting/classrooms. The center also has a library, music room, six pool tables, a lounge area, a well-equipped woodshop in a nearby building, and a large main hall which holds many dances and social programs. This area also houses the senior nutrition site which serves lunch to an average of eighty people per day.

The general Miller Senior Center participants themselves are predominately white and lower-middle to upper-middle class. The male to female ratio is fairly even. More men attend than is common at other centers due to the ample pool and woodshop facilities. Quite a few "regulars" are also observed at the different classes and meetings.

While a few West Lake clients participate in some classes and groups, the group generally retains the music room as a "homerom." This room, like much of the center, is decorated in mauve and has a "warm" feel to

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it. It is carpeted and has a large wooden ceiling fan and lights that dim.

As can be seen in Figures 3 and 4, the layout of the room changed during the observation period. Initially, the four tables were arranged in a block with clients seated around the edges facing the center. During the seventh week staff moved the tables into parallel rows against the east wall. While this created some difficulties in moving about, staff felt that this move helped to increase interaction among clients, and decreased the classroom-like atmosphere of the room.

The music room is equipped with a large bulletin board, stereo equipment, a television with Nintendo game, a piano, and a large wooden chest. The chest was made by volunteers in the Center's woodshop and is used to store activity supplies such as paper, paints, various bingo and board games, puzzles and craft items. Buckets full of markers, cards, and other small items are set out on the tables as are magazines, books, and newspapers.

A seasonally decorated calendar hangs on the bulletin board along with many ever-changing craft items made by clients. The calendar is made of tagboard and numbered squares which are placed on the specified date. A laminated chart used to plan clients' weekly activities rests on the west shelf.

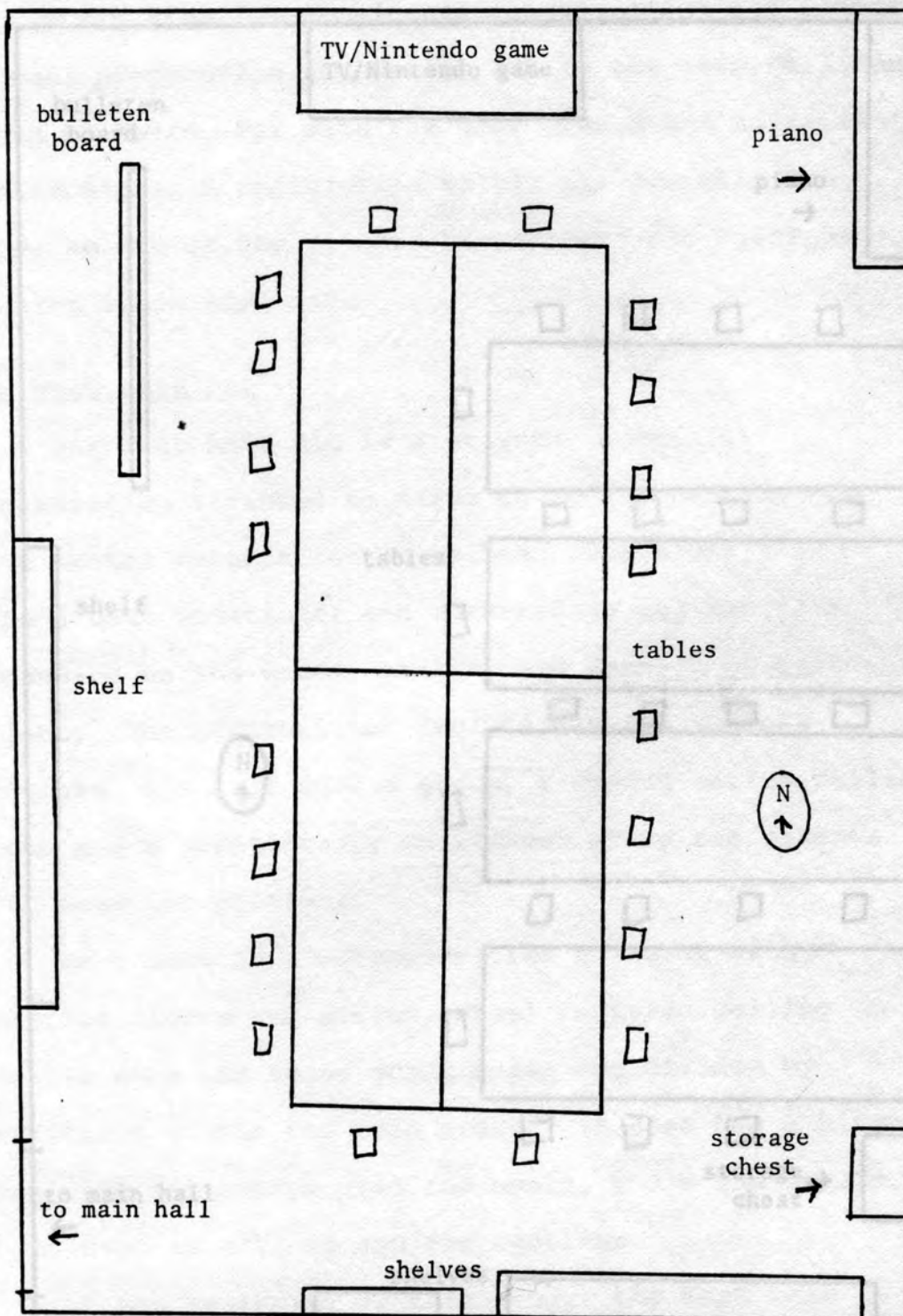


Figure 3. Miller Client domain; music room, Miller Senior Center, initial seven weeks of observation.

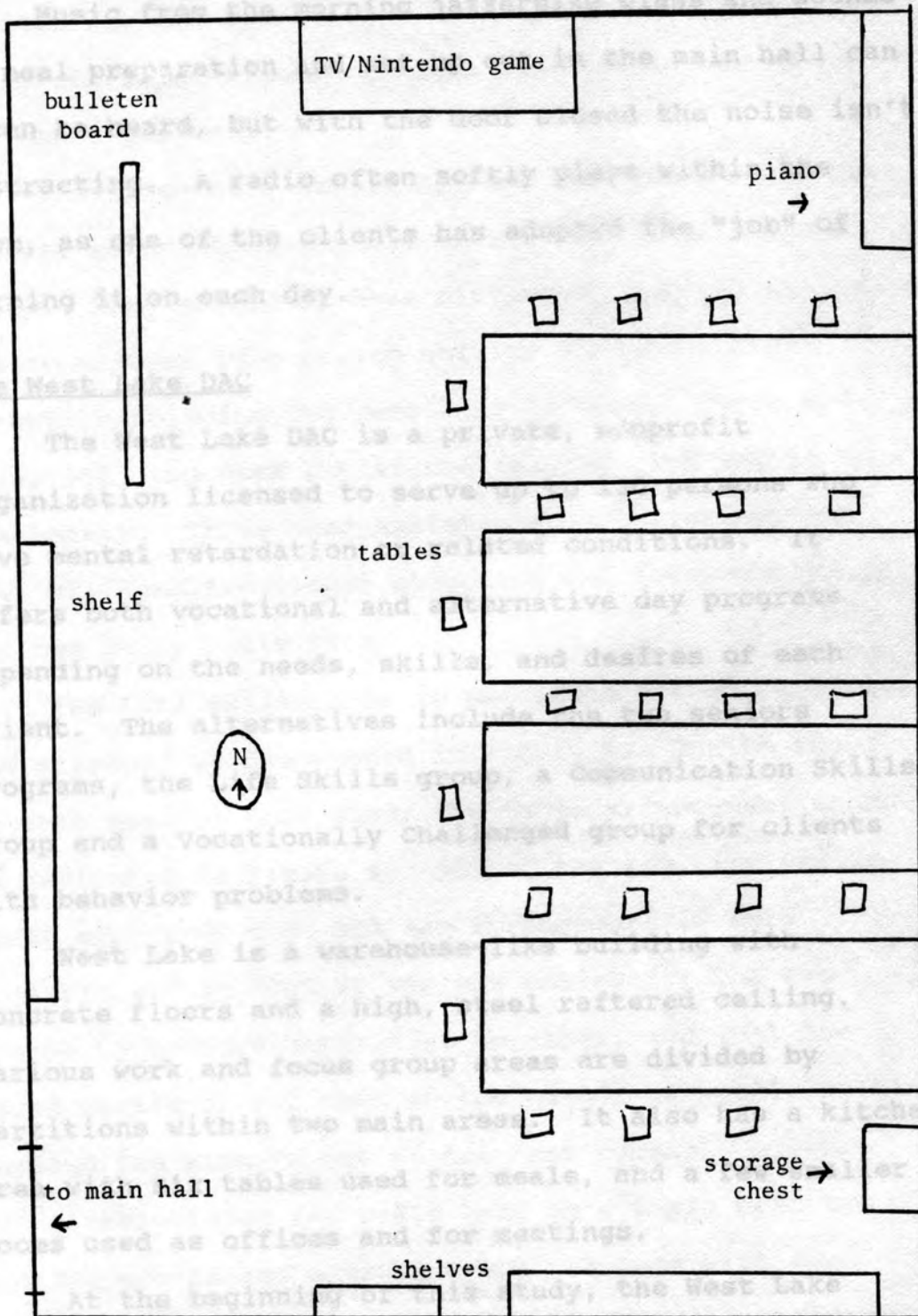


Figure 4. Miller Client domain; music room, Miller Senior Center, final three weeks of observation.

Music from the morning jazzersize class and sounds of meal preparation and set-up out in the main hall can often be heard, but with the door closed the noise isn't distracting. A radio often softly plays within the room, as one of the clients has adopted the "job" of turning it on each day.

The West Lake DAC

The West Lake DAC is a private, nonprofit organization licensed to serve up to 130 persons who have mental retardation or related conditions. It offers both vocational and alternative day programs depending on the needs, skills, and desires of each client. The alternatives include the two seniors programs, the Life Skills group, a Communication Skills group and a Vocationally Challenged group for clients with behavior problems.

West Lake is a warehouse-like building with concrete floors and a high, steel raftered ceiling. Various work and focus group areas are divided by partitions within two main areas. It also has a kitchen area with six tables used for meals, and a few smaller rooms used as offices and for meetings.

At the beginning of this study, the West Lake Seniors had just moved into an area with the Life Skills group. They had previously occupied a rather small room in another area of the building. The primary

reasons for the move were a need for the two groups to share staff and resources and a wish to use that room for other purposes.

The seven Life Skills clients are younger but have similar nonvocational goals as the West lake Seniors group. They generally have difficulty staying on task due to a lower functioning ability than many other clients, including the West Lake Seniors. Three are nonverbal, two need assistance walking, and one is in a wheelchair. Three need assistance in toileting, and they all need individual attention and intervention in various daily activities.

The Life Skills Area is sectioned off by partitions and arranged as diagrammed in Figure 5. During the seventh week of this study the table arrangement changed as indicated in Figure 6. One of the two Life Skills staff explained that the new arrangement is more "functional" in that it was now easier for the two groups to conduct activities together, and that the added partition cut down on the number of people walking through the area to get to the rest rooms.

A television and radio rest on a table near two rocking chairs and a small couch. A cage with two gerbils is near the staff desk. Two sets of shelves hold a variety of magazines, books, puzzles and

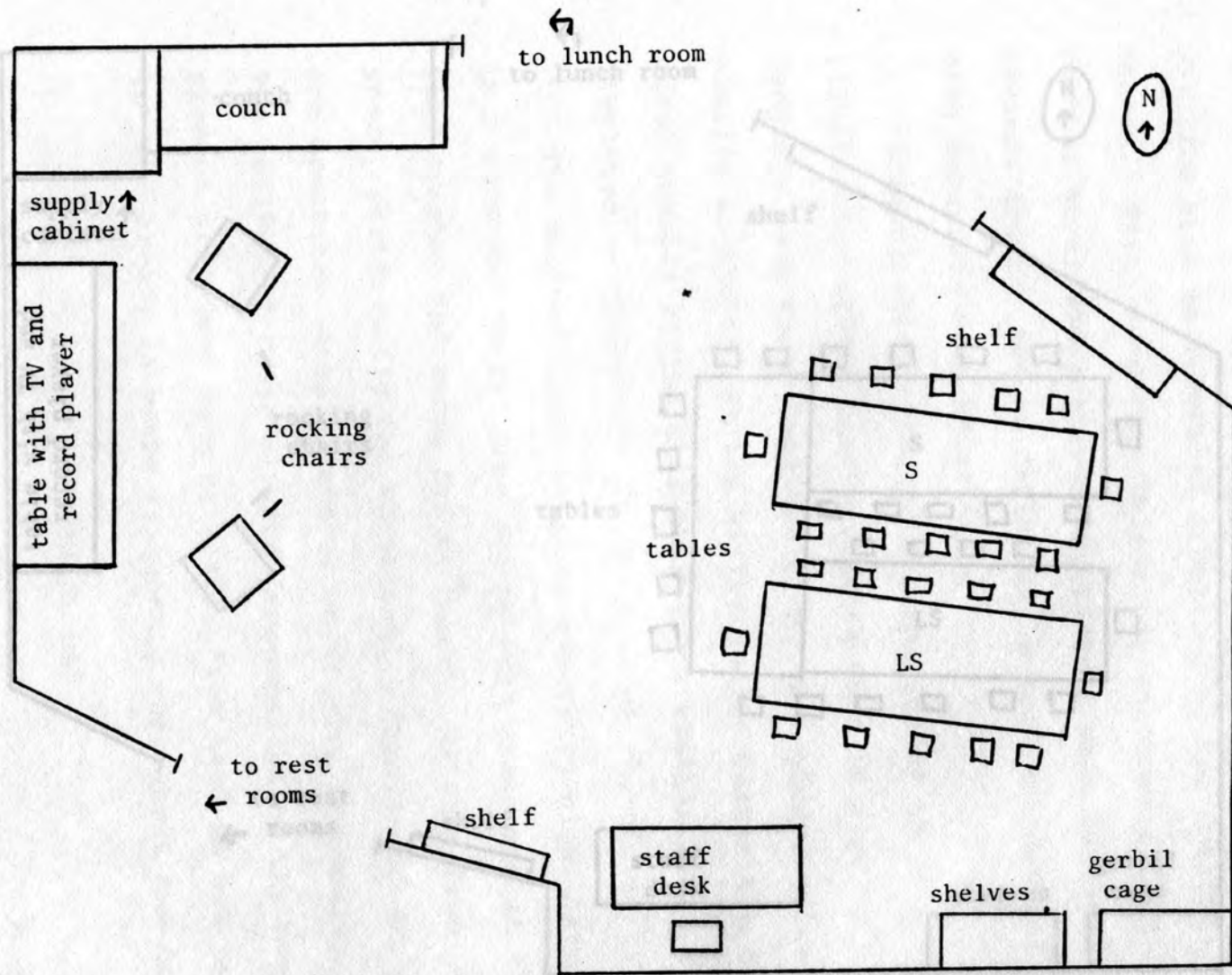


Figure 5. West Lake Senior domain; Life Skills area, initial seven weeks of observation.
 S = Seniors group LS = Life Skills group

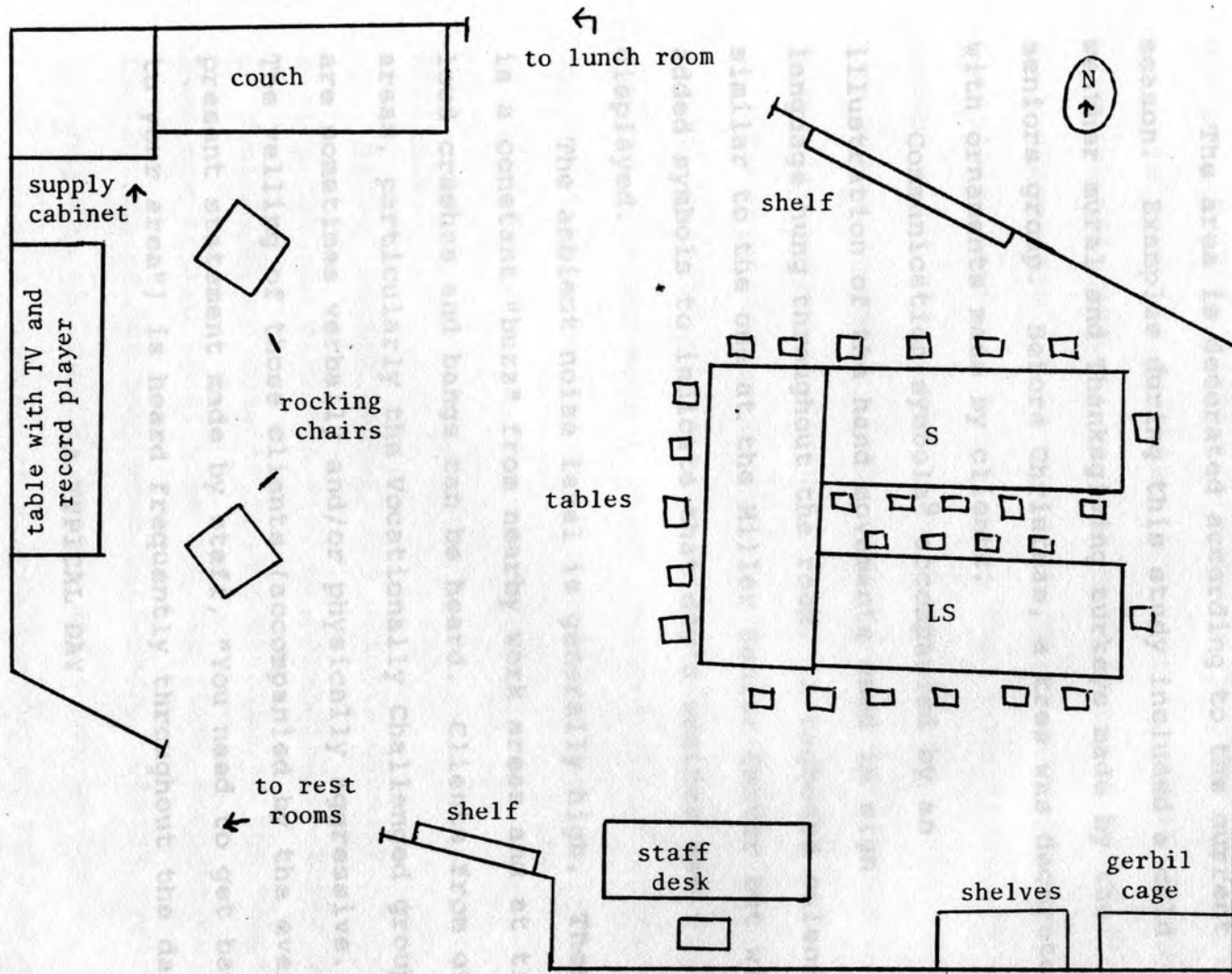


Figure 6. West Lake Senior domain; Life Skills area, final three weeks of observation.

S = Seniors group LS = Life Skills group

games. Most activity supplies are kept in the cabinet in the northwest corner of the room.

The area is decorated according to the current season. Examples during this study included a cold weather mural and Thanksgiving turkeys made by the seniors group. Before Christmas, a tree was decorated with ornaments made by clients.

Communication symbols⁹ accompanied by an illustration of the hand movements used in sign language hung throughout the room. A tagboard calendar similar to the one at the Miller Senior Center but with added symbols to indicate that day's weather are displayed.

The ambient noise level is generally high. There is a constant "buzz" from nearby work areas and at times loud crashes and bangs can be heard. Clients from other areas, particularly the Vocationally Challenged group, are sometimes verbally and/or physically aggressive. The yelling of those clients (accompanied by the ever-present statement made by staff, "You need to get back to your area") is heard frequently throughout the day.

A TYPICAL DAY

Structurally, both groups have similar days. After all staff and clients have arrived there is a period of "orientation," followed by a coffee break, an activity

or two, lunch, more activities, and then the trip home. Activities and outings vary from day to day within each group as well as differing between the two.

Similarities do exist. Clients from both groups have specific objectives that must be met. Staff from both groups facilitate craft projects, provide physical activities, games, read stories, and show films. Both groups visit the library, go shopping, and volunteer at the Humane Society. Every now and then each group plans a special outing or field trip.

In this section morning routines, orientation, and the selection of activities are profiled for each setting. An assessment which compares the characteristics of each environment using the ecological theory of aging follows.

Arrivals

Miller Senior Center: The clients usually arrive between 8:00 and 9:00 AM depending on their place of residence and mode of transportation to the Center. Some are picked up at home and are first brought to the DAC by one of the many West Lake vans. Others arrive directly at the Center via the metro bus or taxi.

One full time staff starts her day at 7:30 AM and is there to greet clients while the other drives a West Lake van route and doesn't arrive until 9:00 AM. The

Green Thumb worker is present from 9:00 AM to 2:00 PM, Monday through Thursday.

Clients are free to work on whatever activity they choose until everyone has arrived. Many will gather the needed supplies without reminders, yet some need encouragement to "Find something to do." Some have preferred activities. Two women spend all their free time completing latch-hook rugs, and one man is never without a deck of cards. Another man can often be seen playing Nintendo--with the encouragement of another who refuses to play himself but will sit nearby and yell, "There it is! . . . Get 'em!" during games.

At any time throughout the day staff may ask the clients to check themselves in the mirror. Reminders are needed more often in the morning as some arrive with crooked collars, food on their faces, or messed hair.

West Lake DAC: The West Lake Seniors arrive at approximately 8:30 AM. They, too, have different modes of transportation. Their staff person drives a van route and is sometimes late getting back. During these times, the two Life Skills staff encourage clients to work on individual activities.

Some have no trouble finding things to do and, in fact, will sometimes refuse to participate in group activities. One man constantly completes puzzles, and another sits apart from the group and looks at

magazines. A woman who works in a vocational area and joins the group only one day per week often sits by herself in a rocking chair and works on crafts.

Other clients often need individual attention in order to complete activities. A man with Alzheimer's symptoms often refuses to sit down, and cannot remember what has been asked of him from one minute to the next. A woman refuses to do anything asked of her unless she is given staff's undivided attention. Some will work on projects when asked, but when finished show little interest in independently initiating another.

Orientation

Miller Senior Center: After all staff and clients have arrived attendance is taken and used partly as a means to facilitate interaction between clients. The staff often asks one of the clients to identify and greet each person called off. If the client merely points to the other, staff says, "What do you say to a person in the morning?" or another similar encouragement to practice greeting skills. Clients are then asked to recite phone numbers and addresses, and many do know them. Again, those that need it are given assistance.

Staff encourage orientation to time and place by asking the group to state the year, month, date, and day of the week. "Where are we?" becomes the next question, and starting out with the room they are in, the group

progresses through to the state of Minnesota and eventually to the country and continent. Some clients always know the answers, and the staff encourages everyone to participate by asking a different person by name each day. Clients also take turns placing the dates on the calendar.

During the orientation the staff sometimes "tests" the clients. For example, on Columbus Day one of the staff asked, "Isn't this the day that Columbus discovered rutabagas in his garden?" When the clients respond in laughter she encourages discussion of "what really happened."

A specific time is also set aside for "Fact or Fiction." The staff makes a series of either true or false statements and the clients respond with an explanation as to whether it is true. Clients seem to know this "routine" and most are eager to participate.

At some point during the morning orientation one of the two staff usually mentions some general concerns about manners and acting appropriately in different situations. The examples are varied but are often related to the expectations of the Miller environment. Staff might ask, "What is the first thing we do we when we go in to use the bathrooms?" or "If you meet someone new, what do you do?" These concerns are also addressed throughout the day as needed.

West Lake DAC: The Seniors and Life Skills groups are often combined during orientation. Staff from one of the groups may be in an office area completing paper work or may be working individually with one of the clients. During separate activities staff from both groups attempt to keep the groups at separate tables (see Figures 5 and 6).

Those in the Seniors group generally participate more in any activity than those in the Life Skills group--such is the case with orientation. Staff from the Life Skills group, especially have a difficult time getting clients to their table. One man in particular will often just stand up and walk away, and another likes to curl up on the couch and go to sleep.

Staff from either or both groups take two baskets of individually wrapped and marked combs out of the supply cabinet and ask clients to comb their hair. Other grooming materials, such as lotion and deodorant, are used by those clients with objectives to do so. Clients are assisted and encouraged as needed.

West Lake Seniors are also asked to recite their phone numbers. Most need prompting in this, and each day staff has the client repeat the correct response. One man is nonverbal and requires assistance in finding the symbol for his place of residence on a communication card he carries in his pocket.

During "current events" period, staff may read from the local newspaper and after reviewing the date, day of the week, month, and year with the Seniors. Again, clients are assisted as needed.

Activities

Miller Senior Center: Staff prepares a monthly chart in advance so that activities are varied. Staff routinely reviews the plans for the day/week with the clients. Clients are given choices, for example, that they can either paint or play Uno in the morning and do crafts or play Yahtzee in the afternoon. They are encouraged to participate in group activities. (Staff explained that some "will do latch-hook or play cards all day if we don't.") However, clients are never forced to participate.

On Mondays they are asked to select from a minimum number of community activities planned for that week. Each option is listed on a chart that rests on a shelf. Depending upon each client's integration objectives, he or she may choose to attend 1 to 3 activities that week. For example, if the options include a trip to the library, volunteering at the Humane Society, shopping, or going to a nursing home for interaction with the residents, one might choose to go to the library and volunteer at the Humane Society.

Individual objectives depend upon a quarterly review by the client's "team." Clients can opt to go on "extra" outings if there is room. Usually only one staff takes clients on outings, so the number has to be kept fairly small.

During the course of this research, staff also began to chart integration options within the Center alongside the rest of community activities. Examples include attending the humanities group, exercise, or craft club. These are activities of the general Center participants and are attended by only a few clients at a time, usually accompanied by the Green Thumb Worker. Twice a month most clients also volunteer at the Center's woodshop in a program that distributes toys to needy children. They sand and paint precut blocks along with volunteers from two area nursing homes.

West Lake DAC: The West Lake Seniors participate in activities similar to the Miller Clients, but they are not as involved in the planning process. While staff working with the Seniors and Life Skills groups often discuss which activities clients might enjoy, they do not present the choices in advance as is done at the Miller Senior Center.

The use of Teaching Resources cards is common at West Lake, but isn't observed at the Miller Senior Center. These cards are grouped by subject such as

"occupations." In this set staff holds up a card and asks "What does this person do?" and discusses each response. This seemed to be an interactive activity that many seniors enjoyed.

West Lake clients use the kitchen facilities about once per week. The Seniors and Life Skills groups are often combined in this activity as cakes, cookies, and cinnamon rolls are made. However, due to the large number of people in the kitchen, few are able to participate in the actual baking process.

While the West Lake Seniors don't have as many opportunities to individually attend groups and classes as the group at the Miller Senior Center, they do attend a senior dining site once per week. The West Lake Seniors' most frequent outing seemed to be shopping (for baking or craft supplies, activity ideas, etc.), but they also visited the library and began to volunteer at the Humane Society during the course of this study.

ASSESSMENT

An important difference in the two groups is the frame of reference in each setting. Clients at the Miller Senior Center attend a facility with the general senior population while those who remain in-house are grouped with the younger, and generally more disabled, Life Skills group.

When asked to describe the basic difference between the two settings the program director replied, "At the senior center the staff is able to spend more time planning and programming activities." She explained that, at West Lake, "so much time is spent in intervention."

A higher proportion of "behavior problems" was evident at the West Lake DAC during the observation period. It was particularly revealing that many clients or staff didn't seem surprised or concerned even when a client from another area became physically aggressive and knocked over the coffee cart, while at the same time another client picked up a chair and threw it across the lunchroom.

While most situations requiring staff intervention aren't as extreme as this, they are much more common than at the Miller Senior Center. The Staff at West Lake is faced with a challenge of trying to provide a "normalized" environment when that expectation isn't always realistic, while the Senior Center environment demands "normal" behavior in order to participate at all.

The West Lake environment itself is designed for people with disabilities. Special training for staff and modifications in environment provide an understanding and enabling atmosphere for clients who may not

otherwise be able to engage in a vocational or day activity setting. These differences in expectations are of interest when considered in light of the ecological theory of aging and its contention that people function best in the "challenge zone." The clients at the more normalized environment of the Miller Senior Center may be more effectively challenged in terms of social skill.

Hygiene and appearance alone are approached quite differently in the two settings. The West Lake Seniors, as a group, are expected to comb their hair in the morning, whether they appear to need it or not. Yet, at any given time throughout the day one observes clients with hair in need of combing. Clients who attend the Miller Senior Center are expected to maintain proper appearance at all times, and the subject is only addressed as needed.

It seems as though the expectations at West Lake are that through the use of objectives, clients will be taught to comb their hair. However, the absence of a presented need to do so distorts the purpose of learning how to maintain proper appearance. There is more emphasis on form rather than on function as compared to the program at the Miller Senior Center. Clients in the West Lake culture are expected to meet a preconceived notion of competency, while those at the

Miller Senior Center must adapt to the standards of a normalized culture.

Orientation is more interactive at the Miller Senior Center. Clients are expected to participate in discussions and humor is often used to approach current events and proper behavior. Clients are also expected to interact more with one another during the attendance period. As noted above, these expectations are carried throughout the day. Staff will often say, "Tell it to ___", or similar phrases to encourage interaction.

The selection of activities at the Miller Senior Center is that of "forced choice." Clients are presented with a variety of options in advance and are expected to make a commitment to participate in at least a minimal number each week.

The key difference is the approach of the two groups in planning. The West Lake group conducted a variety of activities but the researcher, as a participant observer, never knew what game, exercise, or outing would follow. Because clients have certain objectives that must be met it can be assumed that the staff does a certain amount of planning. However, it did not appear that clients had much influence, or even knowledge, of upcoming events. Whereas the staff at the Miller Senior Center reviewed the options in advance in

order to encourage more participation in group activities, those at West Lake did not.

This is not to say that the staff at West Lake disregards client wishes in selecting activities. At times staff made comments such as "Alex seems to like bingo" or "George will participate if you...." Clients were never forced to participate in any activity.

The notion of independence must also be considered in assessing the fit between competency and expectations. The fact that the researcher was so frequently recognized as "staff," and therefore "in charge of" and making decisions for clients at the West Lake DAC is in itself revealing. Clients at the Miller Senior Center are expected to do as much as possible for themselves. From gathering their own materials for independent activities to choosing from certain options in group activities they generally have more control in managing their experience at the day program.

The Miller Senior Center: Bingo is a common afternoon activity at the Miller Senior Center. Each game is based on a "theme" (i.e., Halloween, Animal Picture, and Traffic safety) and picture cards and is intended as a learning device as well as recreation. Staff often uses the game as an opportunity for discussion and asks a variety of questions about each card as it is called. Most clients participate, but some will do so only if she can be the caller, and another

only if he can help someone else. Other clients often assist one another during the game.

Winners are given a prize of a piece of candy. Cards are cleared after the first winner.

CHAPTER V
AN ADDED DIMENSION

A second setting for one of the groups provides an interesting means for investigating variations in program style. The West Lake seniors are observed attending a local senior nutrition site and participating in bingo games prior to the meal each week. These experiences are compared to the regular bingo and mealtime experiences for that group, and to the bingo and mealtime routines of the Miller Clients in their primary environment.

Bingo

The Miller Senior Center: Bingo is a common afternoon activity at the Miller Senior Center. Each game is based on a "theme" (i.e., Halloween, Animal Picture, and Traffic safety) made of picture cards and is intended as a learning device as well as recreation. Staff often uses the game as an opportunity for discussion and asks a variety of questions about each card as it is called. Most clients participate, but one will do so only if she can be the caller, and another

staff asked clients to clear their cards after a stop. One man got upset and argued that it wasn't "fair."

only if he can help someone else. Other clients often assist one another during the game.

Winners are given their choice of a prize, often a piece of candy. Cards are cleared after the first winner. Staff explained that at West Lake more than one client is often allowed to win before cards are cleared. She stated that, although more clients are able to win that way, "learning how to lose is just as important".

The West Lake DAC: Grooming Picture Bingo is frequently played in the mornings at West lake. At times, it is brought into the lunchroom area to be used as a combined activity with baking while waiting for the food to come out of the oven. Communication symbols for items such as "washcloth", "sink", and "soap" are used. Again, staff often talks about each item and the importance of using it.

During the game staff often assists clients by walking around the table(s) and pointing out the squares to be covered. Some of the clients do not pay much attention to the game. As the staff from the Miller Senior Center mentioned, cards are often not cleared after the first winner. On some occasions all clients get a piece of candy at the end of a game. Once, when staff asked clients to clear their cards after a game, one man got upset and argued that it wasn't "fair."

The South Side Community Center: The West Lake Seniors attend a senior dining site once per week at the South Side Community Center. Here, bingo is played every Thursday at 11:30 AM. During the period of this study, the West Lake staff often changed the usual routine and brought the group Thursdays instead of Fridays.

All participants receive "regular" (numbered) bingo cards, including staff. Three or four games are usually played, with the final one being a "blackout." The West Lake Seniors are assisted by staff, who checks everyone's cards after each number. Prizes such as canned fruit or money are given out for each bingo. Clients seem more interested in their cards than at West Lake, and more excited if they win a game.

Meals

The Miller Senior Center: While most of the seniors bring a bag lunch Monday through Thursday and have hot lunch as a group only on Fridays, they usually eat lunch in the dining hall with the general seniors (see Figure 7). At times, a program or meeting at the center draws a large lunch crowd and the clients eat in the music room to make space for those buying a hot meal.

Many tables are reserved for specific groups and marked with labels such as "craft club," "volunteers," "Miller Senior Center Staff," and "West Lake." The two West Lake tables are at the north end of the room

(See X's, Figure 7) and are eat with silverware and napkins by one of the clients.

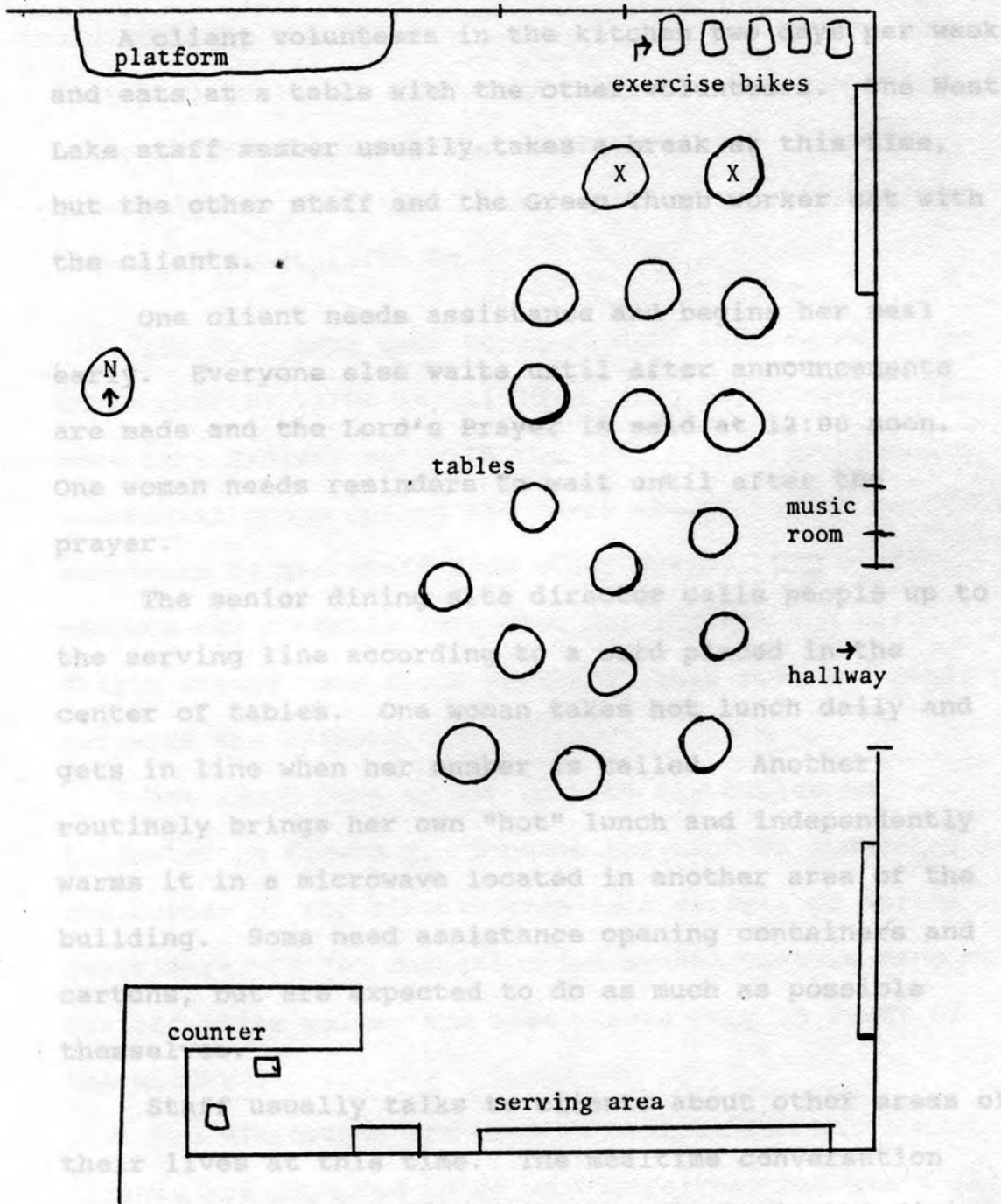


Figure 7. Miller Senior Center dining area, main hall.

X = Miller Clients

reminds clients to display proper table manners,

(See X's, Figure 7) and are set with silverware and napkins by one of the clients.

A client volunteers in the kitchen two days per week and eats at a table with the other volunteers. One West Lake staff member usually takes a break at this time, but the other staff and the Green Thumb worker eat with the clients.

One client needs assistance and begins her meal early. Everyone else waits until after announcements are made and the Lord's Prayer is said at 12:00 noon. One woman needs reminders to wait until after the prayer.

The senior dining site director calls people up to the serving line according to a card placed in the center of tables. One woman takes hot lunch daily and gets in line when her number is called. Another routinely brings her own "hot" lunch and independently warms it in a microwave located in another area of the building. Some need assistance opening containers and cartons, but are expected to do as much as possible themselves.

Staff usually talks to clients about other areas of their lives at this time. The mealtime conversation sounds similar to that of any other table in the dining hall, and laughter is often heard. However, staff also reminds clients to display proper table manners,

asking them to use their napkins or to "slow down a little."

Some of the clients return to the music room when finished, while the rest stay to talk. One man often takes a ride on one of the exercise bikes. Clients generally "do their own thing" until group activities resume at about 12:45 PM.

The West Lake DAC: Lunch at West Lake is eaten in three shifts: 11:00 AM, 11:30 AM, and 12:00 noon. The West Lake Seniors eat with the Life Skills group and a vocational group during the third shift. Lunch is monitored by two staff from other areas. The staff members who normally work with the Seniors and Life Skills groups take their breaks at this time and don't eat with the clients.

The lunch room is set up with six tables as indicated in Figure 8. Lunches are kept on a counter in the corner of the kitchen area in a variety of marked containers. A few communication symbol posters hang on the off-white walls, and some plants hang in front of the windows.

Two microwaves are used to heat up lunches. Most clients are expected to do so themselves, but staff is present to monitor the process, and to do it for those who aren't able. After clients pick up their lunch pails, they sit wherever they find room. Some wander

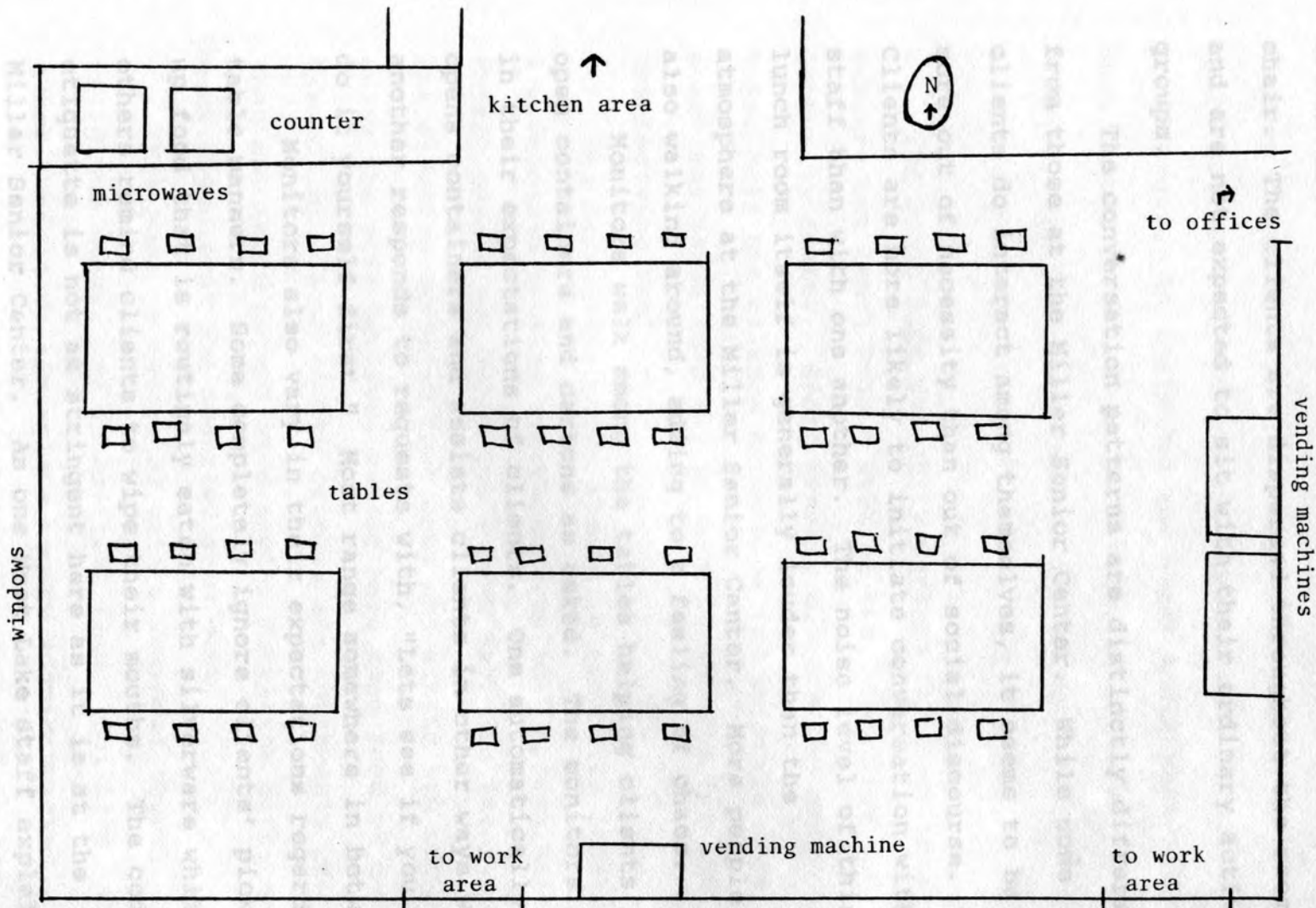


Figure 8. West Lake DAC lunch room.

around until one of the monitors points out an empty chair. The clients are dispersed throughout the room and are not expected to sit with their ordinary activity groups.

The conversation patterns are distinctly different from those at the Miller Senior Center. While some clients do interact among themselves, it seems to be more out of necessity than out of social discourse. Clients are more likely to initiate conversation with staff than with one another. The noise level of this lunch room itself is generally louder than the atmosphere at the Miller Senior Center. More people are also walking around, adding to a feeling of chaos.

Monitors walk among the tables helping clients open containers and cartons as asked. The monitors vary in their expectations of clients. One automatically opens containers and assists clients in other ways while another responds to requests with, "Let's see if you can do it yourself first." Most range somewhere in between.

Monitors also vary in their expectations regarding table manners. Some completely ignore clients' picking up food that is routinely eaten with silverware while others remind clients to wipe their mouths. The code of etiquette is not as stringent here as it is at the Miller Senior Center. As one West Lake staff explains, "There are some things you come to expect."

A list of information is taped to a cabinet in the kitchen for staff who are assigned to monitor a lunch shift so that they may adjust expectations of clients accordingly. It indicates who needs assistance with what, those that need to be watched so that they don't steal food, those that wander, and those who need to be encouraged to eat at all.

The South Side Community Center: The West Lake Seniors eat lunch once a week at the South Side Community Center. Staff usually divides the group and takes half the clients on each of two separate days, or sometimes takes them all at once as she did for the Thanksgiving meal.

The community center itself is centrally located in a subsidized housing apartment complex. Approximately thirty people eat lunch there each day. An interview with the director revealed that many who attend are often below the poverty level and/or have some form of mental disability. Some of the patrons are noticeably younger than one would expect at a senior nutrition site, and many "regulars" are observed each week.

The room is decorated with a seasonal theme, religious items, and an American flag. Quilting and other activities take place in the adjoining area. Two informal presentations are given each month on health or social issues. The director explained that the speakers

"turn people off . . . they like to visit a little and go home." However most come early for bingo on Thursdays.

A volunteer is seated at a table near the door (see Figure 9) to accept donations. The suggested amount is \$1.50 for people aged 62 and up and \$2.85 for those younger. Clients often need assistance in counting out money, and at times need to be monitored to pay the full amount.

Five dining tables are set up according to the number of people who have registered in advance for that meal. Although there are no assigned seats, community center participants seemed to expect West Lake clients to sit at one particular table (see X, Figure 9). When the West Lake group arrives most of the tables are full and that one is almost always empty. West Lake staff described a day when the group got there late and had to eat at separate tables. "Brad picked his nose and waved his arms the whole time, it was terrible." When asked how the other seniors reacted, she said that they were "understanding."

Only on two occasions did other people eat with the group during the observation period. One day a man came in late and sat with the group when the rest of the tables were full. He asked many questions about West Lake and seemed rather friendly. On another day, a

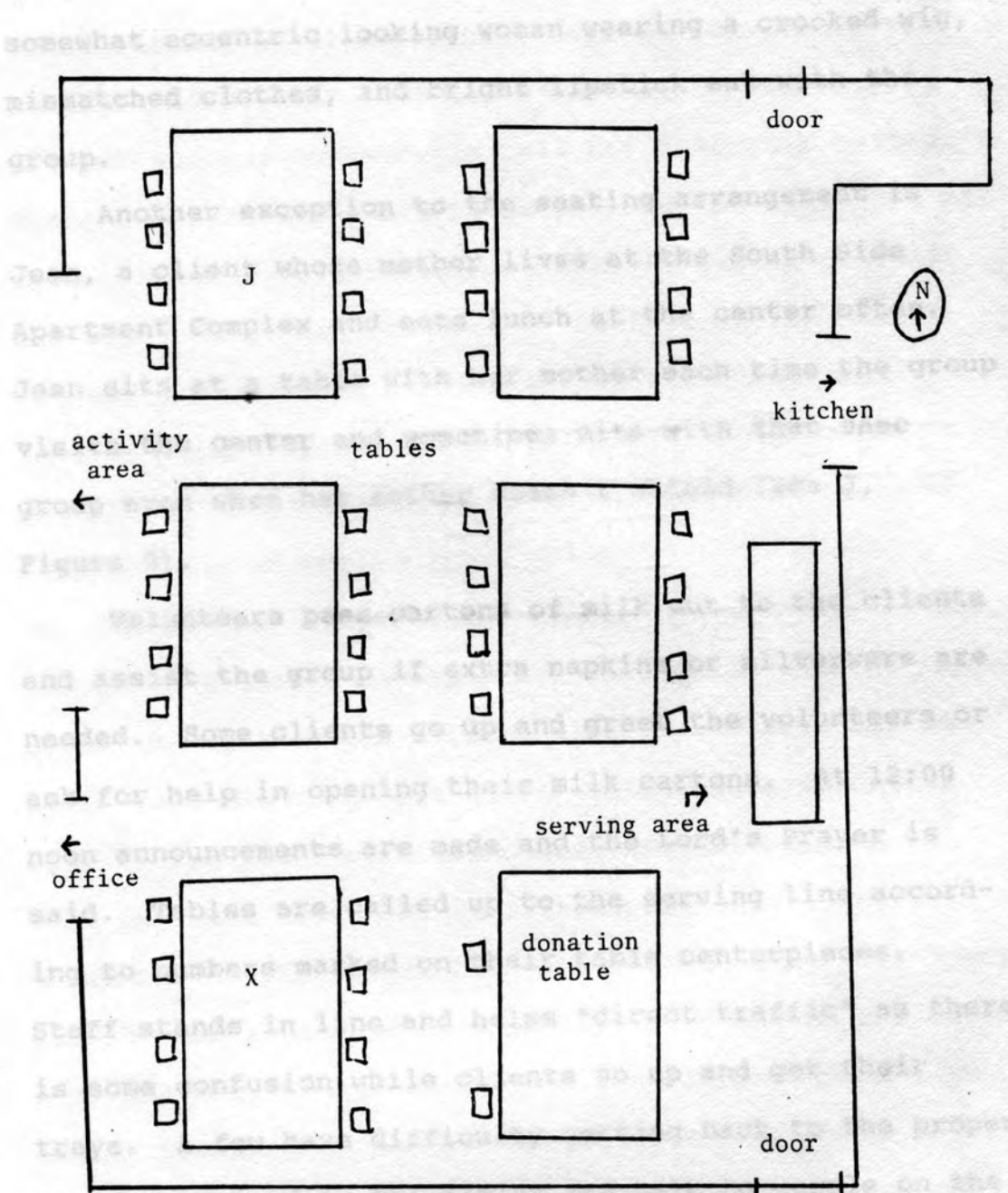


Figure 9. South Side Community Center dining area.
 X = West Lake Seniors J = Jean and her mother

The director and volunteers were friendly and helpful, even when a client's behavior is particularly inappropriate. On two separate occasions Alex, one of the clients, began yelling and became self-injurious

somewhat eccentric looking woman wearing a crooked wig, mismatched clothes, and bright lipstick sat with the group.

Another exception to the seating arrangement is Jean, a client whose mother lives at the South Side Apartment Complex and eats lunch at the center often. Jean sits at a table with her mother each time the group visits the center and sometimes sits with that same group even when her mother doesn't attend (see J, Figure 9).

Volunteers pass cartons of milk out to the clients and assist the group if extra napkins or silverware are needed. Some clients go up and greet the volunteers or ask for help in opening their milk cartons. At 12:00 noon announcements are made and the Lord's Prayer is said. Tables are called up to the serving line according to numbers marked on their table centerpieces. Staff stands in line and helps "direct traffic" as there is some confusion while clients go up and get their trays. A few have difficulty getting back to the proper table, or stand in the aisles and talk to people on the way.

The director and volunteers seem friendly and helpful, even when a client's behavior is particularly inappropriate. On two separate occasions Alex, one of the clients, began yelling and became self injurious

while waiting in line for his tray. He repeatedly hit himself and yelled, "No! Don't want it!" Staff tried without success to have him tell her just what he didn't want, and then asked him to go back to the table and sit down. After everyone was seated he looked up at staff and said, "meat and potatoes." Staff confirmed this request and went and got him a tray with just that. Soon he looked up and said, "pudding." And, by the process of elimination, staff discovered that he had been adverse to the squash.

On another visit to the center the main course was lasagna. Although he had previously eaten this at the center he again began hitting himself and yelling, and staff told him to go sit down. This time a volunteer came to the table with leftovers that she offered to warm up. The West Lake Staff accepted this offer but commented to the researcher that "We can't do this every time." She explained to Alex that from now on she would read the menu to him in advance, and if he didn't like any of the food to let her know so she could keep it off his tray. Otherwise, he could stay home that day. She asserted, "We can't have you having outbursts like that in public."

The staff eats with the clients and assists with cutting meat and opening cartons as needed. A few of the clients routinely race through their meals, getting

food on their laps, faces, and the floor. One man in particular will often pick up his meat and eat it with his hands. At times staff instructs them to "slow down" or "use a spoon." Again, the code of etiquette here is not as strict as at the Miller Senior Center.

ASSESSMENT

The most "normalized" setting for bingo might be at the South Side Community Center in that standard cards are used and the staff plays as well as the clients. Although she continues to monitor everyone's cards she now sits with the clients and participates in the game. Yet while some clients at the Miller Senior Center may act as the caller, this is not the case at the West Lake DAC or the South Side Community Center.

There is an interesting difference in client attitudes toward winning in the two settings. West Lake Seniors seem to expect a "prize" regardless of the actual result of the game while at West Lake. However, when attending the South Side Community Center, where they aren't as likely to win, clients are much more involved in the game.

The most independent meal time setting is the Miller Senior Center. Here clients are more familiar with the routine and by now are able to get up and get their own lunch or heat it in the microwave as needed,

and then clean up their areas when finished. It is normalized in that staff eats with the clients and engage in "normal" conversation. However, staff must also assure that clients will act appropriately and may give reminders at any time.

The West Lake Seniors' mealtime experiences differ greatly between the community center and the DAC itself. At South Side staff eats with clients whereas at the DAC clients are "monitored" as they eat. The West Lake staff is also more likely to remind clients to use proper manners at South Side than she does while at the DAC. It appears that the staff interprets the expectations of the environment and conveys them to the clients.

The use of lists taped to a kitchen cabinet at the West Lake DAC to inform the staff of which clients need assistance or monitoring may be compared to the other two settings in terms of the ecological theory of aging. At the two extremes, the clients at the Miller Senior Center must meet the expectations of that environment in order to participate, while at the West Lake DAC the expectations of the environment changes to meet the needs of clients. Between these two extremes lies the South Side Community Center, where clients must act appropriately "in public" but more allowances are made for a period of learning.

CHAPTER VI

PERSON IN ENVIRONMENT

As outlined in the ethnography, the fit between person and environment depends greatly on the expectations of one's surroundings. Similarly, the definition of "competency" changes from setting to setting.

Theoretically, if the West Lake Seniors were suddenly moved into the Miller Senior Center, various discrepancies would be found with their appearances, behaviors, and own sets of expectations. The seniors with developmental disabilities who attend the Miller Senior Center are thought to be more highly competent than those who remain at West Lake. At the same time, the Miller Clients are thought to be less socially competent than the general senior center participants, as evidenced by staff's role in acting as the interface between the client's and the expectations of the greater environment.

In this section, the varying roles and expectations of staff are shown to be a large component of the client's environment. A review of transitions between

the two settings, retirement as an issue, and declines and increases in competence are described in a presentation of six client profiles. An exploration of the "ideal setting" and implications for policy are reviewed in the final chapter.

STAFF AS A CULTURAL BROKER

As noted in the ethnography, staff expectations of behavior changed from client to client. Staff are aware that one may need help remembering her address while another needs assistance eating lunch. They are expected to orchestrate a different set of expectations for each client, and ideally, keep each in a "challenge zone" so that competence may be raised.

Staff must also orchestrate a different set of expectations for all clients as environments change. As Nahemow, Stokes, and Granfield assert, "The staff makes decisions concerning what is acceptable to wider society and the staff enforces those demands" (1988, p. 7). Stokes identified staff in this position as "cultural brokers" (1990), and explained that they watch the interface between client and environment so as to not disrupt "established cultural norms" (Ibid).

In the West Lake setting, different standards were imposed for when in public. When one man constantly picked his nose one morning before going to the South

Side Community Center staff exclaimed, "Brad, I can't take you with if you're going to do that." When Alex yelled and hit himself at the South Side Community Center staff explained, "We can't have you having outbursts like that in public."

At the Miller Senior Center, however, where clients are constantly "in public," staff are much more likely to simply say, "Please get a kleenex" or otherwise matter-of-factly identify the behavior that needs to change.

One wonders if those same expectations would change if the staff at the Miller Senior Center were to work with those same clients in a less stringent setting. While part of the morning orientation is dedicated to "cultural rules" imposed by the center, many of the expectations held by staff go beyond the Center's identified norms.

Judging by some of the comments made during the observation period, one may be inclined to think that these staff would have a higher expectations regardless of the setting. As one of them stated during the informal interview, "I guess I expect progress." She also emphasized social appropriateness, saying, "Disabilities don't qualify a person for special benefits. There's a saying that 'A disabled person's biggest handicap is someone else's pity.' I think

that's really true." She explained, "I think it has a lot to do with dignity; I figure, I wouldn't want to walk around with food on my face so why should they?"

STAFF AS A PORTABLE ENVIRONMENT

One wonders to what extent client's behavior (i.e., social competence) is influenced simply as a result of changes in the staff themselves. Each staff person approaches clients with a unique set of expectations related directly to his or her perception of that person's competence.

Opportunities to observe changes in staff alone arose on those days when substitute workers filled in for the regular staff. Subtle and not-so-subtle differences were noticed in client's reactions. Some reacted negatively to the changes in routine. When a substitute didn't go through the regular process of orientation at West Lake one of the clients frequently insisted, "I know my address!" throughout the morning.

On the other hand, substitute workers were more apt to approach clients in a new set of ways--to not have preconceived notions about client capabilities and interests. The clearest example of this occurred when a substitute for the West Lake Seniors brought in his own activity project--a bag of old plastic jewelry that could be taken apart and reassembled simply by

snapping and unsnapping the beads. He sat down with the bag, explained it to seniors, and everyone participated. Even Jerry, the man with Alzheimer's symptoms who rarely showed any interest in the group's activities, joined in.

Throughout the day he promoted interest in trying new things rather than focusing on individual deficiencies. For example, he was able to keep Jerry distracted from wanting to leave the group by taking him on periodic "walks" within the DAC whenever he moved away from the table.

Of course, people unfamiliar with the clients may also expect too little of them. The Green Thumb worker had not worked with developmentally disabled people before starting her job at the Miller Senior Center in October of 1991, shortly after this observation began. During the informal interview she spoke of changes she experienced during the initial two months, "At first I looked at them and thought, 'The poor thing,' but now I feel that these people can do a lot more than we think." She added, "For a while I tried to do too much. Some things take longer and I'd get impatient and try to help them."

Exploring the differences in staff expectations is important when one realizes the key role they play in "managing" the client's adaptation level. Automatically

opening a man's milk carton may seem like a small thing, but if he can do it himself he is outside of his "challenge zone," and, taken with other affronts to his competence, his adaptation level may shift to a lower level.

It should be noted that staffs' ability to orchestrate an appropriate level of expectations for clients is often hampered by limitations in the environment itself. Given low staff ratios, inadequate preparation time, and other pressures it is understandable that staff would find it easier to "just do it" rather than wait the longer time it may take the client.

THE TOP FIFTEEN

Other limitations in maintaining a moderate level of challenge for clients arise from limitations in space at the Miller Senior Center. The Center has placed a cap on the number of clients allowed to participate. Currently the cap is fifteen, but no more than fourteen are present at any given time.

In the Spring of 1991 a DAC in another local community closed, and the clients, including a number of seniors, were merged into the West Lake facility. Three from the Miller Senior Center were brought back

in-house at this time to make room for those who might be better served in that setting.

When asked how placements are determined, the program director explained that it is a team decision based on the client's wishes, as well as an assessment of his or her ability to meet the expectations of different environments. Yet she emphasized that while the seniors at West Lake have higher needs, "Everyone would benefit from going to the senior center. We just don't have the resources to do that right now."

It seems that there are a certain number of "slots" available. The "Top Fifteen" clients attend the Miller Senior Center while the rest receive programming in-house. The fact that one man remains in-house due to his frequent seizures and concern over possible reactions of the general senior center participants suggests that another category of "maladaptive" exists which is not directly related to the client's ability to adapt to that setting. In order to attend the Miller Senior Center one's immediate social acceptability is of utmost concern.

PROFILES

On the Border

Some clients are on the dividing line between the two settings and have participated in both. During the

observation period two "openings" became available at the Miller Senior Center. In both cases the openings were filled by clients who had participated at the Center during the initial integration, had been returned to the in-house group for a time, and were now moved back to the senior center.

Alex, age 68, is one of the clients who seems to be "on the border." He is the individual described in the ethnography as having difficulty communicating his wants and needs in an appropriate manner during lunch at the South Side Community Center. Such "outbursts" were a primary reason for his move back to the West Lake Seniors group. They had been increasing in frequency and staff was having a difficult time managing his behavior in such a large group.

Interviews with staff who have worked with him revealed that the primary "reason" for his agitation may be when too much is expected of him. The program director remarked that, at the Miller Senior Center, "The group is much more 'on the go'....He likes to do his puzzles and would prefer not to participate in any group activities, except maybe bingo."

Perhaps the expectations for Alex were too great at the Miller Senior Center. In contrast, while he did complete puzzles in all his spare time at West Lake, he did participate in other activities and only became

agitated only twice--both times were at the South Side Community Center, outside of his regular environment at West Lake. Unfortunately, for purposes of this study, his return to the Center occurred two weeks after the observation ended. An account of Alex's readaptation to the senior center must await further research.

Robert is a 71 year old man who lives in a board and care facility. He, too, was one of the initial group attending the Miller Senior Center from the Fall of 1989 until the Spring of 1991. He was moved back in-house partly due to his desire to resume working. He had been employed on a park crew ¹⁰ for a number of years and often spoke of that while at the Center (Blenkush, 1990).

He had retired from year-round work partly due to his unwillingness or inability to put forth much effort while employed. The program director explained that while this could be tolerated for a summer position, the senior program operates under the same guidelines as the rest of West Lake, and that it isn't fair to others who might work out better on a job.

Robert also had difficulty maintaining the proper standards of hygiene and appearance while at the Miller Senior Center. He insisted that he didn't need to shower or that if he washed his clothes, "They would all be in the wash and I'd run around naked!"

While he seems to be only mildly mentally retarded, he has been diagnosed as having an "unspecified psychosis" and at times can be very uncooperative. If he doesn't want to participate in an activity or otherwise comply with a staff request he makes excuses such as, "My glasses are too small!" or "I can't do that! It'll ruin my shoes!"

He attended the West Lake Seniors Group during the initial seven weeks of this research. When an opening at the Miller Senior Center became available, he was reassigned to that facility after complaining, "We sure do a lot of sitting around here!" and becoming visibly annoyed with members of the seniors' group and other clients at West Lake.

During his first tenure at the Center, Robert was frustrated with not working and with seeing general senior population enjoying activities not open to him. He spoke often of being old and not being able to work anymore, and seemed to have a keen awareness of boundaries. One day he looked up from a magazine he was reading and exclaimed, "Do you know what the trouble is with this place? All the old people are taking over and we can't do anything!" When staff asked him what he wanted to do he spoke of ceramics and woodworking, both of which are paid community education classes and beyond his or the agency's resources (Blenkush, 1990).

Upon his return to the senior center in the Fall of 1991, he seemed pretty excited about seeing familiar people. He greeted many by name and talked a lot about how he'd "been here before." He was eager to participate in activities and ride the exercise bikes. He told the program director, "I think I'll stay here. If I go to the park in these small glasses I'll fall down!"

During the informal interviews, one of the staff who works with the Miller clients wondered how long his excitement would last. She explained that he had recently started making more excuses and had complained of not being "able to do anything." She speculated that he would probably remain at the senior center until Spring when he might want to return to work.

Robert can be viewed as being "on the border" with respect to his placement in the two day programs and his identification with the general senior population. His strong desire to work and his frustration with not being able to do what the general seniors do clash with his difficulty maintaining proper hygiene and the cultural codes of the Miller Senior Center and his workplace.

Retirement

As noted above, some clients have difficulty with the move from work to retirement. As in the general population, people with developmental disabilities may have a difficult time redefining their "sense of self"

upon retirement. Graffam and Turner explained that people with developmental disabilities may have even a stronger identity as workers, "The workshop provides an arena for positive comparisons with clients, a high degree of social stimulation and the maintenance and development of peer relations" (1984, p. 124).

Nancy, age 64, retired in the Fall of 1989 because she was having difficulty staying awake on her full time job. Her case managers discussed the option of retirement with her and she agreed. However, soon after she began attending the Miller Senior Center it became evident that she would much rather work; the day program simply wasn't challenging enough for her. Her placement was reevaluated, and she is now working four days a week and participates in the in-house West Lake Seniors group only on Tuesdays.

On her days with the West Lake Seniors she gathers her materials for craft activities and sits apart from the group while working on them. She is much more independent than the rest of the seniors at West Lake and seems able to challenge herself in her own activities.

Declines in Competence

Some clients have experienced changes in program due to declines in competence. Two of the clients have

suspected Alzheimer's disease, and both have been moved out of the Miller Senior Center because they are unable to meet the requirements of attending that program.

Jerry is a 55 year old man with Down syndrome and symptoms of Alzheimer's disease. He actively participated at the Miller Senior Center from the Fall of 1989 until it became clear that his dementia symptoms were affecting his ability to adapt. He was then returned to West Lake.

One of the staff who works with the Miller Clients explained that she was able to learn little tricks to distract him (e.g., going for a walk or driving around the block with him), but when the "behaviors started leaving the room" (i.e., impacting on general senior participants) he was no longer suitable for that setting. One day staff found that he had locked himself in the bathroom and laid down to take a nap. She reported that he often left the room and refused to come back, insisting that someone was going to pick him up for a wedding, a trip to Hawaii, or work.

During the period of this research Jerry spent much of the day standing near the coat rack in the Life Skills area searching for his jacket and/or clutching his lunchbox. He often seems frightened and confused, and speaks in fragments. He routinely forgets what he

is doing midway and generally needs constant encouragement and direction to stay on task.

The staff who works with the seniors at West Lake pointed out that he seems "better when it isn't so noisy and chaotic." This is consistent with research showing that people with dementia become more agitated with increased stimulation, and that routines should be very structured, focusing on activities that are calming (Johnson & Ollman, 1991).

Ironically, the Miller Senior Center fits the above description much better than the West Lake DAC. The constant commotion and heightened noise level may have only exacerbated his dementia symptoms. However, as the staff at the Miller senior center explained, "He needed individual attention in order to get out of the program what everyone else was getting." While the Center might have provided a more conducive environment, it was difficult to manage his wandering when fourteen other clients also needed attention.

This scenario raises the issue of the need for more alternatives in services. Clients may be better served in an environment which more closely matches their adaptation levels, and which doesn't provide an undue level of negative press.

Alice is a 57 year old woman who also has Alzheimer's symptoms and attended the Miller Senior

Center until her placement was reevaluated. She had lived with her mother most of her life. When her mother was no longer able to care for her she was moved into a nursing home in the Fall of 1990. She now uses a wheelchair and is essentially nonverbal.

At the beginning of this study she would often walk from her wheelchair to the tables in the music room with staff assistance. During the ninth week of the observation staff mentioned that they were having an increasingly difficult time getting her to walk even with help. Staff then went on to explain that they had recently noticed a rapid decline in her skills. "She's aged twenty years in the past six months!" she exclaimed, "We have to practically feed her her entire meal now, and she used to do a lot of it herself."

Staff learned from the nursing home that the staff there had been feeding Alice her entire meal and had not been having her walk at all. They were using a two-person transfer in toileting her. The staff who works with the Miller clients said, "We can't do that here! We only have two staff that can do toileting and we're not always both available." And so, in the week following this study, a care conference was held and it was decided that, due to the deterioration of skills and Alice's aggression in cold weather, she would remain at

the nursing home and receive physical therapy with the hope she might return in the Spring.

Aside from Alice's aggression in cold weather, which was not an issue in keeping her out of a day program before, she is no longer be attending the Miller Senior Center because her skills have declined to a point where she is no longer appropriate for that setting. However, the strong evidence of "learned helplessness" argues against her ability to regain these skills by Spring. Her expectations, and therefore competence, will likely be lowered to fit with the reduction in environmental press.

The staff working with the Miller Clients expressed frustration at this, "We want to help her, but we all have to work together in order for it to work. We know she can do more than she lets on."

Rising to Competence

As described in the literature review, the ecological theory of aging is an adaptation level theory. It holds that expectations which are either too low or too high for an individual will move him or her into a maladaptive zone, and that competence can be raised or lowered depending upon the expectations of one's environment. It predicts that if environmental demands are slowly increased it may be possible for older persons with developmental disabilities to "adapt

to environments with moderately high levels of environmental press" (Nahemow, Stokes, and Granfield, 1988, p. 4).

Louise is a 62 year old woman who came to the Miller Senior Center refusing to participate in any activity, crying uncontrollably, frequently incontinent, and with evidence of hallucinations. She would often become highly agitated and have "tantrums" when any requests were made of her.

She had been employed at the West lake DAC for a number of years and then moved to another community into foster care. During that time she was severely burned as a result of getting into a bathtub full of extremely hot water and was hospitalized for a month. The program director believes that her problems upon moving back to the local community were partly a result of that trauma.

Staff at the Miller Senior Center made it clear from the beginning that they would not tolerate any inappropriate behavior. For example, if she had a "tantrum" right before dinner she ate in the room. They found that Louise was very interested in being "in the community" and that this was a strong motivator to act appropriately.

After prompting her to participate in activities she began to do so grudgingly, especially if she was

allowed to help in some way (i.e., be the "caller" in bingo). An objective for her to participate in activities for a week without without "tantrums" was then set with the reward of going out for lunch or shopping alone with staff.

Staff explained that the breakthrough occurred when Louise finally made that objective and was out with staff. Staff described that when she parked the car in front of a store, Louise looked at her and angrily asked, "Where are we going now?" and staff offhandedly replied, "Crazy. Do you want to go with?"

Staff laughed as she said:

You should have seen her. Her mouth fell open and she stared at me....And then she started laughing, and she giggled the whole time we were in the store. After that something clicked and we realized that humor really works with her.

This description was consistent with observed behaviors. Staff often joked with Louise, but were also firm about the expectations at the senior center. They often reminded, "You need to find something to do" or "You're interrupting." Louise is now described as a "model senior." She is no longer incontinent and is generally compliant. She also meets an objective of independently planning activities for the rest of the group each week. Staff explained that "She still has her moments, but she has come a long way."

At the end of the observation period, Louise was participating in the Miller Senior Center weekly humanities discussion group. As the group was planning to have a seasonal potluck lunch, one of the members informed the West Lake staff, "It's alright if she doesn't bring anything."

One of the staff disagreed with this statement, saying to the other, "Of course she should bring something. She is part of that group," and talked to Louise about what she would like to bring. Louise decided to bring a "three bean salad" and was making plans to purchase and prepare the ingredients when the observation ended in mid-December, 1991.

Proactivity

Louise is an example of a person who was effectively challenged in terms of social competence. She is now making contributions to her environment in albeit "small" ways.

Lawton extends the ecological theory of aging with a description of the transactional nature of environment. "It is people who create social structures, therefore the volitional, proactive contribution of the person to the social structure must be acknowledged" (1989, p. 63).

It should not be overlooked that, when challenged with the proper expectations, older people with

developmental disabilities are capable of adjusting their adaptation level upwards. And, when provided with the opportunity to help shape one's environment, people of any age or capability are likely to do so.

DISCUSSION

In order to more fully understand the complexity of providing service to people with developmental disabilities as they age, more descriptive studies of this type are needed on a larger scale. The following background issues must also be explored as we move forward in providing services to this population throughout their lifespans.

Day Programs

As discussed in the previous chapters, some of the issues in providing service to seniors with developmental disabilities are related to the concept of retirement itself. At what point one should "retire" is difficult to determine even in the general population. Some feel that the definition of aging should be reevaluated for people with developmental disabilities. A greater likelihood of "early decline" has been cited in a number of cases--especially for those with Down syndrome who are likely to develop symptoms of Alzheimer's disease (Cochran & Dillon, 1990).

If the person does retire, what type of day programs should be made available? In this study alone

CHAPTER VII

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better served in a more flexible model where they wouldn't be required to attend each day. When some of the

If the person does retire, what type of day programs should be made available? In this study alone there is a very wide age range of 31 years. Providing service to a very old person with a mild level of mental retardation is not easily comparable to meeting the needs of a younger old person with higher limitations. Specialized programs should be considered for all segments of this unique population. For example, Jerry doesn't really fit in the developmental disabilities model as his needs have advanced more into the realm of age-related changes, but his needs might not be properly addressed in a nursing home either.

Two Different Cultures

As mentioned in the literature review, one of the problems in providing service to the elderly with developmental disabilities has been the dissimilar cultures of the two fields. The developmental disabilities field emphasizes objective measures of progress while aging services focus on maintaining skills, and both hold stereotypes about one another.

The current model of day programming requires a specified number of day activity hours per week in order for the client to receive funding. This case study suggests that perhaps some of the clients would be better served in a more flexible model where they wouldn't be required to attend each day. When some of the

clients at the Miller Senior Center fell asleep during the day, one of the staff wondered, "At this age, maybe this is too much?"

The concept of retirement raises some interesting issues in relation to the ecological theory of aging. Theoretically, one maintains or advances in competence only if effectively challenged. If a client is allowed to stay home or relax more, how will that affect his or her skills?

Choice

While elderly people with developmental disabilities are now "allowed" to play a primary role in choosing their options, many of these people are not familiar with the concept of "choice" as we know it. They were often raised in institutions or very sheltered home settings and have only recently been presented with options. As a program director in one study noted, "Age has given our clients the right to make choices" (Seltzer & Krauss, 1987b, p. 85).

Edgerton further described this phenomenon by stating:

When many older persons with mental retardation are offered opportunities to live more independently they decline the offer, preferring their restricted and routine lives to the unknown of a new life. They not only fear the unknown they have had little experience making choices, and that may be the key difference. (1988, p. 335)

Society-wide stereotypes about aging and retirement as a time of decline also may have an effect on a person's reluctance to retire. As Robert said during the observation, "What's the point of getting old? You can't work anymore!"

Lifelong planning must be practiced so that, as choice and integration become more common for people with developmental disabilities, they may have something to "retire to" rather than simply "departing from" (Janicki, 1990).

Integration

The most normalized environment is said to be one that allows a person to exercise a high level of autonomy in a generic setting where the majority of the people aren't disabled. However, the use of generic services for elderly people with developmental disabilities has raised some issues about "integration" for both fields.

While the director of the Miller Senior Center reports that the general population of seniors has "grown more accustomed to" the Miller Clients, there are many limitations to actual integration. Many people in this generation were raised during a time of routine institutionalization, and are uncomfortable participating in the same service arena as disabled people, arguing, "They don't belong at our center."

Fear, stereotypes, and actual limits in space combine to create an environment where the West Lake clients are expected to abide by a series of "rules" regarding their use of the center. As one of the staff who works with the Miller clients mentioned, "We feel like guests in someone's home."

The Senior Center director himself is mostly concerned about the space limitations at the center. He explained, "It's hard to believe that we run out of room in a place this big, but we do."

Observations confirmed this statement. Many times classes and meetings were held in sectioned-off areas of the main hall, and twice the Miller Clients went to a staff member's house for the day when the center was "too full." The senior center director explained, "Sometimes we don't have much choice, they [the clients] use a prime room every day."

Policy Consideration

The issue of integration is related to historical factors and cultural practices. It probably wouldn't be of concern if people with developmental disabilities had been mainstreamed throughout life and if there had been enough resources to effectively provide individualized service to all. Monk and Cox acknowledge the difficulty in using senior centers, "They manage to operate an array of programs on shoestring budgets with

small staffs, helped considerably by scores of volunteers whose training for working with the frail is likely to be minimal" (1989, p. 24)

Funding sources come with certain limitations. There is a "strong institutional bias which forces people into institutions that might not be necessary were community-based alternatives available and affordable" (Ansello & Rose, 1989, p. 5). "Aging in place" is becoming an issue in the developmental disabilities field as clients are moved from setting to setting in search of appropriate services rather than having the programs meet their needs in their current placements (Jannicki, 1990).

Adaptation to Change

"I don't think everyone has the energy for this kind of routine when they get older." Service providers must not forget how far people with developmental disabilities have come in recent years. Mainstreaming was virtually unheard of forty years ago as people were routinely institutionalized.

Many revisions in practice have been made at both the macro and micro levels. The rearrangement of tables in both seniors' programs with the belief that it will somehow improve those services is an example of the ecological theory of aging in and of itself. These "minor" changes combined with those at the macro level are evidence of an evolution to a more holistic understanding of this population.

The Ideal Setting

One cannot assess the provision of service without imagining a picture of the "ideal setting." In conducting the interviews, staff from both settings were asked, "What would be the ideal setting for elderly people with developmental disabilities?" Many parallels were found in the responses:

The staff member working with the West Lake Seniors and one working with the Miller clients both felt that a home-like setting would be best. One commented, "It would be nice to have a separate room for the different activities, and a place to lay down if they need to....It would be a lot more relaxed." The Life Skills staff also stressed the need for a more relaxed setting, "I don't think everyone has the energy for this kind of routine when they get older."

Another theme was that of having a separate facility. All three staff doing full time direct care work mentioned, "...a separate place close by...." It is interesting that those working at the Miller Senior Center were referring to having a separate facility near the senior center, while the staff working "in house" at West Lake thought it would be ideal to have a building apart from the DAC. Perhaps this too is related to the need for autonomy. As one of the staff at the Miller

Senior Center stated, "It would be nice to just have our own space."

Some mentioned the need for staff to work more individually with clients, emphasizing that, "It's important to find out their interests and keep them active."

The West Lake program director combined all of the above themes in her vision of the ideal setting:

It's really an individual thing....
Volunteering and going out into the community are best. It would be nice to have a higher staff ratio....Maybe someday clients will have their own facility and be the hosts of activities and programs, and invite the general public in.

When all is said and done, it is important to emphasize that the "ideal setting" will never be found. The differences in the people themselves combined with the ever-changing nature of service provision limit our visions of "what works" for each individual at any given time. We are left to assess environments in terms of their ability to strengthen the autonomy and enhance the competence of those individuals we are trying to serve.

allow them to participate, but with caveats regarding their dress, conversation patterns, and actions. Yet we tolerate eccentric or inappropriate behavior in people like ourselves with the excuse that "We all make mistakes."

Perhaps the greatest need for research in this field is in the further AFTERWORD of strengthening.

With the numerous and varied restrictions we have placed on people with developmental disabilities over the years they have shown a remarkable ability to adapt. As we continue to "teach" we can watch and learn. I learned much about myself in attempting to observe the normal daily routines of people's lives.

One afternoon, I was waiting to go on an outing with some of the West Lake clients outside the Miller Senior Center, when I noticed a man digging in an ashtray. My initial reaction, derived from experience working in the developmental disabilities field, prompted me to stop him. It wasn't until I noticed he wasn't a "client" that I no longer felt compelled to intervene.

I realize now that we seem to place even higher standards on the actions of people with developmental disabilities, just as we do with other minorities. We allow them to participate, but with caveats regarding their dress, conversation patterns, and actions. Yet we tolerate eccentric or inappropriate behavior in people like ourselves with the excuse that "We all make mistakes."

Perhaps the greatest need for research in this field is in the further exploration of strengths.

ENDNOTES

With the numerous and varied restrictions we have placed on people with developmental disabilities over the years been used throughout this report, they have shown a remarkable ability to adapt. As we

¹ The word "client" is frequently used in the refrain from "managing" we can watch and learn. people with developmental disabilities. This native language is used throughout this essay to refer to any person contracted for service at the West Lake DAC.

M.L.B.

² The definition of "seniors" is controversial in both the aging and developmental disabilities fields. For purposes of this study, this term refers to people 55+ unless otherwise indicated.

⁴ Green Thumb is an employment program that hires older workers on the basis of income.

⁵ The Miller Senior Center director and the West Lake program director have mutually agreed that no more than fourteen West Lake clients will attend the center on any given day. This is the number they have determined will comfortably fit in the room they occupy most often.

⁶ A genetic link between Alzheimer's disease and Down syndrome has been established with "increasingly convincing evidence that Down syndrome individuals who live beyond the age of 40 are affected with Alzheimer disease" (Miniszek, 1983, p. 378).

⁷ During the initial integration process many of the concerns presented to the West Lake staff had to do with "rules" unfamiliar to the clients such as: remembering to lock the door while using the restroom, not crowding in the lounge, and not going up to strangers wanting to shake hands. Many general senior center participants opposed the integration, stating, "We just don't know what to expect" (Blenkush, 1996).

⁸ Objectives are used in the developmental disabilities field to create goal plans for clients. Most clients have "teams" which include: social workers,

behavior therapists, family members, and representatives from the home and day program placements. They meet on a quarterly basis to review objectives and set new goals.

ENDNOTES

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⁹ Communication symbols are simple, standardized drawings often used in books, boards, or cards, as a means for people who are unable to speak to communicate.

¹⁰ The West Lake DAC contracts many clients for employment in various crews throughout the community. The "park crew" is responsible for cleaning the parks during summer months.

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