

A DESCRIPTIVE STUDY OF HOUSING PREFERENCES FOR PERSONS
WITH DISABILITIES LIVING IN NURSING HOMES IN DUNN COUNTY

By

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ABSTRACT

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This descriptive study replicated a Chicago study concerning housing issues for individuals with disabilities conducted by Access Living and The Center for Urban Research and Learning, Loyola University (Kruger, 2000). The trend for individuals with disabilities is to be able to choose to live independently and to receive community services to support that choice. Unfortunately, many people capable of living in other housing arrangements still live in nursing homes. Individuals are being placed in nursing homes for reasons including: onset of disability, placement after a hospital stay, homelessness; housing conditions (not accessible, inadequate, substandard, filthy, unaffordable, or unsafe) or because of lack of access to personal care services at home. Other states have initiated Medicaid waivers so that nursing home residents

can make a transition from nursing homes to Medicaid supported community-based care. Previous studies showed that with federal dollars and community services, individuals with disabilities can live more independently and enjoy a better quality of life, and such placement also saves taxpayers' dollars.

The specific purpose of this study was to determine if housing problems existed in a rural setting such as Dunn County, Wisconsin and if those problems were identical to or different from the problems in an urban area such as Chicago. An on-site survey of residents in the three nursing homes in Dunn County was conducted. A gap in the literature was addressed by examining rural nursing home placement, disability, daily life activity limitations and self-reported reasons for nursing home placement.

Results showed over 60% of residents did not want to move into a nursing home. The most common reason for nursing home placement, reported by almost two thirds of respondents (63.6%), was the inability to care for self. Other reasons included being afraid that something bad would happen (39.4%), being unable to care for own home/apartment (33.3%), inability to pay bills (12.1%) and lack of transportation (8.2%).

Some individuals (36.4%) chose to move into the nursing home. Survey participants were equally divided when asked if they felt that they could reside more independently. Preferred independent residencies included small apartments, and small group homes; residences in close proximity of others. Many of the individuals who did not report a disability reported a functional limitation. The most common life activity problem was transportation (63.3%). Bathing, housekeeping, walking, shopping taking medications and laundry (30% to 45%) were all life activities requiring assistance according to individuals that participated. Such activity barriers constrain residential choice.

Individuals with disabilities and functional activity barriers in Dunn County could live more independently with community supports such as home health. Individuals with disabilities should be offered informed choices and alternative housing alternatives prior to nursing home placement. Self-report by individuals with disabilities in both the Dunn County study and the Chicago study indicate that independent residency is a preferred choice, but that there are many barriers that prevent individuals with disabilities from residing independently.

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CHAPTER ONE

According to the U.S. Census Bureau (1999), the 1991-92 population for the United States was 251,796,000, with an estimated disabled population of 48,936,000 or roughly 19.4%. The 1990 Census data concluded that 2.3 million residents in institutions were assumed to have disabilities (LaPlante, 1992). It was estimated that 1.8 million of those individuals with disabilities resided in nursing homes and constituted more than 50% of the nursing home population (LaPlante, 1992; Kaye, 1998). Of those 1.8 million nursing home residents, it was estimated that 66% of the residents had mental impairments (LaPlante, 1992).

Unemployment, low self-esteem, lack of transportation, limited (few) support systems, lack of job training and employment opportunities are problems faced by individuals with disabilities (Ma & Coyle, 1999). Other problems such as inadequate health care, safety and housing issues, and community education about disability and rehabilitative services are barriers for individuals with disabilities (Ma & Coyle, 1999). Such problems may limit independent choice of residential housing and the capacity for full community inclusion for individuals with disabilities (Kaye, 1998). Individuals with disabilities without adequate choices for housing may have to compromise their quality of life (Kapur, 2000; Murray, 1999). Historically, individuals with disabilities were kept segregated from the community by institutionalizing them or keeping them home bound (Kaye, 1998; Nelson, Hall, Walsh-Bowers, 1999; DeVaney, 1999). If that is true, are there barriers in Dunn County, Wisconsin for free and informed choice in housing?

Statement of the Problem

The purpose of this study was to determine whether Dunn County residents with disabilities were living in the environment of choice and whether there were barriers that prevented individuals from living either in an assisted living setting or an independent private residence instead of a nursing home. These topics had been addressed in an earlier study

(Kruger, 2000) of disability and nursing home residence in Chicago. This study was designed to explore similar issues in a rural setting.

A telephone survey of three nursing homes and nine community-based, supported, and independent residential facilities was conducted in Dunn County, Wisconsin, by the author to determine if there were sufficient subjects for a replication study (Jacobs, 2000). This survey showed that there were ample numbers of individuals with disabilities residing in Dunn County supported living environments to replicate the Chicago study, "A Study of Housing and Personal Assistance Issues for People with Disabilities Residing in Nursing Homes" (Kruger, 2000).

Questions

This study was designed to explore if there are barriers that affect independent living status for persons with mental, physical or developmental disabilities. Specifically the purpose of this study was to identify whether Dunn County residents with disabilities were living in the environment of choice, and whether there were barriers that prevented individuals from living either in an assisted living setting or in an independent private residence instead of a nursing home. There was one main research question addressed in this study: Are Dunn County nursing home residents with disabilities living in the residence of choice and is this the appropriate choice for them? The study examined the main research question through the following related research questions: Do residents report the presence of disability at time of admission? Do nursing home residents report disability related functional limitation at the time of admission? Do nursing home residents report being satisfied with nursing home placement? What reasons do nursing home residents give for nursing home placement? Subjects for this research were individuals with functional, mental, or developmental disabilities that were residing in nursing homes at the time of the study.

Definitions of Terms

To provide clarity of understanding for the purposes of this research, the following terms were defined:

Activities of Daily Life (ADL). A scale developed through research (LaPlante & Carlson, 1996, Branch & Hoeng, 1997) to measure dependencies in basic self-care or other functions necessary for independent living and avoidance of institutionalized living. Examples of functional activity items reflected on the ADL scale include bathing, dressing, toileting, eating, walking, and the ability to physically get out of a chair. This scale examines the person's ability to perform physical tasks. The ADL scale was one of the sources for the researcher-developed survey used in the current study. For the purposes of this study, ADL (s) refers to the physical functional activities of daily life that enable people to maintain themselves in independent living. Those functional activities that must be performed in daily life will henceforth be described as ADL (s) throughout the body of this paper.

Disability Description and Definition.

Disability has numerous definitions. Each agency or piece of legislation has a slightly different definition (e.g. Worker's Compensation, the American with Disabilities Act, or the Rehabilitation Act). For the purpose of this study the Social Security definition will be used, since it is universally accepted. Disability has been described in the Social Security Administration (SSA) Handbook (1997, p.1) as:

...The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less

than 12 months. A person must not only be unable to do his or her previous work but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful work, which exists in the national economy. It is immaterial whether such work exists in the immediate area, or whether the worker would be hired if he or she applied for work.

Independent Living. Independent living includes any living arrangement with or without others that occurs in the community. Examples of independent living include private individual residences, residences with others, or residence in independent living facilities as described below.

Independent Living Facilities.

Independent living facilities are residential options for people who can live independently but choose to live in close proximity to others, as in a small community of houses or apartments or in a group home with minimal care supports (Bishop, 2000; Branch & Hoeing, 1997; Nelson, Hall, Walsh-Bowers, 1999).

Instrumental Activities of Daily Life (IADL).

A scale (La Plante & Carlson, 1996; Branch & Hoeing, 1997) developed through research to measure dependencies in basic self-care and other functions necessary for independent living. The IADL was designed specifically to measure complex activities that persons with disabilities may find difficult. IADLs are distinguished from ADLs in that IADLs combine both the performance of physical and the cognitive activities necessary to carry out complex tasks required for daily living. Examples of such activities include: preparing meals,

shopping for personal items, managing money, using the phone, doing housework and laundry, taking medications, and finding transportation modes in the community. Many surveys use the IADL to determine if help or assistance is needed from other non-disabled individuals (La Plante & Carlson, 1996; Branch & Hoeing, 1997). This scale was one of the sources for the researcher-developed survey used in the current study. For the purposes of this study, IADL (s) refer to the complex activities of daily life that enable people to maintain themselves in independent living. Those complex functional activities that must be performed in daily life will henceforth be described as IADL (s) throughout the body of this paper.

Nursing Home.

A nursing home provides skilled nursing care and rehabilitation services to individuals with illnesses, disabilities, injuries, and traditionally, to elderly frail individuals. Sometimes nursing homes provide care for people with developmental disabilities or mental illness. Most nursing homes have specialty care, pharmacy services and therapies. Each nursing home is unique in the range of services provided. The size of the facility and the population served determine how many services are provided (Newcomer & Preston, 1995; Bishop, 2000).

Assumptions

Four underlying assumptions were identified with this study. These assumptions were:

1. That Dunn County is a rural setting and that mobility (primarily lack of transportation) is a key issue for independence.
2. That there are insufficient educational and community resource materials available to persons with disabilities in Dunn County.
3. That the residents in nursing homes, assisted living, and supported living are unhappy and do not wish to reside there.

4. That any person sixty-five years of age or older is disabled only as a result of aging and that those disabilities include visual, hearing, mental (dementia), and physical disabilities.

Limitations

Several limitations were identified at the onset of this study. These were:

1. This was a small study and may not be representative of the disabled population in Dunn County as a whole.
2. This study may miss many individuals in the Dunn County area.
3. Individuals may be concerned that by responding to the survey truthfully, that their responses may affect services or that they may be identified by the nursing home.
4. Facilities asked for permission to interview residents may view this survey as a threat to the quality of care and continuation of funding support for the residential facility.
5. Many people may not trust the surveyor and may not participate in this survey.
6. There may be a bias on the part of the person who assists the resident with a disability or the person interviewed may be afraid to answer truthfully.

CHAPTER TWO

Review of the Literature

The problem addressed in this study was whether Dunn County residents with disabilities were living in the environment of choice and whether there were barriers that prevented individuals with mental, physical or developmental disabilities from living either in an assisted living setting or in an independent private residence rather than a nursing home. In this chapter, factors are discussed that were assumed to contribute to nursing home placements based on a thorough review of the literature. Topics reviewed in this chapter include: (a) scope of disability; (b) disability definition; (c) disability and nursing home placement; (d) information, advocacy and service options as barriers to residential choice; (e) physical barriers to residential choice; (f) economics and other barriers to residential choice; (g) residential choice options crisis, and (h) summary and conclusion.

Scope of Disability

According to the U.S. Census Bureau, the 1991-92 population for the United States was 251,796,000, with an estimated disabled population of 48,936,000, or roughly 19.4% of the entire population (U.S. Census Bureau, 1999). The 1990 census data concluded that 2.3 million residents with disabilities live in institutions (LaPlante, 1992). Nursing home residents constituted more than 50% individuals with disabilities, or 1.8 million people (LaPlante, 1992; Kaye, 1998). Americans with disabilities numbered one-fifth of the national population and those figures were predicted to increase in the future (Smart, 2000).

Disability Definition

Visually obvious limitations (e.g. someone using a wheelchair) are easy for individuals to identify as disabilities. Disabilities that are more difficult to detect are those disabilities that

cannot be visually observed, such as epilepsy, diabetes or mental illness. Disability has numerous definitions(Smart, 2000). Each agency and organization has a slightly different definition. For the purpose of this study, the universally accepted Social Security Administration definition will be used as described in the Social Security Administration (SSA) Handbook (1997, p.1):

"The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. A person must not only be unable to do his or her previous work but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful work, which exists in the national economy. It is immaterial whether such work exists in the immediate area, or whether the worker would be hired if he or she applied for work."

Disability and Nursing Home Placement

An extensive literature review for this study corroborated findings by Kruger (2000) that very little research had been conducted examining factors that contributed to nursing home placements versus independent living (Kruger, 2000). Independent living is far more desirable than nursing home placement for individuals with disabilities because of social integration, or opportunities to interact with a variety of others on a regular basis. Such community integration and access have been found to be important quality of life issues for persons with disabilities (Pain, Dunn, Anderson, Darrah & Kratachvil, 1998; Wislon, et al. 1991). Social Integration involves a shift from being invisible to being more visible and integrated in the community

(Kaye, 1998). Compatible with the importance of social integration for persons with disability are findings that it is more common for family members than for residents to be satisfied with nursing home placements (Kapur, 2000; Kruger, 2000).

Kruger (2000) completed 2 surveys of the residents at 17 urban nursing homes in Chicago. The number one response (64.5%) of the 65 nursing home residents, who completed those surveys, indicated that they would prefer not to live in nursing homes if other options were available (Kruger, 2000). Other options to nursing homes were described as varying from group homes, to apartments, to individual housing grouped together in a complex. The Kruger study was conducted in an urban area, which could be expected to have more concentrated and comprehensive services than the services available in a rural setting. Life disruption due to lack of available supports and resources in the Chicago study corroborated evidence in the literature that a lack of services frequently limits programming and life options for elders (Konnert, Gatz & Meyen Hertzprung, 1999) and for those with disabilities (Bishop, 2000).

Information, Advocacy and Service Option Barriers to Residential Choice

A person with a disability, whether physical or mental, can often be discriminated against because of that person's inability to advocate for him or herself (Kaye, 1998). Historically, individuals with disabilities were identified in the medical model as persons who were sick (Kaye, 1998; Smart, 2000). Recent disability legislation, has encouraged individuals with disabilities to assert rights for recognition as individuals that are not sick, but disabled (Kaye, 1998). A person with a disability may not know his or her rights or about service availability (Eberhard, 1999; Swedlund & Nosek, 2000; Kaye, 1998; Roessler & Rumrill, 1998). Sometimes family members or others advocating for the person with a disability are not knowledgeable of

legal protection or services; they may have views that differ from the person with the disability (Condeluci & Williams, 1997; Eberhard, 1999; Lustig, 1999; Smart, 2000).

In the Chicago study by Kruger (2000), the second reason cited for individuals living in nursing homes was lack of information and assistance in finding suitable, affordable housing as well as the lack of adequate community based service options. Advocacy often means the difference between independent living and being placed in a nursing home (Kaye, 1998; Wilson, 1991; Bishop, 2000). Several studies by Roessler and Rumrill (1995; 1998) and studies by Allaire (1998) and Drum (1998) have indicated that a relationship exists between attitudes and understanding of disabilities. Roessler and Rumrill believe that individuals with disabilities need to self-advocate by identifying problems and requesting services (1998). Those services include an exploration of community resources and the opportunity to live as independently as possible.

Physical Barriers to Residential Choice

Not only can the lack of advocacy be a barrier to housing choices, but so can the presence of physical barriers. Physical barriers may be something as common as the presence of steps or doorways that are too narrow for a wheelchair to pass through. Steps or narrow doorways may prevent a person using a wheelchair from entering a room or a residence. Accessibility studies in the Chicago area revealed that 3.9% of single dwellings, 6.6% of 2-9 unit dwellings and 29.9% of 10+ unit buildings were accessible to individuals using wheelchairs (Kruger, 2000). Kaye (1998) found that only 2.9% of Americans with disabilities have housing with accessible features, yet 29.2% of all American families include at least one family member with a disability. The Fair Housing Act of 1988 allows tenants to make rental property alterations at their own expense (Kaye, 1998), but modifications to remove physical barriers require financial resources.

Unfortunately, individuals with disabilities are some of the poorest individuals in the United States (Kaye, 1998; LaPlante & Carlson, 1996).

Economics and Other Barriers to Residential Choice

Other barriers to housing choices that have been described in the literature include education, employment opportunities, health care, safety issues, transportation, and/or rehabilitative services (Ma & Coyle, 1999; Bishop, 2000; Kruger, 2000). All of these barriers restrict access to services or limit the range of living options available to the person with disability. Kruger (2000) found that for persons with disabilities the most common independent living barrier was financial; the lack of adequate income to reside in the residence of preference.

Previous studies discussed the financial aspects for individuals with disabilities who could not afford suitable housing (Bishop, 2000; Edgar, et. al., 1999; Murray, 1999). Housing costs have increased, yet many individuals are receiving fixed Social Security payments (Edgar, et al., 1999; Bishop, 2000). Such fixed incomes are often inadequate for housing when combined with required medical costs and transportation (Bishop, 2000). For example, medication use by persons with disabilities has increased more than medication use by other persons in the United States. In 1994, 81.1% of the population with disabilities reported using prescribed drugs (Health Case Financing Review, 1996).

The 1990 census data concluded that 2.3 million residents with disabilities live in institutions (LaPlante, 1992). Nursing home residents constitute more than 50% or 1.8 million people with disabilities (LaPlante, 1992; Kaye, 1998). Many individuals with disabilities live solely on financial aid supplied by federal income maintenance programs (Kaye, 1998). Individuals that are poor or living at poverty level are twice as likely to need assistance with Instrumental (IADLs) and other Activities of Daily Living (ADLs) (LaPlante & Carlson, 1996).

Residential Choice Options Crisis

The issues of disability, economics and restricted ability to perform ADLs affect people with disabilities in the county studied. The 1990 Census counted 35,909 persons living in Dunn County, Wisconsin (Wisconsin Population Projections, 2000). At the time of this study, Dunn County had three nursing homes with a combined population of approximately 266 residents (Jacobs, 2000).

Currently there is a crisis in human service funding throughout the state of Wisconsin (Bishop, 2000). According to Bishop (2000), all aspects of independent living, including housing choices, are in jeopardy. When services such as home health and transportation are cut, individuals with disabilities are less likely to live independently (Bishop, 2000). Unfortunately, persons with more severe disabilities become institutionalized when funds are reduced for services (DeVaney, 1999).

Supports to carry out daily life activities (ADLs) are among the human services needed to enhance independent living and residential choice. ADL support needs are different for persons with and without disabilities. More persons with disabilities may need such support. Those supports may be required throughout the lifetime and persons with disabilities may need help with instrumental (complex cognitive and physical) activities as well as with the more routine physical support associated with ADLs. Research has shown that persons with disabilities are more likely to need assistance with IADLs than aging individuals without disabilities who most often need help with ADLs (LaPlante & Carlson, 1996). Persons with disabilities need assistance with IADLs & ADLs throughout their life span. Almost 90% of persons with disabilities living in the community reported receiving some type of home care help (Mauser & Miller, 1994). It must

be noted that 42% to 48% of individuals with disabilities who needed help with ADLs and IADLs are under the age of 65 (LaPlante & Carlson, 1996).

Individuals with disabilities often receive support and assistance from families, but are twice as likely as non-disabled persons to live alone (Kaye, 1998). Therefore, those individuals with disabilities must be able to financially support independent housing. Most individuals would prefer to live independently, with nursing home residency as a final or last resort (Kruger, 2000; Wilson, et al., 1991). Until legislation changes are made, (Bishop, 2000) individuals in need of assistance with activities of daily living will continue to be placed in nursing homes.

Summary and Conclusion

Disability is a common occurrence for people residing in the United States, in Wisconsin, and in Dunn County. New legislative efforts, models of disability and enhanced consumer activism have emphasized the importance of consumer choice in all areas of life. One important area of life choice is place of residence. Although individual choice in place of residence is important, there are numerous barriers to the expression of such choice. Among the common barriers are: information, advocacy and availability of service options; physical barriers; economics and various other barriers. Of utmost concern is financing for services that are delivered at the local community level. Lack of funding has been described as a current "crisis" (Bishop, 2000; Snowe, 2000). Funding gaps result in many people with disabilities being forced to reside in nursing homes. There is a need for further exploration of specific disability related service needs if consumers with disability are to have choice in where they reside. Otherwise, lack of funding and services may result in nursing home placement. This study will address a gap in the literature by examining what factors led people with disabilities to live in nursing homes.

CHAPTER THREE

Methodology

The purpose of this study was to identify whether Dunn County residents with disabilities were living in the environment of choice, and whether there were barriers that prevented residents with disabilities from living either in an assisted living setting or in an independent private residence instead of a nursing home. There was one main research question addressed in this study: Are Dunn County nursing home residents with disabilities living in a nursing home residing in the residence of choice and is this the appropriate choice for them?

This was a descriptive replication study that used a self-report survey to examine disability factors related to nursing home placement for residents in Dunn County skilled care facilities. The study examined the main research question through the following related research questions: disability status at the time of admission, disability related functional limitations, and self-described reasons for nursing home placement. Results from this survey were analyzed to determine whether individuals with disabilities were living in settings that they felt were appropriate. Results were also examined to determine whether individuals with disabilities felt that living in a nursing home was an appropriate choice for them.

In this chapter the methodology used to answer the research question will be described. Specific topics covered in this chapter include: (a) research design, (b) populations and subjects, (c) methods for gathering data/instrumentation, (d) data collection, (e) analysis of data, (f) accuracy precautions/strengths and weaknesses of methodology and (g) summary.

Research Design This was a descriptive replication study using a self-report survey to examine disability factors related to nursing home placement for residents in Dunn County skilled care facilities. Specifically, the survey examined place of residence at time of admission to nursing

home, disability status at time of admission, disability related functional limitations, and self-described reasons for nursing home placement.

Population and Subjects

At the time of the study, there were 266 nursing home residents living in 3 different skilled nursing facilities in Dunn County (Jacobs, 2000). Subjects were drawn from this pool of potential respondents.

Administrators and nursing home staff prescreened residents for participation in this study, since the nursing home staff is required to protect the rights of residents by law and by nursing home policy. Individuals with cognitive limitations, or those who were otherwise unable to give fully informed consent were not informed of the study and thus were excluded from the sample. As an incentive, residents were offered a Sacajawea dollar to return completed surveys within two hours of administration. Of those residents informed by facility staff about the study, 33 agreed to participate and were invited to an on-site orientation and administration session. All of the 33 individuals who attended the administration session chose to complete the survey and thus were included in the sample described here.

Methods for Gathering Data/Instrumentation

Instrument A self-administered questionnaire was developed by the researcher to answer the research questions. The instrument was an adaptation of an earlier format used by Kruger (2000) to study housing choice in Chicago. The Chicago format was modified as a self-report survey. The new survey used content area from the IADL (La Plante & Carlson, 1996; Branch & Hoeing, 1997) & the ADL (LaPlante & Carlson, 1996, Branch & Hoeing, 1997) scales which measure functioning in major activities of daily life. Input on the survey was subsequently obtained from area Independent Living staff and from Human Services Long-Term Support staff

to ensure relevance to issues in the local area. A rehabilitation professor proofread the completed survey instrument and revisions were made accordingly.

A previous telephone survey by the researcher determined that there was a need for a study to be conducted in Dunn County because there were individuals with disabilities residing in nursing homes (Jacobs, 2000). For confidentiality and ethical purposes, no names were recorded on the survey. Residents indicated willingness to participate in the study by completing the survey form. The only identifying information collected was the respondent's year of birth. Forms at the three different nursing homes were identical. The researcher-developed instrument included questions related to: place of residence at time of admission to nursing home, disability status at time of admission, disability related functional limitations, and self-described reasons for nursing home placement. A copy of the cover letter, consent form, and the survey can be found in Appendix A.

Data Collection.

In October 2000, the researcher asked for permission to give a brief overview of this study and the importance of data collection to the administrators and appropriate staff of the three Dunn County nursing homes. The researcher obtained permission from all of the nursing home administrators to enter their facility and distribute questionnaires to residents. Staff at all three facilities then explained the study, incentives, and the administration session to individuals they deemed appropriate for participation.

In all three facilities, the facility administrators deemed it absolutely essential that the facility social worker be present during the survey administration session to protect the rights of participating residents and to ensure that individuals that were inappropriate did not participate.

An example of a reason that someone might be deemed inappropriate for participation would be when the nursing home was required to have guardian permission to allow the resident to participate. As soon as a social worker was designated for attendance, the researcher instructed and informed that social worker about the importance of a non-biased study. Each social worker was asked to maintain complete confidentiality regarding resident participation and responses.

The researcher trained one other Vocational Rehabilitation Graduate student to conduct the survey in the researcher's absence. This training included reviewing the study purpose, consent form, the survey instrument, and all other information relevant to the study. This was done to ensure that the assistant could adequately inform and assist all participants. Procedures for providing form completion assistance were also explained for consistent data collection.

During the survey administration session, reasons for the presence of the social worker were explained to residents before survey completion. The researcher or assistant (henceforth called surveyor) informed the residents that they could answer honestly and openly without retribution from the social worker or the facility. The surveyor and social worker both assured residents that their survey answers and participation would be kept confidential. Residents were offered the option to have a family member or advocate present when they completed the survey. One individual chose to have a family member present to assist with the survey questions.

The administration session was held in a room with a closed door to ensure confidentiality and the privacy of all participants. After explaining the purpose of the study, participant rights were explained including the right to withdraw from participation at any time and all measures to protect confidentiality. After the study explanation, self-administered questionnaires/surveys were distributed. Any resident who needed help answering the survey questions was provided assistance by the surveyor.

All residents completed the survey in approximately one hour. Residents gave their surveys to the surveyor. The surveyor checked to ensure that the form had been completed, dropped the survey in an envelope and handed the resident a Sacajawea dollar.

Residents who did not attend the administration session were offered the opportunity to complete surveys and return them by mail. A supply of surveys, return address envelopes and Sacajawea dollars were left with each nursing home. A telephone number was listed at the bottom of each survey in case residents needed assistance in answering the survey questions. No surveys were received through the mail, thus the findings reported here were composed of responses from the 33 residents who attended the administration sessions.

Analysis of Data

Results from completed surveys were collected and tabulated. Nominal level data were analyzed and reported to describe responses to survey items. Demographic data describing the age of respondents was also tabulated. Age data included frequency counts by decade, mean and median age as well as group standard deviation to describe the variability in age within the sample. Analysis of individual item responses within each content area included frequency percentages and cumulative percentages. Responses were rank ordered with frequencies, percentages and cumulative percentages reported in Chapter 4.

Accuracy Precautions: Strengths and Weaknesses of Methodology Strengths

There were a number of strengths associated with the design and methods used in this study. This was a replication study of earlier research in the Chicago area (Kruger, 2000). Thus much of the design had already been field tested, with modifications made to gather data relevant in the chosen rural area. Early consultation with Independent Living staff and Human Staff

Long-Term Support staff also enhanced study fidelity and utility by influencing the design and methods used in the study.

The use of a self-report survey was chosen to enhance confidence in the findings reported here. Obtaining information from the person actually affected by disability and functional limitations enhanced confidence that the person reporting would have sufficient information about a resident's daily life experiences.

The instrument was constructed with minimal responses required so that writing barriers would not preclude participant reporting. Specific examples of activity of daily living difficulties were provided to enhance respondent understanding of the survey questions, as well as to enhance the consistency of reporting. The availability of trained surveyors to answer questions and to assist with survey completion also enhanced the accuracy of reporting in this study.

Measures were taken to ensure resident comfort and confidence in reporting their experiences. Procedures to safeguard confidentiality were put in place and thoroughly explained to participants. Age was the only potentially identifying information collected in this study. Participants also had the option of having a family member or advocate with them during survey administration.

Limitations

A number of limitations were also associated with this study. Some of those limitations were associated with study design. This population may or may not be reflective of the larger population of persons with disabilities residing in the community studied. Participants were selected by virtue of residence in skilled nursing facilities. Residents may have experienced functional limitations due to the aging process and thus nursing home placement with the

availability of skilled care may have been the most beneficial option for them. The study was conducted in a rural county so there were few nursing homes and a small population of residents in the nursing homes to survey. The small sample size may limit application to other areas

The use of a self-report format could limit confidence in findings. There may have been a difference between perceived and actual barriers to residential choice. Residents who were displeased about nursing home placement may have minimized the impact of activity restrictions or may have reported fewer barriers than were actually experienced at the time of nursing home placement.

There were also a number of limitations related to sampling error and selection bias in this study. The participation rate of 33 residents from a total nursing home resident population of 266 is quite low. Nursing home staff selection of residents to participate in the study introduced potential selection bias. Efforts to reduce such bias included the use of pre-existing criteria to screen residents for potential participation. That screening criteria included the ability to make an informed choice about participating. However, no data was collected about those not chosen for participation, so those residents selected by nursing home staff could have varied from non-selected residents in many ways. The nursing home staff did not report the total number of individuals who were told about the survey. It is therefore impossible to tell how many residents were determined inappropriate for participation and how many residents chose not to participate.

Low response rates could suggest that nursing home residents who filled out the survey may have been more physically and mentally motivated to respond. Respondents may have experienced more barriers to independent living and thus wanted to report such concerns. The

use of incentives (Sacagwea dollar) may have biased participation, although the small monetary value of the incentive could make such effects negligible.

The vulnerability of the population also presents methodological barriers to the fidelity of findings. Persons responding to the survey may have feared retribution from the nursing home or staff for giving truthful or untruthful answers. The presence of a staff social worker at the administration sessions may also have influenced participants' responses, despite reassurances of confidentiality and the security of data as explained by surveyors and by the social workers.

Summary

This was a descriptive replication study using a self-report survey to examine disability related factors related to nursing home placement for residents in Dunn County skilled care facilities. Specifically, the survey examined place of residence at time of admission to nursing home, disability status at time of admission, disability related functional limitation and self-described reasons for nursing home placement.

CHAPTER FOUR

Results and Discussion

In this chapter observed results of the study are described. Results from this survey were analyzed to determine if the individuals surveyed in skilled nursing care felt that they were residing in housing of their choice and whether it was the right choice for them. Specific topics discussed in this chapter will include: (a) study plan and procedures, (b) evidence that answers the research question, (c) unanticipated findings and (d) summary of findings.

Study Plan and Procedures

This was a descriptive replication study that used a self-report survey to examine disability factors related to nursing home placement for residents in Dunn County skilled care facilities. The survey examined the place of residence at time of admission to the nursing home, disability status at the time of admission, disability related functional limitations, and self-described reasons for nursing home placement.

At the time of this study, there were 266 nursing home residents living in three different skilled nursing facilities in Dunn County. Subjects who had been pre-screened by administrators and staff for appropriateness and resident protection, were drawn from this pool of potential respondents. A Sacagewea dollar was offered to participants as incentive to complete and return the survey to surveyor within two hours of administration. A total of 33 residents completed surveys at the sessions.

The instrument used for gathering data/instrument was a self-administered survey that included the participant's birth year. The researcher-developed instrument included questions related to: place of residence at time of nursing home admission, disability status at time of nursing home admission, disability related functional limitations, and self-described reasons for

nursing home placement. A copy of the cover letter, consent form, and the survey can be found in Appendix A.

Survey administration was held in a room with a closed door to ensure privacy and confidentiality of the participants. All residents completed the survey within one hour, the surveyor then checked the form to ensure that it had been completed, dropped it into an envelope and gave the resident a Sacajewea dollar. Residents who did not attend the session were offered the opportunity to complete surveys and return them by mail. No additional surveys were returned so results described here reflect the responses of the 33 residents who attended the survey sessions.

Group descriptive data was compiled on this sample of 33 residents, including age information and the place of residence at time of admission to the nursing home. Age information reported includes the range of respondent ages, group mean age, observed mode, and the standard deviation to describe the age variation within the group. Information to respond to the research question and each of the related questions was also examined by analyzing responses to the survey items. Results were tabulated by determining the frequency of survey participant responses for each item and then by calculating percentages of the group that endorsed each item. Observed frequencies for each category of response as well as group percentages will be reported later in this chapter.

Evidence Related to the Research Question

Description of Sample Residents were asked to identify their year of birth and the place of residence prior to nursing home placement to provide greater clarity about the individuals that chose to participate in this study. The following two tables describe this background information.

Table 1, immediately below, describes respondent age in years. Table 2 describes place of residence at time of admission to current skilled care facility.

Table 1: Respondent Age in Years

Age of Participants	Reported Age	Percent	Cumulative Percent
45-55	45,53,55	9.0	9.7
63-69	63,64,65,65,69	15.1	25.8
70-79	70,74,76,77,77,79	18.1	45.2
81-89	81,82,82,84,85,85,87,8788,89,89	33.4	80.6
91-96	91,92,93,94,95,96	18.0	100.0

Thirty-one of the thirty-three individuals that participated in the study responded to the age question. The mean age of the individuals was 78.45, and the median age was 82 indicating that this was an older aged sample. There was considerable age variability within the group with a calculated standard deviation of 13.29 years. The youngest person who responded to the survey was 45 years old, and the oldest person that responded was 96 years old. As mentioned previously, this was a sample of persons in the later years of life. The largest concentration of individuals was found in the eighth decade, or individuals in their 80's at the time of the study. Individuals that were seventy years of age or older consisted of 69.5% of the total sample, with over 51% of the sample older than the age of 81.

In addition to collecting background information to understand the age of the sample that participated in this study, it was important to understand the place that respondents lived immediately prior to moving to the nursing home. The table on the following page illustrates residential status at the time of admission to the skilled care facility.

Table 2: Place of Residence at Time of Admission to Skilled Care Facility Residence

	Frequency	Percent	Valid Percent	Cumulative Percent
1 With someone	11	33.3	33.3	33.3
2 Alone	14	42.4	42.4	75.8
3 Nursing Home	4	12.1	12.1	87.9
4 Group Home	1	3.0	3.0	90.9

5 Independent Living Facility	1	3.0	3.0	93.9
6 Independent Residential Community	2	6.1	6.1	100.0
7. Shelter, prison, institution	0	0	0	100.0
Total	33	100.0	100.0	100.0

All thirty-three of the surveyed respondents answered this question. Of the choices given, a third (33.3%) reported that they had been living with someone else before moving into the skilled care nursing home, while almost half (42.4 %) had been living alone. Four individuals, or 12.1% of residents had been living in a different nursing home previously, one person had lived in a group home, and one person had lived in an independent facility. Two other individuals had been residing in an independent residential community. Over 76% of the individuals surveyed had been either living alone or with someone else. No person indicated that he/she had been residing in a shelter, prison or an institution prior to admission.

Answer to the Research Question.

The research question examined in this study was: Do individuals in skilled nursing care feel that they are residing in housing of their choice and is that nursing home placement the right choice for them? The majority of residents did not report wanting to live in the nursing home. Data analysis showed that only 36.4% of respondents wanted to enter the nursing home when they were admitted. Analysis showed mixed results when examining if the nursing home placement was the right choice for respondents. The majority of residents did report limitations in important activities of daily living. The research question about choice and appropriateness of residence was more thoroughly examined through the specific related research questions answered below.

Answer to the first related research question.

The first related research question was: Do residents report the presence of disability at time of admission? The majority of respondents did report that they were disabled at the time of admission to the skilled care facility. Almost two thirds of the sample (60.6%) reported that they had some type of disabling condition when they entered the skilled care facility. This is illustrated in the table below.

Table 3: Disability: Before Living Here, Were You Disabled?

	Frequency	Percent	Valid Percent	Cumulative Percent
1. Yes	20	60.6	60.6	60.6
2. No	2	6.1	6.1	66.7
3. No, but at least one functional limit identified	11	33.3	33.3	100.0
4. Total	33	100.0	100.0	

Twenty individuals, or 60.6% of the sample responded that they had a disability before admission to the nursing home. Two individuals answered that no, they did not have a disability. Interestingly, eleven individuals, or 33.3%, answered that they did not have a disability but later reported at least one of the functional or self-care limitations described in the next table.

Answer to the second related research question.

The second related research question was: Do nursing home residents report disability related functional limitation at the time of admission? Many individuals (9.1% to 63.6%) reported life activity limitations at the time of nursing home admission and these problems varied. Some of the individuals that reported limitations did not report a disability in the previous question. Specific problems in life activities are detailed in the table on the next page.

Table 4: Reported Problems in Daily Life Activities

Problems with taking medications	Frequency	Percent	Cumulative Percent
1 Yes (checked)	11	33.3	35.5
2 no (not checked)	20	60.6	100.0
Problems with bathing			
1 yes (checked)	15	45.5	48.4

2 no (not checked)	16	48.5	100.0
Problems with shopping			
1 yes (checked)	11	33.3	35.5
2 no (not checked)	20	60.6	100.0
Problems with dressing self			
1 yes (checked)	10	30.3	32.3
2 no (not checked)	21	63.6	100.0
Problems with house cleaning			
1 yes (checked)	13	39.4	41.9
2 no (not checked)	18	54.5	100.0
Problems with meal preparation			
1 yes (checked)	9	27.3	29.0
2 no (not checked)	22	66.7	100.0
Problems with laundry			
1 yes (checked)	11	33.3	35.5
2 no (not checked)	20	60.6	100.0
Problems with walking			
1 yes (checked)	13	39.4	41.9
2 no (not checked)	18	54.5	100.0
Problems with transportation			
1 yes (checked)	21	63.6	67.7
2 no (not checked)	10	30.3	100.0
Problems with paying bills			
1 yes (checked)	7	21.2	22.6
2 no (not checked)	24	72.7	100.0
Problems with other			
1 yes (checked)	3	9.1	9.7
2 no (not checked)	28	84.8	100.0

Transportation (driving car somewhere) was the largest daily living activity problem reported by 63.6% of the thirty-one individuals that answered this survey question.

Transportation was thus the biggest daily living problem reported in this sample. The second greatest problem in life activity was related to self-care, specifically bathing, with 15 individuals, or 45.5% reporting problems with bathing. The next most frequently reported problems related to activities required for personal mobility or the ability to care for a home. Specifically, 13 people (39.4% of respondents) reported problems with housecleaning and walking.

Shopping, taking medications, and laundry were slightly less problematic for individuals in this study as only 33.3% of the participants indicated that they had a problem with those IADL's; yet 60.6% of the participants did not have such difficulties. Similarly, when asked if the person had problems dressing themselves, 30.3% had a problem with dressing, but 63.3% did not. Meal preparation and bill paying were also notably lower barriers to independent living. Less than a third (27.3%) of respondents reported that they had a problem preparing their meals and fewer individuals (21.2%) had problems paying bills. Two individuals failed to respond to any of the listed items.

Answer to the third related research question.

Do nursing home residents report that nursing home placement is appropriate? Results were mixed when examining the data related to this research question. This research question was addressed by asking residents if (a) they felt they could live by themselves despite reported problems with activities, (b) if they felt that the nursing home was the best choice for them and (c) in those instances where respondents indicated that the nursing home was not the only place they could live, what other place of residence they might choose. Although indicating a preference for other placement (67.3% did not want to move to the nursing home), when it came to practicality or ability to live independently, residents were less confident.

The 30 residents who reported problems with daily activities were equally divided on the question of whether they could live by themselves despite those activity problems. A total of 50% of individuals who experienced ADL problems and who responded to this question reported that they could live by themselves, while the other 50% indicated that they felt they could not live by themselves.

A slight majority (57.6%) of all 33 survey respondents felt that the nursing home was the only place they could live. Of those individuals who felt that they could live elsewhere, most (78.6%) felt that the alternative residence would either have to be in an apartment or in a residence with others. Only 21.4% who thought they could live elsewhere, reported that they could live in their own home rather than a nursing home. Thus it appeared that at least half of all residents (57.5%) felt that nursing home placement was appropriate for them (felt satisfied with placement). Data related to this research question are summarized in the following three tables.

Table 5: Activity problems reported: Do you think that you could live by yourself?

	Frequency	Percent	Valid Percent	Cumulative Percent
1 yes	15	45.5	50.0	50.0
2 no	15	45.5	50.0	100.0
Total	30	90.9	100.0	
Missing	3	9.1		
Total	33	100.0		

Three individuals failed to respond to this question. Respondents were equally divided (50%) as to whether they could live alone if they had assistance with activities.

Table 6. Do you think that living in this home is the only place for you to live?

	Frequency	Percent	Valid Percent	Cumulative Percent
1 yes	19	57.6	57.6	57.6
2 no	14	42.4	42.4	100.0
Total	33	100.0	100.0	

All thirty-three of the survey participants responded to this question and 57.6 % of those respondents felt that the skilled nursing home was the best place for them to live. Fourteen, or 42.4% of the survey participants felt that this was not the only place for them to live.

Table 7: If you answered Question 6, No: then where would you live?

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1 at home	3	9.1	21.4	21.4
2 in an apartment	6	18.2	42.9	64.3
3 small home w/others	5	15.2	35.7	
Total	14	42.4	100.0	

Missing	19	57.6		
Total	33	100.0		

All fourteen individuals who had indicated that they felt the nursing home was not the only place for them to live answered this question. Most of those who felt they could live elsewhere indicated that an appropriate alternative would be living in a smaller residence or a residence shared with others. Only 3 of the 14 respondents felt that they could reside in their own home. The other 11 respondents (78.6%) indicated that they could reside in an apartment, or in a small house with others.

Answer to the fourth related research question.

The fourth related research question was: What reasons do nursing home residents give for nursing home placement? All 33 of the survey participants responded to this question. The most common reason for nursing home placement identified by study participants was that the person was unable to care for self. Almost two thirds (63.6%) of the respondents identified this as a reason for nursing home placement. There were also a number of other reasons related to activities of daily living endorsed as factors that precipitated nursing home placement. These reasons varied within the sample and included: being afraid that something bad would happen (13 respondents or 39.4% of the sample), being unable to care for own home/apartment (11 respondents or 33.3% of the sample), not having transportation (6 respondents or 18.2% of the sample) and not being able to pay bills (4 respondents or 12.1% of the sample).

More than a third of the respondents (36.4%) indicated that the nursing home placement was the residence of choice. These respondents indicated that they had wanted to enter the nursing home. An additional 6 respondents or 18.2% of the sample indicated that someone else had made them enter the nursing home. There were 5 respondents (15.2%) who indicated that the nursing home placement was temporary, they had been in the hospital and would return home

later in their recovery process. Data related to this research question are reported in the following table.

Table 8: Why Are You Here

Couldn't take care of self	Frequency	Percent	Cumulative Percent
1 yes (checked)	21	63.6	63.6
2 no (not checked)	12	36.4	100.0
Couldn't pay bills			
1 yes (checked)	4	12.1	12.1
2 no (not checked)	29	87.9	100.0
Couldn't take care of house/apt			
1 yes (checked)	11	33.3	33.3
2 no (not checked)	22	66.7	100.0
Afraid something would happen			
1 yes (checked)	13	39.4	39.4
2 no (not checked)	20	60.6	100.0
No transportation			
1 yes (checked)	6	18.2	18.2
2 no (not checked)	27	81.8	100.0
Someone made me come			
1 yes (checked)	6	18.2	18.2
2 no (not checked)	27	81.8	100.0
I wanted to come			
1 yes (checked)	12	36.4	36.4
2 no (not checked)	21	63.6	100.0
Came from hospital/ Go home later			
1 yes (checked)	5	15.2	36.4
2 no (not checked)	28	84.8	100.0

Twenty-one respondents or 63.6% of the sample indicated that they couldn't take care of themselves. The next most common reason for placement (39.4% of those who responded to the question, Why are you here?) was that they were afraid that something might happen that they couldn't handle by themselves.

Unanticipated Findings

There were several unanticipated study findings. The first unanticipated study finding was the description of the sample population. This was a much older sample of nursing home residents than expected. The largest concentration of individuals who reported about age were

people in their 80s, the other large concentrations represented individuals in their 70s and 90s. This aged group of individuals, ages 60 through 96, accounted for 69.5% of the total population surveyed. The researcher expected to survey older individuals, but also expected to survey much younger individuals with disabilities. The surveyor had advised the nursing home staff of the purpose of the study and a request had been made to include individuals with disabilities. The surveyor had specifically suggested that there may be younger residents residing in the skilled care facilities that would be appropriate to answer the self-administered questionnaire, and requested that such individuals be invited to participate. Findings showed that very few younger nursing home residents were actually included in the sample.

There were also unanticipated findings related to transportation. Two different questions were used when asking whether individuals had problems with transportation. The first question asked if the individual with a disability had a problem with transportation (driving a car somewhere). Later, transportation was again included as a response option for residents to report reasons that they had entered the nursing home. Specifically this question asked if the reason the participant entered the nursing home was because they couldn't get around in the neighborhood (transportation). Transportation was the biggest independent living problem reported in the first question (63.3%), yet the least endorsed reason for nursing home placement (18.2%).

As expected, individuals did perceive that lack of transportation was a self-care and functioning problem since lack of transportation meant that respondents had no freedom to move about in the community at will. It was also anticipated that in this rural survey, transportation would be one of the greatest barriers to living in housing of choice. It was unexpected that people would fail to endorse transportation as a reason for nursing home placement. The finding that

81.8% of the participants did not report getting around in the neighborhood as a reason for nursing home placement was unexpected and will be discussed with conclusions in Chapter V.

Perceptions about the appropriateness of nursing home placement was another area that revealed unanticipated findings. Originally the researcher expected that individuals with disabilities would report that they did not want to live in a nursing home and thus that they would also report that this was not the best place for them. But surprisingly, respondents were equally divided in their responses to the appropriateness of living in a skilled care facility. When individuals had the opportunity to indicate their preferred residence, findings were consistent with pre-study expectations. Only 36.4% indicated that they came to the nursing home as a choice. When nursing home residents surveyed were given an opportunity to indicate their preferences for a more independent residence, most indicated that they would choose to live in close proximity to other individuals; in a small home with others or in an apartment. Few (9.1%) of respondents would choose to live in a private single residence.

These somewhat contradictory findings may be more understandable when other study findings are considered. Although more than a third of the respondents indicated that they came to the nursing home because they wanted to, 63% of respondents indicated that they did not feel that they could care for themselves, and 39.4% indicated that they were afraid that something might happen when they were alone that they could not handle.

In addition to the contradictory housing preference (appropriateness) findings, a number of other unexpected findings have been reviewed. These unanticipated findings included the finding that surveyed nursing home residents were a much older population than expected. Although efforts were made to survey younger individuals with disabilities, few were referred or elected to participate in this study. Analysis of findings also demonstrated that transportation was

a reported self-care or functioning problem for participating Dunn County residents, but that transportation was not a common reported reason for nursing home placement. Finally, residence of choice questions revealed contradictory information with 63% of respondents who had reported functional limitation or problems in ADLs not wanting to move into a nursing home, but 50% of all respondents reporting that they could not live alone with help for daily activities.

Summary

Two areas of the findings from this self-report study of nursing home residents described the sample; age and residence at admission. Of the 33 responses to the age demographic question, only three individuals were under the age of sixty three, and most were in their eighties and nineties. Residential status prior to nursing home admission was also described. More than 76.7% of those responding reported that they had either been living with another person or residing by themselves before they entered the nursing home. Other prior residences included a nursing home, group home, or an independent living facility/ independent residential facility. No person had been residing in a shelter, prison or an institution before admission.

The research question in this self-report survey of Dunn County nursing home residents was: Do individuals in skilled nursing care feel that they are residing in housing of their choice and is that nursing home placement the right choice for them. In this chapter data were reported that showed that the majority (63.6%) of residents cited reasons other than choice for entering the nursing home. Data was mixed on the appropriateness of such placement for residents.

The primary research question was answered by examining data related to whether residents reported disability at the time of admission to the nursing home, if residents reported disability related functional limitations at the time of nursing home admission, if residents

reported that nursing home placement was appropriate and finally, what reasons if any were given for nursing home placement.

Very high disability and activity limitation rates were reported. The prevalence of disability and functional support needs for the current sample of nursing home residents may best be appreciated by summing those reporting disability (63.6%) and those reporting ADL problems but no disability (33.3%), for a resulting 93.9% of all respondents. Thus in this sample, 93.9% of respondents reported disability or related functional limitations.

Functional and self-care problems were common, varied, covered all areas of life and were important in the ability to carry out ADLs and IADLs. Numerous respondents (9.1% - 63.6%) reported difficulties with life activity limitations such as transportation (driving a car somewhere), bathing, walking, house cleaning, laundry, dressing, taking medications, meal preparation, and paying bills.

There was a surprising amount of resignation to nursing home placement. A majority of participating nursing home residents in Dunn County (57.6%) felt that this was the only place for them. Residents were given an opportunity to indicate whether they felt their current placement was appropriate when asked, "If assistance was available with the activities that were barriers to independent living, could you live alone?" Participants responded in equal numbers that if provided assistance with activities, they could/could not live more independently. The residents who felt that they could live more independently indicated that given the choice, they would choose to live in small apartments or in a small house with others.

Residents identified a variety of reasons for nursing home placement. The most common reason for nursing home placement, reported by almost two thirds of respondents (63.6%), was the inability to care for self. As previously discussed, these individuals were having difficulties

with IADLs and ADLs prior to admission. Other reasons for nursing home placement endorsed by the participants included being afraid that something bad would happen (39.4%), being unable to care for own home/apartment (33.3%), lack of transportation (8.2%) and inability to pay bills (12.1%). Some residents (36.4%) chose the nursing home while 18.2% indicated that someone else had made them enter the nursing home. An additional 15.2% of respondents reported that they temporarily resided in the nursing home after a hospitalization.

CHAPTER FIVE

Conclusions and Recommendations

Summary of the statement

The purpose of this replication study was to identify whether Dunn County residents with disabilities were living in the housing environment of choice and whether there were barriers that prevented individuals from living either in an assisted living setting or in an independent private residence instead of a nursing home. The main research question was answered by examining disability status at time of admission, functionally related problems in life activities and self-described reasons for nursing home placement. Disability is a common occurrence for individuals residing in the United States, in Wisconsin, and in Dunn County. Consumer choice is important in all areas of life. Often there are numerous barriers to choices for individuals with disabilities. Lack of funding has been the primary focus of previous disability and residence studies since IADL assistance must often be purchased to retain independent living status (Murray, 1999; Snowe, 2000). This study used a self-report format to examine nursing home placement as well as activity of daily living problems and needs reported by residents in a rural (Dunn County) setting.

Conclusions Drawn from Study

Are people living in the residence of choice? Most surveyed residents (63.6%) indicated that they had not wanted to live in a nursing home. Over 57% of the Dunn County individuals with disabilities that were surveyed reported that they felt the skilled care facility was the only place that they could live. More than 42% of respondents felt that they could live more independently in a small apartment or group home. This author has concluded that individuals with disabilities and functional limitations did not want to move into a nursing home and would

prefer to live in more independent housing if they were informed of such choices and options.

This study strengthens the Chicago study

(Kruger, 2000) findings that individuals preferred not to live in nursing homes. Thus persons with disabilities, whether urban or rural, would prefer a choice to reside more independently.

Are there barriers that prevent people with disabilities from living independently or in an assisted living environment? Most residents (60.6%) reported that they were disabled at the time of admission to a nursing home. Likewise most study participants reported life activity problems at the time of nursing home admission and these problems varied. Some of the individuals who reported functional limitations did not indicate that they had a disability. Thus in this sample, 60.6% of individuals reported a disability and 33.3% stated that they did not have a disability, but had a related functional limitation. People who do not recognize disability presence cannot avail themselves of services. In the study reported here, lack of information appeared to be a major barrier to independence. This is consistent with the advocacy discussion in chapter II that described how difficult it is for people to advocate for or to request services when they do not even recognize that they have a disability.

The most common life activity problem reported in this study was transportation (63.3%), or the inability to drive for independent mobility. Bathing, housekeeping, walking, shopping, taking medications and laundry (30% to 45%) were all activities of daily living that required assistance. Thus individuals with disabilities in this study had many barriers that decreased efficiency with IADL's and/or ADLs. Results of this study suggested that such activity barriers constrain residential choice.

As mentioned previously, analysis suggested that there were significant questions about the validity of respondents' assessment of the appropriateness of nursing home placement. A slight majority of respondents (57.6%) indicated that they were in the best place (nursing home) for them. This contrasted starkly with the high rates of daily living activity and instrumental activity problems (9.1% to 45.5%) that could have been managed with outside resources such as home health if the person were residing in a more independent setting. The individuals studied were not asked if they had informed choices and if they had knowledge of other options such as home health so that they could reside in more independent settings.

Discussion of Chicago Study (Kruger, 2000) Replication

Of the 266 Dunn County residents in nursing homes, the author was only able to receive 33 responses. The low number of responses per nursing facility was comparable to the Kruger (2000) study in Chicago. The Chicago study conducted two waves of surveys of 17 nursing homes that resulted in 65 participants. Access to nursing homes in Chicago was quite difficult. Researchers mentioned that Chicago area nursing home staff might have been concerned about resident responses reflecting negatively on the quality of care for residents. In the study reported here (Jacobs, 2001) nursing homes were found to be protective of the rights of individuals with disabilities and thus the participants in this study were pre-screened for appropriateness.

Interestingly enough, the current survey produced some contradictory answers. In the questions about IADL's, more than 63% of the individuals responded that transportation was a barrier to independent living. There are no taxis in the Menomonie area, and no public transportation system except the very limited bus service for elders and persons with disabilities. The bus is operated only within the city limits and is available only on an appointment basis Monday-Friday during the hours of 9 AM to 4 PM. Due to Dunn County mass transit constraints,

it is not surprising that individuals with disabilities most commonly reported transportation as an independent living problem. Unless people retained the ability to drive, they could not get around in the community. Still this appeared to be perceived as more of a quality of life problem than a problem that resulted in nursing home placement. Only 18.2% of individuals reported transportation as a reason for nursing home placement. In the more urbanized (with available mass transit) Chicago study transportation was not even included as a topic for exploration of the barriers to independent living. The urban study reported some issues (housing and financial) that were not concerns in Dunn County. Reasons for nursing home placement in Chicago included homelessness, movement from an institution, and inadequate or poor housing conditions.

As described earlier, this was an older sample of participants than the Chicago study. Younger individuals did not participate in the study and this may have resulted in the very high rate of disability reported in Dunn County since residents may have had an expectation that an aged individual would also have a disability. Many older individuals live independently for many years, yet it is the expectation that a skilled nursing facility contain aged individuals. The Chicago study reported that the mean age of respondents was 65.17 with a standard deviation of 16.04. The median age was 63 years (Kruger, 2000). In the current study the mean age was 78.45 and the median age was 82.00.

In both studies, some individuals chose to move into the nursing home after they had become disabled because they thought it was the best place for them to live. The presence of disability is not always associated with perceptions that the nursing home is the best choice. In the current study when asked if they could live alone, twenty-nine individuals were equally divided in their response (45.5%) as to whether they could reside independently. The self-reported disability rate in this study was 60.6%, yet half the respondents indicated that they could

live independently with outside sources to help with IADL and/or ADL tasks. The Chicago (Kruger, 2000) study also determined that there were a number of individuals with disabilities residing in skilled nursing facilities

Data from both urban and rural studies suggested that people were living in nursing homes by necessity and not by choice. Ultimate conclusions were consistent; over 60% of individuals residing in nursing homes would prefer to live more independently. In the current study, 63.6% failed to endorse “I wanted to come” (i.e., preference) as a reason for nursing home placement. In the Chicago study similar proportions of residents (64.5%) indicated that they would prefer to live somewhere other than the nursing home. Additional Dunn County findings showed that 57.6 % of participants felt that residence in the skilled care facility was the most appropriate place for them. The Chicago study found that 70.5% of participants felt that residing in a nursing home was adequate. However, as noted previously half of the Dunn County respondents indicated that they could live elsewhere with help. Adequacy is often determined by necessity when options and supports are unavailable.

The data collected in this study was consistent across questions about functional and self-care limitations and about reasons respondents were at the nursing home. Almost 85% of the Dunn County individuals surveyed did not come from a hospital and did not expect to return home. Those surveyed were equally divided in their responses as to whether or not they would be able to live independently if they had assistance with their functional limitations. Unfortunately, the current study did not specifically ask about prior available personal care. However, data from the more urban (resource rich) Chicago study may be extrapolated to rural Dunn County. Chicago respondents were asked about the availability of personal care and 56% of the respondents reported that they did not have personal care prior to nursing home admission.

Thus, since the majority of respondents in Chicago did not have access to personal care, it is anticipated that this lack of personal care services would be even greater in Dunn County. Data from the Dunn County study did support this conclusion when reasons for nursing home placement are considered. Most of the endorsed reasons for nursing home placement related to personal (self and home) care.

Recent legislation in several states is moving toward less institutionalized care and more independent living for individuals with disabilities because the savings to the state, local and federal government are significant (Murray, 1999; Bishop, 2000). In addition to the financial savings for the states and the government, various studies have shown that individuals with developmental disabilities had fewer behavior problems and were happier in community settings (Kapur, 2000). The current literature implies that independent living is a cost effective method for individuals with disabilities to be integrated into the community. Financial resources to pay for the costs associated with community-based supports were not addressed in this study, but this issue had some significance for residential choice in the Chicago study (Kruger, 2000).

Summary

Personal safety and the ability to perform activities of daily living were important concerns to residents with disabilities surveyed in Dunn County nursing homes. Transportation, bathing, housekeeping, walking, shopping, taking medications and doing laundry (30% to 45%) were activities (IADLs) that individuals with disabilities reported as problematic. Decreased efficiency with IADLs are barriers to independence for persons with disabilities. Such barriers result in nursing home placement. Those barriers could be addressed and managed with supportive agencies in the community such as home health and volunteers from non-profit groups. Individuals with disabilities could have assistance and have home health or other

community resources come into their homes to assist with bathing, housecleaning, shopping, laundry, and reminding individuals to take their medications.

Implications for Field

In many regions it is common for health care facilities to have health care options that include independent housing, a smaller residential assisted living facility and a nursing home on the same property. Assisted living allows aging individuals or those with progressive disabilities to transition from being independent to having complex needs met in the adjacent skilled nursing facility. There is one such health care facility in Dunn County but since demand for services exceeds capacity, the assisted living apartments have a waiting list (Personal Communication, 2001). The mean age in this sample may have been older since the availability of assisted living options often results in only the most aged and disabled persons residing in nursing homes.

As mentioned previously, responses that residents were in the best place for them (57.6%) appeared invalid because many life activity problems and reasons for nursing home placement could have been managed with outside resources (e.g. home health) if the person were residing in a more independent setting. Respondents later appeared to confirm this when half indicated that they could live alone with outside help to accomplish IADL/ADL tasks. Participants in this study experienced considerable self-care and functioning problems prior to nursing home admission. These barriers to independent living must be addressed at the local community level through collaborative efforts by supportive parties (families, neighbors, home health, non-profit groups, volunteers, assisted care facilities, Office on Aging, Human Services). Individuals with disabilities who answered the survey questions did not feel that paying bills was a barrier to independent living. No specific questions were asked about financial resources to purchase supports. Individuals with disabilities could have assistance with IADL's and ADL's

and have home health or other community resources come into their homes to assist with bathing, housecleaning, shopping, laundry, and reminding individuals to take their medications. The lack of availability of such supports may have influenced study findings and also increased the number of people who indicated that nursing home placement was the only option for them.

It appears that there were some implications for the field in terms of allocation of resources to support independent living for persons with disabilities. In rural areas like Dunn County, transportation may be an issue that precludes the accomplishment of important life activities while in urban areas resources may need to be focused on the issues of inadequate housing, indigence and transition from prison to maximize independence. These resource and other issues are crucial for quality of life and for the field as a whole when considering the similarity across studies in responses to the main research question, "Are individuals with disabilities residing in the residence of choice and are there barriers to that choice."

Recommendations for the Field

As expected disability shaped perceptions about nursing home placement. More than half of the individuals with disabilities felt that the nursing home was the only place for them, and half felt that if offered assistance with IADLs and ADLs they could reside more independently either in a setting with other individuals or in a small apartment. Health care professionals, advocacy and community groups, schools and others should increase awareness of options for individuals to live independently. Such awareness should also include information and education about disability, and the advocacy, protection and services available to people with disabilities.

A majority (63.6%) felt that they couldn't take care of themselves and thus that they needed to move into a nursing home. The waiting list for assisted living mentioned previously

must be eliminated. A recent announcement by the Wisconsin Survival Coalition stated that 2300 state residents with development disabilities are waiting for housing/supportive services and the average waiting list is more than 4 years which prevents adults from being independent (2001). The Wisconsin Coalition, also referred to a “crisis” (p. 1) in funding and services to support independent living options. This crisis in human services must be resolved. Adequate funding of agencies and services must exist at all levels. Funding levels should also allow new and expanded services to meet the needs that now result in nursing home placement. The next most common response also reflected a need for supportive services. Over 39% of responses to the question, "Why are you here?" indicated that the person was afraid that something might happen that they couldn't handle by themselves.

Fear as a constraint in choice of residential options is a very important finding in this study. This finding suggests that the impact of disability goes beyond the actual functional limits and barriers people experience. This reason for nursing home placement was significant because it suggests that individuals with disabilities were not comfortable living by themselves, or more importantly, that they were fearful of living independently. Moving into a nursing home gave individuals with disabilities in this study a greater sense of security. Fear about living alone is something that many individuals do not discuss, and it was unanticipated by the author that there would be such a strong response to this functional limitation.

As a result of this study it is apparent that a person with a disability or a difficulty with one or more IADL or ADL, may feel vulnerable. Thus it is crucial that such fears be made known and addressed in all service provision. Preemptive planning and services may prevent the occurrence of fear or may help individuals with disability to resolve such fears so that nursing home placement does not become the residence of choice. Practitioners, health care providers,

families, and all others concerned about the well-being of the person with disability must ask about safety and security fears. People with disabilities should be specifically asked if they feel safe living alone. A very important follow up question would be, “What do you need to feel safe?” Alternate resources must be explored to meet intermittent or crisis needs (something bad might happen) so that individuals with disabilities do not feel pressured to move into nursing homes for skilled care and security issues.

Previous studies concerning nursing home placements have focused on the financial aspects of living independently with community resources to support IADL and ADL functioning. This study focused on reasons that individuals with disabilities may or may not want to reside in nursing homes. Very little research has been conducted addressing the reasons individuals with disabilities have for nursing home placement. This study has addressed that gap. It showed that the biggest reasons for nursing home placement were diminished self-care capacity and the fear of dire consequences when self-care capacity was exceeded. Individuals should be informed of alternate health care agencies and then choose the option that is best for them. More research is needed to clarify reasons for nursing home placement and what must be done to assure that individuals with disabilities are residing in the housing of their choice.

Recommendations for Further Research Needed

It is important to note that this was a small study and did not include all individuals with disabilities in Dunn County. This study was limited to a small group of individuals with disabilities in skilled nursing care and may have missed many individuals with disabilities. The population surveyed was a vulnerable population so that those individuals answering the survey may have been apprehensive about participating and/or being truthful in the survey for fear of reprisal from the nursing home staff. Participation selection may have been biased because future

funding and quality of care may have been perceived as being jeopardized. There may have been fewer residents willing to participate because they did not trust the surveyors. Individuals who received survey assistance may have been influenced by the helper or been afraid to answer questions truthfully. More importantly, more research must follow this study to gain specific and clear answers to whether or not individuals with disabilities are given information about the residency of choice so that they can make informed decisions.

There are many recommendations that this author would like to make. These include:

1. Nursing homes are responsible for the safety and well-being of their residents.

Therefore, many individuals must have a guardian present to answer survey questions. This author feels that additional time and effort should be spent in a future study to get a true, unbiased, non-selective group of individuals and possibly to obtain data from other sources (e.g. family) in regard to disability and residence.

2. The author feels that future study should be done to include additional younger individuals with disabilities whose expectations may not include living in a nursing home.
3. The author suggests that a more specific survey instrument should be designed to determine whether individuals were actually given options or choices before they moved into the nursing home. Did they expect to live in a nursing home? Did they have an informed choice about other independent living options? Was personal care available? Did they have adequate funds for such options and supports?
4. Individuals should be asked specifically what it was that they might not be able to handle by themselves if something went wrong. How many individuals were afraid to live alone, and why?

5. Exact disabilities should be identified. Are barriers perceived or actual?
6. The study instrument should be revised so that answers are more exact, so that participants can discern between disability and decreased functional limitations.

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November 11, 2000

Joyce Jacobs
PO Box 933
Torrington, WY 82240

Administrator
Dunn County Skilled Nursing Facility
Menomonie, WI 54751

Dear Administrator:

Thank you for your time to discuss this research project. I appreciated your concern for your residents and your input on my Thesis topic. You had told me to contact you by mid-November since you needed to present my thesis before the board. I hope that you have presented the thesis information to the board members.

I would like to set up a time as soon as possible, in November, if at all possible, to have (graduate student surveyor name) come into the facility and interview (assist) the residents with the survey. I have left the survey, quarters, and directions with him. He may be moving to La Crosse to do his internship at the end of December, so it is imperative that we finish this survey in November or the first of December at the latest so that (graduate student surveyor name) will have ample time to study for his finals. Graduate student surveyor's phone number is:

It is agreeable that you have your social workers and advocates (family members) to assist residents as a designated advocates to assure that patient's rights are being protected. Other nursing home administrators felt that residents would be more likely to talk to someone that they knew and trusted in an interview situation and that having their social worker at the survey site would assure the resident's protection according to nursing home policy and procedures. The surveys may take about an hour to complete.

I adjusted my study to include social workers as advocates and assistants. Other homes scheduled an activity in the morning and the social workers, administrators and nursing staff brought appropriate residents into the activity room (no one was present who wasn't participating) and we conducted the surveys.

It is my hope that we can continue this study. I will have (graduate student surveyor name) get in touch with you.

If you have any questions about this survey please phone me at (phone number) my office during the day, or (phone number) in the evening. Thank you!

Sincerely,

Joyce Jacobs

Consent Form

The purpose of this study is to investigate housing issues for persons with disabilities. To be more specific, are you living in the housing of your choice? Joyce Jacobs or Joyce's assistant, will be handing surveys to persons who reside in Dunn County nursing homes. Other assistants may include the facility social workers, (names listed). Joyce Jacobs is conducting this survey to complete her Master's Degree in Vocational Rehabilitation at University of Wisconsin-Stout in Menomonie, Wisconsin.

To conduct this study, Joyce Jacobs or (graduate student surveyor name) will require approximately fifteen minutes (more or less) of your time to fill out the survey form. The information provided will be kept confidential. Your name will not be used on the survey. Any information that you give on the survey form cannot be connected to you. Neither the nursing home nor the researcher will know who has filled out the completed surveys. If you give your answers orally, the researchers and the facility staff present will protect your confidentiality. They will not reveal your identity or responses to the facility administrator or any one else or identify the facility in any way. All helpers will maintain privacy and confidentiality in this study. The completed surveys will be dropped into a box or envelope and shaken so that the person answering the survey and the nursing home cannot be identified. If at any time you wish to stop filling out the survey, you are free to do so. You do not have to answer any question you do not wish to answer. There are no consequences to these actions. No risk is anticipated from participating with this study other than the possibility of fatigue from answering the questions.

If you need assistance with this survey, the person who handed out the survey, Joyce Jacobs or (graduate student surveyor name), will assist you. Either a family member, or a designated advocate can also help you. If you would rather call (telephone number) before October 26, 2000, the researcher, Joyce Jacobs will assist you. After October 26, 2000 you may phone (telephone number) to speak to Joyce Jacobs.

Thank you for your participation. The first 20 persons who turn in a completed survey will receive a new Sacajawea dollar. The 21st and following persons will receive a quarter. There are no other personal benefits to participating in the study. This study may help to show the need for additional housing and independent housing services in Dunn County. Results of this research study will be available to the nursing home and the participants upon request. I understand that by filling out the survey I am acknowledging consent to participate in the study.

Survey

Read the following statement before beginning:

I understand that by returning this questionnaire, I am giving my informed consent as a participating volunteer in this study. I understand the basic nature of the study and agree that any potential risks are exceedingly small. I also understand the potential benefits that might be realized from the successful completion of the study.

This survey is confidential. My name will not be used on the survey. Information that I state on the survey cannot be connected with me. All information will put in a sealed box or envelope and shaken up so that neither the nursing home nor I can be identified. I understand that I can skip any question that I do not want to answer.

Questions, concerns, or complaints about this research participation should be addressed first to Joyce Jacobs, PO Box 933, Torrington, WY 82240, and second to Dr. Ted Knous, Chair, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research, 11 HH, UW-Stout, Menomonie, WI 54751, phone (715) 232-1126. Thank you.

1. Background Information:

Year of Birth:

In the following questions please circle the response that best answers the question:

2. Residential History: Immediately before coming here to live, were you: (*Circle or mark best answer*)

- A. Living with another person or persons in a house or apartment
- B. Living alone
- C. Living in an institution
- D. Living in a nursing home
- E. Living in a group home
- F. Living in an independent facility
- G. Living in a independent residential community
- H. Living in a prison
- I. Living in a shelter
- J. Other (please specify)

3. Disability: Before living here, were you disabled? (*Circle or mark best answer*)

- A. Yes
- B. No

4. Functional and self-care limitations: If you were disabled before coming here, what did you have problems with? (*Circle or mark all answers that apply*)
- A. Taking medications
 - B. Bathing
 - C. Shopping
 - D. Dressing self
 - E. House cleaning
 - F. Meal preparation
 - G. Laundry
 - H. Walking
 - I. Transportation (driving car to somewhere)
 - J. Paying bills
 - K. Other (please specify)
5. If you had help with one or more of the items listed above, do you think that you could live by yourself? (*Circle or mark best answer*)
- A. Yes
 - B. No
6. Do you think that living in this home is the only place for you to live? (*Circle or mark best answer*)
- A. Yes
 - B. No
7. If you answered Question 7, no: then where would you live? (*Circle or mark the best answer*)
- A. At Home
 - B. In an apartment
 - C. In a small home with other people to help me
 - D. In a hospital
 - E. Other (please specify)
8. Why are you here? (*Circle or mark all answers that apply*)
- A. Couldn't take care of myself, I needed help
 - B. Couldn't pay the bills
 - C. Couldn't take care of the house or apartment I was in
 - D. Was afraid something could happen that I couldn't handle by myself
 - E. Couldn't get around in the community (no transportation)

8. Why are you here? (continued)

F. Someone else made me come here

G. I wanted to come here

H. I came from the hospital and will be going home later

I. Other (please specify)

Mail to:

Joyce Jacobs

(address here)