

# **CMS National Long-Term Care Awareness Pilot Project: Findings from Focus Groups with People with Disabilities and Caregivers**

**Contract No. 500-96-0006**

## **DRAFT Topline Report**

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## EXECUTIVE SUMMARY

### Purpose

To conduct exploratory audience research with people with disabilities and their caregivers as part of the communication strategy development for CMS' National Long-Term Care Awareness Pilot Project.

### Methodology

Five focus groups were conducted in Tampa, FL; Denver, CO; and Litchfield, CT.

- ◆ Target audiences included three distinct groups:
  1. Caregivers of people with developmental disabilities including mental retardation and/or brain injuries;
  2. People with physical disabilities; and
  3. People with mental illness.
- ◆ Professional research facilities, local organizations, and state agencies were used to identify and recruit qualified respondents;
- ◆ Specific criteria was sought among qualified respondents, including a mix of demographics (e.g., gender and race/ethnicity), employment status, income, and eligibility for government benefits;
- ◆ Respondents were asked to discuss their familiarity with and perceptions of long-term care; preparations they have made for the future; best avenues to disseminate long-term care information to people with disabilities and related people; issues related to employment and government programs; and types of support systems for people with disabilities and caregivers.

### Key Findings

Key findings show that respondents, overall, have conducted very little future or long-term care planning because they face a multitude of social and financial barriers related to disabilities. On a daily basis, these barriers tend to override planning for the future. Given this, people with disabilities are not likely to respond to a long-term care planning campaign, but would prefer that these resources be dedicated to campaigns regarding more immediate concerns and needs. For example, people with disabilities and caregivers:

- ◆ Experience ongoing problems with federal entitlement programs, such as qualifying for benefits, accessing services, and staying on the rolls of various government programs;
- ◆ Feel there are limited services, programs, training, and information available to people with disabilities and caregivers and a lack of awareness of existing programs;
- ◆ Are hindered by discrimination and a myriad of employment issues when trying to find or maintain jobs;
- ◆ Realize that they might benefit by structuring their living situations and geographic location based on the available services in an area, but are hesitant to move due to the frustration of having to start over to find supports; and
- ◆ Are forced to adopt manipulative behaviors in order to navigate complex and unresponsive social service systems, potentially reinforcing the stigma and marginalization that persons with disabilities may already experience.

### Recommendations

- ◆ Consider a nationally coordinated, locally implemented information and education effort related to more immediate needs of people with disabilities.
- ◆ Educate potential employers and the general public to the strengths of persons with disabilities.

## INTRODUCTION

As one component of consumer research for the Centers for Medicare and Medicaid Services' (CMS)<sup>1</sup> Long-Term Care Awareness Pilot Campaign, the MEDSTAT team conducted a total of 24 focus groups with various categories of potential target audience members in 6 different cities. Within this component, part of the research focused on the needs and attitudes that people with disabilities have related to long-term care. Due to the importance of long-term support services in enabling some people with disabilities to work, and in order to address some broader questions posed by CMS, questions on employment issues were also included in the discussions. Findings from focus groups conducted with people with disabilities and their caregivers are outlined in this report; findings from focus groups with the general market audience are discussed in a separate report.<sup>2</sup>

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<sup>1</sup> Formerly known as the Health Care Financing Administration (HCFA).

<sup>2</sup> In addition to conducting focus groups with people with disabilities and related populations, Barents conducted 19 focus groups with two general categories of potential target audiences in 5 different cities: Baltimore, MD; Pittsburgh, PA; Tampa, FL; Fresno, CA; and Denver, CO. These categories included: 1) Spanish and English-speaking people actively engaged in pre-retirement planning or actively thinking about what their lives will be like when they stop working; and 2) Spanish and English-speaking people providing non-professional caregiving to aging individuals.

## METHODOLOGY

A total of 5 focus groups were conducted with people with disabilities or caregivers of people with disabilities in 3 cities: Tampa, FL; Denver, CO; and Litchfield, CT.<sup>3</sup> Focus groups were employed in this study to elicit open-ended feedback on campaign research questions. This methodology afforded the research team opportunities to explore multiple viewpoints regarding knowledge, attitudes, and beliefs about long-term care that will inform the development of campaign concepts, messages, and strategy.

Target audiences included three distinct groups:

1. Caregivers of people with developmental disabilities including mental retardation and/or brain injuries;
2. People with physical disabilities; and
3. People with mental illness.

Table 1 (below) outlines focus group participants by research site.

**Table 1. Focus Groups by Site**

Site	Type of Group
Tampa, FL (1 focus group) May 18, 2001	◆ Caregivers of people with mental retardation
Denver, CO (2 focus groups) June 5 & 6, 2001	◆ People with physical disabilities ◆ Caregivers of people with developmental disabilities including mental retardation and/or brain injuries
Litchfield, CT (2 focus groups) June 18, 2001	◆ People with physical disabilities ◆ People with mental illness

Methods of recruitment. A variety of recruitment methods were used to identify qualified participants. Methods used include:

- ◆ *Professional research facilities.* Respondents for the Tampa and Denver focus groups were recruited by professional research facilities using traditional recruiting avenues such as telephone lists and advertisements in the local papers.<sup>4</sup>
- ◆ *Local organizations.* In all three cities, local organizations serving people with disabilities were involved in identifying qualified respondents. For the Denver focus groups, Craig Hospital, a well-known rehabilitation hospital, and the Colorado Cross-Disability Coalition recruited members and former and current spinal cord injury patients. Also, the United

<sup>3</sup> The two Connecticut focus groups were held at a hotel in Litchfield, CT, but the majority of respondents reside in Torrington, which is one of the largest towns in Connecticut and adjacent to Litchfield.

<sup>4</sup> See Attachment One for a copy of the advertisement placed in the *Tampa Tribune* to recruit individuals for the Tampa caregivers group.

Cerebral Palsy Agency posted an announcement on its electronic listserv seeking respondents. In Litchfield, a local independent living center and an agency serving persons with mental illness helped identify qualified participants. Other local disability action groups, including the Advocacy Center for People with Disabilities, Inc., a non-profit organization providing protection and advocacy services in the State of Florida, the Florida Chapter of TASH<sup>5</sup> at the University of Florida in Gainesville, FL, and the Family Care Council in Pinellas County aided in the search for participants for the Tampa focus group.

- ◆ *State agencies.* For the Litchfield focus groups, local officials within the State Medicaid agency/Bureau of Rehabilitation Services at the Connecticut Department of Social Services identified a sample of individuals with disabilities who might participate in the focus groups. The State of Colorado Department of Health Care Policy and Financing and the Developmental Disabilities Program and the Florida Department of Human Services also identified names of potential participants.

Screeners to recruit participants. Recruitment screeners were developed to ensure the participation of qualified participants.<sup>6</sup> For all of the focus groups a mix of demographics and other criteria was sought, such as gender, race/ethnicity, and employment status. Individuals were not asked to participate if they had been employed or volunteered in a setting related to market research, health care, insurance, or government health services. Secondary screening criteria included whether an individual qualified or was waiting to qualify for government benefits (e.g., Medicare, Medicaid, Supplemental Security Income (SSI), Supplemental Security Disability Income (SSDI), or the Plan for Achieving Self-Support (PASS-plan)).<sup>7</sup>

Professional research facilities in Tampa and Denver received screeners to recruit non-referred and referred participants and provided research space, equipment and support. A local independent living center in Litchfield, CT screened participants and organized logistics for the focus groups which were convened at a local inn. Transportation was provided to and from the focus groups for those who needed it.

Moderator's guide. MEDSTAT team members and CMS contracted and worked with a professional focus group moderator to develop a moderator's guide for the focus groups. The guide was revised throughout the course of the research with the objective of further exploring existing and evolving research questions and other disability policy areas. The moderator's guide was also modified based on the makeup of the focus group. The moderator, MEDSTAT team members, and CMS team members collaborated and revised the guides between focus group cities and sessions based on research needs.<sup>8</sup> Topics of discussion and exercises outlined in the moderator's guide included:

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<sup>5</sup> Formerly known as the Association of People with Severe Disabilities.

<sup>6</sup> Recruitment screeners were modified after the Tampa focus group. See Attachment Two for copies of recruitment screeners used for each of the focus groups.

<sup>7</sup> See Attachment Three for demographics of respondents.

<sup>8</sup> See Attachment Four for a copy of the most current version of the moderator's guide.

- ◆ Pre-group exercise where respondents were asked to think about a person close to them and describe what they think that person's life will be (or is) like at age 80;<sup>9</sup>
- ◆ Issues related to employment;
- ◆ Issues related to government programs;
- ◆ Support systems and needs of people with disabilities and their caregivers;
- ◆ Perception of long-term care and preparations made for the future; and
- ◆ Best avenues to disseminate long-term care information to Americans with disabilities.

Observing focus groups and synthesizing findings. The moderator conducted the focus groups while members of the MEDSTAT and CMS teams observed and took research notes using laptop computers. Following research sessions, team members met to debrief, exchange ideas and observations, and suggest improvements for subsequent focus groups. Several members of the MEDSTAT team independently reviewed videotapes of the focus groups to validate research notes and topline findings.

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<sup>9</sup> Pre-group exercise conducted at Tampa focus group only.

## KEY FINDINGS

Focus groups with people with disabilities and caregivers provided valuable insight into the daily struggles these populations encounter. These findings are a stark contrast to the focus groups with the general market audience. Key findings show that most respondents with disabilities or their caregivers have conducted very little, if any future or long-term care planning because they face a multitude of social and financial barriers related to disabilities. On a daily basis, these barriers override any planning for the future. Given this, people with disabilities are not likely to respond to a long-term care campaign, but would prefer that these resources be dedicated to campaigns regarding more immediate concerns and needs.

Key findings from discussions on long-term care show that people with disabilities and their caregivers:

- ◆ Have given some thought as to what type of long-term care they would need twenty years from now, but very few have conducted any formal planning;
- ◆ Worry about what would happen to themselves and to those they care for as they age, but have done little to address this concern;
- ◆ Are familiar with the term “long-term care,” but negatively equate it with nursing homes and being institutionalized;
- ◆ Understand the significant financial costs of retirement and long-term care, but are prohibited from saving any money because of asset limits of federal programs;
- ◆ Would rather die quickly in order to avoid the issue of needing nursing home care, becoming a burden on others or family members, or losing dignity and independence; and
- ◆ Avoid talking with other family members about long-term care plans.

Other important findings on general barriers show that people with disabilities and caregivers:

- ◆ Experience ongoing problems with federal entitlement programs, such as qualifying for benefits, accessing services, and staying on the rolls of various government programs;
- ◆ Feel there are limited services, programs, training, and information available to people with disabilities and caregivers and a lack of awareness of existing programs;
- ◆ Learn many lessons as they navigated the system that they wish they had known in advance;
- ◆ Express interest in a long-term support services checklist that could be incorporated into other informational materials;
- ◆ Are enthusiastic and long to be working, but are hindered by discrimination and a myriad of employment issues when trying to find or maintain jobs;
- ◆ Request up-to-date information such as: options for financing care; organizations that offer advice in navigating the system; job training information; contact information for local advocacy organizations and State and Federal disability offices; legal information;

government programs for which low-income individuals with disabilities may be eligible; support groups; and housing options.

- ◆ Realize that they might benefit by structuring their living situations and geographic location based on the available services in an area, but are hesitant to move due to the frustration of having to start over to find supports;
- ◆ Do have support systems (e.g., family and friends), but do not find them helpful in providing information about long-term supports;
- ◆ Hear about available services for people with disabilities and related populations through word-of-mouth, especially from other people with disabilities or other caregivers (more so than the general market, this population is receptive to messages received through local avenues including friends, credible local disability or community-based organizations, or support groups for people with disabilities and their families or caregivers;
- ◆ Express strong distrust of government and mainstream sources (for example, one respondent indicated that he would “assume [information and materials] are skewed to the way HCFA wants us to look at it.”); and
- ◆ Are forced to adopt manipulative behaviors in order to navigate complex and unresponsive social service systems, such as concealing their disability or mental illness when applying for private insurance or employment through lying and manipulation. This behavior discourages the ability to openly communicate with employers about needed supports and can potentially reinforce the stigma and marginalization that persons with disabilities may already experience. When re-entering the workforce, persons with disabilities are challenged to unlearn these behaviors.

## RECOMMENDATIONS

### **Consider a nationally coordinated, locally implemented information and education effort related to more immediate needs of people with disabilities.**

An information and education campaign would be more relevant if centered around issues of interest to people with disabilities, such as employment, stigma and discrimination, available resources, and payment for services. Persons with disabilities express a general lack of awareness of locally contingent information that relates to these needs. While the information may exist, there is a disconnect between the resources and consumers who need the information, particularly after they no longer participate in formal education. In general, persons with disabilities express a strong desire for more information that would help explain their support services options. A national campaign may be crafted in a way that disseminates information through trusted, local intermediaries and that can be tailored by communities to include local information where applicable. It may link the available resources that are often needed by consumers after they are no longer interfacing with these intermediaries. While aging caregivers of people with disabilities are in need of long-term care information and could be the audience for a specialized campaign, they are unlikely to be motivated by more general market long-term care messages. This type of campaign may not fit into the larger general market long-term care awareness campaign, but the need for such information dissemination and awareness has proven a prevalent theme among persons with disabilities.

### **Educate potential employers and the general public to the strengths of persons with disabilities.**

Respondents suggest that it would be helpful for public agencies to provide employers with information about the strengths, desires, and abilities of persons with disabilities to work. In particular, people with mental illness express frustrations with the stigma of mental illness and felt compelled to conceal their conditions from their employers and therefore did not receive needed supports. For example, they want employers to be aware of the necessity for compromises such as flexible work schedules to deal with stresses. Persons with physical disabilities also confront challenges as employers initially questioned their productivity. A large-scale information campaign may educate the general public to the strengths of people with disabilities, their value in the workforce, and the potential compromises that may be made for a more inclusive work environment.

## OBSERVATIONS

### Perceptions and familiarity with long-term care<sup>10</sup>

- ◆ As with focus groups with the general market, “long-term care” was a term with which people were familiar. For the most part, the term “long-term care” sparked negative thoughts in respondents’ minds, as they associated the words with nursing home or institutional care. Additional answers included other formal, informal, and family types of care services: “It’s around-the-clock care,” and “I’m receiving it right now with home health aides and nurses coming in to take care of me.”
- ◆ Respondents declared that dignity was very important; persons with physical disabilities were particularly vocal in identifying this theme. Quality of life, security, control, and independence were also highly valued. Needing long-term care was equated with a loss of independence, freedom, and the ability to maintain a stable quality of life for respondents. For persons with mental illness, overcoming the stigma of their condition was also a central issue.
- ◆ Nursing home care conjured up negative thoughts of fraud and abuse as well as loss of independence among respondents. Many viewed nursing homes as the last resort or option in their life or for the person they care for. One respondent stated, and many other respondents in the same group concurred, that suicide was a more palatable option than being put in a nursing home and losing dignity, “If I can’t live independently, then I don’t want to go on.” For several respondents who had already spent time living in institutional settings and had struggled to gain an independent lifestyle, the prospect of returning was emotionally wrenching.
- ◆ While there were no explicit conversations about expenses, it seemed that respondents understood the potential expense of long-term care and the fact that Medicare pays for only a small portion of care.
- ◆ Some respondents agreed that it would be helpful to persons with disabilities if persons without disabilities could realize that their condition was only temporary and that eventually most people faced the likelihood of some loss of ability. One respondent suggested that disability be thought of as another chapter in the book of one’s life.

### Long-term care planning

- ◆ Long-term planning, particularly related to long-term care, was not on respondents’ radar screen. Generally, respondents were too consumed dealing with immediate problems related to their disabilities. Most respondents also pointed out the futility of planning ahead because situations and health conditions could potentially change and taking action to protect one’s

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<sup>10</sup> All “perceptions and familiarity with long-term care” findings mirror the general market audience’s perceptions and familiarity with long-term care. See *Topline Report of Findings from Focus Groups with the General Market Audience* for more details.

future, such as saving to buy a home, could negatively affect eligibility to receive benefits. A caregiver remarked, “You don’t know what the circumstances will be because it depends on the conditions of the person in the future.”

- ◆ Caregivers, more often than persons with disabilities, expressed more fear than respondents in the general market when asked to think about the future. They appeared scared to face the question of what would happen to the person they cared for after they were no longer able to care for them. However, aging caregivers indicated that they had done little to address this concern. When asked about future arrangements, most caregivers said they would prefer that another family member take care of the person they cared for rather than using a group home or other formal services. Yet, this desire was complicated by the fact that they did not want to place a burden on their family members.
- ◆ In addition to a general lack of planning on the part of respondents, many people with disabilities did not believe that their parents had made any formal long-term plans. One participant’s parents were in their fifties, and when asked if they had made any plans he said, “They’re too young to think about it.”
- ◆ When respondents were asked how they envisioned their lives and goals in twenty years, many cited positive goals such as being healthy and happy, working, driving, living independently and living with dignity. They did not think about potential further losses in abilities.

### **Issues with employment**

- ◆ According to caregiver respondents in all sites, training programs and work opportunities for people with physical disabilities and developmental disabilities were limited.
- ◆ In addition to lack of training and work opportunities, people with physical disabilities or mental illnesses fought other barriers: stereotypes from employers and co-workers, and stigmas surrounding physical and mental disabilities. Respondents remarked that their disabilities hindered them from obtaining a job because employers viewed them as being incapable of holding down a job, inattentive, unproductive, taking longer than “normal people” to perform tasks, not dependable, or having the propensity to “fly off the handle.” Also, many employers were not understanding if people with mental illnesses had to take time off or had gaps in employment. As one respondent said, “Being mentally ill opens you up to a lot of abuses.” Fear of stigmatization led many respondents to conceal their illness, thus decreasing opportunities for their employers to develop an understanding of their needs and abilities.
- ◆ Fear of losing benefits created employment disincentives for people with disabilities. When asked what the biggest issue was about having a job, one respondent of the mental illness focus group remarked about “the fear of losing assistance.” The majority of respondents wanted to work more hours, make more money, and advance their careers, but income limits put them at risk of losing government benefits. For instance, one respondent with a physical disability who was employed lost SSI and Medicaid because his income increased when he was promoted to a higher position. He was able resume receiving benefits (1619b) by making an agreement with his employer not to pay him more than \$8.50 an hour. “That’s what’s

wrong with social programs; you get in and stay at the bottom where there's nowhere to go," remarked another respondent.

- ◆ Fear of insurance discrimination also led some individuals to hide their disabilities. For example, one respondent who had cystic fibrosis felt compelled to lie about her condition in order to be covered by her husband's insurance.
- ◆ When asked to discuss their ideal working environment, many respondents described a flexible, pressure-free job where they could be their own bosses, work at their own speed on their own schedule, and in some cases work out of their homes.
- ◆ Most caregivers were not able maintain a job with income outside their caregiver duties because being a caregiver was a full-time responsibility.

### **Supports**

- ◆ While supports vary by geographic area and personal situation, the focus groups suggested that most respondents, caregivers, and people with disabilities lacked strong support networks. Many respondents indicated that their support network consisted of friends and family members who lived near by. However, when asked to describe these relationships, many stated that friends and family did not understand their unique needs and did not understand what it was like "to walk in their shoes."
- ◆ A number of respondents said government agencies were not very supportive.

### **Issues with government programs**

- ◆ Respondents said that there was a lack of services and programs for caregivers and people with disabilities. Programs such as support groups, training programs, job programs (e.g., resume building, job searching, interview training) for caregivers and people with disabilities were almost nonexistent or sparse some areas. Also, respondents stated that they would have to move to specific cities to get services, but they did not want to move elsewhere for fear of losing the fragile network created and having to start over to locate supports.
- ◆ While a few training workshops and programs for people with disabilities and related populations did exist, as one respondent explained, "You have to dig to find services." All groups expressed concern that they probably were not aware of half of the services and programs available for people with disabilities. Most of the respondents lamented that programs were not well publicized. Respondents also voiced the sentiment that direct service providers were not aware of all the programs available or may not share information with clients. One respondent said, "They don't tell you anything that is out there; how are we to know about all these programs with no one to tell you?" For example, in Colorado focus groups, approximately half of the participants had never heard of the Ticket to Work program.<sup>11</sup> In Connecticut, while respondents knew that the program existed, they were not aware of specific program requirements.

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<sup>11</sup> Officially known as the Ticket to Work and Work Incentives Improvement Act of 1999, this Act improved access to employment training and placement services for people with disabilities who want to work.

- ◆ Qualifying for government and non-government programs has been a barrier for people with disabilities. One respondent said it was very difficult getting into the Medicaid waiver program. She added, “It’s like they don’t want you; like they’re spending money out of their own pockets.”
- ◆ Once a person qualifies and is receiving benefits, accessing government programs is a very burdensome and lengthy process. One caregiver’s son waited three years to enter a training workshop, which teaches technical skills to persons with developmental disabilities.
- ◆ All respondents expressed frustration over income eligibility caps and asset requirements of government programs. As mentioned previously, income eligibility caps on government programs hindered a respondent’s job status and created disincentives to work or get married. One participant separated from her husband because she would not have been able to receive benefits. Another respondent sadly stated that his wife’s income counted against his eligibility. Government programs also hindered ownership of assets. Some caregivers, in particular, were worried about losing benefits if the person they cared for possessed too many assets.

### **Sources of Information**

- ◆ Local disabilities groups were helpful disseminators of information to people with disabilities and related populations to an extent, but word of mouth is much stronger. One respondent explained, “You get more information from talking to other people who have been there than from support groups.” Most respondents said they discovered programs and available services through talking with other families and parents at meetings and social dances for people with disabilities. One respondent mentioned hearing about programs through other people at the Ronald McDonald House.
- ◆ Respondents reported that persons with disabilities did not immediately reference federal and state government agencies as sources of information. “They don’t have a lot of information and are not very helpful,” said one respondent. Another respondent added, “They don’t jump out to give it (information) to you.”
- ◆ While the majority of participants said they utilized the Internet as a source of information, many also said the Internet provided only basic information, did not address specific questions, and was often outdated. Many remarked that finding the right information was a cumbersome and time-consuming process. One person said, “It’s too jumbled; you could spend all day.”
- ◆ Respondents from the physical disability focus groups suggested that an appropriate spokesperson might be selected from members of general and specific disability groups (e.g., spinal cord) or independent living centers. The appeal of this type of spokesperson is that he/she may understand first-hand the daily barriers and struggles people with disabilities encounter. Social workers from specialized hospitals, such as Craig Hospital that specializes in spinal cord injuries, were also suggested. One messenger not favored was Christopher Reeves. Although he has a disability, many respondents stated that they would identify much more with a spokesperson from the local community who faced similar social and financial issues.

**ATTACHMENT ONE:**

**ADVERTISEMENT USED TO RECRUIT PARTICIPANTS  
FOR TAMPA FOCUS GROUP**

**\$\$\$ FOR YOUR OPINIONS!!**

**Schwartz Consumer Research Is Looking For People Who Are CAREGIVERS To  
Individuals With Mental Retardation**

Participants **will receive \$75.00** at the end of this 2-hour discussion as a thank you.  
NO SALES OR CLINICAL RESEARCH.

**CALL NOW ..... 813 207 0332**

To take part in this important opinion study

**ATTACHMENT TWO:**

**PHONE INTRODUCTION USED TO RECRUIT PARTICIPANTS  
FOR LITCHFIELD, CT FOCUS GROUP**

### Description

Independence Northwest is providing assistance to Boston College and a company called the Barents Group to help identify persons with disabilities who may want to participate a focus group discussion. We are looking for persons with a diagnosis of serious mental illness to participate in discussions about their lives. Participants must be between the ages of 25 and 55.

It is a chance to earn a little money for participating in a two-hour discussion. We are calling to see if you would like to be considered.

The discussions will be held on June 18, 2001 in Litchfield, Connecticut. Participants **will receive \$100.00** at the end of the 2-hour discussion as a thank you. Costs for travel and assistance in getting to the sessions will also be covered. **THESE DISCUSSIONS WILL NOT INVOLVE SALES OR CLINICAL RESEARCH.**

**The discussion will be about health and support issues.**

**They don't tell us any more because they don't want you to think about it ahead of time. There are no right or wrong answers, they just want your honest opinions about the questions asked in the discussion.**

**Would you like us to pass your name on?**

**Thanks for your time!**

**ATTACHMENT THREE:  
RECRUITMENT SCREENERS**

**SAMPLE SCREENER FOR CAREGIVERS OF PEOPLE  
WITH MENTAL RETARDATION**

**Long-Term Care Awareness Screener  
(Please over-recruit to ensure 8 participants per group)**

**Group Specifications**

◆ **1 group (Tampa)**

- Racially mixed, caregivers of people with mental retardation

Group No. _____	Respondent #: _____
Respondent Name: _____	
Respondent Address: _____	
Respondent City: _____	State: _____ Zip Code: _____
Respondent Phone: (_____) _____ --- _____	(PLEASE PRINT CLEARLY)

Hello, my name is \_\_\_\_\_ of \_\_\_\_\_. This is not a sales call. I am calling to ask you if you would like to be part of a discussion group about health and employment issues. As part of a study being done by the Department of Health and Human Services, we are seeking the opinions of the disability community. The discussion will be conducted with about 8 other caregivers of people with mental retardation. Would you be interested in participating?

- \_\_\_ Yes (CONTINUE)
- \_\_\_ No

Q1. ( ) Male <=== **DO NOT ASK** (Seek 50% for each group)  
( ) Female

Q2. Have you ever worked or volunteered in any type of market research firm, health care setting, insurance company, or for any government health agency (**Recruiter: Do not read-- e.g., health insurance, hospital, nursing home, home health agency, assisted living facility, adult day care, social work**)?  
( ) Yes (**Thank respondent and end call.**)  
( ) No ← **Continue**

Q3 . Do you consider yourself: (Caucasian not to exceed 75%)  
( ) Caucasian  
( ) African American  
( ) Asian American  
( ) Hispanic  
( ) Native American  
( ) Other – Please Identify.

Q4 . What is the highest level of education you have completed?

- Sixth grade or less ← **Continue**
- Grades 7-12 ← **Continue**
- Some college or more ← **Continue (Recruit no more than 50% in any category)**

Q5. Are you currently married? **(Seek 50% married)**

- Yes
- No

Q6. Are you currently or have you ever been the primary caregiver for a person with mental retardation for more than six months? By primary caregiver, we mean being the primary person responsible for helping that person with everyday basic care functions like bathing and dressing. **[Recruiter: If the respondent only helps with activities like housekeeping, lawn care, or groceries, do not select YES.]**

- Yes ← **Go to Q8**
- No ← **(Thank respondent and end call)**

Q8. Does the person you care for currently qualify for Medicare (or is waiting to qualify)?

- Yes, currently qualifies
- No, waiting for two-year time limit
- No, doesn't qualify (recruit no more than 25%)

Q10. How old is the person for whom you are caring?

- less than 25 years old **(Thank respondent and end call.)**
- Between 25-55 years old ← **Continue**
- More than 55 years old **(Thank respondent and end call.)**

Q11. How old are you?

- Less than 40 years old **(Thank respondent and end call.)**
- Between 40-70 years old ← **Continue**
- More than 70 years old **(Thank respondent and end call.)**

Q12. Are you currently employed in a position that provides income?

- Yes ← **Continue**
- No ← **Continue (seek 60%)**

Q13. When are you planning to retire? *(Do not read answers)*

- In 2 years or less ← **Continue**
- More than two years but less than ten ← **Continue (seek 50%)**
- More than ten years ← **Continue**
- Already retired

Q14. Is your total household income *(read choices)*

- Less than \$10,000? **(Thank respondent and end call.)**
- Between \$10,000 and \$18,000?
- Between \$18,000 and \$39,000?

- ( ) Between \$39,001 and \$50,000? **(Recruit no more than 3)**
- ( ) Between \$50,001 and \$60,000? **(Recruit no more than 2)**
- ( ) Between \$60,001 and \$80,000? **(Recruit no more than 2)**
- ( ) Over \$80,000? **(Recruit no more than 2)**

**Invitation: Racially mixed, men and women who are caregivers for loved ones with Mental retardation.**

Thank you for answering my questions. You are eligible to participate in our group discussion. Your group will be held on May 18 at 3pm. It will last about 2 hours and you will be paid \$75 for your time.

Can you attend?

Yes

No

#### **INSTRUCTIONS FOR RECRUITERS**

##### **TERMINATE IF ONE OR MORE OF THE FOLLOWING IS "YES":**

- HAS PARTICIPATED IN GROUPS IN PAST 12 MONTHS
- WORKS IN THE INSURANCE INDUSTRY
- WORKS FOR THE GOVERNMENT, MEDICARE, OR MEDICAID

##### **MAKE SURE PARTICIPANT MEETS THE FOLLOWING CRITERIA**

##### **CHECK EACH ONE:**

- IS MADE AWARE OF THE CO-OP FEE TO BE PAID
- UNDERSTANDS VERY CLEARLY WHERE/WHEN GROUP IS TO BE HELD

*I, \_\_\_\_\_ (Recruiter's Name) hereby certify that this participant qualifies to be included in the focus group because he/she meets ALL REQUIREMENTS ABOVE.*

*Recruiter Signature: \_\_\_\_\_ Date: \_\_\_\_\_*

**SAMPLE SCREENER FOR PEOPLE WITH PHYSICAL DISABILITIES**

**Long-Term Care Awareness Screener  
(Please over-recruit to ensure 8 participants)**

**Group Specifications**

◆ **1 group**

- Racially mixed, low to middle income, men and women with physical disabilities

Group No. _____		Respondent #: _____
Respondent Name: _____		
Respondent Address: _____		
Respondent City: _____	State: _____	Zip Code: _____
Respondent Phone: (_____) _____ --- _____		(PLEASE PRINT CLEARLY)

Hello, my name is \_\_\_\_\_ of \_\_\_\_\_. This is not a sales call. I am calling to ask you if you would like to be part of a discussion group about health and employment issues. As part of a study being done by the Department of Health and Human Services, we are seeking the opinions of the disability community. The discussion will be conducted with about 8 other people also with physical disabilities. Would you be interested in participating?

- Yes (CONTINUE)
- No

In order to follow the research guidelines, I need to ask you some background information.

Q1. ( ) Male <=== **DO NOT ASK** (Seek 50% for each group)  
( ) Female

Q2. Have you ever worked or volunteered in any type of market research firm, health care setting, insurance company, or for any government health agency (**Recruiter: Do not read-- e.g., health insurance, hospital, nursing home, home health agency, assisted living facility, adult day care, social work**)?  
( ) Yes (**Thank respondent and end call.**)  
( ) No ← **Continue**

Q3 . Do you consider yourself: (Caucasian not to exceed 75% in each group)  
( ) Caucasian  
( ) African American  
( ) Asian American  
( ) Hispanic  
( ) Native American  
( ) Other – Please Identify.

Q4 . What is the highest level of education you have completed?

- Sixth grade or less ← **Continue**
- Grades 7-12 ← **Continue**
- Some college or more ← **Continue (Recruit no more than 50% in each group)**

Q5. What is your age? (*Read answers if respondent hesitates to give age*)

- Under age 25 (**Thank respondent and end call**)
- Age 25-40 ← **Continue (Recruit at least 50% in each group)**
- Age 41-55 ← **Continue**
- Over age 55 (**Thank respondent and end call**)

Q6, Could you tell me what physical disability you have? I am interested in those disabilities that affect you most on a daily basis. \_\_\_\_\_

\_\_\_\_\_  
(Note: Recruit if person has physical disability and brain injury; if they have mental illness, but not mental retardation, exclude from the group.)

- Primarily physical disability
- I don't have a disability (**Thank respondent and end call**)

Q7. Do you currently qualify for Medicare (or are you waiting to qualify)?

- Yes, currently qualifies
- No, waiting for two-year time limit
- No, doesn't qualify (**Recruit no more than 50% for group 1**)

Q8. Do you have a Plan for Achieving Self-Support (known as a PASS-plan) related to Supplemental Security Income or SSDI?

- Yes, has a PASS plan (**Ideally recruit at least 2 with PASS**)
- No, doesn't have a PASS plan
- Doesn't know

Q9. Are you currently employed in a position that provides income?

- Yes ← **Continue**
- No ← **Continue (seek 60%)**

Q10. When are you planning to retire? (*Do not read answers*)

- In 2 years or less ← **Continue**
- More than two years but less than ten ← **Continue**
- More than ten years ← **Continue**
- Already retired (Thank respondent and end call.)

Q11. Is your total household income (*read choices*)

- ( ) Less than \$10,000? ← **Continue (Recruit no more than 1)**
- ( ) Between \$10,000 and \$18,000? ← **Continue**
- ( ) Between \$18,000 and \$39,000? ← **Continue**
- ( ) Between \$39,001 and \$50,000? ← **Continue (Recruit no more than 1)**
- ( ) Between \$50,001 and \$60,000? ← **Continue (Recruit no more than 2)**
- ( ) Between \$60,001 and \$80,000? ← **Continue (Recruit no more than 2)**
- ( ) Over \$80,000? (**Thank respondent and end call.**)

**Invitation : Racially mixed, low to moderate income, men and women with physical disabilities**

Thank you for answering my questions. You are eligible to participate in our group discussion. Your group will be held on June 5, 1:00-3:00 p.m. The facilities are physically accessible, and lunch will be served at 12:00 p.m. The discussion will last about 2 hours and you will be paid \$100 for your time and the costs of any assistance you may need. If you need help with travel arrangements, that will be provided.

Can you attend?

- Yes
- No

In order to help with our planning for the group, I need to ask you a few more questions.

Will you need help with transportation to the facility?  Yes  No

Do you use any equipment to get around? (e.g. wheelchair, cane, walder, etc.)  
 Yes  No

If yes, please specify: \_\_\_\_\_

Do you need help with any of the following activities?

	Yes	No
Eating	_____	_____
Using the toilet	_____	_____
Reading	_____	_____
Writing	_____	_____

Do you have a personal care attendant who might be accompanying you to the facility?  
 Yes  No

**INSTRUCTIONS FOR RECRUITERS****TERMINATE IF ONE OR MORE OF THE FOLLOWING IS "YES":**

- HAS PARTICIPATED IN GROUPS IN PAST 12 MONTHS
- WORKS IN THE INSURANCE INDUSTRY
- WORKS FOR THE GOVERNMENT, MEDICARE, OR MEDICAID

**TERMINATE IF THE PERSON DOES NOT HAVE A DISABILITY****MAKE SURE PARTICIPANT MEETS THE FOLLOWING CRITERIA  
CHECK EACH ONE:**

- IS MADE AWARE OF THE CO-OP FEE TO BE PAID
- UNDERSTANDS VERY CLEARLY WHERE/WHEN GROUP IS TO BE HELD
- UNDERSTANDS THAT THE FACILITIES ARE PHYSICALLY ACCESSIBLE
- UNDERSTANDS THAT TRANSPORTATION CAN BE ARRANGED IF NEEDED
- HAS THE CHANCE TO EXPRESS ANY DIETARY PREFERENCES

I, \_\_\_\_\_ (*Recruiter's Name*) hereby certify that this participant qualifies to be included in the focus group because he/she meets ALL REQUIREMENTS ABOVE.

Recruiter Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**SAMPLE SCREENER FOR CAREGIVERS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES INCLUDING MENTAL RETARDATION AND/OR BRAIN INJURIES**

**Long-Term Care Awareness Screener  
(Please over-recruit to ensure 8 participants per group)**

**Group Specifications**

◆ **1 group**

- Racially mixed, caregivers of people with developmental disabilities including mental retardation and/or brain injuries

Group No. _____		Respondent #: _____
Respondent Name: _____		
Respondent Address: _____		
Respondent City: _____	State: _____	Zip Code: _____
Respondent Phone: (_____) _____ --- _____		(PLEASE PRINT CLEARLY)

Hello, my name is \_\_\_\_\_ of \_\_\_\_\_ This is not a sales call. I am calling to ask you if you would like to be part of a discussion group about health and employment issues. As part of a study being done by the Department of Health and Human Services, we are seeking the opinions of the disability community. The discussion will be conducted with about 8 other caregivers of people with mental retardation, developmental disabilities, and/or brain injuries. Would you be interested in participating?

- \_\_\_ Yes (CONTINUE)
- \_\_\_ No

Q1. ( ) Male <=== **DO NOT ASK** (Seek 50% for each group)  
( ) Female

Q2. Have you ever worked or volunteered in any type of market research firm, health care setting, insurance company, or for any government health agency (**Recruiter: Do not read-- e.g., health insurance, hospital, nursing home, home health agency, assisted living facility, adult day care, social work**)?  
( ) Yes (**Thank respondent and end call.**)  
( ) No ← **Continue**

Q3 . Do you consider yourself: (Caucasian not to exceed 75%)  
( ) Caucasian  
( ) African American  
( ) Asian American  
( ) Hispanic  
( ) Native American  
( ) Other – Please Identify.

Q4 . What is the highest level of education you have completed?

- Sixth grade or less ← **Continue**
- Grades 7-12 ← **Continue**
- Some college or more ← **Continue (Recruit no more than 50% in any category)**

Q5. Are you currently married?

**(Seek 50% married)**

- Yes
- No

Q6. Are you currently or have you ever been the primary caregiver for a person with mental retardation, developmental disability, and/or brain injury for more than six months? By primary caregiver, we mean being the primary person responsible for helping that person with everyday basic care functions like bathing and dressing. [**Recruiter:** *If the respondent only helps with activities like housekeeping, lawn care, or groceries, do not select YES.*]

- Yes ← **Go to Q8**
- No ← **(Thank respondent and end call)**

Q8. Does the person you care for currently qualify for Medicare (or is waiting to qualify)?

- Yes, currently qualifies
- No, waiting for two-year time limit
- No, doesn't qualify (recruit no more than 25%)

Q10. How old is the person for whom you are caring?

- less than 25 years old (**Thank respondent and end call.**)
- Between 25-55 years old ← **Continue**
- More than 55 years old (**Thank respondent and end call.**)

Q11. How old are you?

- Less than 40 years old (**Thank respondent and end call.**)
- Between 40-70 years old ← **Continue**
- More than 70 years old (**Thank respondent and end call.**)

Q12. Are you currently employed in a position that provides income?

- Yes ← **Continue**
- No ← **Continue (seek 60%)**

Q13. When are you planning to retire? (*Do not read answers*)

- In 2 years or less ← **Continue**
- More than two years but less than ten ← **Continue (seek 50%)**
- More than ten years ← **Continue**
- Already retired

Q14. Is your total household income (*read choices*)

- Less than \$10,000? (**Thank respondent and end call.**)
- Between \$10,000 and \$18,000?
- Between \$18,000 and \$39,000?
- Between \$39,001 and \$50,000? (**Recruit no more than 3**)
- Between \$50,001 and \$60,000? (**Recruit no more than 2**)
- Between \$60,001 and \$80,000? (**Recruit no more than 2**)
- Over \$80,000? (**Recruit no more than 2**)

**Invitation: Racially mixed, men and women who are caregivers for loved ones with  
Mental retardation, cognitive, and/or brain injury.**

Thank you for answering my questions. You are eligible to participate in our group discussion. Your group will be held on May 18 at 3pm. It will last about 2 hours and you will be paid \$75 for your time.

Can you attend?

- Yes
- No

## INSTRUCTIONS FOR RECRUITERS

**TERMINATE IF ONE OR MORE OF THE FOLLOWING IS "YES":**

- HAS PARTICIPATED IN GROUPS IN PAST 12 MONTHS
- WORKS IN THE INSURANCE INDUSTRY
- WORKS FOR THE GOVERNMENT, MEDICARE, OR MEDICAID

**MAKE SURE PARTICIPANT MEETS THE FOLLOWING CRITERIA  
CHECK EACH ONE:**

- IS MADE AWARE OF THE CO-OP FEE TO BE PAID
- UNDERSTANDS VERY CLEARLY WHERE/WHEN GROUP IS TO BE HELD

I, \_\_\_\_\_ (*Recruiter's Name*) hereby certify that this participant qualifies to be included in the focus group because he/she meets ALL REQUIREMENTS ABOVE.

Recruiter Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**SAMPLE SCREENER FOR PEOPLE WITH MENTAL ILLNESS**

**Long-Term Care Awareness Screener  
(Please over-recruit to ensure 8 participants)**

**Group Specifications**

◆ **1 group**

- Racially mixed, low to middle income, men and women with a mental illness

Group No. _____		Respondent #: _____
Respondent Name: _____		
Respondent Address: _____		
Respondent City: _____	State: _____	Zip Code: _____
Respondent Phone: (_____) _____ --- _____		(PLEASE PRINT CLEARLY)

Hello, my name is \_\_\_\_\_ of \_\_\_\_\_ This is not a sales call. I am calling to ask you if you would like to be part of a discussion group about health and employment issues. As part of a study being done by the Department of Health and Human Services, we are seeking the opinions of the disability community. The discussion will be conducted with about 8 other people also with mental illnesses. Would you be interested in participating?

- Yes (CONTINUE)
- No

In order to follow the research guidelines, I need to ask you some background information.

Q1. ( ) Male <=== **DO NOT ASK** (Seek 50% for each group)  
( ) Female

Q2. Have you ever worked or volunteered in any type of market research firm, health care setting, insurance company, or for any government health agency (**Recruiter: Do not read-- e.g., health insurance, hospital, nursing home, home health agency, assisted living facility, adult day care, social work**)?  
( ) Yes (**Thank respondent and end call.**)  
( ) No ← **Continue**

Q3 . Do you consider yourself: (Caucasian not to exceed 75% in each group)  
( ) Caucasian  
( ) African American  
( ) Asian American  
( ) Hispanic  
( ) Native American  
( ) Other – Please Identify.

- Q4 . What is the highest level of education you have completed?
- Sixth grade or less ← **Continue**
  - Grades 7-12 ← **Continue**
  - Some college or more ← **Continue (Recruit no more than 50% in each group)**
- Q5. What is your age? (*Read answers if respondent hesitates to give age*)
- Under age 25 (**Thank respondent and end call**)
  - Age 25-40 ← **Continue (Recruit at least 50% in each group)**
  - Age 41-55 ← **Continue**
  - Over age 55 (**Thank respondent and end call**)
- Q6, Could you tell me what mental illness you have?. \_\_\_\_\_
- 
- Primarily mental illness
  - I don't have a disability (**Thank respondent and end call**)
- Q7. Do you currently qualify for Medicare (or are you waiting to qualify)?
- Yes, currently qualifies
  - No, waiting for two-year time limit
  - No, doesn't qualify (**Recruit no more than 50% for group 1**)
- Q8. Do you have a Plan for Achieving Self-Support (known as a PASS-plan) related to Supplemental Security Income or SSDI?
- Yes, has a PASS plan (**Ideally recruit at least 2 with PASS**)
  - No, doesn't have a PASS plan
  - Doesn't know
- Q9. Are you currently employed in a position that provides income?
- Yes ← **Continue**
  - No ← **Continue (seek 60%)**
- Q10. When are you planning to retire? (*Do not read answers*)
- In 2 years or less ← **Continue**
  - More than two years but less than ten ← **Continue**
  - More than ten years ← **Continue**
  - Already retired (Thank respondent and end call.)
- Q11. Is your total household income (*read choices*)
- Less than \$10,000? ← **Continue (Recruit no more than 1)**
  - Between \$10,000 and \$18,000? ← **Continue**
  - Between \$18,000 and \$39,000? ← **Continue**
  - Between \$39,001 and \$50,000? ← **Continue (Recruit no more than 1)**
  - Between \$50,001 and \$60,000? ← **Continue (Recruit no more than 2)**
  - Between \$60,001 and \$80,000? ← **Continue (Recruit no more than 2)**
  - Over \$80,000? (**Thank respondent and end call.**)

**Invitation : Racially mixed, low to moderate income, men and women with mental illnesses.**

Thank you for answering my questions. You are eligible to participate in our group discussion. Your group will be held on June 5, 1:00-3:00 p.m. The facilities are physically accessible, and lunch will be served at 12:00 p.m. The discussion will last about 2 hours and you will be paid \$100 for your time and the costs of any assistance you may need. If you need help with travel arrangements, that will be provided.

Can you attend?

Yes

No

---

**INSTRUCTIONS FOR RECRUITERS**

**TERMINATE IF ONE OR MORE OF THE FOLLOWING IS "YES":**

HAS PARTICIPATED IN GROUPS IN PAST 12 MONTHS

WORKS IN THE INSURANCE INDUSTRY

WORKS FOR THE GOVERNMENT, MEDICARE, OR MEDICAID

**TERMINATE IF THE PERSON DOES NOT HAVE A DISABILITY**

**MAKE SURE PARTICIPANT MEETS THE FOLLOWING CRITERIA**

**CHECK EACH ONE:**

IS MADE AWARE OF THE CO-OP FEE TO BE PAID

UNDERSTANDS VERY CLEARLY WHERE/WHEN GROUP IS TO BE HELD

HAS THE CHANCE TO EXPRESS ANY DIETARY PREFERENCES

I, \_\_\_\_\_ (*Recruiter's Name*) hereby certify that this participant qualifies to be included in the focus group because he/she meets ALL REQUIREMENTS ABOVE.

Recruiter Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**ATTACHMENT FOUR:**  
**DEMOGRAPHICS OF RESPONDENTS**

City	Gender	Education	Race	Married	Disability	Medicare	Pass Plan	Employed in Position that Provides Income	When are you going to retire?	Income	Age	Relation to Patient	Age of Patient
Tampa	Male	Some College	African American	Yes	Caregiver	No - Waiting for 2 yr. time	N/A	Yes	More than 10 yrs	18- 39 K	44	Parent-Child	62
Tampa	Female	Some College	Caucasian	Yes	Caregiver	Yes	N/A	No	Already Retired	39-50 K	55	Sister	41
Tampa	Female	7 through 12	Caucasian	Yes	Caregiver	Yes	N/A	No	Already Retired	18- 39 K	72	Parent-Child	50
Tampa	Female	Some College	Caucasian	Yes	Caregiver	Yes	N/A	No	More than 10 yrs	18- 39 K	44	Sister	40
Tampa	Female	7 through 12	Hispanic	Yes	Caregiver	Yes	N/A	No	Already Retired	18- 39 K	64	Parent-Child	38
Tampa	Male	7 through 12	African American	No	Caregiver	No - Waiting for 2 yr. time	N/A	Yes	More than 10 yrs	10-18 K	47	Nephew	17
Tampa	Female	7 through 12	Caucasian	Yes	Caregiver	No - Doesn't Qualify	N/A	No	Already Retired	60-80 K	57	Parent-Child	45
Tampa	Female	Some College	African American	No	Caregiver	No - Doesn't Qualify	N/A	Yes	More than 10 yrs	18-39 K	47	Parent-Child	23
Tampa	Male	Some College	Caucasian	Yes	Caregiver	Yes	N/A	Yes	More than 10 yrs	60-80 K	52	Ward	25
Denver	Female	7 through 12	African American	No	Caregiver	Yes	N/A	No	2 yrs or less	10-18 K	40-70	Parent-Child	25-55
Denver	Female	7 through 12	Caucasian	Yes	Caregiver	Yes	N/A	Yes	Already Retired	39-50 K	70+	Parent-Child	25-55
Denver	Female	7 through 12	Caucasian	Yes	Caregiver	Yes	N/A	Yes	10+ yrs	18-39 K	40-70	Parent-Child	<25
Denver	Female	Some College	Caucasian	Yes	Caregiver	Yes	N/A	Yes	10+ yrs	60- 80 K	40-70	Parent-Child	<25
Denver	Female	7 through 12	Hispanic	Yes	Caregiver	Don't Know	N/A	No	10+ yrs	10-18 K	<40	Parent-Child	<25
Denver	Male	Some College	Caucasian	Yes	Caregiver	No	N/A	Yes	10+ yrs	18-39 K	40-70	Parent-Child	<25
Denver	Female	7 through 12	Caucasian	Yes	Caregiver	Yes	N/A	Yes	10+ yrs	50-60 K	40-70	Parent-Child	<25
Denver	Female	Some	Caucasian	no	Physical	No	No	No	10+ yrs	10-18 K	41-55	N/A	N/A

		College											
Denver	Male	Some College	Caucasian	yes	Physical	Yes	No	No	10+ yrs	18-39 K	25-40	N/A	N/A
Denver	Female	Some College	Caucasian	no	Physical	Yes	No	Yes	2-10 yrs	10-18 K	41-55	N/A	N/A
Denver	Male	Some College	Caucasian	no	Physical	Yes	No	No	10+ yrs	10-18 K	25-40	N/A	N/A
Denver	Female	Some College	Caucasian	no	Physical	Yes	No	Yes	10+ yrs	<10 K	41-55	N/A	N/A
Denver	Female	Some College	Other	no	Physical	No	No	Yes	10+ yrs	10-18 K	41-55	N/A	N/A
Denver	Female	7 through 12	Other	yes	Physical	No	No	Yes	10+ yrs	18-39 K	41-55	N/A	N/A
Denver	Female	Some College	Caucasian	no	Physical	Yes	Yes	No	10+ yrs	10-18 K	25-40	N/A	N/A
Denver	Male	Some College	Caucasian	no	Physical	No	No	Yes	10+ yrs	60-80 K	25-40	N/A	N/A
Denver	Female	Some College	Caucasian	yes	Physical	No	No	Yes	10+ yrs	60-80 K	25-40	N/A	N/A
Litchfield	Male	Some College	Caucasian	no	Physical	No	Yes	No	N/A	18-39K	25-40	N/A	N/A
Litchfield	Female	7 through 12	Caucasian	no	Physical	Yes	Yes	Yes	10+ yrs	<10K	25-40	N/A	N/A
Litchfield	Male	7 through 12	Caucasian	yes	Physical	Yes	Don't Know	Yes	10+ yrs	18-39 K	41-55	N/A	N/A
Litchfield	Male	Some College	Caucasian	yes	Physical	No	Yes	No	N/A	18-39 K	25-40	N/A	N/A
Litchfield	Female	7 through 12	Caucasian	yes	Mental	Yes	No	Yes	10 + yrs	<10K	41-55	N/A	N/A
Litchfield	Female	Some College	Caucasian	no	Mental	Yes	No	No	N/A	<10K	41-55	N/A	N/A
Litchfield	Male	7 through 12	Caucasian	no	Mental	Yes	No	No	N/A	<10K	41-55	N/A	N/A
Litchfield	Female	7 through 12	Caucasian	no	Mental	No	Don't Know	No	N/A	10-18K	25-40	N/A	N/A
Litchfield	Male	Some College	Caucasian	no	Mental	Yes	No	No	2-10 yrs	10-18 K	25-40	N/A	N/A

**ATTACHMENT FIVE:**  
**MODERATOR'S GUIDE**

**MODERATOR'S GUIDE**  
**LONG-TERM CARE CONSUMER RESEARCH— People with Disabilities**  
**June 2001**

## **WELCOME**

Thank you for joining us today.

### **Introduce Self**

This project is for the federal government. We are here today to try to make health information and education more responsive to consumer needs.

Before we start today, I'd like to talk about a few things:

- ◆ I am interested in all of your ideas, comments, and suggestions
- ◆ I'd like to hear from everyone
- ◆ There are no right or wrong answers to the questions
- ◆ All comments—both positive and negative—are welcome. Please don't worry about offending me with anything you might say—it's important that I know how you feel.
- ◆ Please feel free to agree or disagree with one another. We would like to have many points of view.
- ◆ Behind me is a one-way mirror. Behind it are people helping me today.
- ◆ This discussion is being video and audio-taped, so that we can take better notes on what you all have to say. We may also show the tapes to others who are interested in the results, but could not be here today. Before coming into the room you signed a release giving us permission to video/audio tape you during this discussion. All comments are confidential and used for research purposes only.
- ◆ I'd like this to be a group discussion, so you needn't wait for me to call on you. Please speak one at a time, so that the tape recorder can pick up everything.
- ◆ Your insights today will help guide the development of health communications materials—that is, messages about health or healthcare you might hear on the radio, see on TV or in brochures, flyers or articles—that the federal government is doing for people like you.

## **INTRODUCTIONS**

Tell me about yourself; where you live; whom you live with; family; your disability; do you work? what do you like to do for fun? Socially?

## SECTION 1: ISSUES RELATED TO EMPLOYMENT

Some of you in the group have paid jobs and others do not. I want to ask you about people with disabilities who are not working in paid employment. You can answer about yourself or about someone you know.

- ◆ Have you worked before? Have you tried to work?
- ◆ For those of you not currently working, do you see yourselves working again?
- ◆ What do you see as barriers to employment for people with disabilities?
- ◆ What would it take for you to be employed again?
- ◆ Do you think that people needing long-term supports and services are able to work? If not, what do you think prevents them? What do they need to be able to work?
- ◆ Do you think that more people needing long-term supports would be able to work if they could receive help to get to work or while at work?
- ◆ Do you think that many people with disabilities don't work because they are afraid of losing health benefits that cover long-term supports (for example: Medicaid.)?
- ◆ Have you heard about the Medicaid Buy-in program that allows working people with disabilities to keep Medicaid health benefits? Where did you learn about it? Do you think this is something that would help people who are not currently working?
- ◆ Do you think that more people would work if they had information about programs that would let them keep Medicaid health benefits even if they were working? What would be the best ways of getting this information to people?
- ◆ I'm wondering if you could tell me what "misconceptions" people have about working when needing long-term support.
- ◆ What needs to be said to get people more interested in working even if they have needs for long-term supports and services?
- ◆ What needs to be said to potential employers to help them realize that many people with disabilities can be good workers, even if they need long-term supports or services?

## SECTION 2: DISCUSSION ON LONG TERM CARE

Describe the picture that comes to mind when I say "Long-Term Care?" Where have you heard this term before? What do you think it means? Do you like the term? Why/why not? What other names do you like for this kind of help?

- ◆ If you currently have long-term support needs, how are they provided to you (family, friends, Medicaid provider, other formal provider)
- ◆ How do you describe the things you need or will need or the kinds of help?
- ◆ What can people do to prepare for their changing needs? What have you done?
- ◆ Who does this kind of planning for you or your family?

*[At this point, if it hasn't already come up, you can tell participants that we are using the term Long Term Care to describe the things/services needed when you can't fully care for yourself. The campaign we are planning is to try to inform people about the need for Long-Term Care. If appropriate, you may ask them to discuss how/why their interpretation differs from the definition you offered. Also, if they've expressed a preference for another term, from this point on, use the term preferred by the group in place of long-term care.]*

1. One of the things we are thinking about, as an action that people can do in preparing for long-term support needs is talk to family members and other trusted individuals. Have you talked with your family members about your future needs? What was the discussion like? What would you think if you saw an ad that said, "Talk to your family about long-term care?" How would you do this? Who would you talk to? When? What do you think this could accomplish? What do you see as the downside to talking to your family about this? Who are other people, besides family, that you would more likely talk to/listen to when it comes to this subject?
2. Another action that we're thinking about suggesting as a way to prepare for long-term support needs is to think about where you live. Have you made any decisions about your living situation based on your future needs, not just things you need right now. For example, have you moved to an accessible home that has features that you don't need now but might need in the future? Have you moved or thought about moving to a different part of the country that might better meet your needs? Have you made any decisions about where you live based on who could live with you or near you in the future?

### **SECTION 3: COMMUNICATION**

- ◆ Who would the best people to give you information? Who would be most believed? *[If open-ended discussion needs prompting, use a probe list including: family, friends, newspaper, TV, magazines, internet, radio, doctor, Medicaid, legislator, celebrities]*
- ◆ In your community, who are the people/places that command respect? I'm thinking about those people/places that you listen to when they speak.
- ◆ Where would you turn in your community for more information about working and keeping long term care benefits or planning for you long term needs? Where else could this information be placed so that you would be most likely to see it and pay attention to it?

Thanks again for you help today.