

*I wish I had known ...  
... I could have stayed in my own home!*

**Barriers To Independence:  
A Study of Housing and Personal Assistance Issues  
for  
People with Disabilities Residing in Nursing Homes**

**Access Living  
&  
The Center for Urban Research and Learning  
Loyola University Chicago**

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## **Research Team**

Louis Delgado  
Policy and Program Analyst  
Center for Urban Research and Learning  
Loyola University Chicago

Tracy Hudson  
Graduate Fellow  
Center for Urban Research and Learning  
Loyola University Chicago

Rene David Luna  
Civil Rights Team Leader  
Access Living

Joy Rogers  
Professor of Curriculum, Instruction, and Educational Psychology  
Department of Counseling Psychology  
Loyola University Chicago

Eraina Ross  
Undergraduate Research Assistant  
Center for Urban Research and Learning  
Loyola University Chicago

Karen Tamley  
Director of Programs  
Access Living

Tom Wilson  
Personal Assistant and Health Care Team Leader  
Access Living

### **Report prepared by**

Daniel J. Kruger  
Consultant and Lecturer of Psychology  
Center for Urban Research and Learning and Department of Psychology  
Loyola University Chicago  
April, 2000

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Access Living, 310 S. Peoria, Suite 201, Chicago, IL, 60607-3534 Phone: (312) 226-5900  
[www.luc.edu/depts/curl/index.html](http://www.luc.edu/depts/curl/index.html)

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## *Executive Summary*

In 1998, Access Living and Loyola University Chicago's Center for Urban Research and Learning began a collaborative partnership to document the conditions influencing the placement of disabled people in a nursing home, and to identify the barriers that prevent nursing home residents from living independently. The team developed a survey instrument with quantitative and qualitative items and contacted nursing homes across the city of Chicago to generate survey respondents. Two waves of survey interviews produced a total of 65 respondents from 17 nursing homes.

Data from the administration of this survey revealed that 64.5% of respondents would prefer not to live in the nursing home if the opportunity were available. Although 70.5% considered their current living situation to be adequate, a large majority did not find it to be a desired option. The magnitude of the decrease in respondents' socialization activities since moving into the nursing home had a significant impact on whether they considered the nursing home to be adequate. Respondents also reported a significant decrease in accessible income since moving to the nursing home. This drop in income averaged \$433.23 per month. The respondents cited their current financial situation as the top barrier to living in the community. A lack of information and assistance with regard to affordable, accessible housing, and a lack of adequate community-based service options for people with restrictive medical conditions were also frequently cited as barriers.

Access Living contends that many people with disabilities currently living in nursing homes could live more independently when provided with affordable, accessible housing and assistance in the activities of daily living. Prior to the nursing home, housing for 35.2% of respondents did not meet the needs of their disability. A consumer-driven model where the direction of government funding is at the discretion of the individual would enable more individuals to remain in the community. Several states have found that independent housing and home-based personal assistance services provide a cost-effective alternative to nursing home placement. This model would make it possible for individuals to choose to remain integrated in the community.

## *Highlights of findings and recommendations*

### **Key Findings**

- ❶ Sixty-four and a half percent of those surveyed would prefer to live somewhere else if the opportunity were available, although the majority considered conditions and personal care in the nursing homes to be adequate. The preference to live somewhere else was influenced by the respondent's judgement of whether housing was adequate.
- ❷ After moving into a nursing home, respondent's socialization decreased significantly in 13 of 16 activity areas. The greater the decrease in socialization, the more likely the nursing home was judged to be inadequate.
- ❸ There was a statistically significant drop in discretionary income after moving into a nursing home. The mean drop in discretionary income was \$433.23 per month.
- ❹ Prior to the nursing home, housing for 35.2% of respondents did not meet the needs of their disability.
- ❺ Top barriers to living in the community included respondent's poor financial situation, lack of information and assistance with regard to affordable accessible housing, and lack of adequate community based service options for people with restrictive medical conditions.

### **Five types of situations were found to precede placement in nursing homes:**

- ❶ Individuals who were homeless or had housing that was inadequate, substandard, filthy, or unsafe.
- ❷ Individuals who had adequate housing, but needed personal assistance.
- ❸ Individuals who had inaccessible housing and did not know how to or could not find affordable accessible housing.
- ❹ Individuals with no prior disabilities who had adequate housing, and were directed to the nursing home after a hospital stay.
- ❺ Individuals who felt that the nursing home was the best place for them to live.

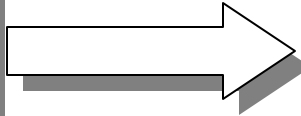
### **Recommendations**

- ❶ Increase the availability of affordable, accessible housing and explore means of providing accessible housing on the open market.
- ❷ Develop a consumer-driven funding model where individuals choose where to direct resources.
- ❸ Use a social assessment in addition to an economic cost/benefit analysis for nursing home residents or prospective residents who are candidates for affordable accessible housing.
- ❹ Increase awareness and utilization of community-based housing and personal assistance options.
- ❺ Conduct further research on the process and outcomes of providing community-based services and independent living as an affordable, accessible alternative to nursing home placement.

# Model of current placement results and recommendations for change

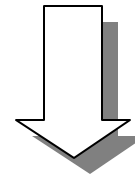
**Person with a disability, injury, or restrictive medical condition who:**

- 1. Is homeless, or has inadequate housing**
- and/or**
- 2. Needs assistance with activities of daily living**
- and**
- 3. Lacks information and/or control in decision making**

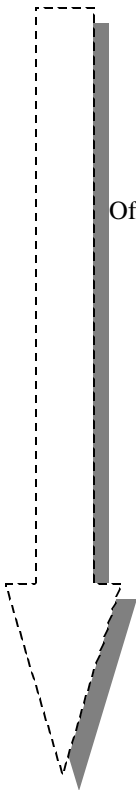


## Recommendations

- 1. Develop consumer driven funding model.**
- 2. Increase awareness, existence and utilization of home and community based care.**
- 3. Develop additional affordable, accessible housing.**
- 4. Conduct further research on these issues**



Often leads to



## Benefits

- 1. Increased proportion of people with disabilities living in the community**
- 2. Greater independence, socialization and human dignity**
- 3. Increased consumer control of financial resources creates an incentive for additional housing options.**
- 4. Lowered cost of service provision**
- 5. More efficient and effective use of public resources**

Placement in nursing home

Leads to

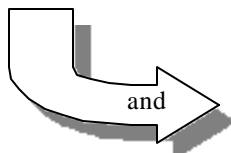
Decrease in socialization activities

Predicts

Judgement of housing inadequacy

Predicts

Desire to live somewhere else



Decrease in accessible income

Results in

Inability to obtain affordable accessible housing in the community

## *Integrated Summary of Results and Conclusions*

This report highlights a survey research project stemming from a collaborative partnership between Access Living, a center for service, advocacy and social change for people with disabilities, and the Center for Urban Research and Learning at Loyola University Chicago. The goals of this project were to document the social conditions that influence placement in a nursing home, and identify the barriers to nursing home residents with disabilities who would rather live independently.

Access Living has noted a longstanding institutional bias that results in people with disabilities residing in nursing homes, and has witnessed an increase in these placements in recent years. Access Living wished to discover the factors contributing to decisions for placement in such institutions versus an independent living alternative. A literature review found that this question had not been addressed. Article topics were generally directed to service and quality control of institutional living, and quality of life issues for people with disabilities. A few studies were found to address the issue of long-term housing for people with disabilities. The research team decided that this preliminary study would focus on people with physical disabilities living in nursing home settings, the reasons why people were admitted to nursing homes, and the housing preferences of these individuals.

Hulsman and Chubon (1989) note the development of services funded under a Medicaid waiver to maintain disabled adults in their homes to prevent premature institutionalization. Evaluation of these programs has traditionally taken a cost analysis approach. Hulsman and Chubon (1989) conducted an exploratory study examining the quality of life of 20 clients in a community long-term care program, as compared to 20 nursing home residents requiring comparable levels of care. No significant differences were found in the appraisal of quality of life, however the authors attribute this result to the standards of comparison for each type of resident. Nursing home residents may be comparing themselves more favorably to peers with conditions such as dementia, while community residents may see their quality of life as lower than that of others in their community.

Hayashi (1990) interviewed 83 people in Japan with physical disabilities living in a nursing home specially designed for people with physical disabilities. Even in this specially designed environment, nearly 60% of those interviewed would prefer to live somewhere else. Almost 40% of respondents stated they would prefer to live in the community rather than in an institution. Residents considered privacy and self-esteem to be important concerns in a nursing home.

The Access Living and CURL research team developed a framework for the type of information to be gathered and developed a survey instrument and study protocol based on this outline. The instrument contained quantitative and qualitative items for data collection. Items targeted information pertaining to residential and financial status, level of social activity, and general satisfaction with living conditions prior to and during nursing home living.

One section asked residents if they would opt for an alternate housing situation if it were available. Residents who desired alternative housing were asked to describe the barriers they perceived in obtaining housing and to describe the living situation they would desire. These open-ended questions were designed to gauge if the identified requirements for desired condition addressed the needs of the respondent's disability, or whether other factors predominated.

The Access Living/CURL collaborative research team began with a list of 110 long-term care facilities provided by the Illinois Department of Health. Geographical Information Systems (GIS) was used to locate the homes on a map of the Chicago area. Based on an inspection of this map, homes were divided into three groups based on the commonly accepted regional division of Chicago into north, south and west sides. The research team decided that at least four homes from each area would be randomly selected to generate an equal distribution of sample sites. Five residents were sought for interviews at each home site. Sites and interviewees were numerically coded on the survey instrument to maintain confidentiality. Face-to-face interviews were conducted with residents by Access Living or CURL staff and assistants, who recorded the responses of the residents. Interviewees signed an informed consent form stating their agreement to participate with the knowledge of the study's purpose, possible risks, and confidentiality of their responses. These interviews were conducted between April and August of 1999.

The research team found that gaining access to the nursing homes was very difficult. Two waves of survey interviews produced a total of 65 respondents from 17 nursing homes. There is a concern of sampling bias toward residents with fewer needs, as well as toward residents living in higher-quality nursing homes. Interviewers reported greater difficulty gaining access to residents in many nursing homes. Nursing homes that accepted interviews may have felt more confident in the quality of their programs. In addition, interviews were often restricted to those residents in TV or recreation rooms. Residents confined to their rooms are not likely to be represented in the results. These potential biases could lead to a higher reported mean satisfaction than the actual level in the general nursing home population.

Detailed results are presented in the Survey Results section. The data indicate that the most effective approach to improve the quality of life for residents who are unable to live outside of the nursing home may be to increase the frequency of socialization activities, especially outside of the nursing home. The decrease in socialization activities since moving into the nursing home was the sole statistically significant predictor of whether housing was considered adequate, and the judgement of adequacy/inadequacy was the sole significant predictor of whether respondents would prefer to live somewhere else if the opportunity was available. It is possible that there are other significant predictors of whether a nursing home is considered adequate; these could be measured in future studies.

Five trends were identified for the reasons why respondents are living in nursing homes: (1) Many seemed to be in the nursing home because they were homeless, in inadequate, substandard, filthy, or unsafe housing or inaccessible, inadequate housing. For these individuals, the nursing home is probably an improvement from their



prior situation. (2) Some people had adequate housing but could not get the personal assistance that they needed. Thirteen out of the 29 people (44.3%) who had disabilities prior to living in the nursing home did not receive personal care. (3) Some people had adequate but inaccessible housing and did not know how, or were unable to find affordable accessible housing. In the city of Chicago, only 3.9% of single-family unit, 6.6% of 2-9 unit and 29.9% of 10+ unit buildings are wheelchair accessible. The average accessibility of 16.2% in Chicago is still higher than the average accessibility of 7.2% for suburban Cook County and 13.7% for the collar (Kane, Lake, McHenry, and Will) counties (Smith, 1999). (4) Some people with adequate housing were not disabled prior to going to the nursing home and were directed to the nursing home after a hospital stay. (5) Some people chose or were placed in the nursing home after becoming disabled and feel it is the best place for them to be.

The majority of respondents felt their living situations and personal care in the nursing home were adequate, although a majority stated that they would prefer to live somewhere else if the opportunity was available (See Table 7). The finding that 64.5% of nursing home residents would prefer to live somewhere else is similar to the figure reported by Hayashi in 1990. Although nursing home care may be considered adequate, residents appear to miss the privacy, independence and level of activity in their previous residences. When asked to describe what they would want to have in their ideal residence, the vast majority cited basic amenities such as televisions, radios, personal space, adequate climate control, and a bed. For some residents, transition to an accessible residence and daily living assistance could significantly improve their quality of life. For example, when asked about barriers to community living, one respondent replied, "who would help me, I can't take all my medicine by myself."

Some residents in private nursing homes appeared enthusiastic when asked about their living conditions, "absolutely, I won't find anything else in the world like it. We Danish handle it all." Favorable responses on the adequacy of nursing home living included; "Yes, it's comfortable, it's all I need," and "Yes, they look after our needs, I don't need much help." Others stated that the housing was adequate, but qualified their response; "It's all right but I don't want to be here," "It's okay. Where else could I go?" Some of those who did not find the housing adequate felt they did not have control over their housing situation, "I have no choice. I can't afford what I'd really like." Others emphasized the lack of personal autonomy, "no, I don't like it...it makes you feel dependent [on others] instead of dependent on yourself." Some felt strongly about the inadequacy of their residence; "no, there is no privacy. It smells, I want to get out of here," "no, I hate being here!"

According to Access Living, several decades of efforts attempting to improve conditions in nursing homes have proven to be inadequate. Many people with disabilities currently living in nursing homes could live more independently when provided with assistance in the activities of daily living. Nursing home residents most often cited their financial situations as a barrier to alternative living. While survey results indicated that individuals in nursing homes are left with very little discretionary income, there is actually a considerable cost to residing in a nursing home. This money is often paid directly to the nursing home, bypassing the individual. Although it is not known

whether individual respondents reported their total or only their discretionary income, 12 individuals (18.4%) reported an income of only \$30 per month. If individuals were able to allocate the finances currently used by the nursing home, they would be able to obtain personal assistance and independent housing. This could not only improve the quality of life for these individuals, it may also be more economical for the funding sources. In this sample, 76.6% of respondents reported government programs as a source of income (see Table 1). Positive results of redirecting these resources towards keeping people integrated in the community have been established.

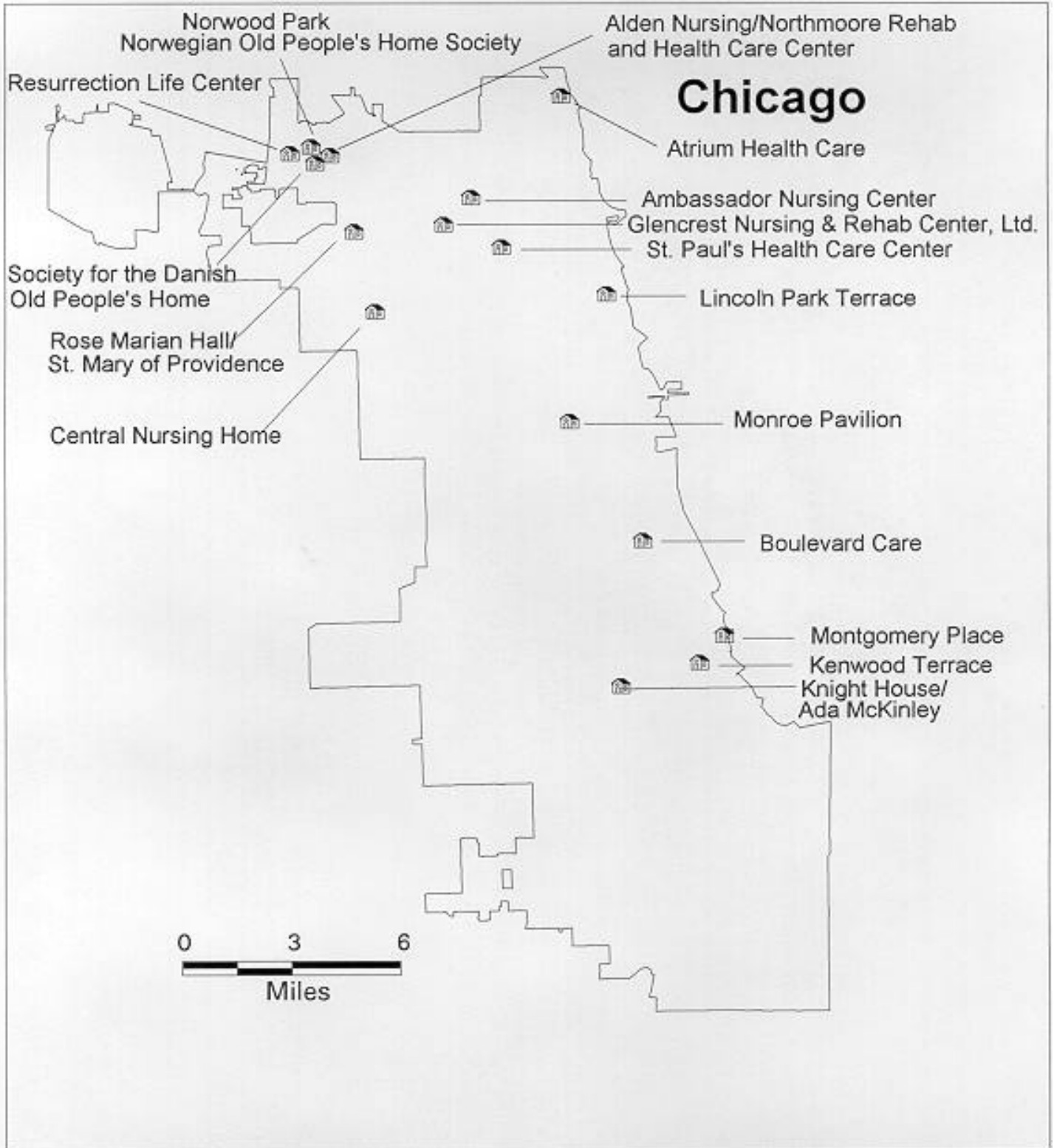
Some state officials have explored alternatives to automatic nursing home placement. Oregon has adopted the principle that nursing homes are to be placements of “last resort.” In 1982, Oregon gained approval from the federal government to use Medicaid funding to provide home and community-based care (HCBC) to people at risk of having to enter a nursing home. The state implemented statewide screening for all nursing home applicants, to ensure that applicants required this level of care. Oregon also encouraged the development of assisted independent housing (Coleman, 1998). Between 1983 and 1994, Oregon saved an estimated \$446.8 million, comprising 19% of the projective long term care budget (Alecxih, Lutzky, Corea, & Coleman, 1996). A study conducted by Vermont’s Agency of Human Services concluded that Medicaid waivers for home and community-based services were a cost-effective method for assisting citizens’ transition from nursing homes into the community (Murray, 1999).

State officials in Indiana estimate an average expenditure of \$36,400 per nursing home resident in 1996, compared to \$8,122 for the average individual receiving HCBC in the same year. For Maine, the 1996 estimates were \$22,570 spent for nursing home residents and \$7,650 spent for those receiving HCBC (Coleman, 1998). There are an estimated 1.9 million people in the United States with disabilities living in nursing homes at an annual cost of \$40,784 per person. The estimated cost of providing personal assistance services, enabling an individual to live more independently, is only \$9692 a year (ADAPT, 1996). Hundreds of millions of dollars could be saved if a substantial portion of these individuals transitioned into home and community-based services. In this study, 56% of respondents reported that they did not have personal care prior to entering the nursing home (See Table 5). Future research should determine the proportion of individuals directed towards a nursing home primarily because they needed personal care.

In conclusion, there are several advantages to promoting home and community-based services as an alternative to placement in a nursing home. The majority of respondents in this study stated that they would prefer to live in alternative housing, with the help of personal assistants, if this were available. One respondent coherently summarized these issues with this remark about personal assistance, "I didn't know you could get it. I wish I did know then. I could have stayed in my own home!" The quantity of socialization activities and level of accessible income for these individuals dropped after moving into a nursing home. Home and community-based services have

proven to be a cost-effective alternative to nursing home placement in a number of states that have experimented with these programs.

# Locations of nursing homes surveyed



## Survey Results

### I. Description of participants

Sixty-five nursing home residents responded to the interview, 55.4% of respondents (36) were male, 44.6% (29) were female. The mean age of respondents was 65.17 with a standard deviation of 16.04. The median age was 63 years. Of those who responded, 54.5% reported having a disability before moving to a nursing home. All statistics are given in valid percentages, cases where data is missing for that item are not included in the percentages.

### II. Income History

Table 1: Income history

<b>Type of income:</b>	<b>Percentage of sample with income type immediately prior to living in the nursing home</b>	<b>Percentage of sample currently receiving income type</b>
Social Security/SSDI/ SS Elder	43.5	44.1
Supplemental Security Income	29.7	38.3
Full-time job	27.9	0.0
Accumulated Savings	18.5	15.0
Part-time job	12.3	0.0
Contributions from family	12.3	8.3
Wages of spouse or housemate	6.2	1.7
General Assistance	4.8	0.0
Inheritance	3.3	1.7
Temporary job	3.3	0.0
Settlement from Lawsuit	1.6	0.0
Alimony	1.6	0.0
Veteran's Administration	1.6	1.7
Pension	1.6	1.7
Investments	1.6	1.7
Medicaid and Medicare	0.0	1.7
Workman's Compensation	0.0	1.7
Gifts from charitable groups	0.0	0.0

There was a statistically significant difference in income after moving into a nursing home. The mean drop in monthly income was \$433.23, to \$476.34. The median monthly household income dropped from \$700 to \$500 after moving into the nursing home. This difference may represent the loss of discretionary income, the money available once nursing home fees have been paid, as reported by some individuals.

### III. Residential History

Table 2: Residential history from infancy until present day.

<b>Type of Residence</b>	<b>Percentage of sample</b>
Parental family	93.8
Alone	73.8
Spouse and/or own children	72.3
Nursing home	72.3
Extended family	27.7
Non-relatives of own choosing	20.0
Institution	15.4
Non-relatives in group home	9.2
No residence/Shelter	7.7
Prison	6.2
Foster family	3.1

Table 3: Stated reason for living in a nursing home.

<b>Reason for being in a nursing home</b>	<b>Number in sample</b>
Needed someone to take care of them	22
Injury or medical problems	8
"It is easier for me"	8
Had a stroke	7
Was hospitalized	5
Had no where else to go	4
Disability	3
Family thought it was needed	3
Wants to be around people	2
No comment	2
Completing parole	1
Parkinsons	1
Alcoholism and injury	1
Need IV antibiotics every 6 hours	1
No money b/c illness	1
Don't know	1
Could not find accessible housing	1

#### IV. Frequency of Socialization Activities

Table 4: Frequency of socialization activities

Activity	Percentage involved in prior residence and currently while in nursing home											
	Daily		Weekly		Monthly		Yearly		At least once		Never	
Church*	3.4	0.0	46.6	25.4	13.8	13.6	10.3	6.8	5.3	5.1	20.7	45.8
School	5.4	1.7	3.6	3.3	3.6	0.0	1.8	1.7	0.0	1.7	85.7	91.7
Job*	43.1	0.0	5.2	1.7	0.0	1.7	0.0	1.7	0.0	3.4	51.7	91.5
Visit relatives*	5.2	5.2	34.5	13.8	29.3	13.8	10.3	5.2	3.4	6.9	17.2	55.2
Spectator Sports*	1.7	1.7	13.8	5.2	8.6	1.7	12.1	1.7	1.7	0.0	62.1	89.7
Participant Sports*	1.7	0.0	10.2	1.7	10.2	3.4	1.7	0.0	3.4	1.7	72.9	93.1
Theater*	0.0	0.0	16.9	3.4	23.7	3.4	13.6	5.2	6.8	1.7	39.0	86.2
Concerts*	0.0	0.0	7.0	0.0	14.0	1.7	10.5	3.4	5.3	1.7	63.2	93.1
Shopping*	5.3	0.0	50.9	10.3	29.8	22.4	3.5	1.7	0.0	5.2	10.5	60.3
Out of town travel*	0.0	0.0	0.0	5.2	11.9	1.7	33.9	6.9	16.9	5.2	37.3	81.0
Parks*	5.0	5.2	11.7	3.4	23.3	12.1	15.0	5.2	5.0	3.4	40.0	70.7
Picnics*	0.0	1.7	6.7	0.0	13.3	5.2	28.3	10.3	8.3	3.4	43.3	79.3
Clubs*	0.0	1.7	13.3	3.4	20.0	5.2	0.0	1.7	6.7	0.0	60.0	87.9
Political or Advocacy groups	0.0	1.7	1.7	0.0	3.4	0.0	1.7	0.0	5.2	1.7	87.9	96.6
Banking*	1.8	0.0	17.9	1.8	32.1	8.8	3.6	1.8	0.0	0.0	44.6	87.7
Other	2.7	0.0	8.1	7.5	10.8	5.0	0.0	0.0	5.4	2.5	73.0	85.0

Note: \*Indicates a statistically significant decrease in frequency of activity during residence in a nursing home.

#### V. Housing Adequacy

Table 5: Housing and personal assistance adequacy prior to nursing home

	Was prior housing adequate?	Did prior housing meet needs of disability?	Was there personal care?	Was this help adequate?
<b>Response</b>	<b>Percentage</b>			
Yes	82.5	42.6	31.3	35.3
No	15.9	35.2	56.3	5.9
Not applicable	0.0	16.7	10.9	56.9

Don't remember	1.6	3.7	0.0	0.0
No comment	0.0	1.9	1.6	2.0

Table 6: Top concerns of those who felt prior housing did not meet their disability needs

Top concerns of those who felt prior housing did not meet their disability needs:	
Concern	Frequency
Residence was not easily accessible	11
Needed more help with daily chores	3
Roommate(s) was a (were) disorganized housekeeper(s)	2
Residence was in dangerous area	2
Housing was of poor quality	2

Table 7: Housing adequacy in nursing home

	Is current housing adequate?	Is there personal care?	Is this help adequate?	Would you like to live somewhere else?
Response	Percentage			
Yes	70.5	85.7	78.6	64.5
No	29.5	11.1	17.9	35.5
Not applicable	0.0	3.2	3.6	0.0

Table 8: Top barriers to affordable accessible housing

Barrier	Frequency
Financial situation	20
Poor health	5
Lack of information about affordable accessible housing	4
Need for assistance in seeking affordable accessible housing	3
Needs assistance with daily living	3
On waiting list	3
None	2
Family is concerned about safety, etc.	2
Limited mobility	2
Lack of transportation	2
Restrictive medical condition	1
Doctor preventing move	1
Currently waiting to finish application to obtain an apartment	1
Alcoholism, no job	1
Alternative housing not wheelchair accessible	1



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### Interview Consent Form

PROJECT TITLE: Housing Issues for Persons with Disabilities

I, \_\_\_\_\_, state that I am over eighteen

years of age and that I wish to participate in a collaborative research project being conducted by Loyola University's Center for Urban Research and Learning and Access Living.

The purpose of this study is to investigate housing issues for persons with disabilities. We will be specifically conducting face-to-face interviews with persons with disabilities who reside in Chicago area nursing homes.

To conduct this study, the researcher would like us to interview you for approximately one hour ( more or less). Please be advised that the information provided during the interview will be coded and kept confidential. If at any time during the interview you wish to stop 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 in participation with this study other than the possibility of fatigue from answering the questions.

I freely and voluntarily consent to my participation in this research project.

\_\_\_\_\_  
Signature of Interviewee

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

# DRAFT INTERVIEW PROTOCOL

**Read the following statement to all participants before beginning:**

Thank you for agreeing to meet with me. I would like your permission to interview you for a study conducted by Center for Urban Research and Learning (CURL) at Loyola University in cooperation with Access Living. We are a center for independent living and are seeking to identify the range of choices open to persons who live in nursing homes. If you agree to be interviewed, we promise to code the information you give so that neither your name nor the name of your nursing home can be identified from the data. We will not give the information to the nursing home. We will conduct the interview in an area where staff and other residents cannot overhear your comments. If, at any time during the interview, you want to stop, you are free to do so. You don't have to answer any question you do not want to answer. If you would like us to do so, we will be happy to send you a copy of the final study which will contain aggregate data from all the people we interview.

**Background Information:**

Month and Year of Birth:

Gender:

Residential History: (From the time of your infancy until today, list the places you have lived.) For each, inquire if it was:

- A. Resides with own parental family
- B. Resides with foster family
- C. Resides with extended family
- D. Resides with spouse and/or own children
- E. Resides alone
- F. Resides with other non-relatives of own choosing
- G. Resides with other non-relatives in group home
- H. Resides in nursing home
- I. Resides in institution
- J. Resides in prison
- K. Has no residence and/or in day to day shelter facilities

1. Think about the residence you had **immediately prior** to living in the nursing home.
  - A. Were you disabled prior to moving to a nursing home?
  - B. Which of the following were sources of your income (more than one may apply)?
    - 1) Wages or salary from regular full time job
    - 2) Wages or salary from regular part time job
    - 3) Wages from temporary or day to day work
    - 4) Wages of spouse or housemate
    - 5) Contributions from parents or other family members
    - 6) Social Security
    - 7) Supplemental Security Income

- 8) Workman's Compensation
- 9) Settlement from lawsuit
- 10) Inheritance
- 11) Gifts from charitable organizations
- 12) Lived off prior accumulated savings
- Other \_\_\_\_\_

C. What was the total amount of that income? \_\_\_\_\_

D. In what year was that your income? \_\_\_\_\_

E. When you lived there, approximately how frequently did you go to the following places:

Daily    Weekly    Monthly    Yearly    at least once    never

- Church
- School
- Job
- Visit Relatives
- Spectator Sports
- Participant Sports
- Theater
- Concerts
- Shopping
- Out of town travel
- Parks
- Picnics
- Clubs
- Political or Advocacy Organizations
- Banking
- Other

F. Prior to nursing home residence did you regard your housing situation as adequate (prior to coming to the nursing home)? Why or why not? Did your prior housing situation meet the needs of your disability? Explain.

G. Were you getting help with personal care? Describe. Who provided this help? Did you regard this help as adequate? Why or why not? Explain.

H. Why are you living in a nursing home?

2. Please answer the next questions based on your **current** situation in your current nursing home.

A. Which of the following are sources of your income (more than one may apply)?

- 1) Wages or salary from regular full time job
- 2) Wages or salary from regular part time job
- 3) Wages from temporary or day to day work
- 4) Wages of spouse or housemate
- 5) Contributions from parents or other family members
- 6) Social Security (SSDI)
- 7) Supplemental Security Income
- 8) Workman's Compensation
- 9) Settlement from lawsuit
- 10) Inheritance
- 11) Gifts from charitable organizations
- 12) Lived off prior accumulated savings
- Other \_\_\_\_\_

B. What is the total amount of that income? \_\_\_\_\_

C. Approximately how frequently do you go to the following places:

Daily    Weekly    Monthly    Yearly    at least once    never

Church

School

Job

Visit Relatives

Spectator Sports

Participant Sports

Theater

Concerts

Shopping

Out of town travel

Parks

Picnics

Clubs

Political or Advocacy Organizations

Banks

Other

D. Do you regard your housing situation in the nursing home as adequate ? Why or why not? Explain.

E. Are you getting help with Personal Care, this includes help with shopping, laundry etc.? Describe. Do you regard this help as adequate? Why or why not? Explain.

3. If you could live someplace other than a nursing home, would you like to do that? (If yes, continue. If no, terminate interview.)

- A. Do you see any financial problems that keep you from living someplace else? (If yes, ask the person to explain.)
  
- B. Do you see any problems with feeling that you would be more isolated if you lived someplace else? (If yes, ask the person to explain.)
  
- C. Do you see any problems with getting assistance in ADL that keep you from living someplace else? (If yes, ask the person to explain.)
  
- D. What is would you say is the barrier keeping you from seeking an alternate housing situation?
  
- E. Please take a moment to envision the way you would really like to live. For this question, don't worry about what it would cost or how you would get the services. Please just describe the living situation that you would most like to have.