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**A Growing Crisis in Health and Long-
Term Services and Supports for Midlife
and Older Persons with Disabilities:
Changes from 2002 to 2005**

by

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A Growing Crisis in Health and Long-Term Services and Supports for Older Persons with Disabilities: Changes from 2002 to 2005

A. Introduction

Adults with disabilities of all ages want to live independently and exercise choice and control over decisions that affect their health and essential daily activities. Few current data are available on potential barriers to independent living, access to health care, and the quality of life of middle-aged and older persons with disabilities, especially those ages 50–64. In particular, few current data on changes in their lives over time—both positive and negative—are available. To help fill this gap, this issue brief presents follow-up data from a subgroup of persons 50 and older with disabilities originally interviewed in 2002 by Harris Interactive for the AARP report, *Beyond 50.03: A Report to the Nation on Independent Living and Disability*. That report found that people with disabilities 50 and older needed more and better options for independent living, and made a series of policy recommendations to encourage such options.

B. Purpose

The purpose of this issue brief is to identify differences and similarities between 2002 and 2005 in respondents' perceptions of their quality of life, need for assistance with everyday activities and other supports that permit independent living, and health care. The survey also included some questions on the livability of their communities, housing, and technology, topics that are not examined here. (See the appendix for a copy of all of the survey results.)

C. Methods

In 2005, Harris Interactive re-interviewed those respondents who had expressed willingness in the 2002 survey to be recontacted. A majority of the 1,102 respondents in the 2002 survey (601 persons) had expressed willingness to be recontacted.

The sample for this report is 287 U.S. adults ages 52 or older who have a disability (referred to hereinafter as “persons with disabilities”) and who participated in *both* the 2002 and 2005 surveys. The response rate was almost 50% of the 601 who had originally agreed to be recontacted. Data were weighted to be representative of the entire sample of persons who agreed to be recontacted in the 2002 AARP study.

All 2005 interviews were conducted by phone; they averaged 21 minutes in length. The margin of error for the total sample is ± 5.9 percentage points.

Significance is reported at the 5 percent or less confidence level.

Description of the Sample

Table 1: Characteristics of the Resampled Group, 2005

Gender	Male	44%
	Female	56%
Age (2005)	50–64	51%
	65 or older	49%
Race	White	85%
	Black	10%
	Hispanic	4%
Income	\$15,000/year or less	37%*
	\$15,000–\$35,000/year	32%
	\$35,000/year or more	30%
Attended college		47%
Living alone		32%
Severity of disability	Slight/Moderate	36%
	Somewhat Severe	42%
	Very Severe	22%

*Significant change between 2002 and 2005.

With the exception of income, there were no significant changes in the three years in any of the above characteristics. Persons with disabilities were more likely to have incomes of \$15,000 or less in 2005 than in 2002.

No changes occurred in the proportions of respondents with physical and sensory limitations. However, significantly more individuals reported experiencing a cognitive or emotional disability than in 2005.

Table 2: Type of Disability, 2002 and 2005

	2002	2005
Base	n=287	n=287
Limited physical mobility	82%	85%
Vision or hearing impairment	30%	31%
Cognitive or emotional condition	17%	26%*

Types of disability are not mutually exclusive.

*Significant change between 2002 and 2005.

Source: Harris Interactive AARP Beyond 50 Survey: 2002 and 2005 data.

D. Key Findings

Almost no good news

With only one exception,¹ no improvement occurred between 2002 and 2005 in any aspect of quality of life about which respondents were queried. Almost all indicators related to quality of life and health and long-term supportive services remained constant or worsened between 2002 and 2005. In addition, the survey findings suggest a growing crisis in the affordability of both health services and long-term services to help persons with disabilities live independently.

Quality of life is declining

Most persons with disabilities continued to say they are generally satisfied with the quality of their lives i.e., about 34% were “very satisfied” and 43% “somewhat satisfied” in both years.² However, their views on more specific indicators were significantly more negative in 2005 than in 2002. In 2005, persons with disabilities were more likely than in 2002 to say that they:

- have been prevented from reaching their full abilities due to their disability (69 % in 2005 versus 60% in 2002)
- expect the quality of their lives to get worse over the next four years (70% versus 55%)
- have difficulty working at a job or business (73% versus 63%)
- are not able to drive a car every day (44% versus 32%).

In addition, more than half (53%) of respondents said their condition had worsened over the prior two years.

Concern about the cost of personal assistance services, such as help with daily activities like bathing and cooking, is increasing

In 2005, persons with disabilities were more likely than in 2002 to report concerns about being unable to pay for the cost of nonmedical, long-term services and supports; those concerns doubled between 2002 and 2005, from 12% to 24%.

Health care and insurance costs are issues of growing concern

In 2005, the cost of health care and need for better medical insurance also had become even greater concerns for adults with more severe disabilities, compared with those with less severe disabilities, than in 2002:

¹ One positive note was that persons with disabilities said they had more control over when and what they ate in 2005 than in 2002.

² By rough comparison, 61% of persons ages 18 and older without disabilities said they were “very satisfied” and 32% “somewhat satisfied” in responses to an identical question in a survey conducted by Harris Interactive for the National Organization on Disability in 2004.

- In 2005, 44% of older persons with more severe disabilities had postponed needed health care because it was not affordable, compared to 15 % of adults with less severe disabilities. The difference, 29%, was far greater than in 2002, when 36 % of persons with more severe disabilities had postponed health care, compared to 24 % of persons with less severe disabilities (a difference of 12 %).
- The proportion of persons with severe disabilities who said that having better medical insurance would cause a major improvement in the quality of their lives rose to 61% in 2005, compared to those with less severe disabilities (42%).

Better medical insurance and a way to pay for long-term services and equipment, cited by more than half of respondents in both 2005 and 2002, were the two top changes respondents said would cause a major improvement in the quality of their lives.

Family support remains the bulwark; paid help is uncommon

Family and other informal caregivers continue to be the primary source of help persons with disabilities receive.

As in 2002, about 60% of people with severe disabilities received help with everyday daily activities, such as bathing, dressing, shopping and cooking, as did about 30% of those with less severe disabilities.

Among those who received regular help, about 81% continued to receive unpaid help from family members, predominantly spouses/partners or children, and predominantly from persons living in the same household (about 75%). In both 2005 and 2002, only about 20% received paid help.

Unmet need for help with basic daily activities persists; cost is an even bigger barrier than in 2002

Nearly three in ten respondents reported in both 2005 (28%) and 2002 (27%) that they need more help than they were receiving with everyday activities like bathing, dressing, cooking and shopping:

- Even more respondents said the main reason they did not receive enough help is because they could not afford it (74% in 2005 versus 59% in 2002).
- When asked about *other* reasons they did not receive enough help,³ the top responses in 2005 were limitations in their informal caregivers' ability to provide even more help than they were already providing, for example, due to their responsibilities in the labor force (47%). Other responses included not knowing where to go to get additional help (41%); not being able to find anyone reliable to provide the help (39%); and feeling too embarrassed to ask for more help (34%).

³ This question was not asked in 2002.

Preferences for family assistance are even stronger—except for 24-hour care

Preferences for assistance from family and friends with everyday activities such as bathing and cooking were even stronger in 2005 than in 2002 (57 % versus 47%), while preferences for care provided by agency workers at home declined (from 35% to 27%). Only small proportions preferred care in other settings, such as assisted living (about 11%) and nursing homes (about 2%).

However, when asked about preferences if they should need 24 hour help, respondents' top choice continued to be care provided at home by an agency (42% in 2005 and 36% in 2002), followed by family care at home (25% in 2005 versus 32% in 2002).

Preferences for consumer-directed services continue

About 40% of persons with disabilities continue to say their condition has caused them to lose control over how they spend money and who provides them with services; about 60% say they have lost control over when and where they are able to go out.

When asked about possible ways in which *publicly funded* home-based services could be provided, the respondents' preferred option continued to be having the money go directly to them (see table 3 below). They would then pay for the services and manage the workers themselves. However, more individuals wanted an agency to pay the workers in 2005 (34 %) than in 2002 (26 %), although they still wanted to be able to manage the workers and services themselves.

Table 3: Preference for Home Care Services Among Three Options, 2002 and 2005

	2002	2005
Base	n=287	n=287
In option one, the money goes to an agency. The agency provides the services and manages the workers.	82%	85%
In option two, the money goes to you. You then pay for the services and manage the workers.	30%	31%
In option three, you manage the workers and the services the workers provide, and the money goes to the agency and the agency pays the workers.	17%	26%*

*Significant change between 2002 and 2005.

Source: Harris Interactive AARP Beyond 50 Survey: 2002 and 2005 data.

Needs for assistive devices continue

Respondents were more likely to use assistive equipment to help with daily activities in 2005 than in 2002 (46% versus 38%). The most common types were walkers, canes, or crutches. However, the same proportion of respondents in both years (about one third) said there was a device or product that they do not have but think could improve their lives. The top choices were home modifications to improve mobility, wheelchairs or scooters, and aids for bathing or using the toilet.

Differences by age⁴

In both 2005 and 2002, younger adults (52–64) with disabilities were more likely than adults age 65+ to report that their disability

- is severe
- results in difficulty
 - working
 - dressing, bathing, or getting around inside the home
- has prevented them from reaching their full potential

Compared with 2002, younger adults (52–64) in 2005 were even more likely than their older counterparts to

- believe that having more control over decisions and services and help needed would cause a major improvement in their lives
- postpone needed health care because it was not affordable
- prefer having control over payment and management of home care service workers
- believe there are assistive devices and equipment that could improve their quality of life

Differences by severity of disability⁵

Compared with 2002, in 2005 persons with more severe disabilities were more likely than those with less severe disabilities to report that

- their condition has worsened
- having better medical insurance would cause a major improvement in their lives
- they had postponed needed health care because it was not affordable

In both years, persons with more severe disabilities were more likely than those with less severe disabilities to

- receive help with everyday activities from one or more people with everyday activities, typically from their own family members or friends
- be less satisfied with their lives
- believe there are assistive devices and equipment that could improve their quality of life

Additionally, persons with more severe disabilities were more likely to indicate that they had less control over when and where they are able to go out, how they spend their money, and who provides services. However, there was a decrease in the percentage of respondents both with more severe and less severe disabilities who said they had less control over when and what they eat.

⁴Data tables are available upon request. Only differences in responses between the 2002 and 2005 samples that are at least 6 percentage points are reported.

E. Conclusions and Discussion

The one measure for which we found improvement—in which respondents no longer feel as much loss of control over when and what they eat—is small comfort in light of the other life challenges persons with disabilities are confronting. The high proportion of persons with disabilities who report declines in important measures of quality of life is disturbing. While some of their pessimism may reflect a worsening of their condition, it appears that growing financial barriers to receiving essential health and long-term services and supports play an important role as well. And it is those who are most vulnerable—persons with severe disabilities and those who have unmet needs for help with basic daily activities—who expressed the greatest concerns about affordability.

The continuing reliance upon family and friends as the primary source of help is not surprising, since paid formal assistance, even for persons with very severe disabilities, is uncommon in the United States. However, the results suggest that families are often overwhelmed and strained, and are simply unable to arrange, coordinate, and provide all of the care needed. The top barrier cited by persons who reported needing additional help was their inability to pay for such services. Other reasons included the inability of their family members and friends to provide even more help than they were already providing due to other demands on their time and the restrictions of their job responsibilities. Persons with unmet needs for services also were significantly less likely to prefer that all of the help be provided by family and friends.

The continuing crisis in our health care system is evidenced by the even higher proportions of persons with severe disabilities who postponed needed health care in 2005 than in 2002. The numbers tell the story—more than two out of five (44%) with severe disabilities postponed health care because it was not affordable, and well over half (61%) said having better medical insurance would cause a major improvement in the quality of their lives. Persons ages 52–64 were the most likely to have postponed care.

Evidence is accumulating of the critical role assistive technologies can play in helping persons with disabilities remain independent. A higher proportion of older persons (65+) with disabilities were using at least one such device in 2005 than in 2002. However, in both 2002 and 2005, a similar share of older persons (65+) with disabilities (23%) expressed unmet need for such devices, suggesting that needs for additional devices may accompany the worsening of chronic conditions.

F. Policy Implications

More affordable home and community-based services (HCBS) for persons with disabilities is unquestionably a pressing policy need.⁵ Medicaid, the primary public payer for long-term services and supports, *entitles* individuals to nursing home care, whereas providing HCBS is *optional*. While almost all states have been rebalancing their Medicaid spending to overcome institutional bias, progress has been uneven and slow.⁶ In addition, there are often long waiting lists. Both federal and state policies should expand access to HCBS and allow consumers to choose the setting in which they wish to receive services. In addition, federal and state policy should expand HCBS options for lower- and middle-income persons not eligible for Medicaid and strengthen support services for family caregivers.

Publicly funded consumer-directed services, funded primarily through Medicaid, have been increasing in recent years. Such programs empower persons with disabilities to make decisions about services they wish to receive and how they wish to receive them. Data in this survey again demonstrate that consumer-directed services are a critical option for persons with disabilities, who prefer such programs to agency-directed services, as well as for their family caregivers. In 2005, a larger proportion than in 2002 preferred to have an agency pay the workers, a finding that is consonant with growth in consumer-directed programs that use fiscal agents or other means to deal with payroll, taxes, and withholding.⁷

A need for more family-centered policies is another clear implication of this report. In particular, it appears that providing paid, formal services to back up family caregivers could help to reduce unmet needs among people with disabilities and help families sustain their caregiving roles. Among persons age 65 and older with disabilities, the most recent trend has been toward increasing reliance on family care alone and declining use of formal care.⁸ However, families cannot always do it all alone. In addition, it is important to recognize, assess, and address a family caregiver's own support needs,⁹ such as training and respite. Research has shown that family caregivers are more likely than noncaregivers to have health problems of their own.¹⁰ Workplace policies that give family caregivers more flexibility in meeting their responsibilities are also needed.

The lack of adequate health insurance for persons with disabilities again emerged as warranting immediate attention. A large and growing number of persons with severe disabilities said they simply went without needed health care and that better medical insurance would help their lives

⁵ For data on the number of persons receiving HCBS by state, and state spending on HCBS, see *Across the State 2006: Profiles of Long-Term Care and Independent Living* by Ari Houser, Wendy Fox-Grage, and Mary Jo Gibson, AARP Public Policy Institute, December 2006.

⁶ Wendy Fox-Grage, Barbara Coleman, and Marc Freiman, *Rebalancing: Ensuring Greater Access to Home and Community Based-Services*, AARP Public Policy Institute, FS 132, September 2006.

⁷ Enid Kassner, *Consumer-Directed Home and Community-Based Services*, AARP Public Policy Institute, FS 128, May 2006.

⁸ Brenda Spillman and Kirsten J. Black, *Staying the Course: Trends in Family Caregiving*, AARP Public Policy Institute, PPI Issue Paper #2005-17, November 2005.

⁹ Lynn Friss Feinberg, Kari Wolkwitz, and Cara Goldstein, *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*, AARP Public Policy Institute, #2006-09, March 2006.

¹⁰ A. Ho, S. R. Collins, K. Davis, and M. M. Doty, *A Look at Working-Age Caregivers' Roles, Health Concerns and Needs for Support*, Issue Brief (New York: The Commonwealth Fund, August 2005).

enormously. Persons ages 50–64 with disabilities who are not eligible for Medicaid or Medicare are particularly vulnerable.

One important step toward reducing unmet needs for assistive technologies among persons with disabilities would be to provide broader coverage in Medicaid HCBS waiver programs. However, additional steps will be necessary because public funding of assistive technologies is a patchwork, with many gaps.¹¹

Finally, in a broader policy perspective, these data illustrate the need for major reform of both our nation’s health care system and its long-term care policies. Findings in this report signal the growing crisis in health care and long-term services and supports for older persons with disabilities and their families.

¹¹ Marc Freiman et al., *Public Funding and Support of Assistive Technologies for Persons with Disabilities*, AARP Public Policy Institute, PPI Issue Paper #2006-04, January 2006.

Appendix

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*AARP
Beyond 50 Survey
2002 and 2005 Data*

SUBJECTS FOR QUESTIONNAIRE

SECTION 200:	SCREENING
SECTION 300:	DISABILITY ISSUES
SECTION 400:	QUALITY OF LIFE AND COMMUNITY
SECTION 600:	HEALTH CARE
SECTION 800:	HOUSING
SECTION 900:	TECHNOLOGY
SECTION 100:	DEMOGRAPHICS

- **Total sample includes 287 U.S. adults ages 52 and over who have a disability. These respondents participated in a similar survey in 2002 and agreed to be re-contacted at a later date for the present survey.**
 - **Data are weighted to be representative of the sample of respondents who agreed to be contacted again in the 2002 study.**
- **For the 2005 study, interviewing was conducted by telephone from March 14 - 24, 2005.**
- **For the 2002 study, interviewing was conducted by telephone from September 17-29, 2002**
- **The margin of error for the total sample of 287 respondents is +/-5.9 percentage points.**

Notes on reading the results

The percentage of respondents has been included for each item. An asterisk (*) signifies a value of less than one-half percent. A dash represents a value of zero. Percentages may not always add up to 100% because of computer rounding or the acceptance of multiple answers from respondents answering that question.

SECTION 200: SCREENING

BASE: SPEAK ON BEHALF (Q255/1 OR Q257/1)

Q259 What is your relationship to the person in your household with a disability?

	<u>Wave 1 (2002)</u> <u>(n= 19*)</u>	<u>Wave 2 (2005)</u> <u>(n= 4*)</u>
Spouse/Partner	78	19
Sibling	10	-
Child	3	58
Friend	2	-
Parent	-	12
Other relative	-	-
Nurse/caregiver	-	-
Other	8	11
Not sure	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS

Q237 Just to confirm, does a health problem, disability or handicap currently keep you/this person from participating fully in work, school, housework, or other activities, or not?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes, keeps me or someone else from participating fully	79	91
No, does not keep anyone from participating fully	20	9
Not sure/Don't know	1	*
Decline to answer	-	-

BASE: ALL RESPONDENTS

Q239 And, just to confirm, do you/does this person in your household have any of the following long-lasting conditions?

	<u>Yes</u>	<u>No</u>	<u>Not sure/ Don't know</u>	<u>Decline to answer</u>
A condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting or carrying				
Wave 1 (2002) (n= 287)	82	18	-	-
Wave 2 (2005) (n= 287)	85	15	-	-
Blindness, deafness or a severe vision or hearing impairment				
Wave 1 (2002) (n= 287)	30	70	-	-
Wave 2 (2005) (n= 287)	31	69	-	-
A physical, mental, or emotional condition that increases the difficulty of learning, remembering, or concentrating				
Wave 1 (2002) (n= 287)	17	82	1	*
Wave 2 (2005) (n= 287)	26	74	-	-

BASE: ALL RESPONDENTS OR PROXY

Q280 Respondent vs. Proxy Interview

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Respondent participated	92	91
Proxy interview	8	9

**Caution should be exercised when interpreting these results as data are based on a small sample size. Please note that with a base this small, the data is more qualitative than it is quantitative.*

SECTION 300: DISABILITY ISSUES

BASE: ALL RESPONDENTS OR PROXY

Q305 How severe would you/this person say your/their disability or health condition is?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Very/Somewhat Severe (net)	61	64
Very severe	26	22
Somewhat severe	35	42
Slight/Moderate (net)	39	36
Moderate	32	29
Slight	7	7
Not sure/Don't know	*	-
Decline to answer	-	*

BASE: ALL RESPONDENTS OR PROXY

Q315 Compared to two years ago would you/this person say today that your/their disability or health condition has improved, worsened or stayed about the same?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Improved	N/A	9
Worsened	N/A	53
Stayed about the same	N/A	38
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: ALL RESPONDENTS OR PROXY

Q325 For each one, please tell me if you have/this person has any difficulty performing the activity due to your/their disability or health condition.

	<u>Yes</u>	<u>No</u>	<u>Not Sure/ Don't Know</u>	<u>Decline to Answer</u>
Working at a job or business				
Wave 1 (2002) (n= 287)	63	33	3	1
Wave 2 (2005) (n= 287)	73	26	2	-
Going out alone, for instance to shop or visit a doctor's office				
Wave 1 (2002) (n= 287)	41	59	*	-
Wave 2 (2005) (n= 287)	41	59	*	-
Dressing, bathing or getting around inside your (their) home				
Wave 1 (2002) (n= 287)	34	65	*	-
Wave 2 (2005) (n= 287)	39	61	-	-

BASE: ALL RESPONDENTS OR PROXY**Q327** Approximately how often do you/does this person drive a car?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Drives a car at least once a week (net)	76	69
Every day	44	32
A few times a week	26	31
Once a week	5	6
Once or twice a month	2	4
A few times a year	2	3
You (They) do not drive at all.	21	24
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY**Q330** How many people regularly help you/this person with everyday activities like bathing, dressing, cooking and shopping because of your/their disability or health condition?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
0	54	49
1	32	38
2	10	10
3 or more	4	3
Not sure	*	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY**Q331** Do you/Does this person need more help than you/they receive now?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Yes	27	28
No	73	72
Not sure/Don't know	1	-
Decline to answer	-	-

BASE: NEED MORE HELP**Q332** What is the main reason why you do not/this person does not receive enough help?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 97*)</u>	<u>(n= 95*)</u>
It is too expensive or you (they) can't afford to pay for more help.	59	74
You (They) can not find anyone reliable to provide the help.	15	1
You (They) do not want to ask your (their) family or friends for more help.	9	9
It is too much trouble to arrange.	3	1
Another reason not mentioned	8	15
Not sure	5	-
Decline to answer	1	-

**Caution should be exercised when interpreting these results as data are based on small sample size.*

BASE: NEED MORE HELP

Q334 What are the other reasons why you do not/this person does not receive enough help?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 95*)</u>
Family or friends do not have the time to provide additional help.	N/A	53
Family or friend's job responsibilities do not permit more help	N/A	47
You (they) do not know where to go to get additional help	N/A	41
You (They) can not find anyone reliable to provide the help.	N/A	39
You (they) feel embarrassed to ask for additional help.	N/A	34
It is too much trouble to arrange.	N/A	32
You (They) do not want to ask your (their) family or friends for more help.	N/A	20
It is too expensive or you (they) can't afford to pay for more help.	N/A	11
Another reason not mentioned	N/A	5
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: RECEIVE REGULAR HELP

Q335 Is the person who provides you/this person with help paid or unpaid?

	<u>Wave 1 (2002)</u> <u>(n= 146)</u>	<u>Wave 2 (2005)</u> <u>(n= 158)</u>
Paid	21	19
Unpaid	79	81
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: RECEIVE REGULAR HELP

Q340 Is this person a family member or friend or some other type of relationship?

	<u>Wave 1 (2002)</u> <u>(n= 146)</u>	<u>Wave 2 (2005)</u> <u>(n= 158)</u>
Family member	74	78
Friend	6	4
Other relationship	19	18
Not sure/Don't know	-	-
Decline to answer	-	1

**Caution should be exercised when interpreting these results as data are based on small sample size.*

BASE: RECEIVE REGULAR HELP FROM FAMILY MEMBER**Q342** What type of family member provides you/this person with this help?

	<u>Wave 1 (2002)</u> <u>(n= 112)</u>	<u>Wave 2 (2005)</u> <u>(n= 125)</u>
Spouse or partner	74	71
Child	12	13
Sibling	4	6
Daughter or son in law	3	6
Parent	1	3
Mother or father in law	1	-
Aunt or uncle	1	-
Cousin	-	-
Other family member	5	1
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: RECEIVE REGULAR HELP**Q345** Does this person live with you/this person with a disability or health condition?

	<u>Wave 1 (2002)</u> <u>(n= 146)</u>	<u>Wave 2 (2005)</u> <u>(n= 158)</u>
Yes, person lives with me (this person)	72	75
No, person does not live with me (this person)	28	25
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: RECEIVE REGULAR HELP**Q355** Thinking about the help that you receive/this person receives, how satisfied are you/is this person with the following characteristics of your/their help?

	<u>Very/ Somewhat Satisfied (net)</u>	<u>Very Satisfied</u>	<u>Somewhat Satisfied</u>	<u>Neither Satisfied nor Dissatisfied</u>	<u>Very/ Somewhat Dissatisfied (net)</u>	<u>Somewhat Dissatisfied</u>	<u>Very Dissatisfied</u>
Training/knowledge							
Wave 1 (2002) (n= N/A)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Wave 2 (2005) (n= 158)	94	63	31	2	3	3	*
Emotional support							
Wave 1 (2002) (n= N/A)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Wave 2 (2005) (n= 158)	91	61	30	1	7	3	4
Availability							
Wave 1 (2002) (n= N/A)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Wave 2 (2005) (n= 158)	89	60	29	4	8	7	1
Cost							
Wave 1 (2002) (n= N/A)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Wave 2 (2005) (n= 158)	82	60	21	7	11	2	9

Not sure/Don't know and Decline to answer responses are not shown, and constitute about 1% of all responses.

BASE: RECEIVE REGULAR HELP**Q360** Did you/this person have a choice in who would provide you/them with the help that you/they needed?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 158)</u>
Yes	N/A	48
No	N/A	52
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: DID NOT HAVE CHOICE IN WHO WOULD PROVIDE HELP**Q365** Why did you/this person not have a choice in who would provide you/them with the help that you/they needed?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 96*)</u>
The help I (they) receive was the only help I (they) could afford.	N/A	37
I (they) was assigned this person.	N/A	11
I (they) couldn't find anyone else.	N/A	9
Someone else made the decision.	N/A	8
Other reason	N/A	54
Not sure/Don't know	N/A	2
Decline to answer	N/A	2

BASE: RECEIVE REGULAR HELP**Q370** Compared to two years ago, has the amount of help you receive/this person receives increased, decreased or stayed the same?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 158)</u>
Increased	N/A	35
Decreased	N/A	10
Stayed the same	N/A	55
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: HELP HAS INCREASED OR DECREASED**Q375** In terms of how this help is paid for, which of the following best describes how this has changed?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 80*)</u>
There has been no change in how the help is being paid for.	N/A	75
I (They) now have both unpaid and paid help.	N/A	13
You (they) used to have unpaid help; now it is paid.	N/A	5
You (they) used to have paid help; now it is unpaid.	N/A	4
Not sure/Don't know	N/A	3
Decline to answer	N/A	-

**Caution should be exercised when interpreting these results as data are based on small sample size.*

SECTION 400: QUALITY OF LIFE AND COMMUNITY

BASE: ALL RESPONDENTS OR PROXY

Q400 How satisfied are you/is this person with life in general -- very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, or very dissatisfied?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Satisfied (net)	75	77
Very satisfied	35	34
Somewhat satisfied	41	43
Neither satisfied nor dissatisfied	6	9
Dissatisfied (net)	18	14
Somewhat dissatisfied	13	11
Very dissatisfied	5	4
Not sure/Don't know	1	-
Decline to answer	*	-

BASE: ALL RESPONDENTS OR PROXY

Q405 Do you/this person feel that your/their disability or health condition has in any way prevented you/them from reaching what you/they feel are your/their full abilities as a person, or not?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes, prevented	60	69
No, did not prevent	39	31
Not sure/Don't know	1	-
Decline to answer	-	*

BASE: ALL RESPONDENTS OR PROXY

Q410 Do you/Does this person expect your/their quality of life will get better or worse over the next four years?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Will get better	21	19
Will get worse	55	70
No change	15	10
Not sure/Don't know	8	1
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q425 For each of the items I list, do you/does this person think it would cause a major improvement, a minor improvement or no improvement at all in your/their quality of life?

	Would Cause Improvement (net)	Major Improvement	Minor Improvement	No Improvement At All	Not Sure/ Don't Know	Decline to Answer
Being able to get safely to places you (they) wish to go, like stores, restaurants, work, places of worship, and entertainment						
Wave 1 (2002) (n= 287)	73	50	22	26	2	-
Wave 2 (2005) (n= 287)	64	37	27	36	-	*
Receiving better insurance for your (their) medical needs						
Wave 1 (2002) (n= 287)	71	55	16	29	-	-
Wave 2 (2005) (n= 287)	72	54	18	28	*	-
Having more control over decisions about the services and help you (they) need						
Wave 1 (2002) (n= 287)	70	50	20	28	2	-
Wave 2 (2005) (n= 287)	66	38	28	33	1	-
Receiving more understanding and support from family, friends, and others						
Wave 1 (2002) (n= 287)	68	40	28	30	2	*
Wave 2 (2005) (n= 287)	64	31	33	36	*	-
Having a way to pay for long-term services (such as help with bathing or shopping) and equipment						
Wave 1 (2002) (n= 287)	66	45	21	33	1	-
Wave 2 (2005) (n= 287)	64	47	17	36	*	-
Having better access to public buildings and facilities						
Wave 1 (2002) (n= 287)	64	38	26	36	-	-
Wave 2 (2005) (n= 287)	60	34	25	40	-	-
Having someone whom you (they) know and trust to help you (them) with daily activities						
Wave 1 (2002) (n= 287)	62	37	25	37	1	-
Wave 2 (2005) (n= 287)	63	35	28	36	1	-

BASE: ALL RESPONDENTS OR PROXY

Q430 Overall, how would you/this person rate your/their community as a place to live for people with disabilities or health conditions like yours/theirs? Please give your/their community a grade from A to F where an "A" represents "excellent", a "B" represents "very good", a "C" represents "satisfactory", a "D" represents "below average" and an "F" represents "terrible."

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
A	17	17
B	26	31
C	37	32
D	12	16
F	4	4
Not sure/Don't know	3	-
Decline to answer	*	-

BASE: ALL RESPONDENTS OR PROXY

Q435 For each one, please give your/this person's community a grade from A to F where an "A" represents "excellent", a "B" represents "very good", a "C" represents "satisfactory", a "D" represents "below average" and an "F" represents "terrible" for people with disabilities or health conditions like yours/theirs. What grade would you/they give your/their community on...?

	<u>Great (A, B net)</u>	<u>A</u>	<u>B</u>	<u>C</u>	<u>D</u>	<u>F</u>	<u>Not Sure/ Don't Know</u>	<u>Decline to Answer</u>
Being able to get to most of the places you (they) wish to go safely.								
Wave 1 (2002) (n= 287)	62	27	35	20	10	6	1	2
Wave 2 (2005) (n= 287)	56	22	34	31	8	5	*	-
Providing bathrooms accessible to people with disabilities or health conditions like yours (theirs)								
Wave 1 (2002) (n= 287)	53	18	36	20	12	8	4	2
Wave 2 (2005) (n= 287)	50	15	35	28	16	6	*	-
Providing parking for people with disabilities or health conditions like yours (theirs)								
Wave 1 (2002) (n= 287)	52	24	28	19	14	9	3	2
Wave 2 (2005) (n= 287)	56	27	29	22	14	6	*	2
Providing safe and well run parks, community centers and recreation centers.								
Wave 1 (2002) (n= 287)	49	19	30	23	9	10	7	2
Wave 2 (2005) (n= 287)	45	16	29	33	15	5	2	-
Providing information about services and activities available in your (their) community.								
Wave 1 (2002) (n= 287)	46	17	29	28	13	10	1	2
Wave 2 (2005) (n= 287)	37	11	26	33	20	9	1	-
Offering accessible public transportation for people with disabilities or health conditions like yours (theirs).								
Wave 1 (2002) (n= 287)	40	14	26	19	15	15	9	2
Wave 2 (2005) (n= 287)	35	12	23	28	22	14	1	-
Providing a wide variety of services to help you (them) maintain your independence as you (they) grow older.								
Wave 1 (2002) (n= 287)	37	12	25	26	14	12	7	3
Wave 2 (2005) (n= 287)	37	13	24	34	21	8	*	-
Offering dependable public transportation.								
Wave 1 (2002) (n= 287)	36	12	24	24	12	19	7	3
Wave 2 (2005) (n= 287)	34	14	20	25	21	18	1	*

BASE: ALL RESPONDENTS OR PROXY

Q472 How much has your/this person's disability or health condition affected your/their level of control in the following areas? Has your/their disability or health condition caused you/them to have a lot less control, somewhat less control, more control or has it had no effect on your/their control over...

	<u>Less Control (net)</u>	<u>A lot less Control</u>	<u>Somewhat Less Control</u>	<u>More Control</u>	<u>Had No Effect On Control</u>	<u>Not Sure/Don't Know</u>	<u>Decline Answer</u>
When and where you (they) are able to go out							
Wave 1 (2002) (n= 287)	62	29	33	6	30	2	*
Wave 2 (2005) (n= 287)	63	23	39	4	34	-	-
When and what you (they) eat							
Wave 1 (2002) (n= 287)	41	16	26	9	48	3	*
Wave 2 (2005) (n= 287)	30	13	18	6	63	1	-
How you (they) spend money							
Wave 1 (2002) (n= 287)	39	22	17	8	50	4	*
Wave 2 (2005) (n= 287)	41	19	22	8	50	*	*
Who provides services to you (them)							
Wave 1 (2002) (n= 287)	36	14	22	10	49	5	*
Wave 2 (2005) (n= 287)	42	16	26	5	53	1	-

BASE: ALL RESPONDENTS OR PROXY

Q475 Looking to the future, what are your/their biggest worries or concerns about having a disability or health condition?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Loss of mobility or activity	33	33
Loss of independence	29	19
Loss/decrease of financial assets	12	9
Being unable to pay for the cost of care or services	12	24
Becoming housebound, confined to living quarters	9	5
Inability to maintain relationships with family and friends	4	5
Being unable to work, or more limited at work	4	4
Loss of mental capacity such as Alzheimer's	3	3
Loss of ability to participate in hobbies or special interests	2	4
Loss of intimacy	*	1
Other	26	49
Not sure/Don't know	7	5
Decline to answer	2	-

SECTION 600: HEALTH CARE

BASE: ALL RESPONDENTS OR PROXY

Q600 What type of health insurance are you, yourself/this person covered by? Are you/they covered by...?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Medicare	N/A	70
Health insurance or HMO through work or a union	N/A	28
Medicaid	N/A	24
Health insurance from some other source	N/A	19
Public health plan like Veterans Health Benefits	N/A	11
Health insurance or HMO bought directly by you or other family member, such as Medigap	N/A	9
I do not have any health insurance	N/A	2
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: ALL RESPONDENTS OR PROXY

Q605 In the past twelve months, have you/this person ever put off seeking health care which you/they felt you/they needed because you/they could not afford it, or not?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes, put off or postponed getting health care	32	34
No, did not put off or postpone	68	66
Not sure/Don't know	*	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q610 Overall, how do you/this person feel about the health care services that you/they have used in the last few years? Would you/they say you/they are very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, or very dissatisfied?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Satisfied (net)	76	77
Very satisfied	41	37
Somewhat satisfied	34	40
Neither satisfied nor dissatisfied	8	5
Dissatisfied (net)	15	18
Somewhat dissatisfied	9	13
Very dissatisfied	6	5
Not sure/Don't know	*	*
Decline to answer	*	-

SECTION 800: HOUSING

BASE: ALL RESPONDENTS OR PROXY

Q805 Are there any modifications or home improvements you/this person would like to make to your/their home that would make it easier to for you/them to live there?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes	43	41
No	56	59
Not sure/Don't know	*	-
Decline to answer	*	-

BASE: WOULD LIKE TO MAKE HOME IMPROVEMENTS

Q810 What modifications or home improvements would you/this person like to make?

	<u>Wave 1 (2002)</u> <u>(n= 150)</u>	<u>Wave 2 (2005)</u> <u>(n= 141)</u>
Grab bars in bathroom	34	59
Accessible shower with no shower lip	30	53
Ramp(s)	26	38
Extra handrails in hall/stairs	25	35
Raised toilet	25	30
Extra wide doors/halls	21	32
Lever door handles instead of knobs	20	29
Accessible bathroom features, not listed above	19	38
Lowered cabinets	17	36
Push bars on doors	16	18
Elevator or chair lift	13	31
Modified wall sockets/light switches	12	27
Modified sink faucets	10	25
Accessible kitchen features, not listed above	10	22
Other improvements	25	15
None of these	8	-
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q825 Have you/Has this person moved in the past 2 years?

	<u>Wave 1 (2002)</u> <u>(n= N/A)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes	N/A	6
No	N/A	94
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: MOVED IN PAST TWO YEARS

Q830 What type of living arrangement did you/this person move to?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= N/A)</u>	<u>(n= 15*)</u>
Your (Their) own home or apartment	N/A	60
A private residence shared with family members other than your (their) spouse	N/A	11
A retirement community that offers MANY services including help with bathing, dressing, and getting around	N/A	8
A retirement community that offers A FEW services such as housekeeping or group meals	N/A	-
Other	N/A	21
Not sure/Don't know	N/A	-
Decline to answer	N/A	-

BASE: ALL RESPONDENTS OR PROXY

Q845 If you/this person needed assistance with everyday activities like bathing, dressing, cooking and shopping, what would be your/their first choice for receiving such assistance?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Family and friends provide all of the assistance at home	47	57
Care is provided at home by an agency	35	27
Care is provided in an assisted living or other residential setting	12	11
Care is provided in a nursing home	1	2
Other	2	3
Not sure/Don't know	3	*
Decline to answer	*	-

BASE: ALL RESPONDENTS OR PROXY

Q850 If you/this person needed care 24 hours a day, rather than just help with everyday activities, what would be your/their first choice for 24-hour care?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Care is provided at home by an agency	36	42
Family and friends provide all of the assistance at home	32	25
Care is provided in an assisted living or other residential setting	23	19
Care is provided in a nursing home	5	12
Other	1	2
Not sure/Don't know	3	-
Decline to answer	*	-

**Caution should be exercised when interpreting these results as data are based on small sample size. Please note that with a base this small, the data is more qualitative than it is quantitative.*

BASE: ALL RESPONDENTS OR PROXY

Q855 Home care services paid for by the government could be provided in several different ways. I'm going to describe three possible ways that the government could pay for home care services. Then I will ask you the option you/this person would prefer if you/they needed these services.

If you/this person needed these services, which of these three options would you/they prefer?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
In option two, the money goes to you (them). You (They) then pay for the services and manage the workers.	55	45
In option three, you (they) manage the workers and the services the workers provide, and the money goes to the agency and the agency pays the workers.	26	34
In option one, the money goes to an agency. The agency then provides the services and manages the workers.	17	20
Not sure/Don't know	1	1
Decline to answer	*	*

SECTION 900: TECHNOLOGY

BASE: ALL RESPONDENTS OR PROXY

Q900 Do you/Does this person use any special equipment, technology or assistive devices to help you/them with your/their daily activities?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes	38	46
No	62	54
Not sure/Don't know	*	-
Decline to answer	-	-

BASE: USE SPECIAL EQUIPMENT OR DEVICES

Q905 Which type of the following special equipment, technology or assistive devices do you/does this person use?

	<u>Wave 1 (2002)</u> <u>(n= 123)</u>	<u>Wave 2 (2005)</u> <u>(n= 132)</u>
Walker, cane, or crutches	72	67
Aids for bathing or using the toilet, such as: tub or shower bench or rails, raised toilet seat, toilet hand rails, bed pans	55	52
Orthopedic equipment, such as orthopedic shoes, orthotics, braces for arm, leg, or back	45	37
Other home modifications for movement, such as railings, ramps, wide doorways	44	45
Miscellaneous other devices, such as a prostheses (e.g., artificial limbs), TENS (transcutaneous electrical nerve stimulator)	44	13
Wheelchair or scooter	40	48
Other aids for daily activities, such as a reacher or grabber, dressing aids such as a zipper pull)	39	36
Communication and reading equipment, such as: closed captioning, TTY/TDD, communication board, speech synthesizer, computer screen enlarger, reading machine	22	18
Special furniture, such as a hospital bed	17	21
Hearing aids	16	14
Driving aids such as a modified pedal or device to help turn on key	11	6
Oxygen or respirator	7	12
Major home modifications, such as a lift, elevator	6	8
Another type of special equipment or technology not mentioned	22	17
Not sure/Don't know	-	-
	-	-

base: DO NOT Use special equipment (in 2002)/all respondents OR PROXY (in 2005)

Q910 Is there any device or product that you believe/this person believes would improve your/their quality of life if you/they could have it available?

	<u>Wave 1 (2002)</u> <u>(n= 164)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes	32	34
No	67	65
Not sure/Don't know	1	1
Decline to answer	-	-

BASE: BELIEVE A DEVICE OR PRODUCT WOULD IMPROVE QUALITY OF LIFE

Q912 What would that device or product be? Would it be...?

	<u>Wave 1 (2002)</u> <u>(n= 49*)</u>	<u>Wave 2 (2005)</u> <u>(n= 111)</u>
Wheelchair or scooter	54	39
Hearing aids	54	24
Aids for bathing or using the toilet, such as: tub or shower bench or rails, raised toilet seat, toilet hand rails, bed pans	50	38
Orthopedic equipment, such as orthopedic shoes, orthotics, braces for arm, leg, or back	43	30
Walker, cane, or crutches	39	15
Other home modifications for movement, such as railings, ramps, wide doorways	36	40
Communication and reading equipment, such as: closed captioning, TTY/TDD, communication board, speech synthesizer, computer screen enlarger, reading machine	30	21
Other aids for daily activities, such as a reacher or grabber, dressing aids (e.g., zipper pull)	26	25
Major home modifications, such as a lift, elevator	23	22
Oxygen or respirator	7	13
Special furniture, such as a hospital bed	7	17
Driving aids such as a modified pedal or device to help turn on key	1	11
Miscellaneous other devices, such as a prostheses (e.g., artificial limbs), TENS (transcutaneous electrical nerve stimulator)	9	16
Another type of special equipment or technology not mentioned	21	25
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q915 Do you/Does this person personally use a computer at home, work or in some other place?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes	70	76
No	30	24
Not sure/Don't know	-	-
Decline to answer	-	-

**Caution should be exercised when interpreting these results as data are based on small sample size.*

SECTION 100: DEMOGRAPHICS**BASE: ALL RESPONDENTS OR PROXY**

Q105 What is the highest level of school you have/this person has completed or the highest degree you/they have received?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
High school or less (net)		53
Less than high school (grades 1-8)	2	2
Completed some high school (grades 9 – 11, 12 but no diploma)	8	11
High school graduate	45	39
Some college (net)		28
Completed some college	20	22
Associate's degree	8	6
College grad or more (net)		19
College graduate (e.g., B.A., A.B., B.S.)	11	10
Some graduate school	*	2
Completed Postgraduate (e.g., M.A., M.S., Meng, Med, MSW, MBA, MD, Dds, DVM, LLB, JD, Ph.D., EdD)	5	6
Not sure/Don't know	*	-
Decline to answer	-	*

BASE: ALL RESPONDENTS OR PROXY

Q110 What is your/this person's current marital status?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Married	55	55
Single, never married	9	7
Divorced	12	13
Separated	3	3
Widowed	20	20
Living with partner	2	2
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q115 Which of the following best describes your/this person's living arrangements?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Live alone	30	28
Live with spouse or partner	55	54
Live with other family members	14	16
Live with other non-family members	1	2
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q500/Q120 Which of the following categories best describes your/this person's current employment situation - are you/they...?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Employed (net)		13
Working full-time	7	6
Working part-time	5	7
Unemployed but looking for work	1	2
Unemployed and not looking for work	3	4
Retired	45	44
Completely unable to work because of disability	40	45
Homemaker	5	5
Other	1	*
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q130 Which of the following income categories best describes your/this person's total 2001/2004 household income? Was it...?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
\$15,000 or less (net)		37
\$7,500 or less	11	15
\$7,501 to \$15,000	17	22
\$15,001 to \$35,000 (net)		32
\$15,001 to \$25,000	23	16
\$25,001 to \$35,000	10	16
\$35,001 to \$75,000 (net)		20
\$35,001 to \$50,000	10	10
\$50,001 to \$75,000	15	10
More than \$75,000 (net)		10
\$75,001 to \$100,000	6	6
\$100,001 or over	3	3
Not sure/Don't know	2	1
Decline to answer	3	1

BASE: ALL RESPONDENTS OR PROXY

Q140 Are you/Is this person of Hispanic origin such as Mexican American, Latin American, Puerto Rican, or Cuban?

	<u>Wave 1 (2002)</u> <u>(n= 287)</u>	<u>Wave 2 (2005)</u> <u>(n= 287)</u>
Yes, of Hispanic origin	6	4
No, not of Hispanic origin	94	96
Not sure/Don't know	-	-
Decline to answer	-	-

BASE: ALL RESPONDENTS OR PROXY

Q145 Do you/this person consider yourself/themselves to be...?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
White	80	85
Black/African American (net)	11	10
Black	10	4
African American	1	6
Asian or Pacific Islander	1	1
Native American or Alaskan native	1	3
Other race	6	2
Not sure/Don't know	1	*
Decline to answer	-	*

BASE: ALL RESPONDENTS OR PROXY

Q155 Gender

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Male	43	44
Female	57	56

BASE: ALL RESPONDENTS OR PROXY

Q275 Age

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
52 – 64 (net)		51
50 – 54	21	14
55 – 59	16	19
60 – 64	15	18
65+ (net)		49
65 – 69	18	17
70 – 74	17	13
75+	12	19
Refused	-	N/A
MEAN	63.8	65.5
MEDIAN	63.1	64

BASE: ALL RESPONDENTS OR PROXY

Q156 Including you/this person, how many adults, 18 or over, live in this household?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
1	36	35
2	51	52
3 or more	13	13
MEAN	1.8	1.8
MEDIAN	1.8	1.8

BASE: ALL RESPONDENTS OR PROXY

Q160 If one of our researchers wanted to personally interview you about your opinions, in confidence, to get a more complete understanding of your/this person's perspective, would you be willing to have a follow-up conversation with a researcher?

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 287)</u>
Yes	100	87
No	-	13
Not sure/Don't know	-	*
Decline to answer	-	-

BASE: WILLING TO TALK TO RESEARCHER

Q165 Similarly, would you be interested in talking with a representative of the news media about your/this person's views on this topic. In this case you would be identified as the person making the comments, with your name being used and your discussion quoted.

	<u>Wave 1 (2002)</u>	<u>Wave 2 (2005)</u>
	<u>(n= 287)</u>	<u>(n= 258)</u>
Yes	53	54
No	43	46
Not sure/Don't know	2	*
Decline to answer	2	-