



TEXAS CENTER *for*
DISABILITY STUDIES

Going Home: The Meaning of Relocation in Texas

A Report Prepared by

The Texas Center for Disability Studies

at

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for

Texas Department of Aging and Disability Services

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Introduction

While the historical movement towards deinstitutionalization began over forty years ago (Davidson & Hoge, 1996), it was only recently legally mandated in the Olmstead Act of 1999 (Olmstead v. L.C., 527 U.S. 581). Individuals with disabilities today are seeking lives with more independence, autonomy and integration within their communities. However, studies on deinstitutionalization, also referred to as relocation, are only just beginning to look at the consequences, benefits, and outcomes of deinstitutionalization for persons with disabilities moving out of nursing homes. Deinstitutionalization is the process of moving individuals with disabilities out of institutions and back into the community (Giblin, 1991). According to Davidson and Hoge (1996), a vast majority of individuals with mental illness prefer to live in the community. Very little research exists that targets other specific disability groups. While some research indicates individuals prefer living in the community, there are many facets of community living that need thorough research and exploration.

Preliminary research in the field of deinstitutionalization/relocation has begun to investigate issues such as quality of life and social integration, development of social networks and community supports (Ager & Myers, 2001; Beadle-Brown & Forrester-Jones, 2003; Bostock & Gleason, 2004; Brunt & Hansson, 2002; Brunt & Hansson, 2004; Christine, 2004; Cummins & Lau, 2003; Emerson, 1999; Forrester-Jones & Carpenter, 2002, Forrester Jones & Carpenter, 2006). Additional issues such as housing resources, transportation, and health care coordination are also significant components of the relocation process. Little has

been done to explore the experiences and processes of people from different ethnic groups (Lee, Woo, & Mackenzie, 2001).

Negative social reactions (Accordino & Porter, 2001) have influenced the deinstitutionalization movement. Historically, some individuals with disabilities have been considered as violent and dangerous (Schellenberg & Wasylenki, 1992; Torrey & Stieber, 1993). Community members sometimes perceive a threat of violence and criminal behavior (Torrey & Stieber, 1993). The negative attitudes from community members can act as a major obstacle to successful deinstitutionalization (Hahn, 1988; Hodgins & Sheilagh, 1993).

In addition, public policy initiatives as well as allocation of resources such as supported housing have significantly influenced the deinstitutionalization/relocation process. Creating housing options for individuals with little income is essential for relocation to work. Along the way, the voice of the consumer, the individuals directly affected by relocation, has only been heard through sporadic commentary on the process.

Therefore, hearing and understanding the diverse voices and experiences of individuals directly affected by deinstitutionalization/relocation is important to ensure that individual wants and needs are met. In order to develop more comprehensive resources as well as enhance greater accountability of service providers towards meeting the needs of individuals relocating to the community, research must focus on addressing the salient problems identified directly by consumers involved in the process. There is a need for research to emphasize and reveal the experiences and events of individuals'

deinstitutionalization/relocation experiences. Qualitative research can present profound insights into this area of inquiry (Lee, Woo, & Mackenzie, 2001).

The Texas Center for Disability Studies conducted a qualitative research study to understand the relocation process through the personal stories of individuals relocated from a nursing home back into the community. Understanding the personal perspectives of the individuals' experiences provided valuable insight into the relocation process.

The research design involved in-depth interviews with two groups of participants: (1) individuals relocated from nursing homes back into the community; and (2) agency/facility staff involved in relocation services. The individual interviews gathered firsthand knowledge about personal perceptions, beliefs, and attitudes pertaining to their experiences in the nursing home and the relocation process. The agency and facility staff interviews gathered information about each person's role, successes, barriers, and best practices in regards to the process of relocating consumers from the nursing home to the community.

Nine consumers from six different areas of the state were interviewed for the research study. In addition, four agency staff members were interviewed, in order to gather information about relocation from a service provider perspective.

Design of the Study

No existing research was found that targets individual experiences of living in nursing homes, then relocating to the community. While research indicates individuals prefer living in the community, there are many facets of community living that need thorough research and exploration. For this reason, this study was exploratory. The purpose of this study was

to investigate the perceptions, feelings, beliefs, and experiences of individuals who have recently returned to the community after living in a nursing home; to investigate their experiences with the relocation process; and to investigate the perceptions and experiences of the agencies. A qualitative design was used to develop an interview guide, and principles of grounded theory informed the data analysis procedures. This research was guided by the fundamental principles of naturalistic inquiry (Lincoln & Guba, 1985), with the use of grounded theory techniques (Strauss & Corbin, 1998). This section includes the data collection procedures, a description of the participants and the data analysis.

Data Collection

The research design and all the protocols for this project were approved by The University of Texas at Austin Institutional Review Board (IRB). Confidentiality standards were followed in the de-identification and protection of the data. A team of doctoral level researchers at the Texas Center for Disability Studies (TCDS) designed and supervised the study.

Researchers conducted in-depth, open-ended interviews with all the participants. An interview guide was created, piloted, and revised, and then utilized to gather data from individuals relocating from nursing homes to the community and agency/facility staff. The consent form was translated into Spanish, and a Spanish-speaking researcher was available to conduct interviews in Spanish. These interviews were translated into English, and included in the data analysis.

Purposive sampling was used to select the participants in this study. Relocation specialists from the state-funded contractors who were providing relocation services

described the study and asked potential participants if they would like to be interviewed (see relocation study flyer Attachment A). The relocation specialists provided potential participants with a toll-free phone number to call to indicate interest in the study. When potential participants subsequently contacted the researchers to express interest in the study, a screening interview was conducted via the telephone (see screening interview Attachment B). Researchers selected participants who met criteria for the study and who helped to achieve maximum diversity.

Nine consumer interviews were conducted at the homes of the participants in six areas of Texas: Austin, Lubbock, El Paso, Central Texas, Houston, and Dallas/Fort Worth. All of the interviews were audio-taped after verbal and written consent was obtained from the participants (see consent forms Attachment C). The audio-tapes were transcribed verbatim by research staff at TCDS, then reviewed and de-identified by the interviewer.

All of the consumer interviews followed a similar format, although it should be understood that the interviews were conversations, not question and answer sessions (see interview protocol for consumers Attachment D). The consumer interviews gathered information about the participant's perceptions, feelings, beliefs, and experiences related to the life in a nursing home, the relocation process, and the adequacy of relocation services.

Four interviews with the agency staff were conducted by phone or email by TCDS research staff. Agency staff interviews were also audio-taped and transcribed verbatim by research staff, then de-identified by the interviewer.

The interviews with the agency staff gathered information about the participant's role within the agency or facility as it related to the relocation process, their successes, barriers,

and suggestions from their perspective (see interview protocol for agency and facility staff Attachment E).

Participants

Two distinct groups of participants were included in this study. Each of these groups is described in this section of the report. A total of 13 individuals were interviewed.

Consumers

Consumers, for the purpose of this study, are defined as individuals who lived in one of the six regions, and who worked with a relocation specialist to move from a nursing home back into the community. Consumers were at least 21 years old and medically stable. A total of nine consumers were interviewed; all in person at their home. Because the interviews had the potential to be sensitive, the interviewers were experienced qualitative researchers. All of the participants appreciated the opportunity to share their story and expressed gratitude for the opportunity to tell their stories.

Five of the consumers were European Americans, three were African American, and one was Latino. Ages ranged from 34 to 87. Disabling conditions were stroke, multiple sclerosis, cerebral palsy, diabetes, amputation, heart attack, decubitus ulcers, and alcoholism.

Agency Staff

Staff in organizations providing assistance in relocating consumers from the nursing home to the community were also interviewed. A total of four staff members responded to the researchers' e-mail queries to participate in the study, although repeated attempts were made to get more participation. These interviews took place over the telephone or by e-mail.

Data analysis

A phenomenological perspective, based on grounded theory, was used to analyze the data in this study. This approach is used by researchers to determine the meaning, structure, and essence of the lived experiences, both individually and collectively. It requires gathering data through in-depth interviews with people who have direct experience with the phenomenon of interest; those who have “lived the experiences.”

The research team at TCDS developed the research design and interview protocols. After IRB approval and initiation of data collection, the team met to discuss and solve operational issues and problems, as well as discuss preliminary impressions of the data as it was coded. Preliminary codes, the conceptual names given to the events and incidents found in the raw data (the transcribed interviews) were developed by this team comprised of interviewers and transcribers. Researchers then coded and analyzed the data into themes.

Introduction to Consumers

The goal of the relocation process is to develop and implement services to transition Medicaid eligible individuals from nursing homes to the community. Consumers who had been recently relocated were interviewed and audio-taped, in a conversational manner. They were asked to describe their disability or illness and the circumstance that led up to their placement in a nursing home, in an effort to understand what circumstances led them to this decision. The interviewer attempted to understand, from the consumers’ perspective, what returning to the community after living in a nursing home was like, and the specific experiences the consumer had with relocation services.

The following is a summary of major themes that emerged from these interviews. This summary is not a complete account of the themes inherent in the data. The data from these interviews will continue to be coded and analyzed, to examine specific areas of the data for more subtle themes.

The researchers would like to acknowledge the individuals who welcomed them into their homes, and shared part of their unique relocation experience. We were privileged to be allowed to share their experiences.

Consumer Themes

Issues in the nursing home

The decision to enter a nursing home was a difficult one for all of the consumers who participated in the study. Nursing home care was generally a last resort, and was needed due to the death of family member (caretaker), heart attack, stroke, or a progressive condition. The participant's functional limitations included wheelchair use, transfers, dialysis, tube feeding, overall weakness, toileting, and self care. Living in the nursing home presented challenges for all the participants. Safety, including problems with medications and outright neglect, was identified as the primary issue. The lack of privacy and forced dependency were also themes that emerged from the consumer data. Finally, consumers expressed their strong feelings about life in the nursing home.

Safety

"They never locked any doors at that nursing home, not one, never locked a door. (People) could come and go anytime day or night."(C2)

"Scary, scary. I stayed scared all the time." (C1)

Medication

Several consumers talked about the safety concerns involving medication.

"Out of 50 times, they tried to give me the wrong medication 35 times..." (C1)

"Half the nurses there were good, half were bad and the administration was horrible and the one nurse I had at night, see one night I was up, it was pretty late- about 11:00 and I was just sitting there talking to her and she said can you watch the med cart for me and I was like you don't want to leave your med cart. That's dangerous. People around here will steal those drugs and be gone and you don't even know me. Not that I would ever take it but she left me there for 2 ½ hours. That's pretty scary and then she tried to give me one of the other patient's medicine one time and tried to give the other patient my medicine. Every night that woman tried to give _____ my medicine and tried to give me - _____ medicine. We knew what we were supposed to take and we thought how many other people is see giving the wrong medicine to! (C2)

Another participant's husband expressed concern about the medication his wife received at the nursing home.

"My wife was getting a big bunch of pills, one of the pills was for anxiety and ... I also notice that with some of these anxiety pills she was forgetting and she was not herself and I went back to find out what they were giving her and then they explained to me this pills is for that and this one is for anxiety, and I said I was telling you over and over again,

SHE DOESN'T NEED ANXIETY PILLS. You tell to the doctor, because every time she gets these pills she start to behave very odd and she is not her own self and my wife is not like that! (C8)

Neglect

The consumers discussed some of the neglect they experienced in the nursing homes. The consumer's husband also observed neglect on several occasions.

"We have a few cases from some people that work there, abusing her, aggravating her, not changing her... Every day I was there...I wrote a letter to this people and I got to a point that I have to call the state because I complained to the director of the nursing home and they gave the people (staff) the benefit of the doubt ...Because this lady was aggravating my wife that she wasn't sick that was everything in her head because my wife told her when they turn her over because she was suffering from a hairline fracture on her upper right leg...so when she was in the nursing home she told the people to be careful when they turn her over because her leg hurts a lot and one of the ladies said: 'there is nothing with you because all is in your head' and my wife told her: 'I had been in the doctor and I am in a doctor's care' and she said: 'all is in your head'. So I went to the director and I told him: 'I don't want her close to my wife at anytime at all' and they changed the staff to another department." (C8)

"When my wife went back to the nursing home they didn't have beds so they put my wife on the floor, and there was a big fat colored lady and I said: 'Ma'am please!' And she said: 'I am going to find her a bed' and I said: 'my wife is in the floor!' and I said: 'and she don't have a linen, and my wife has just have an operation, she is going to have an infection!' and she said: 'well, I will get her something' and she came back and threw a pamper on top of her and said: 'I will be back!' and she never came back!" (C8)

Privacy

Privacy was another theme that was identified throughout the study. One consumer said *"...they had male nurse's aides. I didn't like having a man take care of me...I just don't prefer to be displayed like this. I want dignity."* (C3)

This consumer had difficulty sleeping at night because the nursing home did not *"have enough people there and you can hear...yelling and screaming and the ones that are in pain are moaning and it's horrible...like watching a horror movie."* (C4)

Independence

This consumer lamented the lack of independence that they were allowed in the nursing home.

"My attitude was I wasn't going to be pushed around and treated like cattle, like the other ones." (C4)

Another participant shared the same sentiment *"...this was the administrator! She was very loud and rude and screamed at me. I told her...I don't expect to be bossed around. This is my home right now. Ya'll are working for us...it was a nightmare."* (C5)

Feelings

When consumers were asked to discuss their overall feelings about the nursing home, they all expressed feelings of frustration and despair.

"Demoralizing, it's like they are not even nice to you, they are condescending. You see if they are condescending to the older patients what are they going to do? But I was young enough and healthy enough to fight back and they didn't like that." (C5).

"The nursing home is a place to go and die." (C6)

"It was like being incarcerated." (C4)

"You have to do what they say do. A lot of them people there, I feel sorry for...because there ain't nothing else they can (do)." (C7)

"I felt useless! I wanted to go back to work...to do things! I was so frustrated." (C3)

"You're just a piece of property.... oh, I wouldn't put a dog in there. I'm sorry but it's true."(C1)

Relocation

When consumers were ready to go back home they found out about relocation from a variety of sources: a flyer in the library, managed care service coordinator, from another person in the nursing home, and by word of mouth. The time for participants to be relocated into the community ranged from three to eight months.

Barriers in the relocation process

Barriers in the relocation process included housing availability, time, and caseworker overload. Once consumers were relocated they received accommodations based on their individual needs.

"I get 33 hours a week of provider care. (She) comes in the morning for two hours, then she comes back in the evening to put me to bed." (C3)

"_____ helped me move. ...they helped me with a little groceries...a bed and a table and a microwave and a coffeepot. They gave me plenty of food and stuff to hold me over." (C1)

"I needed a ramp, and fix the bathroom....it took three days to make the bathroom so I could use it." (C7)

"They made sure I had everything I needed as far as medical...potty chairs, wheelchair, medical supplies, everything. They were just wonderful." (C2)

Benefits of relocation

Several of the participants appreciated the physical therapy and the social activities that were offered by the nursing home but all the consumers reported being happy and had a very strong preference for living in the community.

"I am happy, yes indeed! I can go in there and roll up that ramp, and I can go to the bathroom, or I can sit here and talk. And it feels safe, to be home." (C1)

"I told a friend of mine, this is like my penthouse apartment. I love it. It's in a great part of (town). This is the nicest place I have ever lived. The carpet is new; the furniture is new. It's a penthouse apartment. I think of it as a penthouse apartment!" (C4)

"It's a relief of pressure, a relief of tension, and it makes you feel like you're human. And you know I can do the same thing for myself that they were doing for me at the nursing home. But it feels different. Like if I want to take a bath all day...or if I want to take my time and eat... I just relax." (C1)

"Well basically here I can do whatever I want to do. I am comfortable. I have my own room. If I want privacy all I have to do is close my door. No one will bug me. And I can cook what I want to eat!" (C5)

"I'm not as stressed." (C4)

"I go to my computer class, and I come back and sometimes I sit on the porch there, and listen to the church bells. I read my book, or watch TV." (C3)

Summary of Consumer Interviews

The consumers interviewed for this study had negative experiences in the nursing home but relatively positive experiences with the relocation process. Consumers all preferred living in the community and valued their independence. The importance of doing a better job to get the word out about relocation was evident. *"Let people know these services are available! A lot of people don't know!" (C2)* Clearly these consumers appreciated the value of community living and the importance of relocation services that allowed them a place to really call home. They felt safe and supported in their homes, and often felt that they received better services than they had received in the more expensive nursing home.

Agency Staff

The agency staff interviewed were independent living center administrators and relocation and community specialists. Staff roles in the process included running the day to day operation of the agency as well as going into the nursing homes and relocating individuals back into the community. Data about the relocation process, their successes, barriers, and suggestions from the agency perspective will be discussed. It is important to note that the researchers were not able to get a good representation of the agencies' perspectives due to a lack of participation; only three of the six regions of the state are represented in this part of the analysis. Repeated invitations were made to staff to participate

in the study to expand awareness of the issues and successes with relocation, however, only four individuals responded.

Barriers

Political and systemic barriers were mentioned, including lack of funding and differences between programs.

"We have problems with the funding....but there are some more problems. I have consumers that live in non-STAR+PLUS counties, and it's so hard to get them relocated... the DADS worker in the county...well, I couldn't say I think she don't know...but to me, it's like a brick wall. I have found the consumer, he's ready to go, we found a place for him to move to, we picked his furniture...the whole nine-yards, but of course it's been about three weeks now, and I still haven't been able to move with the DADS worker." (AP3)

"Ironically, our greater challenges have been in coordinating with DADS. Caseworker attrition rates are high, and we sometimes lose weeks as workers resign and cases are reassigned. Occasionally we have workers who refuse to share any information with us, even though we are on the same team." (AP4)

"Another barrier that I've had... if have a check for our consumers, to shop... if we have like four or five checks out, Wal-Mart will not accept them, so, of course, if a person is being relocated that day, or the day before, and they're not accepting the check, then no money is available, and I, one time, I was told that I needed to, maybe, use some of my own funds, to purchase this stuff. And I told them, 'No.' Because I didn't, you know, I'm not associated with that, and then I didn't have the money available for that." (AP3)

"..The funds that they make available, well there's a \$2,500 grant... The TLC grant, and then the TAS grant. And each person is supposed to be eligible to qualify for up to

\$2,500 in each one of those... however the TLC funds, takes way too long to get it and if you don't get it before the person moves, they take it back anyway. And...the TLC is supposed to cover things that the TAS won't or doesn't, you know like TV's or something like that, which they call a luxury item but if someone's home bound, they need TV to know what's going on... I don't even attempt to get the TLC money, and then the TAS money... I'm the one that goes out and prices items, and writes down, and goes over things with the consumer that they need or want, and then I send the list to the state case worker and they go down the list and they tell me, 'Oh, that's not going to cost...', you know they change stuff and give me whatever they think I can get stuff for. So...I end up in lots of battles with case workers ...and I don't understand the case workers, I'm not sure what word I should use, like some of them, I'm stepping on their toes, I'm doing over half of leg work for a transition, but these case workers, when I call them with questions or concerns, it's like I'm bothering them ..." (AP1)

"...we struggle with DADS policies at times. For example, we're working with a couple of consumers who rely on wheelchairs for mobility. However, my understanding is that CBA will not construct wheelchair ramps (or perform residential repair) until after the consumers are already home. This can make it hard to safely relocate a resident who desperately needs an accessibility or safety repair." (AP4)

One participant expressed initial difficulty gaining entrance into the nursing home to discuss the relocation process with nursing home residents.

"At first I had problems with, entering into the nursing home... people, consumers who was on the interest list, that we were supposed to go and assess, I had problems the nursing home not wanting me to actually speak to the consumer." (AP3)

Consistently, agency staff stated that lack of housing, transportation, community and informal supports were barriers to relocation success. One participant talked about the lack of support that individuals relocating into the community face during the process.

"For people who might actually have family that would have them in their homes, return to the home or something, for the family to actually understand, see, and understand that they're not going to be responsible for the care-taking, you know I've had several... young adults whose family just not even willing to try it with them going back to the family home because, you know, 'I work, and I can't be missing work for this or that' you know and even though I talk to them about the home-health aide coming, and they're right because sometimes they just don't show up." (AP1)

Another participant pointed out cultural barriers in regard to community supports.
"...from my experience Hispanic individuals are much more likely to have family and informal supports in the community than Whites or Blacks." (AP2)

Successes

When asked about the successes they have witnessed in the relocation process, participants expressed different points of view. *"I'm not really sure that I've seen any...successes of the process. And the thing I tell people when I'm talking to them about it is basically the state is doing this because the Federal government said they had to. And it's pretty much set up to fail. But they don't care if it really works or not..."* (AP1)

Another participant said ...we're getting a little, getting more out now, as the program progress. We're getting more out... it's much easier, because you're knowing what to do and how to do it...you knowing that the people are satisfied." (AP3)

In discussing how agencies inform individuals about the relocation process, all four participants indicated that word of mouth was generally how individuals find out about the process. Other methods include: contacting the social worker at the nursing home, leaving brochures at the nursing home, leaving flyers at libraries, church, and other places in the community.

Overall Summary of Staff Interviews

The analysis of the staff interviews revealed a limited number of themes because of a lack of participation. However, all the staff expressed concern about the systemic barriers that they faced on a daily basis and how these barriers make it harder to relocate individuals. Based on the participation that we received, the participants indicated that more training is needed to better serve the consumer... *"I can call like my executive director, or my counterpart in our _____ office that does the same thing, but I would say we're all about on the same level as far as doing the transition. And then, I do have a contact with the state who helps me out...when I might have certain issues with case workers... because I've had quite an experience with the actual case workers of the consumers that don't know anything about transition."* (AP1)

Confusion with all the programs also was mentioned by several participants as an area of concern within the process... *"I was asked by a _____ to come and train her unit, on the Medicaid waivers and the transition program. I said, 'That's you all's program!' ... The system is confusing. Everyone knows a different answer."* (AP1)

This group also identified a strong need for more communication and teamwork between the Texas Department of Aging and Disability Services and other agencies and within their own agencies.

"And don't think that you can run the whole program. I have had so many times my coordinator to tell her 'I'm tired of trying to be four people' and you know that hurt my feelings like... I know I am doing the best that I can do and you're just one person, don't degrade the rest of 'em, you know the rest of us. We're all working to make this successful."
(AP3)

The perception that there is a lack of training, lack of collaboration with DADS and within the agencies, and lack of team work seemed to be a common theme. While some participants saw some successes they all felt that the process needed work.

Overall Summary

Although there were significant limitations to this study, particularly in relation to the low participation of agency staff, the data suggest some important policy related information. The study also suggests that more needs to be understood about the relocation process, the experiences of agency staff in providing services, and the operational components of successful programs. Clear delineation of best practices would serve the consumers, and no doubt result in more efficient expenditure of funds.

Consumers in this study clearly disliked their nursing home experiences. Although nursing homes provide an important service to certain people, for adults with disabilities, nursing home care may not be the most appropriate long-term placement. All of the adults

interviewed had negative experiences in the nursing homes, and were extremely grateful for the assistance provided to them so they could move back to the community. Nursing home safety issues are certainly beyond the scope and purpose of this project, however, researcher couldn't help but be concerned at some of the horrific stories told about nursing homes. Certainly this is an area that may need further research and/or oversight.

Consumers in this study clearly liked living in the community. Although some cited loneliness as a problem, it was certainly small compared to the freedom, privacy, and dignity of living on their own. The feeling of independence after the enforced dependence of the nursing home was treasured. The sense of relief these individuals felt at having control of their lives again was palpable. The deep gratitude for the services and ongoing support of the relocation specialists make it clear that this is a very successful program from a consumer perspective.

None of these consumers would have been able to move back to the community without relocation assistance. The poverty of the individuals interviewed was acute, and family support was minimal if it existed at all. For the participants in this study, relocation programs were the only way they could have left the nursing home environment. In general, the feeling about relocation specialists was of deep gratitude and appreciation, even as they wished the relocation services could have moved faster. Participants felt that more people need these services and should know they exist. They felt lucky to have been told about the programs and to have received services.

From the perspective of these consumers, relocation was more than a success; it gave them their lives back. The value of such a significant quality of life change is difficult to measure in dollars, even though services in the community are much less expensive than nursing home care.

Attachment A

Relocation Flyer

RELOCATION STUDY



Are you willing to discuss your experiences about your recent move out of a nursing home and into the community?

Researchers at the Texas Center for Disability Studies at the University of Texas at Austin want to hear your story! We are conducting interviews to find out more about your recent move. The interview will last about an hour and you will be compensated \$50 for your time.

What do you need to do if you want to participate?

- ✓ Call the Texas Center for Disability Studies toll free at: 1(800) 828-7839 or in Austin at 512-232-0740. Our TTY number is 512-232-0762.
- ✓ Ask to speak to a member of our research team. We will answer any questions that you may have and set up a time when we can come to a location of your choice to do the interview.
- ✓ After you complete the interview, we will give you a \$50 gift card.

This research project is funded by the Texas Department on Aging and Disability Services (DADS) and has been approved by the Internal Review Board of the University of Texas at Austin.

Attachment B

Screening Interview

Screening interview

Thank you for your interest in our study about relocation. We are trying to understand what kinds of experiences people have had as they have relocated from a nursing home back into their home community. I would like to get some information from you to help us in determining your eligibility to participate in the study.

1. Have you moved from a nursing home back to the community?

If no, thank them for calling, and explain the purpose of the study and why they don't qualify.

If yes

2. Where do you live now? (House, apt, supported housing, assisted living, etc.)

3. How long have you lived there? (How long has it been since they moved from the nursing home?)

4. How long were you in a nursing home?

5. This study will involve an interview. Someone will come to your home or anyplace that is convenient for you, and talk to you about your experiences in moving back home. That person will need to audiotape your conversation so she can remember what you say. Would this be OK with you?

If yes, then get demographic info:

Name:

Address:

City:

Phone numbers (get all numbers where a person could be reached) When is the best time to contact you?

Please tell me a little more about you:

Are you male or female?

What is your age?

How would you describe your ethnicity or race?

What kind of illness or disability do you have? What kinds of community support services did you need to move back home?

Thank you so much for giving me this information. If you qualify to participate in the study, we will call you back and make arrangements to come and meet you and talk about your experiences.

Attachment C

Consent Forms

Attachment D

Consumer Interview Protocol

Interview Protocol for Consumer Participants

My name is.... And I am a researcher at the University of Texas. I would like to talk to you today about your experiences with relocating from a nursing home back to the community this year. As we discussed on the phone, you were referred to this study because you worked with a relocation specialist to move out of a nursing home. We are trying to understand the process of relocation, so that we can figure out what works best for people. When we talked on the phone you indicated you were willing to talk to me about your experiences during that time; is it still OK with you to talk to me? I need you to understand that you can stop talking to me at any time, just tell me you want to stop, and you don't have to answer any questions you don't want to answer. Talking to me won't influence your ability to obtain services from the (Name of agency) or anyone else; this is strictly voluntary. It's important that you don't feel anyone is making you talk about this. (Ask participant to paraphrase back to you, so that you can check for understanding and consent)

What I want to do is ask you questions about what is going on in your life right now, some questions about your disability, and what kinds of services and supports you need to be as independent as possible. We'd like to know what life was like for you in the nursing home as well as what life is like for you now (and then a couple of questions about your experiences as a woman or member of racial or ethnic minority) and then we'll be finished. Remember, if you get tired, or if I ask something you don't want to answer you can stop at any time. Telling me about your story and your experiences will help us understand what we can do to help other people. We think you can give us some good advice about that.

The following guide is to help the interviewer stay in the area of focus – the relocation process. It should not limit emergence of information that is not included.

Disability

Would you describe your illness or disability to me? What types of supports or services do you need to help you manage your illness or disability?

Nursing home:

What happened that resulted in your admission to the nursing home? Describe a typical day in the nursing home. What did you like best about your life there? What did you like least?

How did you hear about relocation? Who talked to you about what it would take to relocate back to the community? How did you feel about going through the relocation process before it happened?

Relocation Process

Who was involved in your relocation? What kinds of services had to be put into place before you could move home? How long did it take? Who was most helpful? What made that person particularly helpful? What kinds of problems did you run into when trying to relocate?

Current activities:

Describe a typical day now. What do you like most about your life now? What do you like least?

Where do you live? Is there anything you would want to change about your living situation? Can you describe some of the relationships you have with people in your living environment?

What do you do for fun?

Relationships/social support

Who helps you out? Do you have people you can hang around with? People you can call if you need something?

Financial

Do you have unusual expenses related to your illness? Do you feel you have enough money to live on?

When you think back, was the nursing home experience helpful for you?

If there were a perfect service delivery system for you, what would it include?

Conclusion

Looking back, is there anything that you would have done differently, knowing what you know now? Do you have any advice for other people with your type of disability who are in nursing homes?

Is there anything I haven't asked that will help me understand more about relocating people from nursing homes back into the community?

Attachment E

Relocation Staff Interview Protocol

Interview Protocol for Relocation Staff Participants

My name is ... and I am a researcher at the University of Texas. I would like to talk with you about your experiences with the process of relocating consumers from nursing homes to the community. As we discussed on the phone, you were referred to this study (name of consumer) because you were involved in his/her relocation process. We are trying to understand what your experiences have been like, and what your perceptions about relocation are so that we can try to identify the successes, barriers, and best practices.

When we talked on the phone you indicated you were willing to talk to me about your experiences; is it still OK with you to talk to me? I need you to understand that you can stop talking to me at any time, and that you don't have to answer any questions that you don't want to answer. Talking to me won't influence your relationship with any of the agencies you are involved with now, and your participation is strictly voluntary. Is this OK and do you have any questions for me now?

What I want to do now is ask questions about your experiences with the relocation process.

The following guide is to help the interviewer stay in the area of focus.

For Agency and Facility Staff:

1. What is your role in your agency?
2. How did you hear about the process of relocation?
3. What are the barriers to successful relocation back to the community?
4. What could be done to improve relocation?
5. What successes did you see in relocation?