

January 2006

# Medicaid Home and Community-Based Services: Survey of Aged and Disabled Medicaid Beneficiaries

## Chart Book

Submitted to

**Lisa Maria B. Alexih**  
**The Lewin Group, Inc.**  
3130 Fairview Park Dr., Suite 800  
Falls Church, VA 22042

Prepared for

**Susan Radke**  
Centers for Medicare & Medicaid Services  
Office of Research, Development, and Information  
Mail Stop C3-19-26  
7500 Security Boulevard  
Baltimore, MD 21244-1850

Prepared by

**Galina Khatutsky, M.S.**  
**Valentina Akhmerova, M.S.**  
**Wayne L. Anderson, Ph.D.**  
**Joshua M. Wiener, Ph.D.**  
RTI International  
Health, Social, and Economics Research  
411 Waverley Oaks Road, Suite 330  
Waltham, MA 02452-8414

RTI Project Number 09123.001

**MEDICAID HOME AND COMMUNITY-BASED SERVICES:  
SURVEY OF AGED AND DISABLED MEDICAID BENEFICIARIES**

**Chart Book**

Authors: Galina Khatutsky, M.S.  
Valentina Akhmerova, M.S.  
Wayne L. Anderson, Ph.D.  
Joshua Wiener, Ph.D.

Elderly and Physically Disabled

Medicaid HCBS Beneficiary Project Director: Joshua M. Wiener, Ph.D.

Overall Project Director: Lisa Maria B. Alexih

Federal Project Officer: Susan Radke

RTI International\*

CMS Contract No. 500-96-005

January 2006

This project was funded by the Centers for Medicare & Medicaid Services under contract no. 500-96-005. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. RTI assumes responsibility for the accuracy and completeness of the information contained in this report.

---

\*RTI International is the trade name of Research Triangle Institute.

## CONTENTS

1. INTRODUCTION AND SUMMARY OF FINDINGS .....	1
2. DEMOGRAPHICS .....	3
3. MARITAL STATUS AND LIVING ARRANGEMENTS .....	6
4. HEALTH AND FUNCTIONAL STATUS .....	10
5. INFORMAL AND FORMAL SUPPORT .....	22
6. UNMET NEED FOR ADL/IADL ASSISTANCE IN THE PAST MONTH .....	31
7. PERSONAL ASSISTANCE .....	42
8. SATISFACTION WITH CARE .....	49
9. CONSUMER DIRECTION .....	58
10. CASE MANAGEMENT .....	63
11. PAID HELPER DEMOGRAPHICS .....	65
12. SOCIAL AND RECREATIONAL ACTIVITIES .....	66
13. EDUCATION AND EMPLOYMENT .....	67
14. SATISFACTION WITH LIFE DURING THE PAST MONTH .....	69
REFERENCES .....	72

### List of Figures

Figure 1. Respondent Age .....	3
Figure 2. Respondent Hispanic or Latino Origin .....	3
Figure 3. Respondent Race .....	4
Figure 4. Respondent Gender .....	4
Figure 5. Respondent Education: Highest Grade/Level of School Completed .....	5
Figure 6. Respondent Personal Income Before Taxes .....	5
Figure 7. Marital Status .....	6
Figure 8. Living Arrangements .....	6
Figure 9. Mean Number of People in Respondent's Household .....	7
Figure 10. Bedroom Arrangement .....	7
Figure 11. Satisfaction with Living Arrangement .....	8
Figure 12. Amount of Crime in the Neighborhood .....	8
Figure 13. Type of People in Respondent's Building .....	9
Figure 14. Self-Reported Health Status (Compared to Other People of the Same Age) .....	10

Figure 15. Respondent Currently Receiving Help with Light Housework/Laundry .....	10
Figure 16. Respondent Currently Receiving Help Shopping for Groceries/Personal Items.....	11
Figure 17. Respondent Currently Receiving Help Preparing Meals.....	11
Figure 18. Respondent Currently Receiving Help Managing Medications.....	12
Figure 19. Respondent Currently Receiving Help with Walking/Getting About.....	12
Figure 20. Respondent Currently Receiving Help with Transferring out of Bed/Chairs .....	13
Figure 21. Respondent Currently Receiving Help with Bathing .....	13
Figure 22. Respondent Currently Receiving Help with Toileting .....	14
Figure 23. Respondent Currently Receiving Help with Dressing.....	14
Figure 24. Respondent Currently Receiving Help with Eating/Feeding .....	15
Figure 25. Mean Number of Limitations in Activities of Daily Living (ADLs) .....	15
Figure 26. Number of Limitations on Activities of Daily Living (ADLs) .....	16
Figure 27. Mean Number of Limitations in Instrumental Activities of Daily Living (IADLs)...	16
Figure 28. Number of Limitations on Instrumental Activities of Daily Living (IADLs).....	17
Figure 29. Ever Been Resident/Patient in a Nursing Home.....	17
Figure 30. Eyesight .....	18
Figure 31. Hearing .....	18
Figure 32. Pain in the Past Four Weeks.....	19
Figure 33. Pressure Sores in the Past Six Months .....	19
Figure 34. Bladder/Bowel Incontinence in the Past Six Months .....	20
Figure 35. Proxy Status.....	20
Figure 36. Proxy Type .....	21
Figure 37. Receive Unpaid Help with Personal Care .....	22
Figure 38. Mean Number of Unpaid Helpers Last Week .....	22
Figure 39. Relationship with Primary Unpaid Helper .....	23
Figure 40. Relationship with Secondary Unpaid Helper .....	23
Figure 41. Is There a Main Unpaid Helper? .....	24
Figure 42. Relationship with Unpaid Helper who Helps the Most.....	24
Figure 43. Paid Helpers from an Agency/Organization.....	25
Figure 44. Paid Helpers Hired Directly by Respondent/Family .....	25
Figure 45. Paid Helpers who are Family/Friends .....	26
Figure 46. Mean Number of Paid Helpers Last Week.....	26
Figure 47. Paid Helper Lives in the Same Household.....	27
Figure 48. Is Any Paid Helper a Family Member/Friend or Neighbor?.....	27
Figure 49. Relationship with Primary Paid Helper.....	28
Figure 50. Relationship with Secondary Paid Helper.....	28
Figure 51. Total Mean Number of Paid and Unpaid Helpers Last Week.....	29
Figure 52. Stability of Paid Helper Staffing .....	29
Figure 53. Respondent Controls When and How Things are Done.....	30
Figure 54. Unmet Need in the Past Month: Dressing .....	31
Figure 55. Unmet Need in the Past Month: Bathing.....	31
Figure 56. Unmet Need in the Past Month: Eating/Feeding.....	32
Figure 57. Unmet Need in the Past Month: Transferring Out of Bed/Chairs .....	32
Figure 58. Unmet Need in the Past Month: Walking.....	33
Figure 59. Unmet Need in the Past Month: Cooking.....	33
Figure 60. Unmet Need in the Past Month: Toileting.....	34

Figure 61. Unmet Need in the Past Month: Shopping .....	34
Figure 62. Unmet Need in the Past Month: Light Housework .....	35
Figure 63. Respondent Takes Medications on a Regular Basis.....	35
Figure 64. Unmet Need in the Past Month: Medication Management .....	36
Figure 65. Unmet Need in the Past Month: Obtaining Medications.....	36
Figure 66. Mean Number of Unmet Needs in the Last Month (ADLs and IADLs).....	37
Figure 67. Main Reason Respondent Didn't Obtain Medicine in the Last Month (For Respondents with Unmet Need for Obtaining Medication Only).....	37
Figure 68. Unmet Need: Special Equipment to Help with Task.....	38
Figure 69. Reasons Special Equipment Not Obtained.....	38
Figure 70. Receiving Home Delivered Meals (For Home-Dwelling Respondents Only).....	39
Figure 71. Receiving Meals in Residence's Dining/Lunch Room (For Group-Home Respondents Only).....	39
Figure 72. Receiving Meals at an Adult Day Care Facility/Other Program (For Home-Dwelling Respondents Only).....	40
Figure 73. Unmet Need in the Last Month: Transportation.....	40
Figure 74. Use of Special Bus/Cab/Van Service in the Past Month.....	41
Figure 75. Length of Time Paid Help Received at Home.....	42
Figure 76. Mean Number of Paid Helpers in the Past 6 Months .....	42
Figure 77. Affiliation of Paid Helpers .....	43
Figure 78. Individual Responsible for Replacement of Paid Helpers.....	43
Figure 79. Sources of Help Until a Paid Helper is Replaced.....	44
Figure 80. Problem or Difficulty Finding a Replacement .....	44
Figure 81. Types of Problems/Difficulties Finding Replacement Paid Workers (For Those Who had a Problem or Difficulty).....	45
Figure 82. Mean Number of Weekdays Paid Helper Provided Care Last Week.....	45
Figure 83. Paid Help Availability on Saturday/Sunday Last Week.....	46
Figure 84. Mean Number of Hours of Paid Help Last Week .....	46
Figure 85. Adequacy of Hours of Paid Help Provided .....	47
Figure 86. Replacement Availability for Usual Paid Helper .....	47
Figure 87. Replacement When Paid Helper is Not Available .....	48
Figure 88. Overall Satisfaction with Paid Care /Help.....	49
Figure 89. Perceived Control by Respondent Over Life.....	49
Figure 90. Respondent Difficulty in Resolving Problems with Paid Helpers .....	50
Figure 91. Responsibility for Monitoring Paid Helper Job Quality and Schedule .....	50
Figure 92. Responsibility for Signing Paid Helper Time Sheet.....	51
Figure 93. Respondent Ability to Get Along with Paid Helper.....	51
Figure 94. Respondent Difficulty in Communicating with Paid Helper .....	52
Figure 95. Reasons for Communication Difficulties Between Respondent and Paid Helper (For Those Who Had a Problem).....	52
Figure 96. Frequency of Paid Helper Ignoring Respondent in the Past Month.....	53
Figure 97. Frequency of Paid Helper Being Impatient/Rushing Respondent in the Past Month	53
Figure 98. Frequency of Paid Helper Assisting Quickly Enough with Toileting (For Those with Toileting Difficulty).....	54
Figure 99. Ever Complained to Care Manager/Service Coordinator of Paid Helper Ignoring/Being Impatient with Respondent.....	54

Figure 100. Did Care Manager /Service Coordinator Resolve the Problem (For Those Who Complained).....	55
Figure 101. Frequency of Paid Helper Treating Respondent Badly in the Past Month.....	55
Figure 102. Respondent Perception of Paid Helper as Competent and Well-Trained.....	56
Figure 103. Respondent Perception of Paid Helper as Respectful of Person and Preferences....	56
Figure 104. Frequency of Selected Problems with Paid Helpers (For Non-Group Home Residents Only).....	57
Figure 105. Seriousness of Selected Problems with Paid Helper (For Non-Group Home Residents Who Experienced Selected Problems Only) .....	57
Figure 106. Respondent Given a List of Agencies/Individuals to Choose from When Selecting Paid Helper.....	58
Figure 107. Responsibility for Choosing Paid Helper .....	58
Figure 108. Familiarity of Respondent/Family Member with Paid Helper Before Hiring.....	59
Figure 109. Reason for Familiarity of Respondent/Family Member with Paid Helper Before Hiring .....	59
Figure 110. Opportunity for Respondent/Family Member to Interview Paid Helper Before Hiring .....	60
Figure 111. Level of Respondent Choice of Tasks Paid Helpers Should Perform.....	60
Figure 112. Respondent Satisfaction with Level of Choice Over Tasks Paid Helpers Should Perform .....	61
Figure 113. Level of Respondent Choice of Time/Days Paid Helper Comes .....	61
Figure 114. Respondent Satisfaction with Level of Choice Over Scheduling Paid Helper .....	62
Figure 115. Is One Individual in Charge of Respondent’s Overall Care?.....	63
Figure 116. Individual in Charge of Overall Care of Respondent.....	63
Figure 117. Frequency of Communication Between Respondent and Person Who Helps Coordinate Personal/Social Services .....	64
Figure 118. Respondent Level of Satisfaction with Amount of Care Coordination Received....	64
Figure 119. Main Paid Helper of Hispanic or Latino Origin.....	65
Figure 120. Main Paid Helper Race.....	65
Figure 121. Mean Number of Days Going Out (Alone or with Someone).....	66
Figure 122. School/Training Programs/Class Participation in the Past Six Months .....	67
Figure 123. Work For Pay in the Past Six Months (Any Amount).....	67
Figure 124. Unpaid Work in the Past Six Months (Any Amount) .....	68
Figure 125. Would Like to Work at a Paid Job .....	68
Figure 126. Respondent Felt Full of Energy.....	69
Figure 127. Respondent Felt so ‘Down in the Dumps Nothing Could Cheer You Up’ .....	69
Figure 128. Respondent Felt Calm and Peaceful.....	70
Figure 129. Respondent Felt Worn Out.....	70
Figure 130. Respondent Felt a Happy Person.....	71
Figure 131. Respondent Felt Pushed Around in Life .....	71

SOURCE: RTI’s analysis of the Survey of Aged and Disabled Medicaid Beneficiaries conducted by Mathematica Policy Research, Inc., 2004. Results are unweighted.

## 1. INTRODUCTION AND SUMMARY OF FINDINGS

The *Medicaid Home and Community-Based Services: Survey of Aged and Disabled Medicaid Beneficiaries Chart Book* is a product of a large CMS-funded project conducted by The Lewin Group and its subcontractors, RTI International, the University of Minnesota's Research and Training Center on Community Living, Mathematica Policy Resource and the Medstat Group (Wiener, Tilly, & Alecxih, 2002). The study's primary goals are to examine the financing and delivery of Medicaid home and community-based services.

The Survey of Aged and Disabled Medicaid Beneficiaries collected survey data on older people and younger persons with physical disabilities who used Medicaid home and community-based services. The survey obtained information on the demographic composition of beneficiaries, their health and functional status, the extent of informal support, as well as detailed data on the scope and types of paid personal care received. Other topics of interest included consumer satisfaction with paid care, consumer control over personal care services, and demographic characteristics of primary paid helpers.

Survey data were gathered by Mathematica Policy Research, Inc., from 2,597 community-residing Medicaid beneficiaries receiving home and community-based services in six states—Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan (Snell, Zhao, Lu, Potter, & Ciemnecki, 2005).<sup>1</sup> The states were chosen to represent a range of “developed” and “developing” home and community-based services systems. The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among states based on the number of home and community-based services beneficiaries. Because of the major policy interest in differences between older and younger persons with disabilities, the survey sample was stratified by age (younger than 65 years of age vs. 65 years of age or older).

The sample of Medicaid home and community-based services beneficiaries represented the following distribution by state:

Alabama	N=326
Kentucky	N=680
Maryland	N=213
Washington	N=601
Wisconsin	N=173
Michigan	N=604

Survey respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about 36 minutes to complete, was conducted primarily through telephone interviews using a computer-assisted telephone

---

<sup>1</sup> Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

interviewing (CATI) system (N = 2,458) with some in-person interviews (N = 143).<sup>1</sup> The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy.

The *Medicaid Home and Community-Based Services: Survey of Aged and Disabled Medicaid Beneficiaries Chart Book* presents descriptive data from the survey in a bar chart format for all variables by domain. Results are presented for the total sample (blue bars), and then separately for younger persons with disabilities (red bars) and for people aged 65 and over (green bars). The results are unweighted. We present proportions for categorical variables and means for continuous variables. For some variables, the categories were collapsed for easier presentation. Corresponding variable names are listed at the bottom of each chart. The graphs were produced using STATA/ SE version 9 software.

Major findings from the survey include:

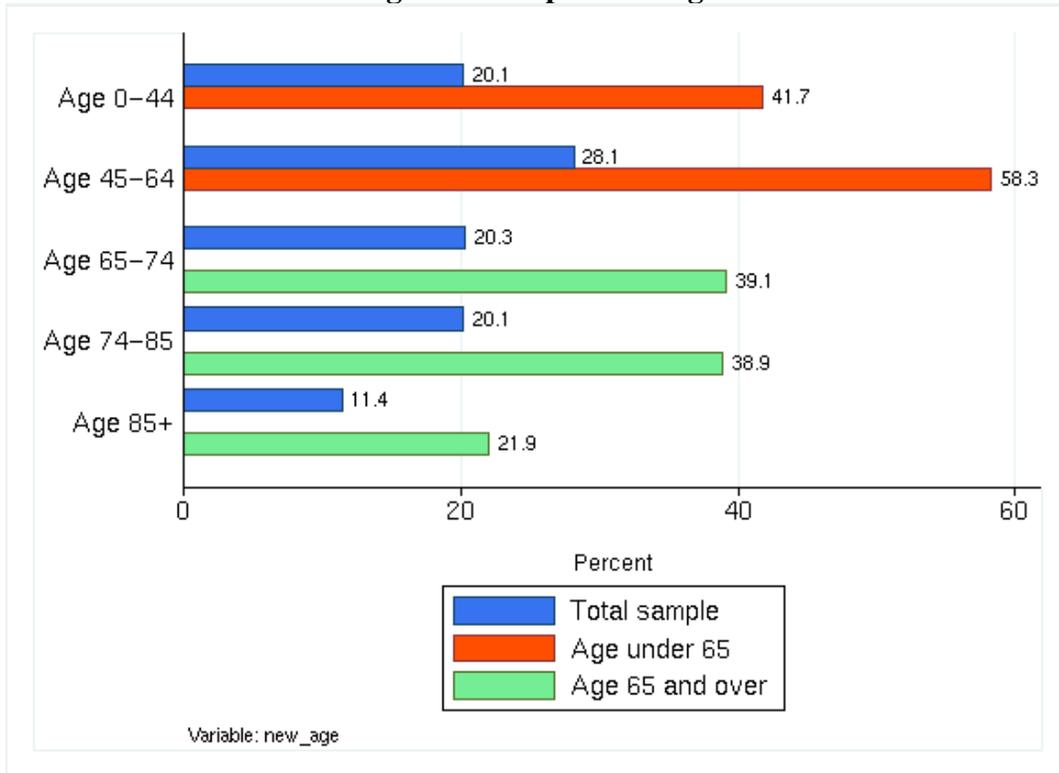
- In terms of demographic characteristics, survey respondents included a significant proportion of minority beneficiaries, were mostly female, and had low levels of education. The majority of respondents was not married and had very low income.
- To qualify for personal care assistance, either through Medicaid home and community-based services waivers or state plan services, a person needs to have substantial health problems and functional limitations. The survey found high levels of poor or fair health status, substantial functional impairment and significant amounts of pain. Pressure sores were also relatively common. Judging by a high proportion of proxy responses, a significant portion of participants experienced cognitive impairment. Given these significant health issues, the relatively low level of unmet need for ADL/IADL assistance reported in the survey was surprising.
- The great majority of the Medicaid home and community-based services beneficiaries in the 6 surveyed states reported a high degree of overall satisfaction with paid personal care and positively rated their relationship with paid helpers. A majority of respondents were satisfied with the amount of choice and control over scheduling and tasks performed, but a significant minority reported that they wanted more hours of personal care.
- In arranging and receiving personal care, beneficiaries reported several challenges. Sometimes they reported having difficulty finding a replacement worker and experienced lack of paid help on weekends. They also reported that some of the paid personal care workers were showing up late, not showing up on scheduled days, or not working hard enough.

---

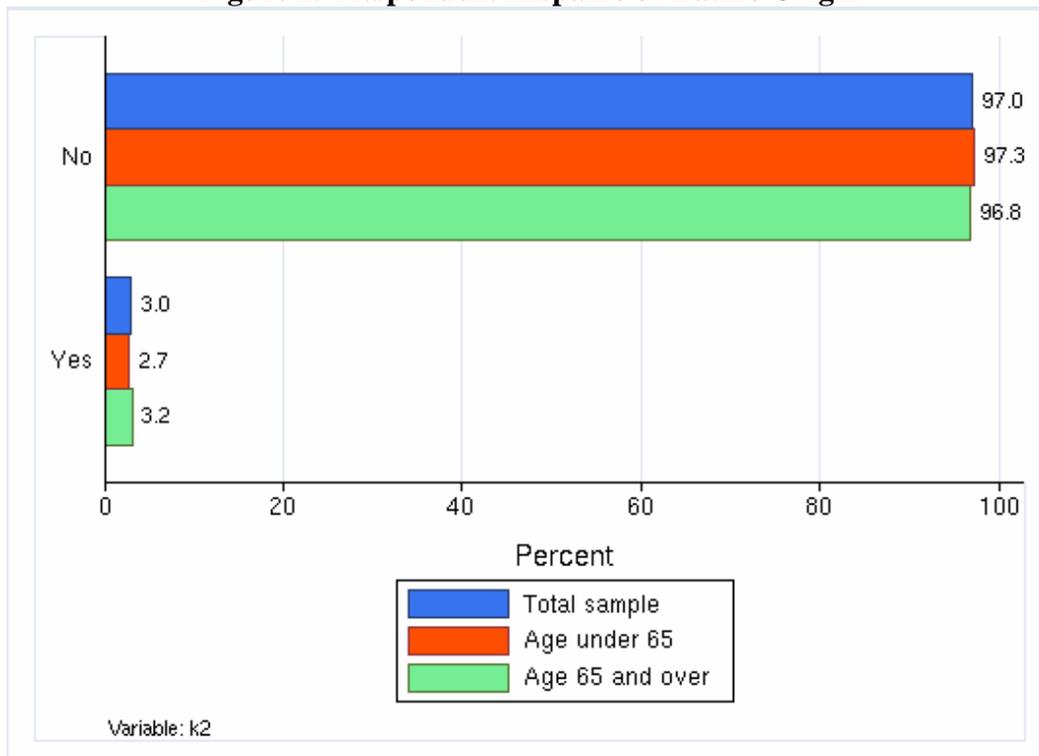
<sup>1</sup> Four observations were later determined to be duplicates and were removed from the sample.

## 2. DEMOGRAPHICS

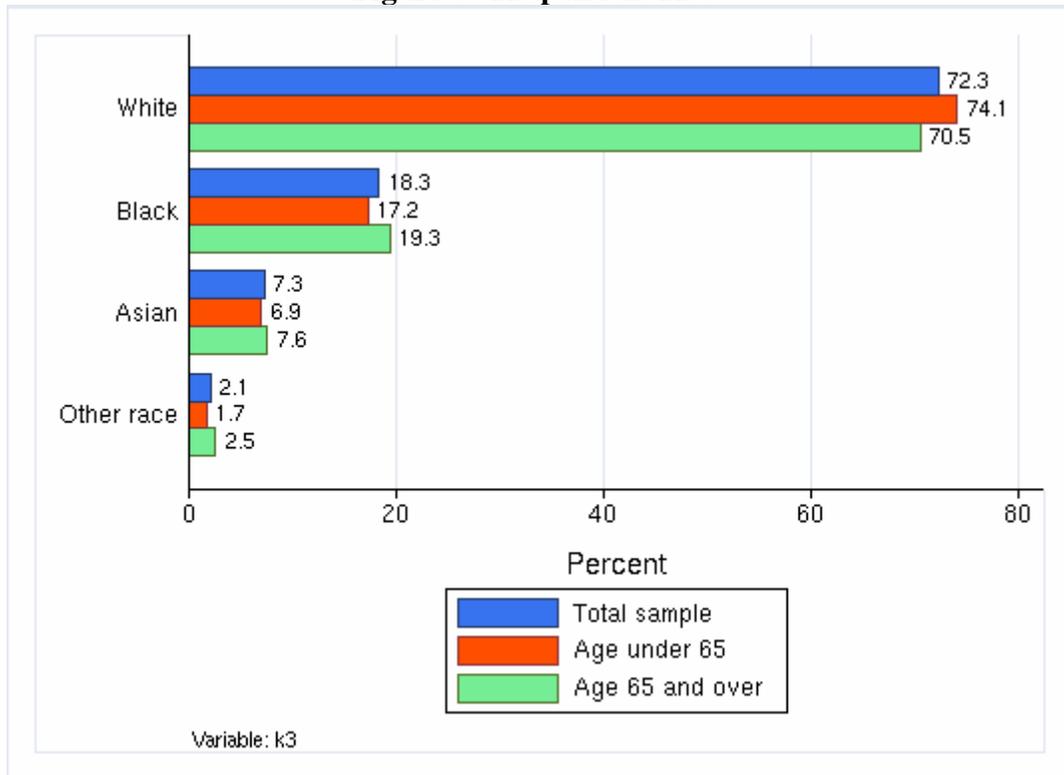
**Figure 1. Respondent Age**



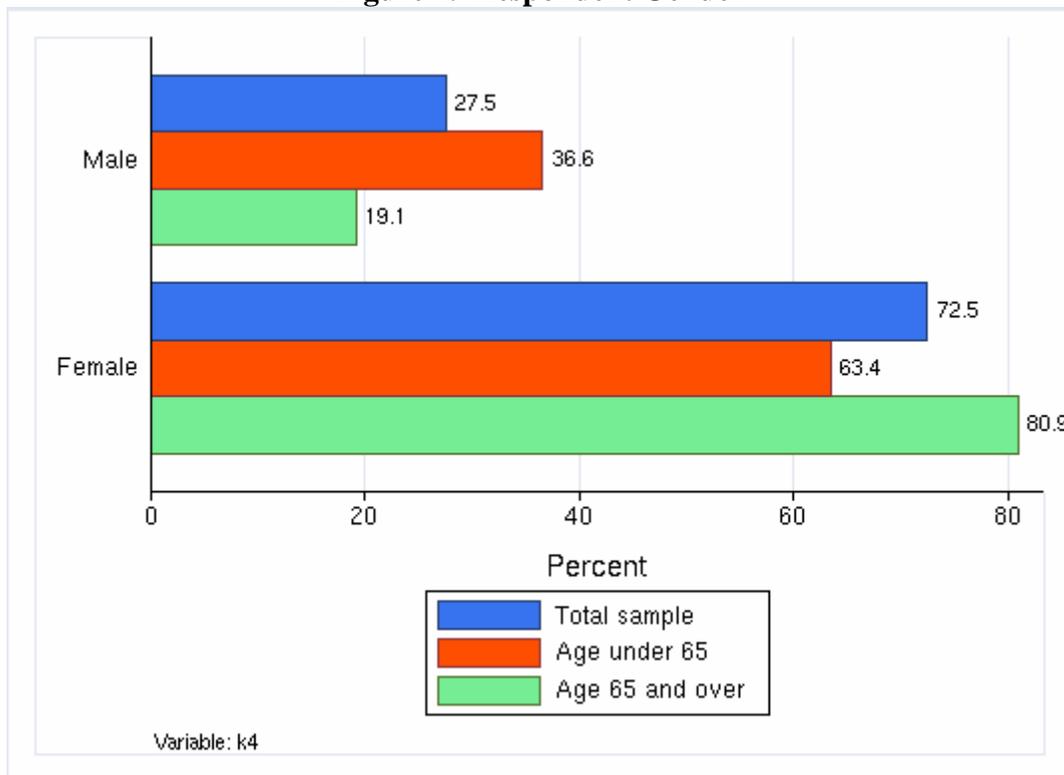
**Figure 2. Respondent Hispanic or Latino Origin**



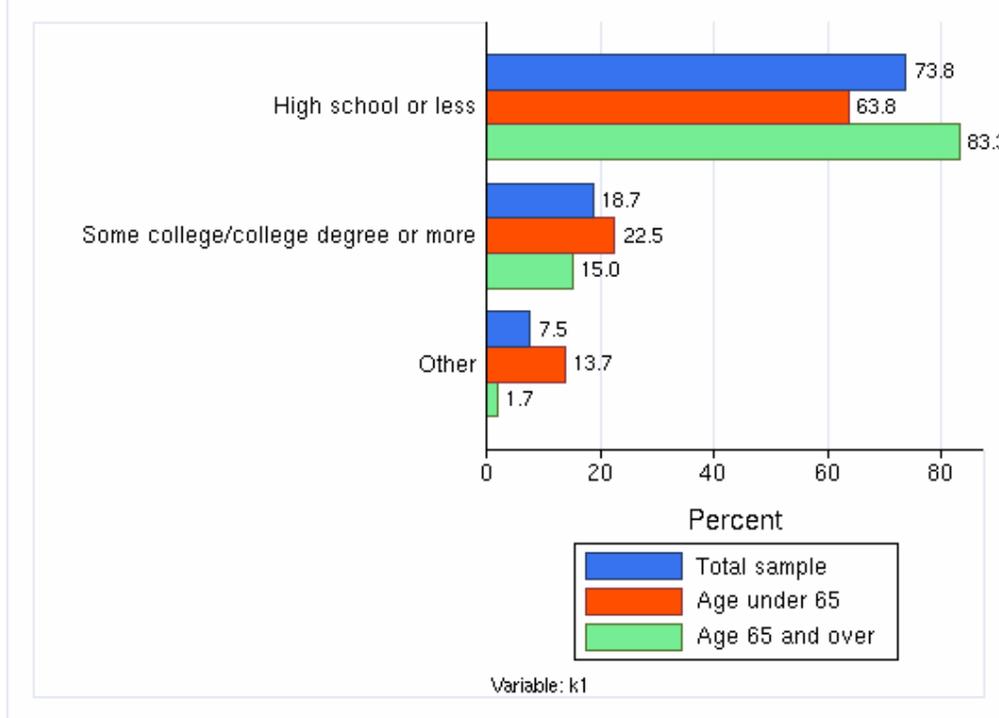
**Figure 3. Respondent Race**



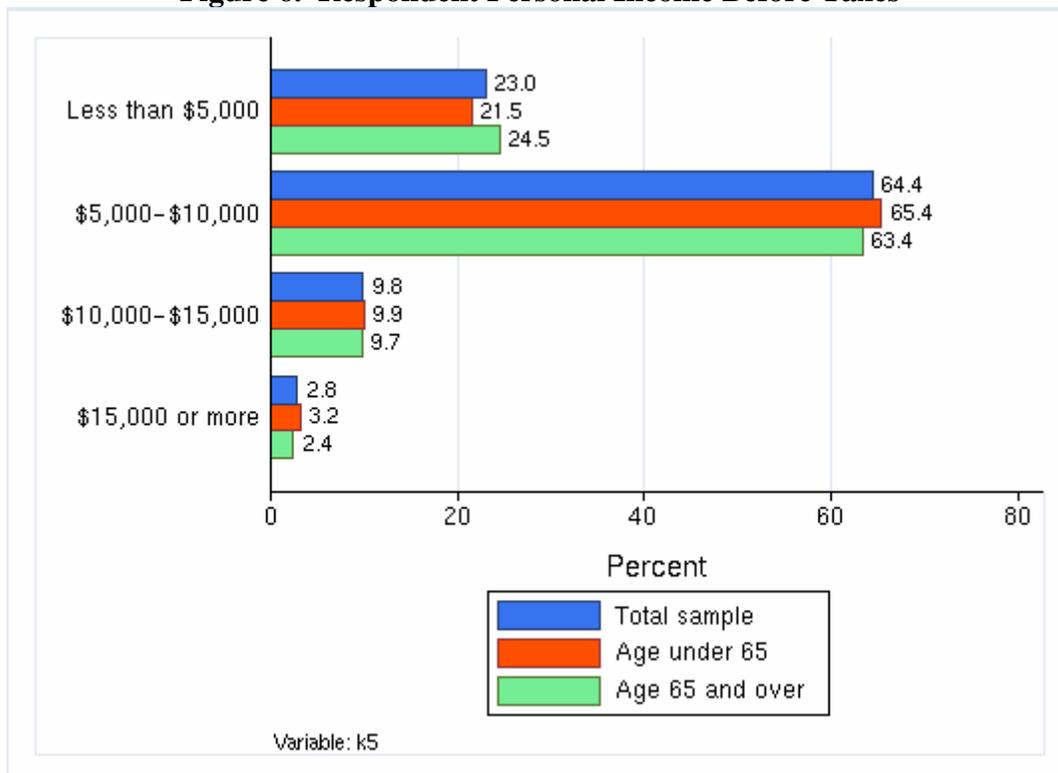
**Figure 4. Respondent Gender**



**Figure 5. Respondent Education: Highest Grade/Level of School Completed**

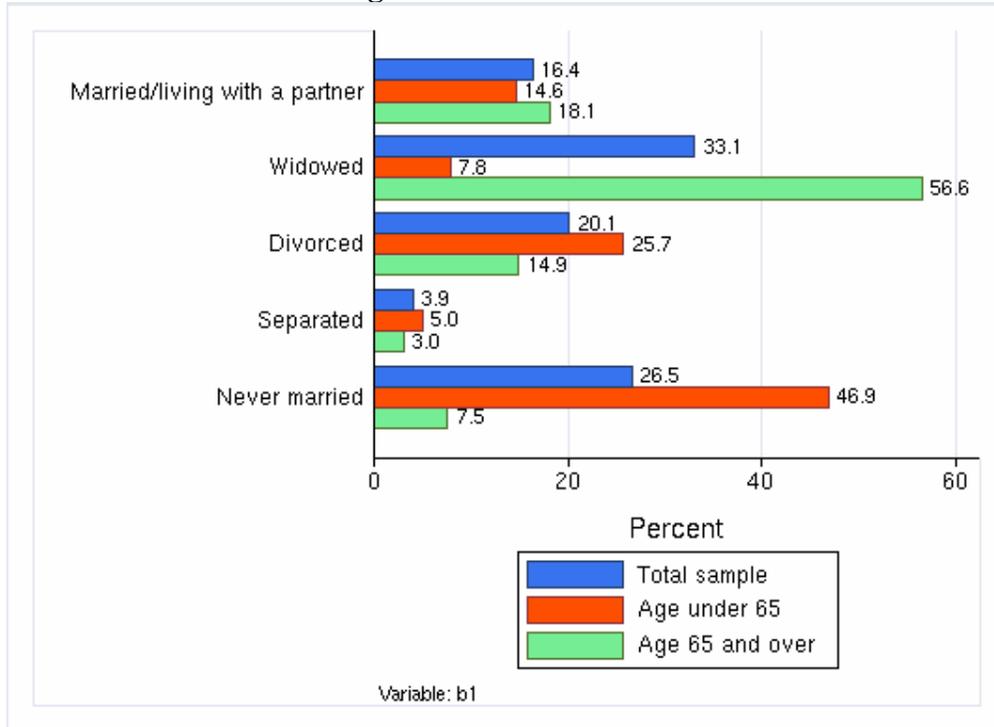


**Figure 6. Respondent Personal Income Before Taxes**

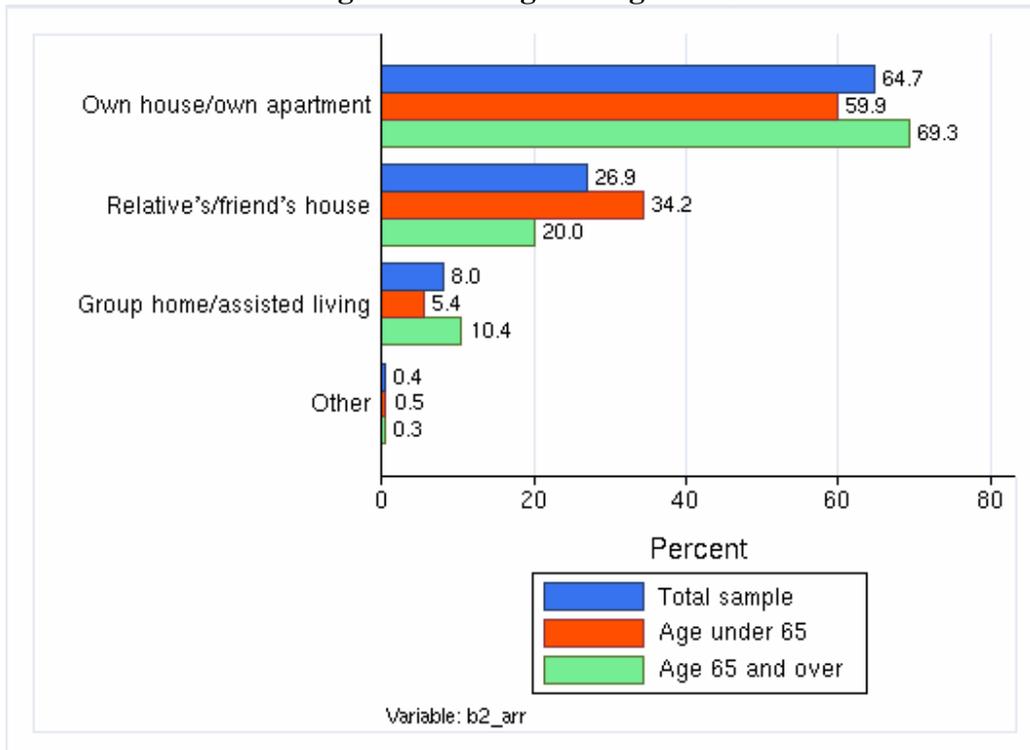


### 3. MARITAL STATUS AND LIVING ARRANGEMENTS

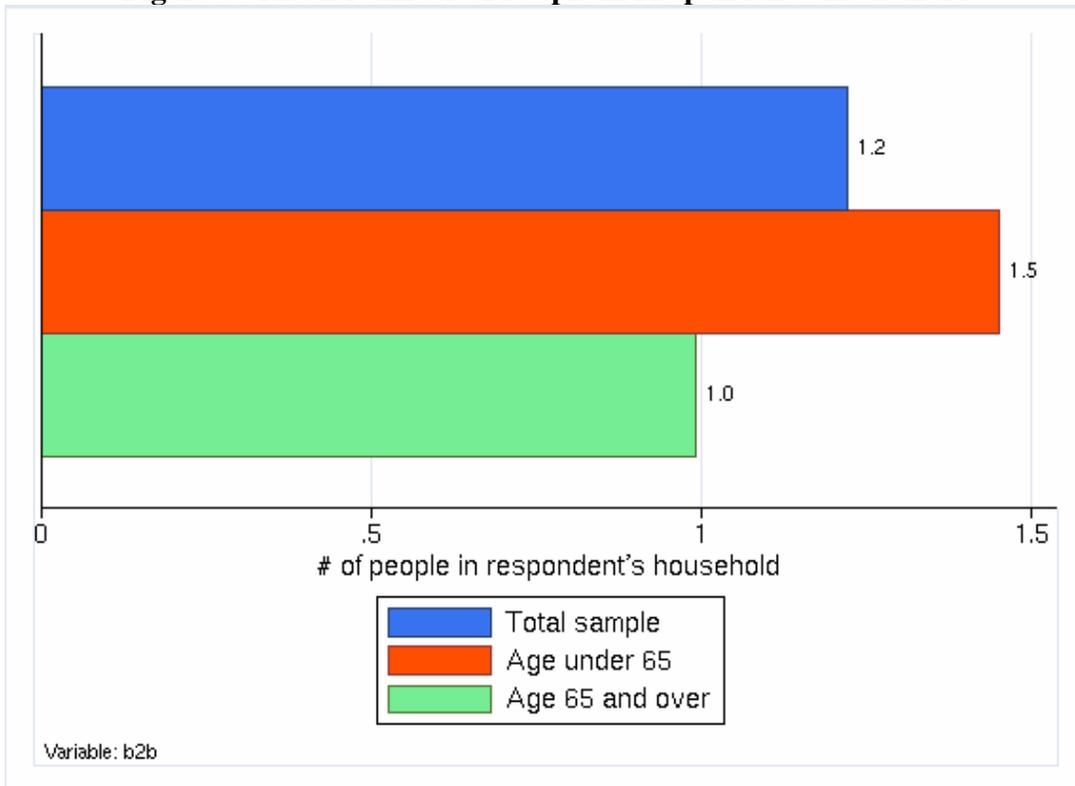
**Figure 7. Marital Status**



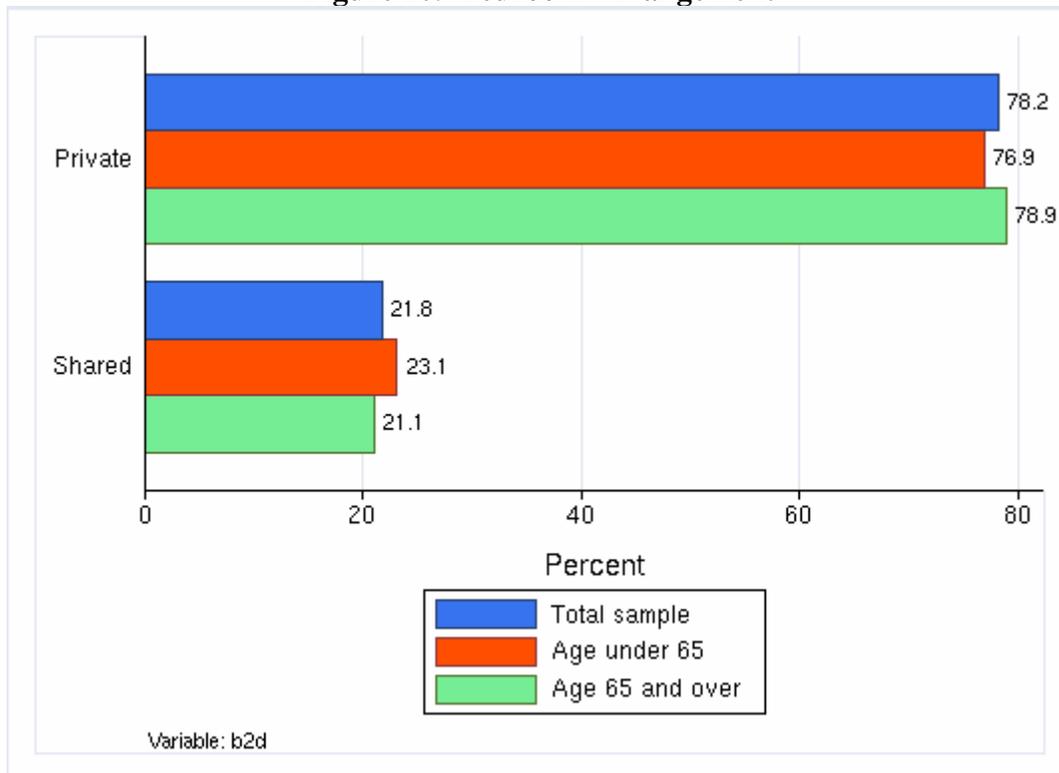
**Figure 8. Living Arrangements**



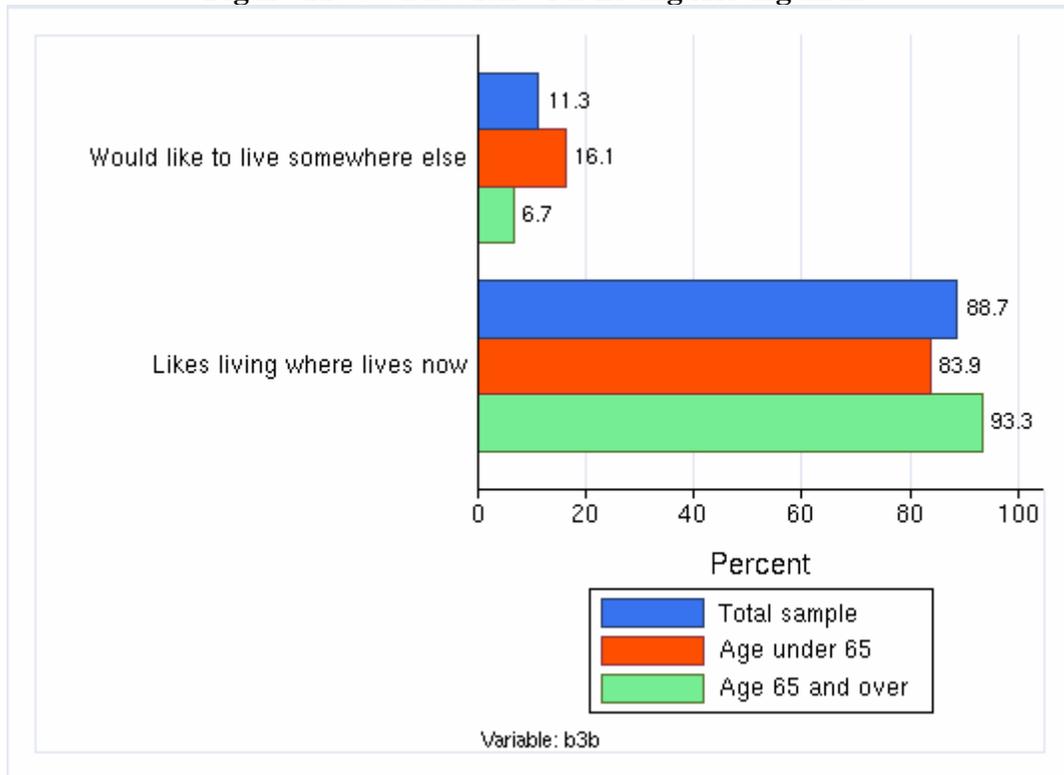
**Figure 9. Mean Number of People in Respondent's Household**



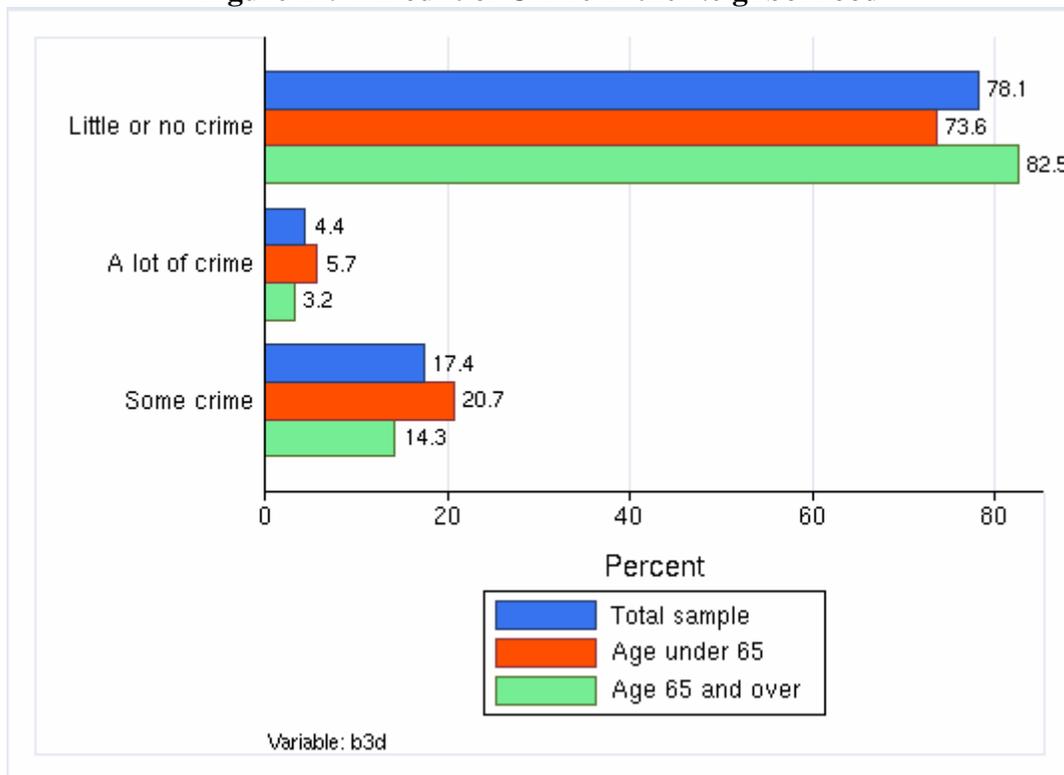
**Figure 10. Bedroom Arrangement**



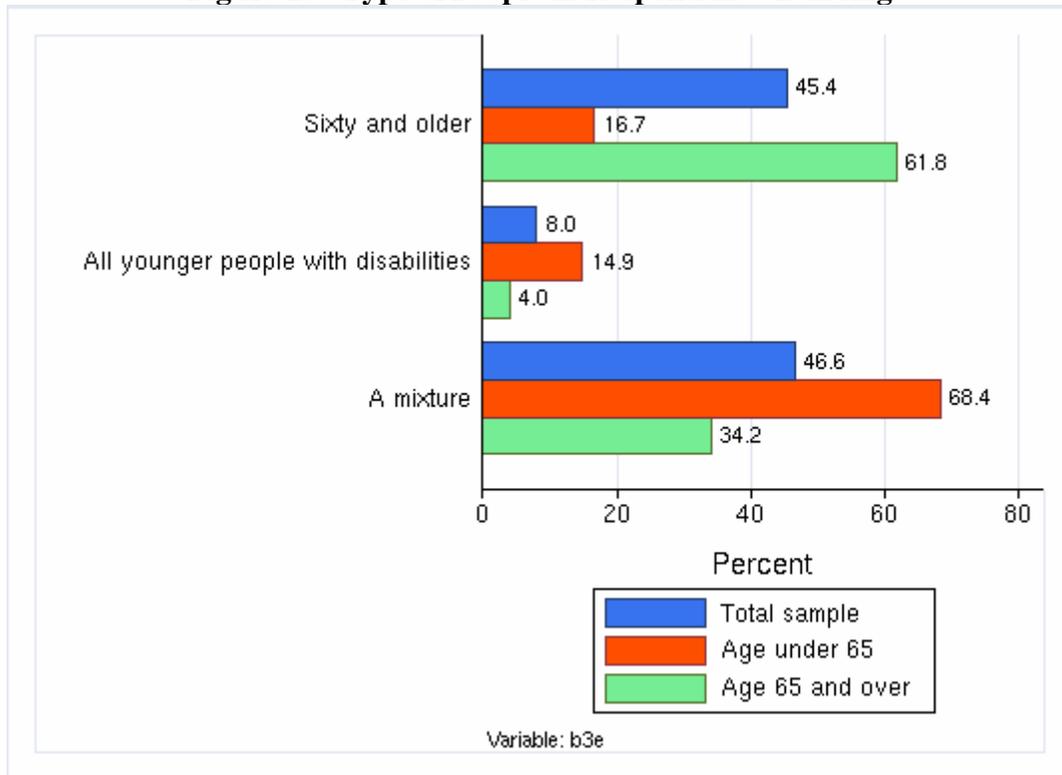
**Figure 11. Satisfaction with Living Arrangement**



**Figure 12. Amount of Crime in the Neighborhood**

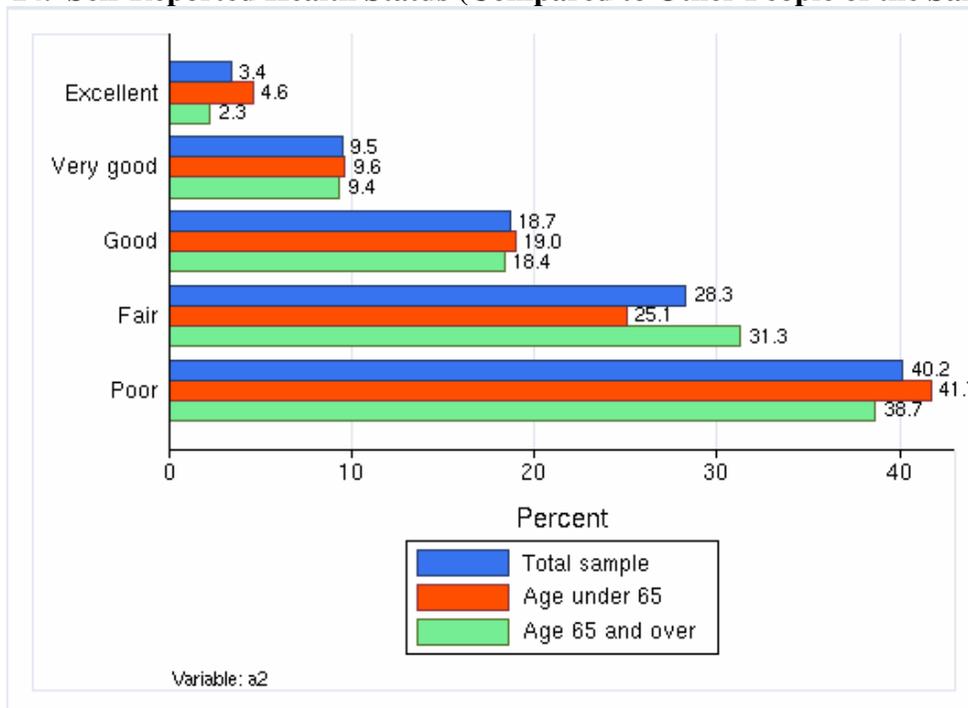


**Figure 13. Type of People in Respondent's Building**

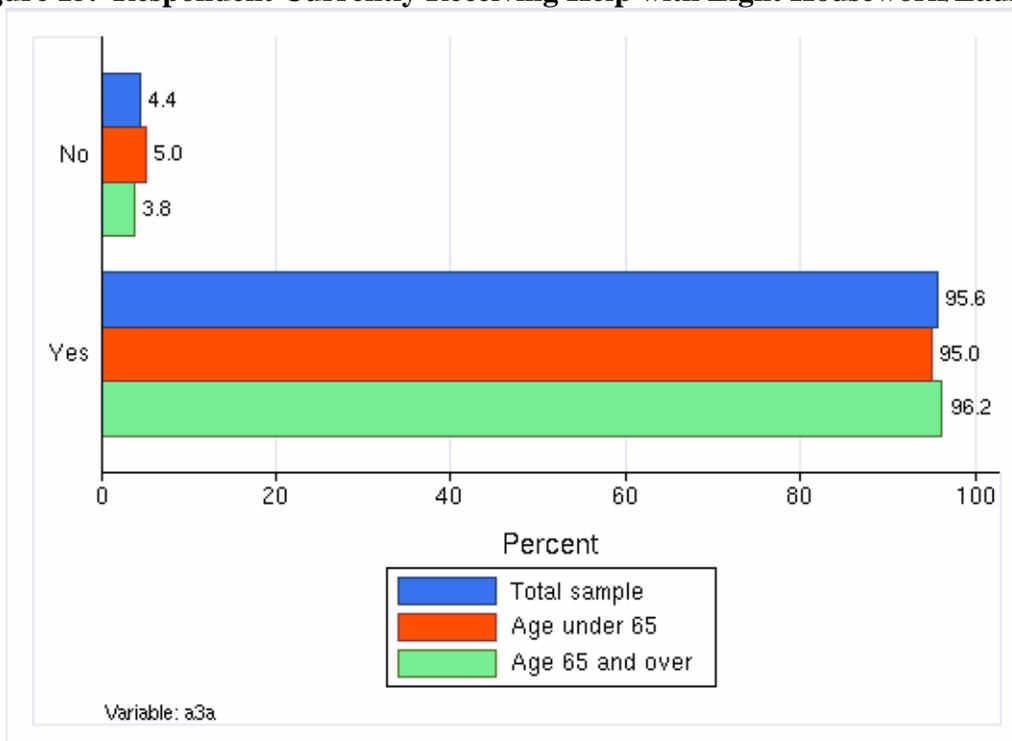


#### 4. HEALTH AND FUNCTIONAL STATUS

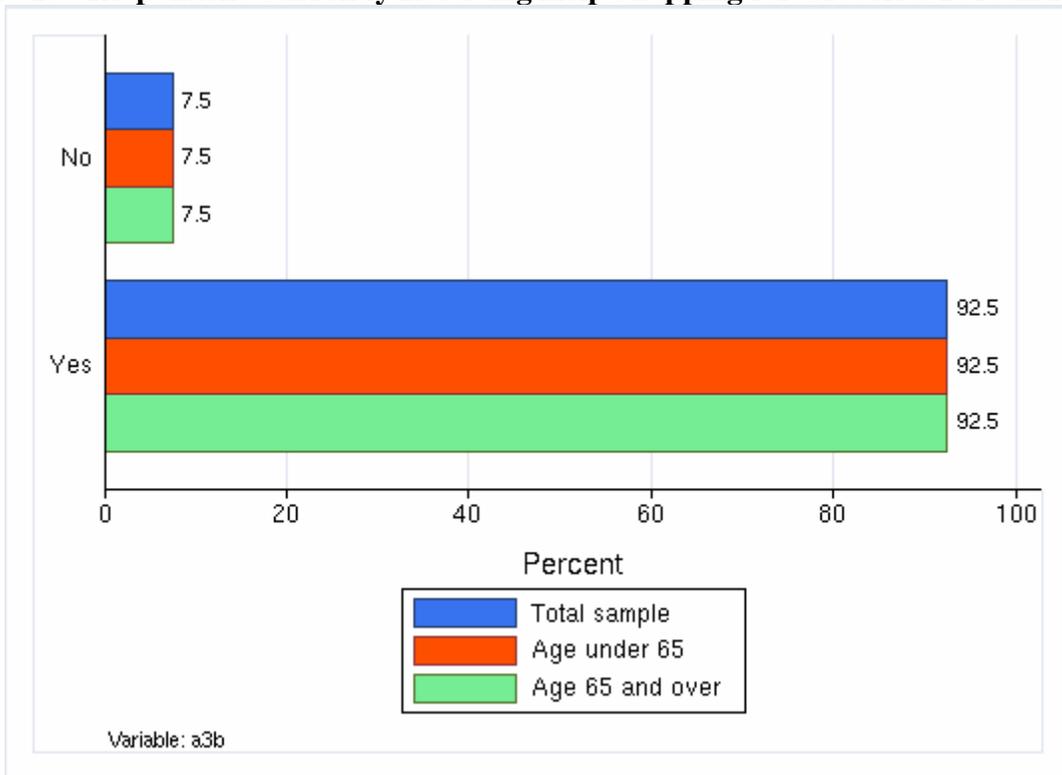
**Figure 14. Self-Reported Health Status (Compared to Other People of the Same Age)**



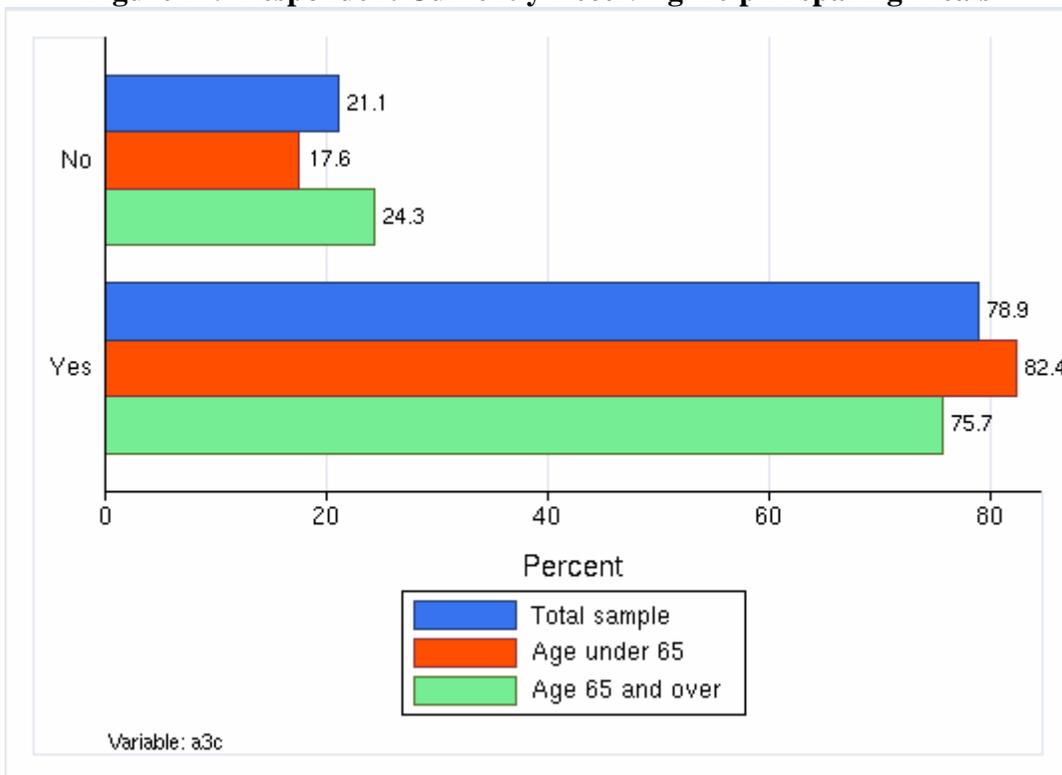
**Figure 15. Respondent Currently Receiving Help with Light Housework/Laundry**



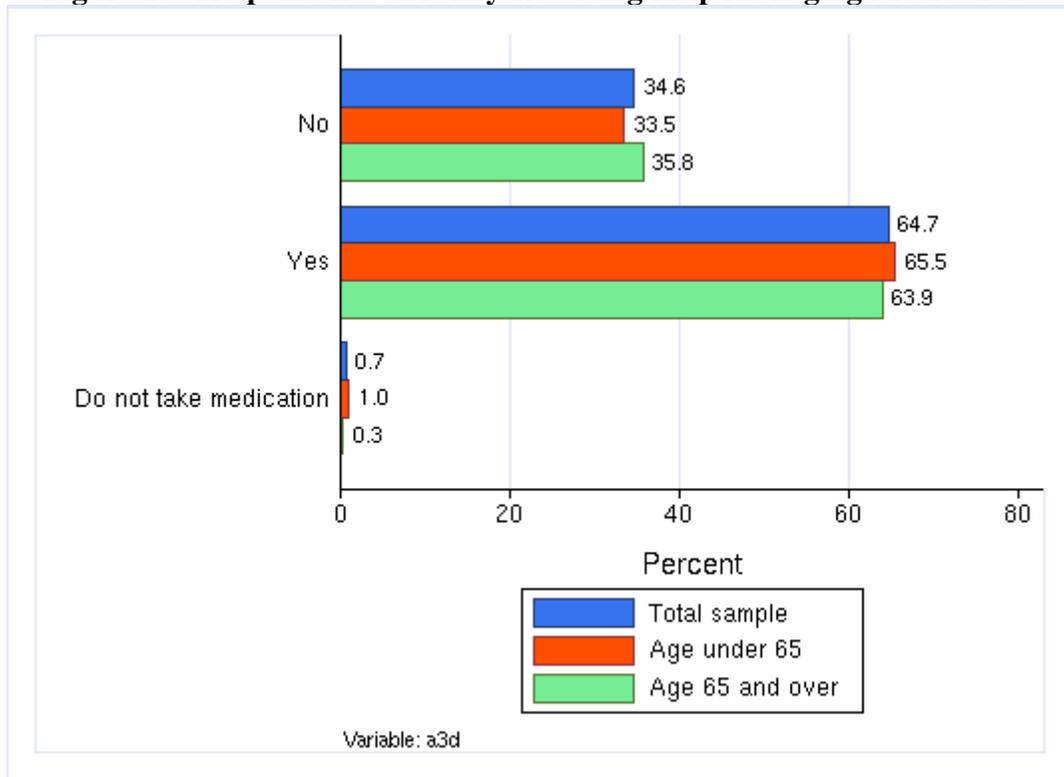
**Figure 16. Respondent Currently Receiving Help Shopping for Groceries/Personal Items**



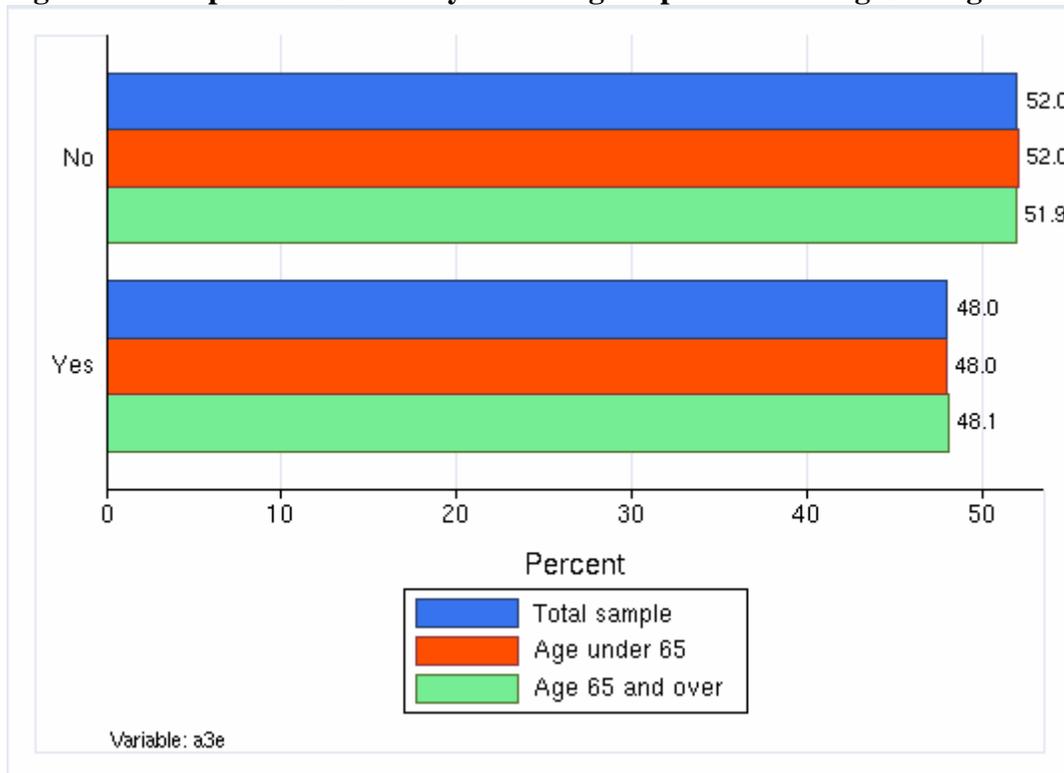
**Figure 17. Respondent Currently Receiving Help Preparing Meals**



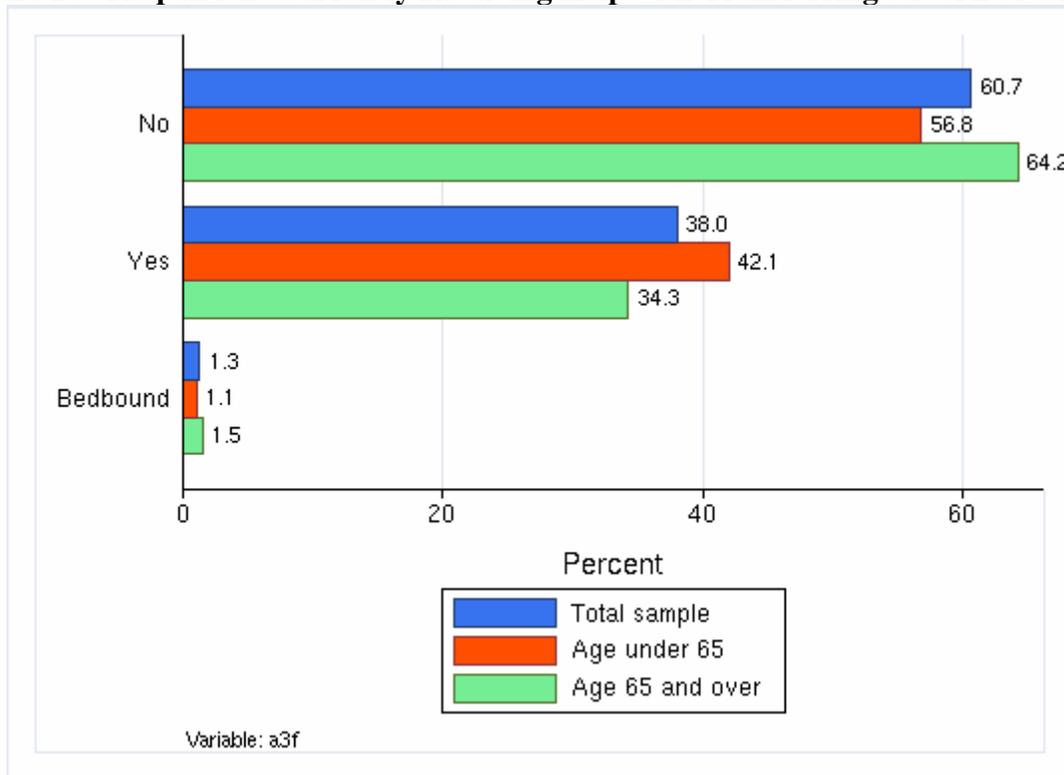
**Figure 18. Respondent Currently Receiving Help Managing Medications**



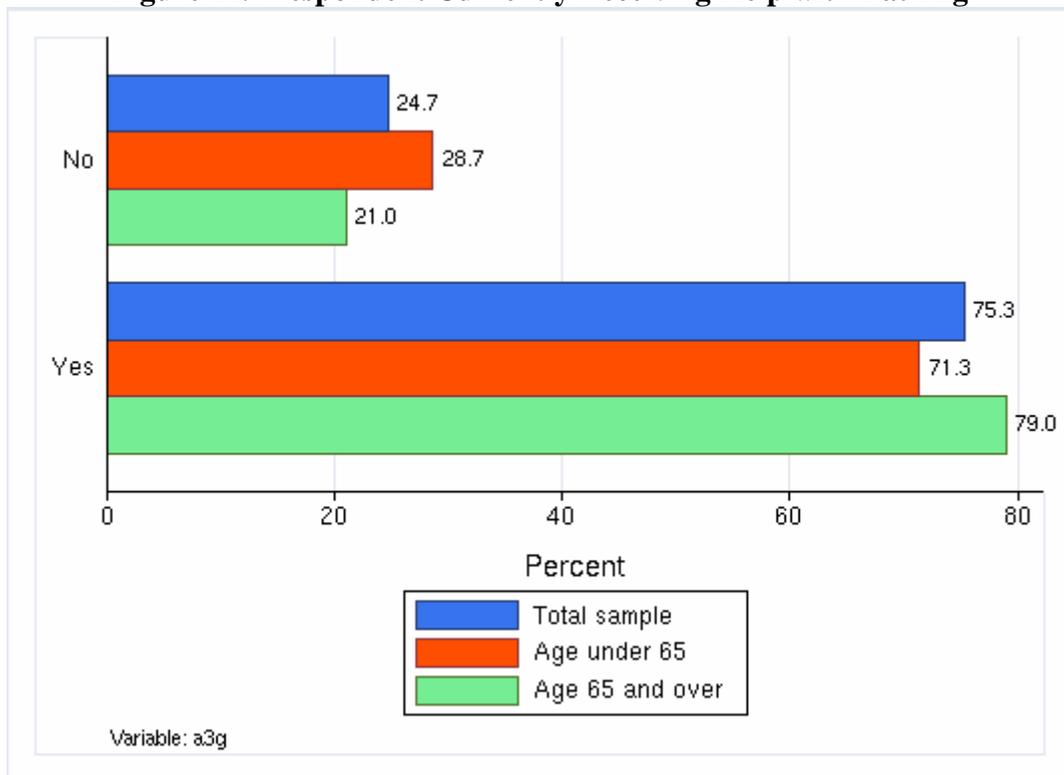
**Figure 19. Respondent Currently Receiving Help with Walking/Getting About**



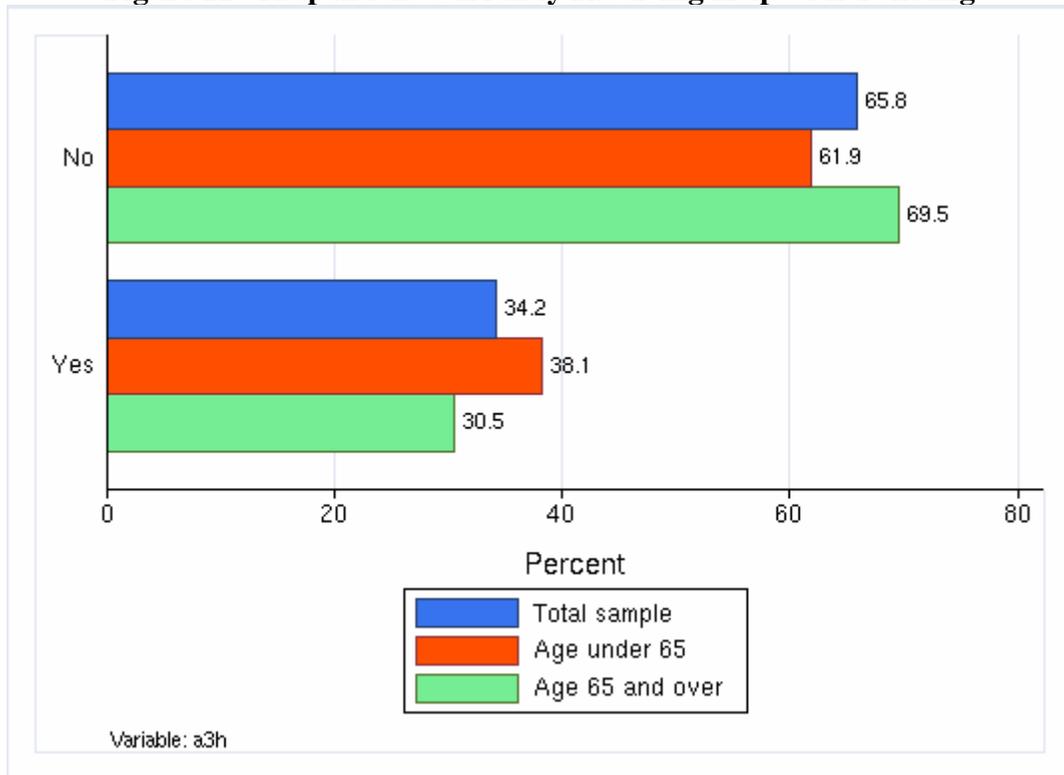
**Figure 20. Respondent Currently Receiving Help with Transferring out of Bed/Chairs**



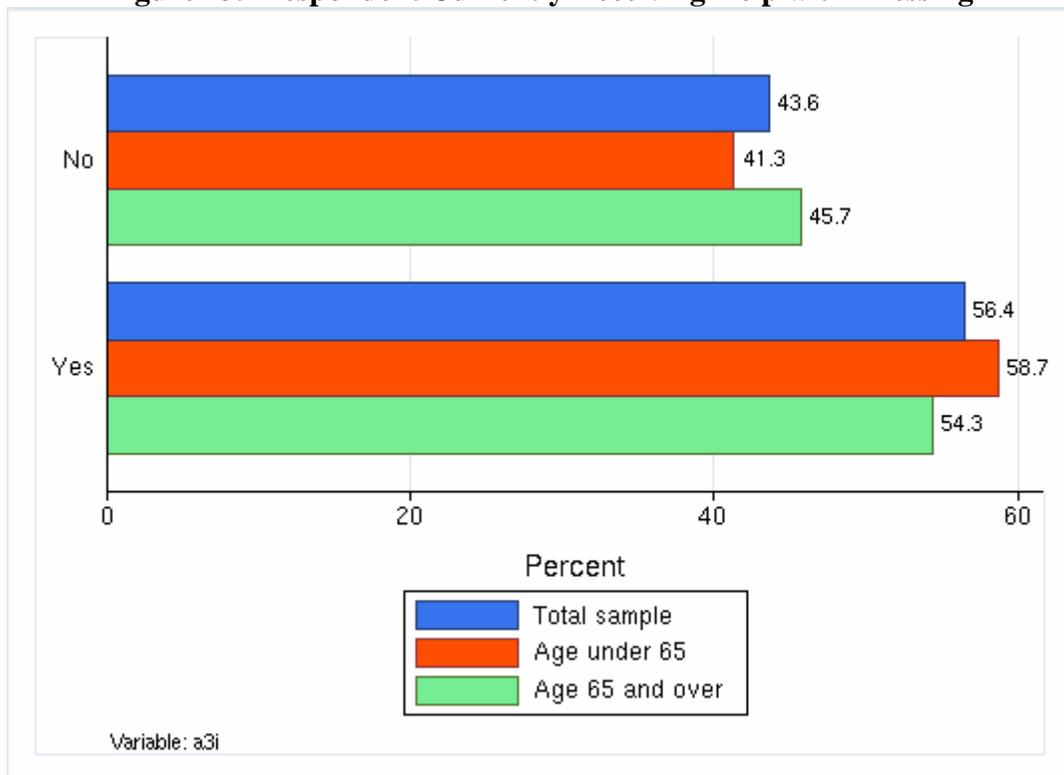
**Figure 21. Respondent Currently Receiving Help with Bathing**



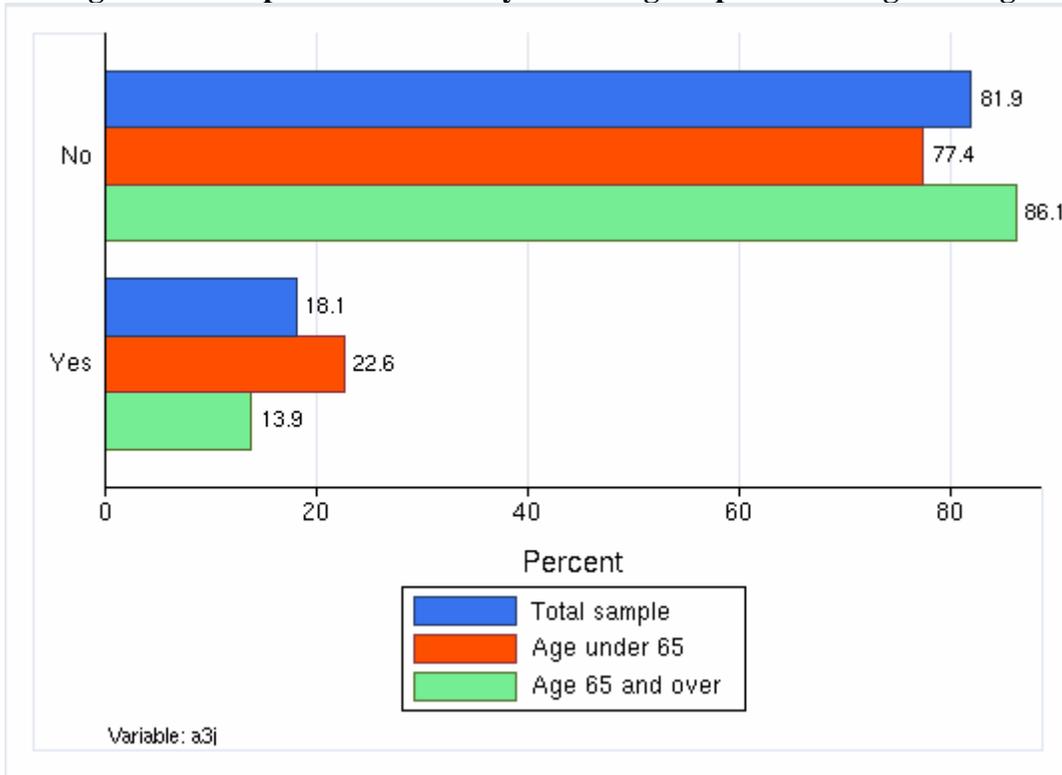
**Figure 22. Respondent Currently Receiving Help with Toileting**



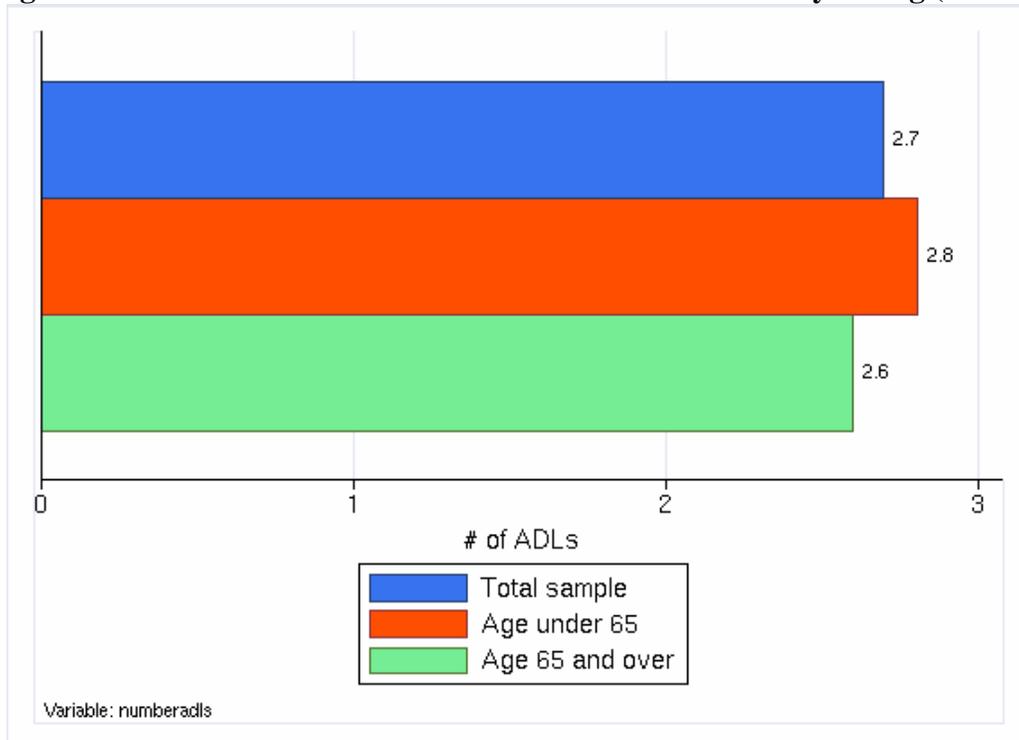
**Figure 23. Respondent Currently Receiving Help with Dressing**



**Figure 24. Respondent Currently Receiving Help with Eating/Feeding**

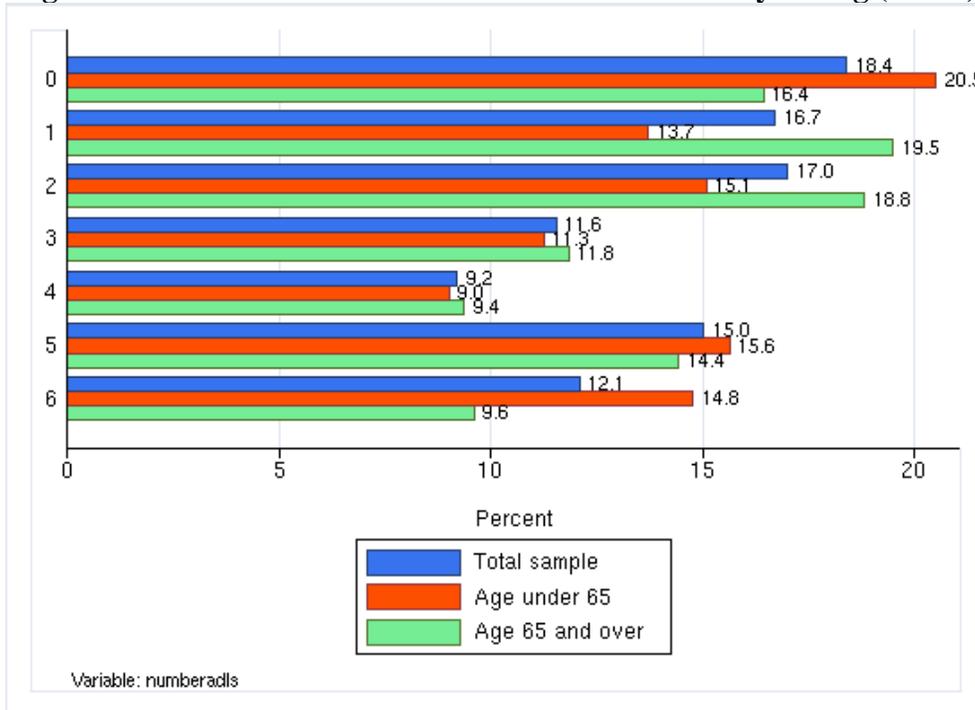


**Figure 25. Mean Number of Limitations in Activities of Daily Living (ADLs)<sup>3</sup>**

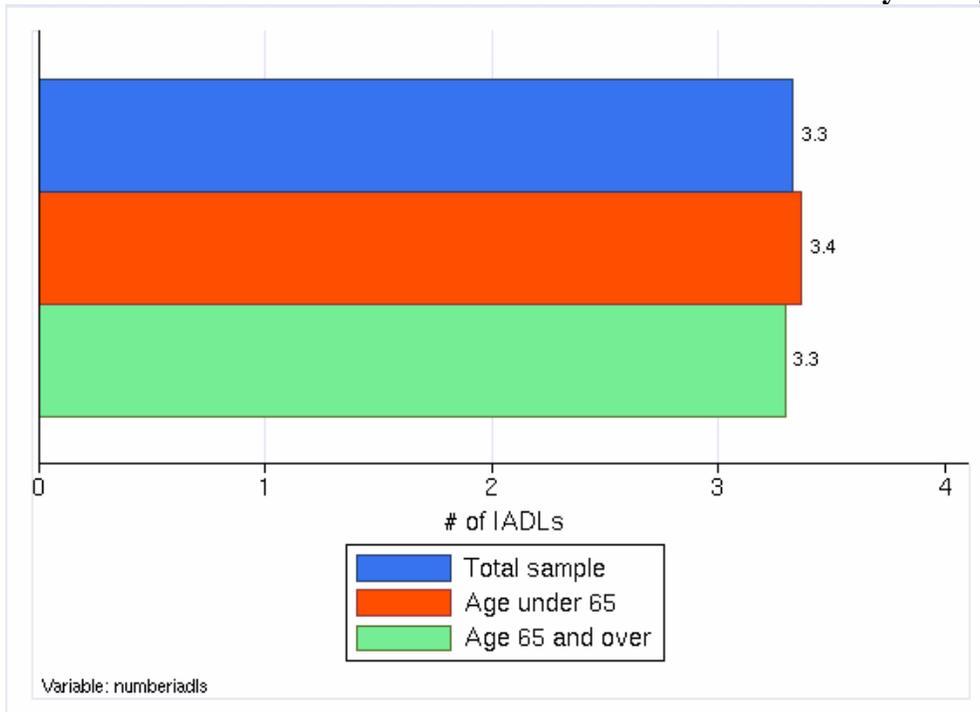


<sup>3</sup> ADL scale ranges from 0 to 6.

**Figure 26. Number of Limitations on Activities of Daily Living (ADLs)**

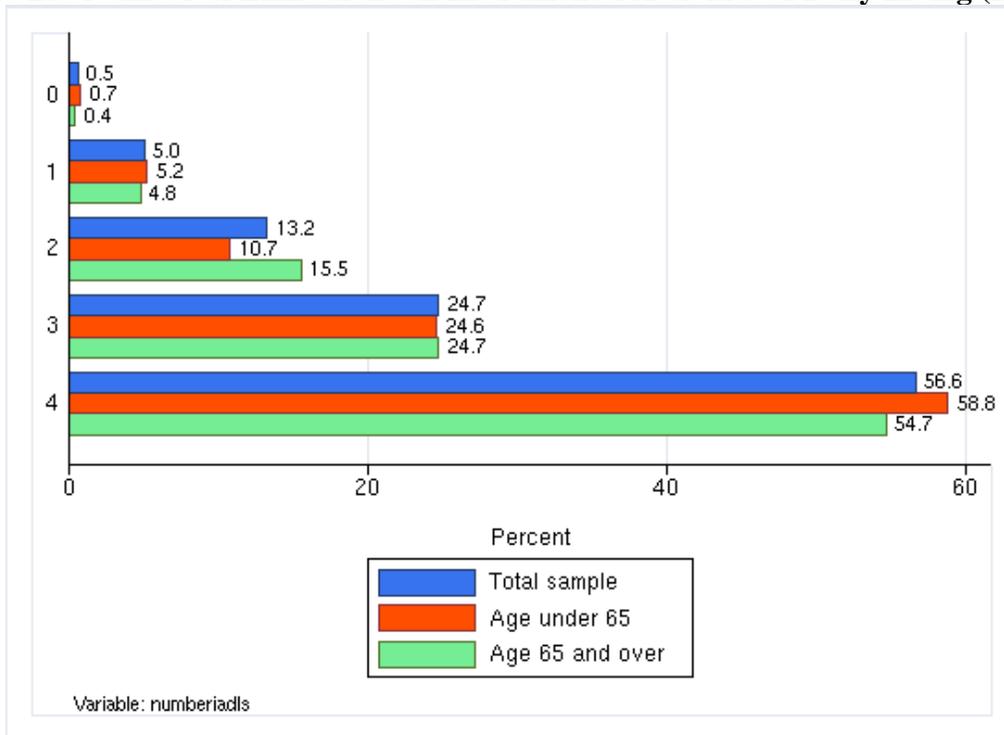


**Figure 27. Mean Number of Limitations in Instrumental Activities of Daily Living (IADLs)<sup>4</sup>**

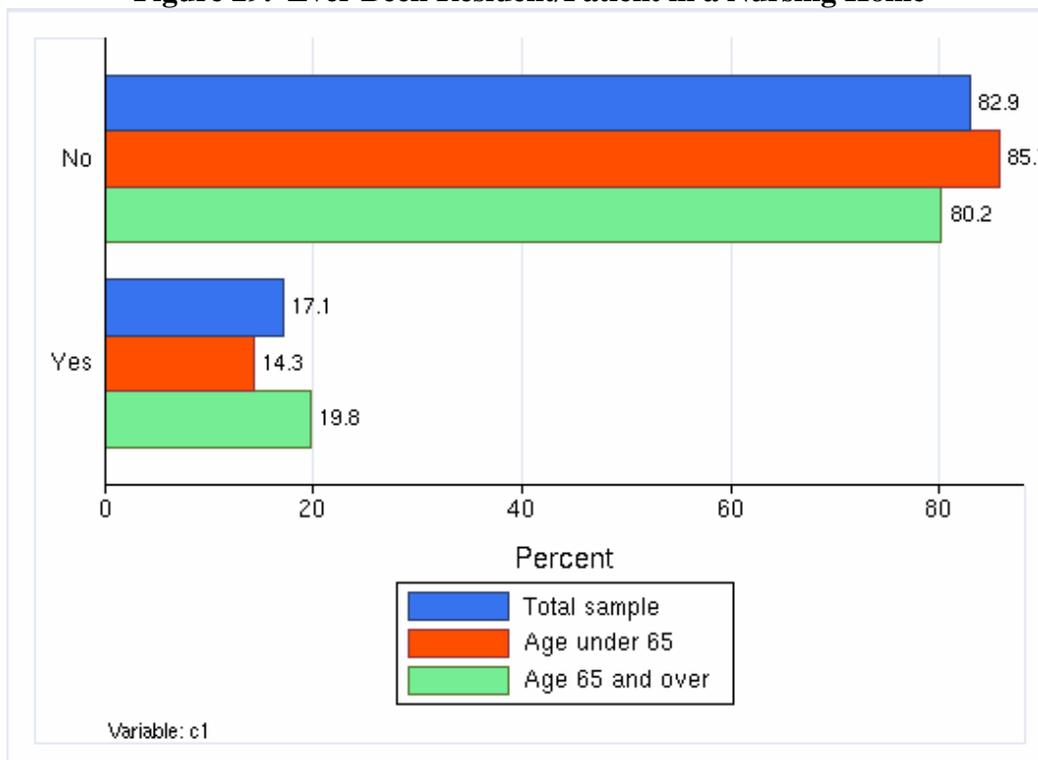


<sup>4</sup> IADL scale ranges from 0 to 4.

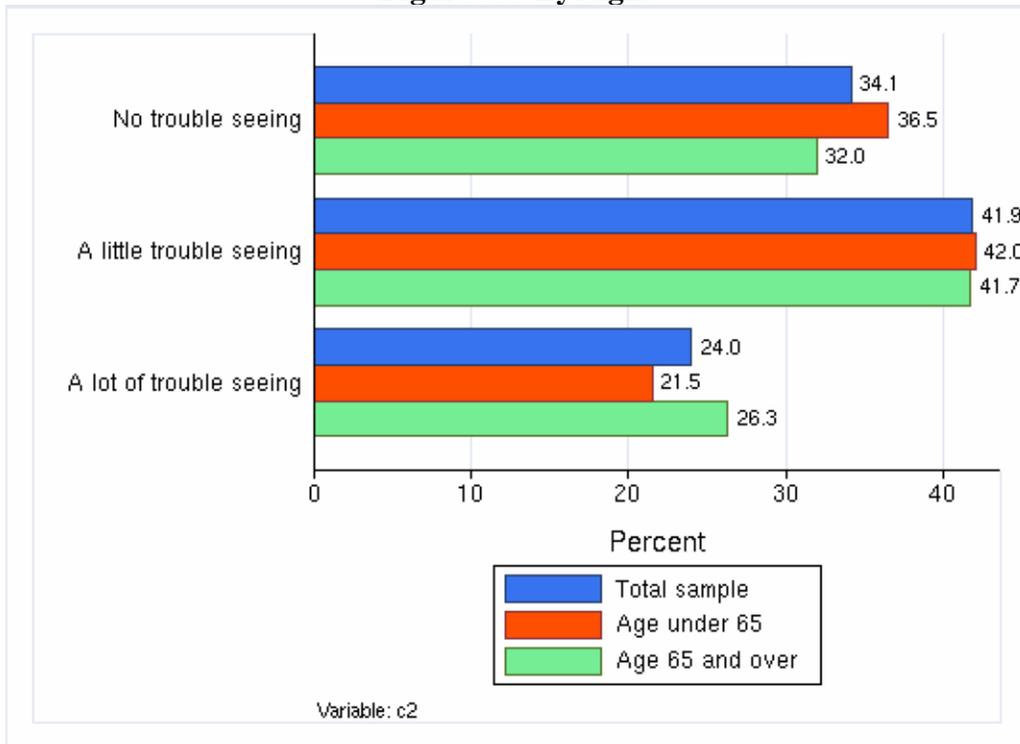
**Figure 28. Number of Limitations on Instrumental Activities of Daily Living (IADLs)**



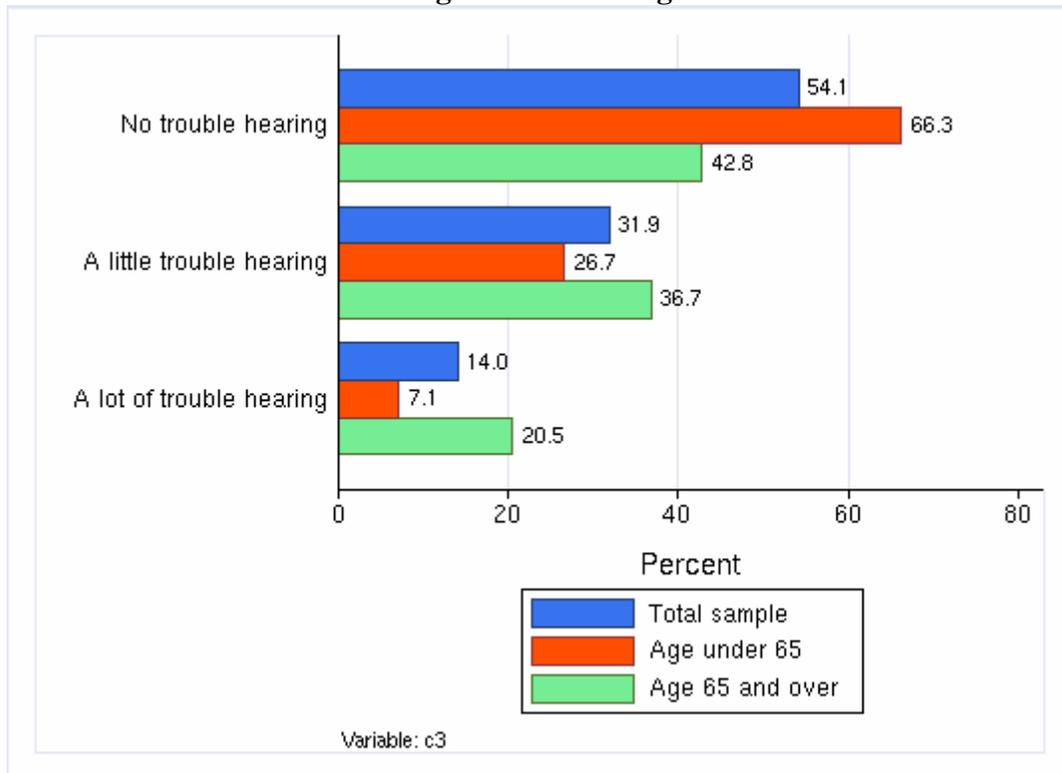
**Figure 29. Ever Been Resident/Patient in a Nursing Home**



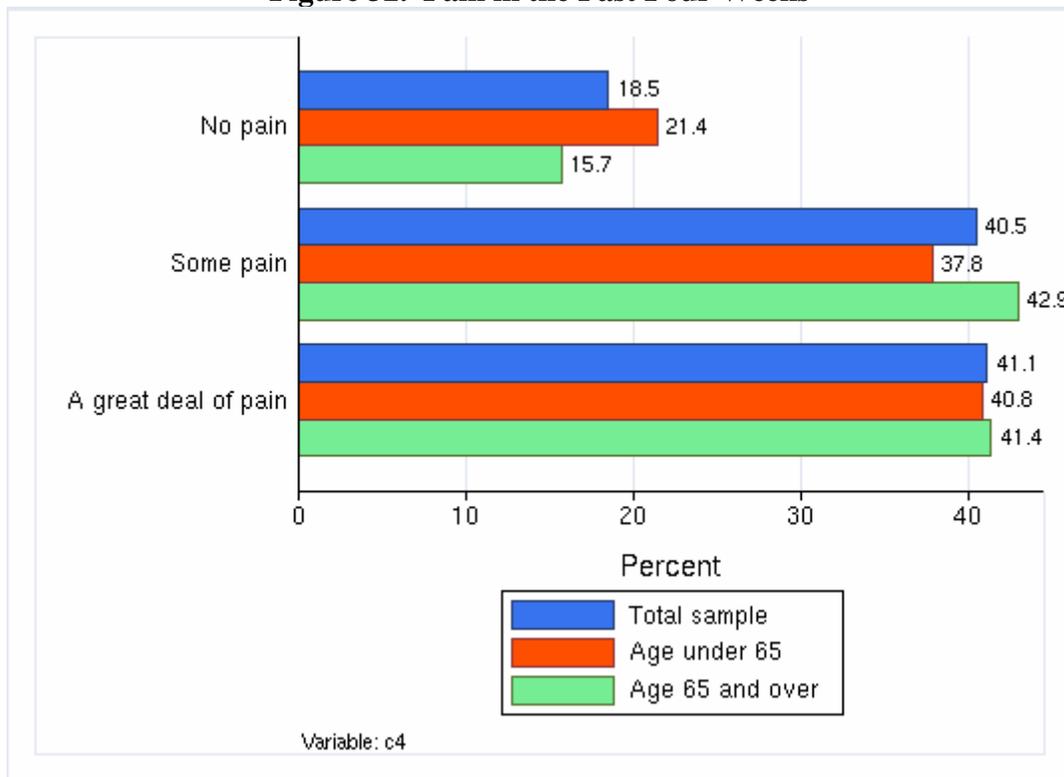
**Figure 30. Eyesight**



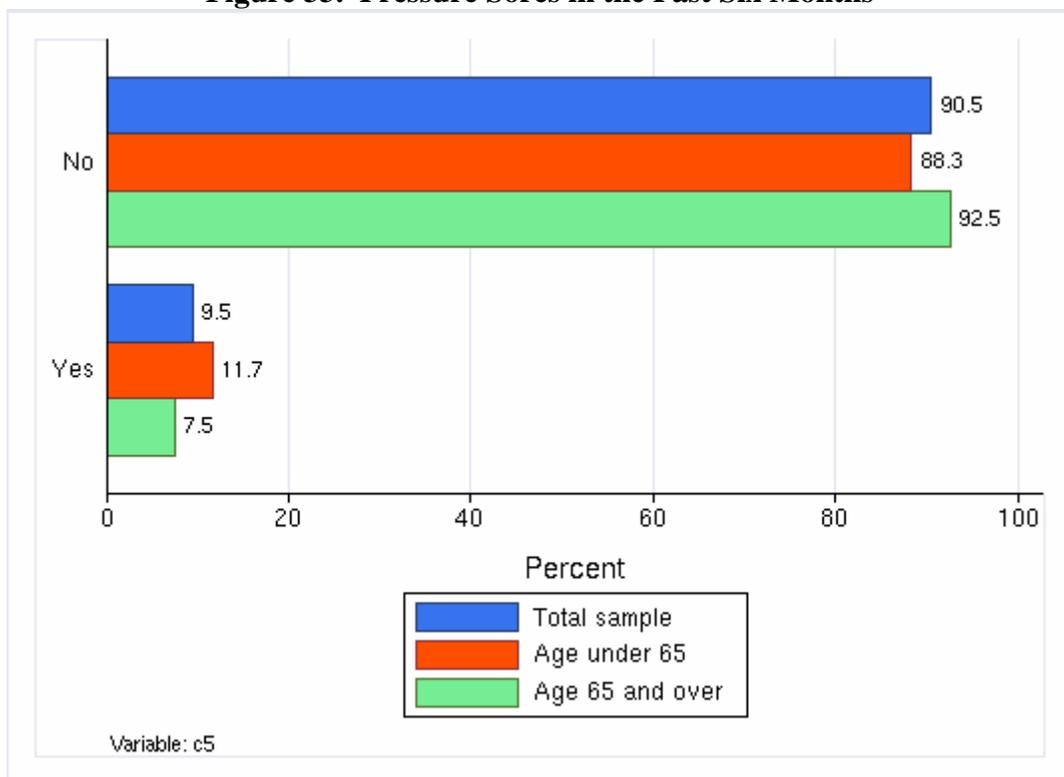
**Figure 31. Hearing**



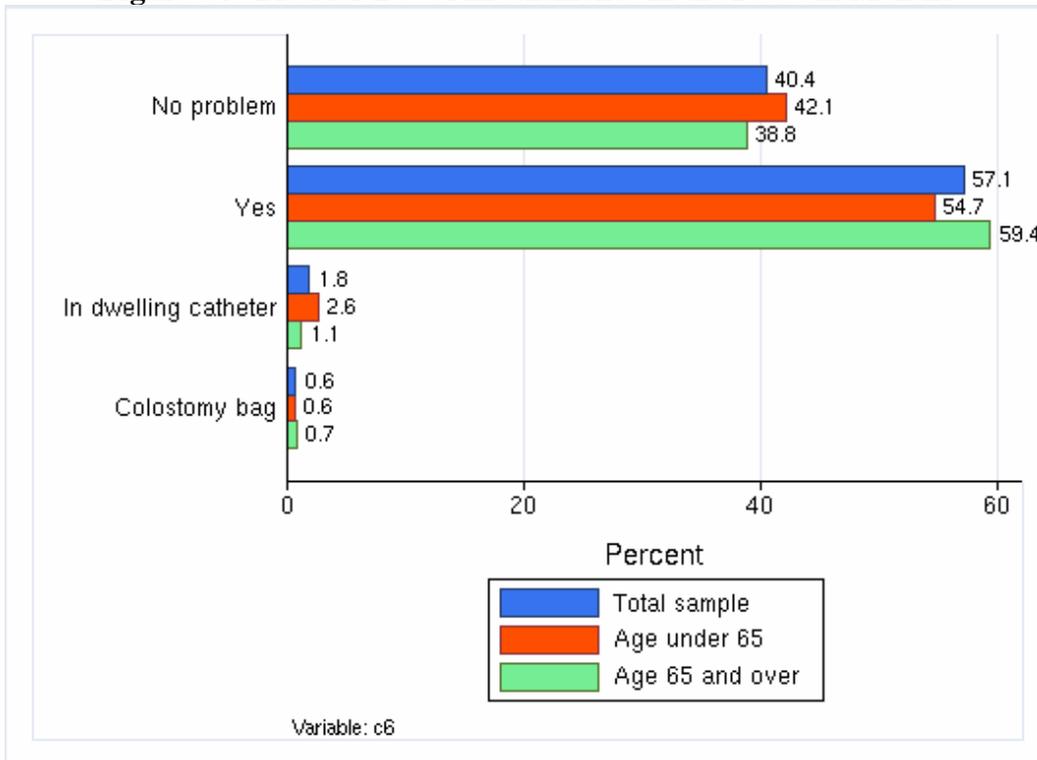
**Figure 32. Pain in the Past Four Weeks**



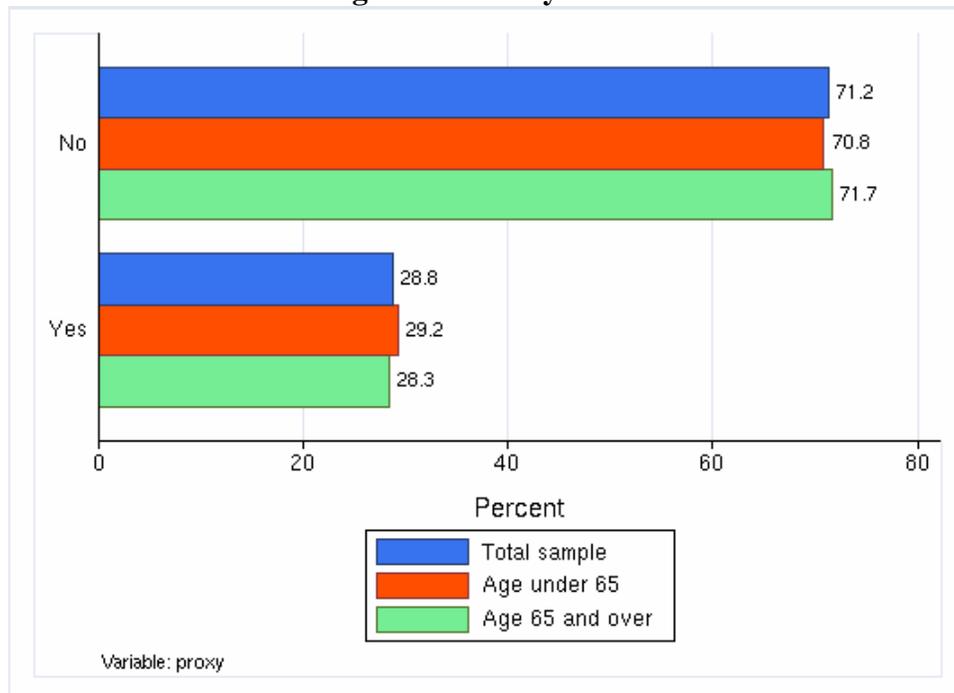
**Figure 33. Pressure Sores in the Past Six Months**



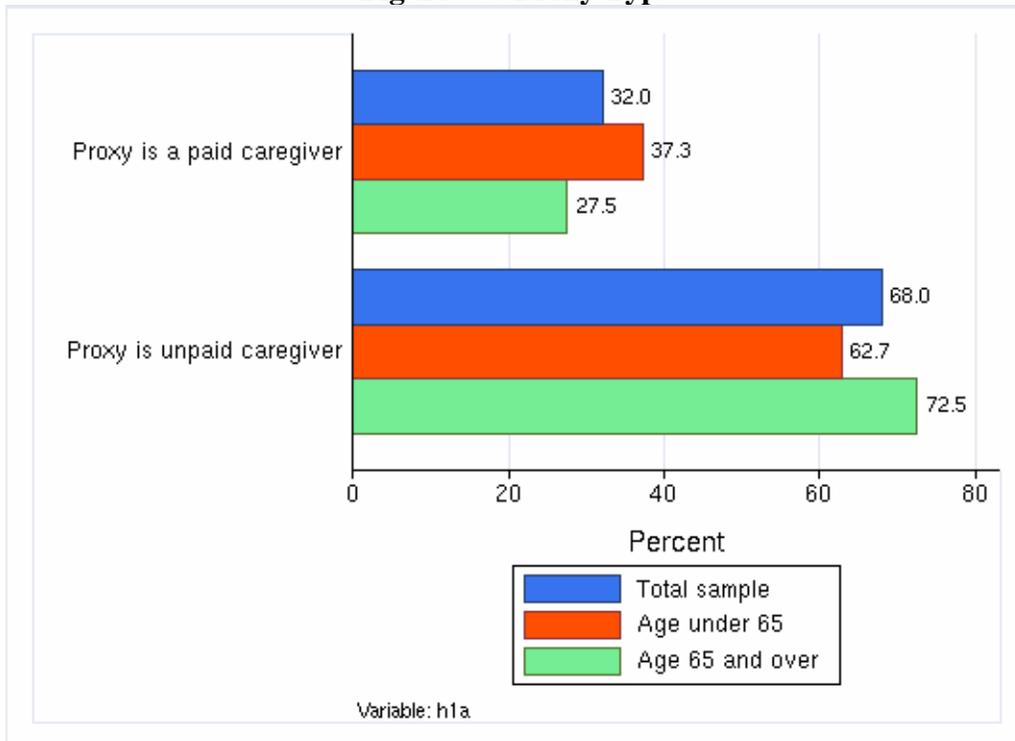
**Figure 34. Bladder/Bowel Incontinence in the Past Six Months**



**Figure 35. Proxy Status**

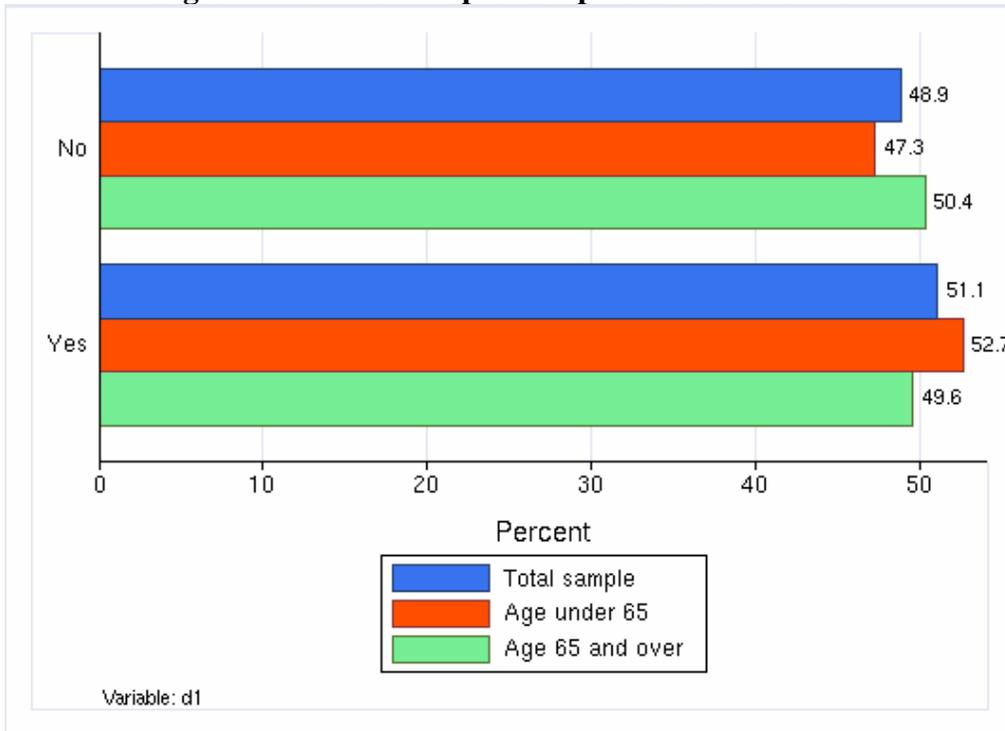


**Figure 36. Proxy Type**

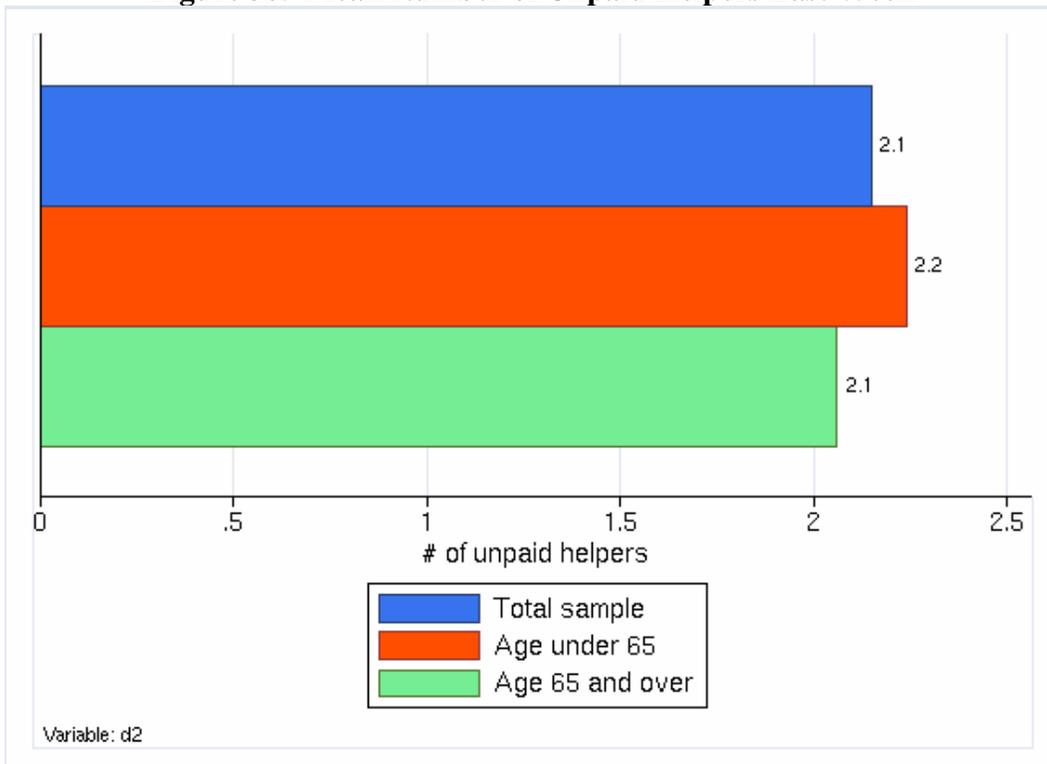


## 5. INFORMAL AND FORMAL SUPPORT

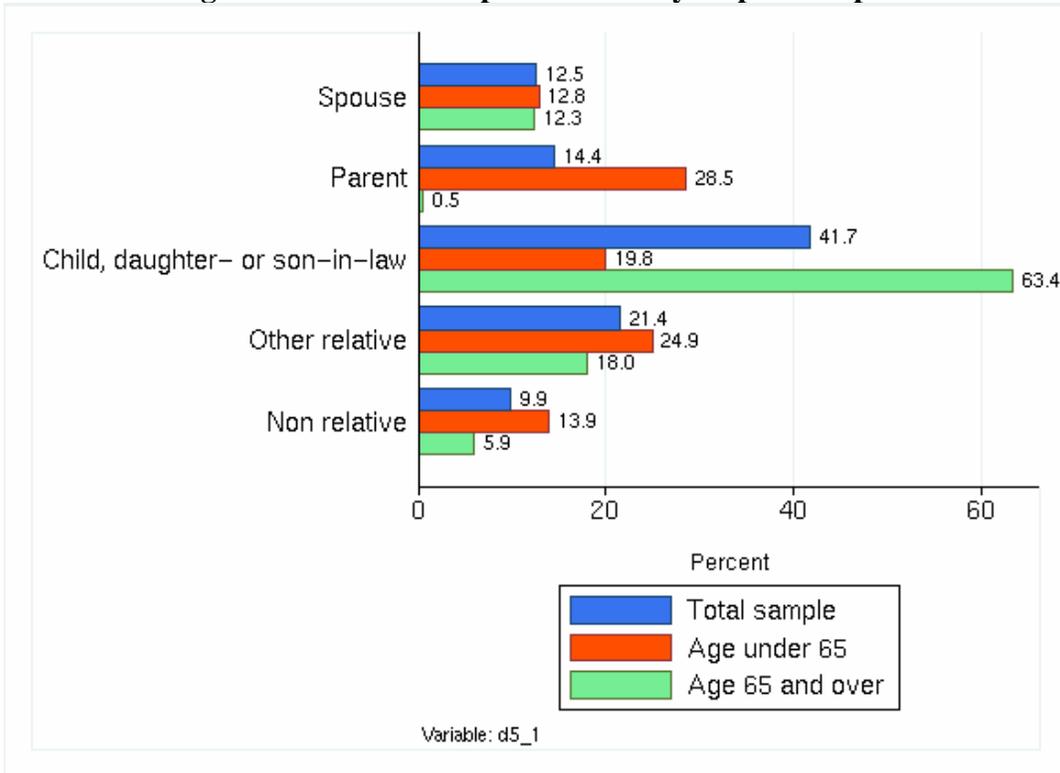
**Figure 37. Receive Unpaid Help with Personal Care**



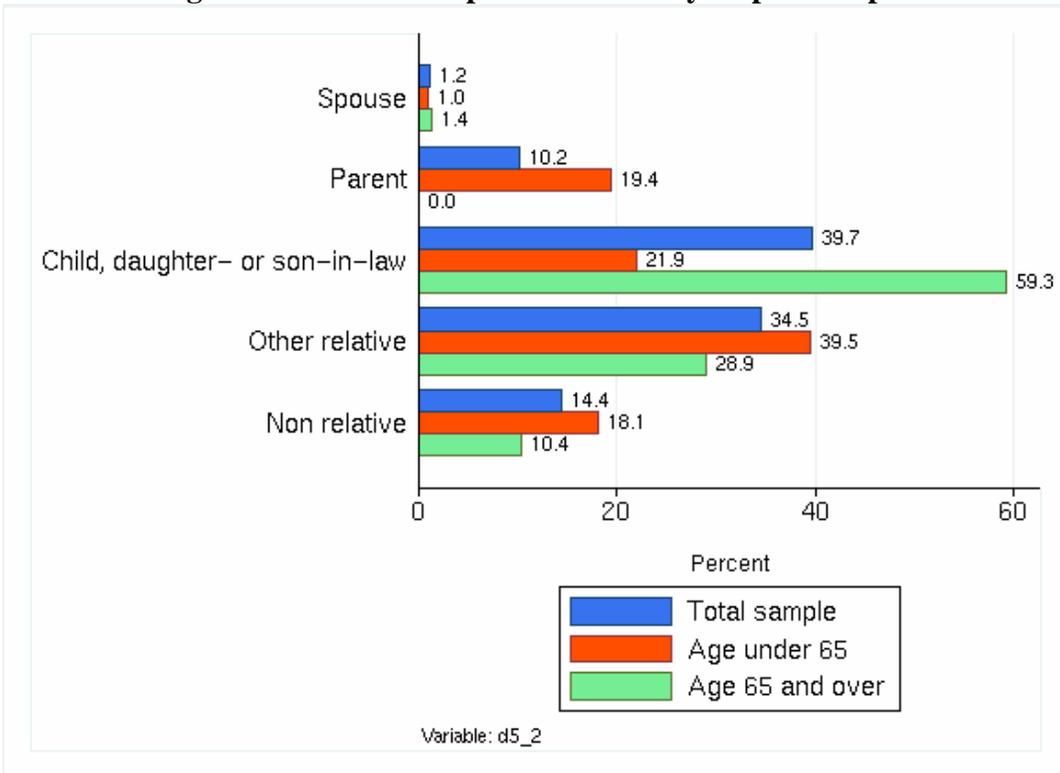
**Figure 38. Mean Number of Unpaid Helpers Last Week**



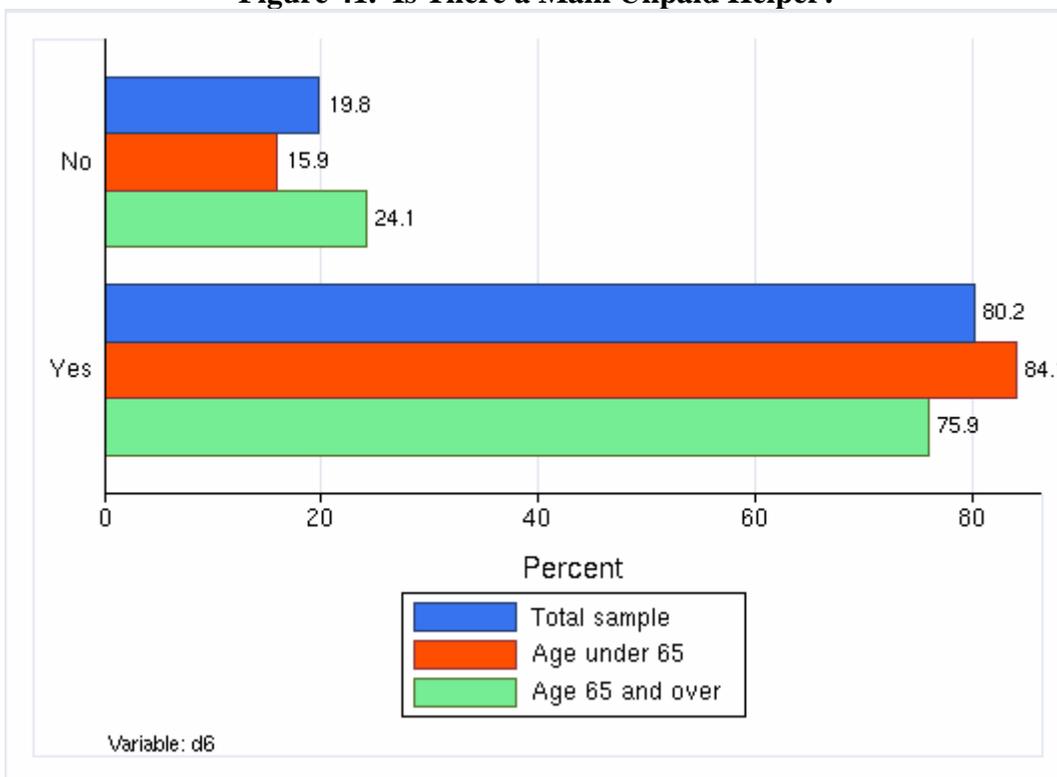
**Figure 39. Relationship with Primary Unpaid Helper**



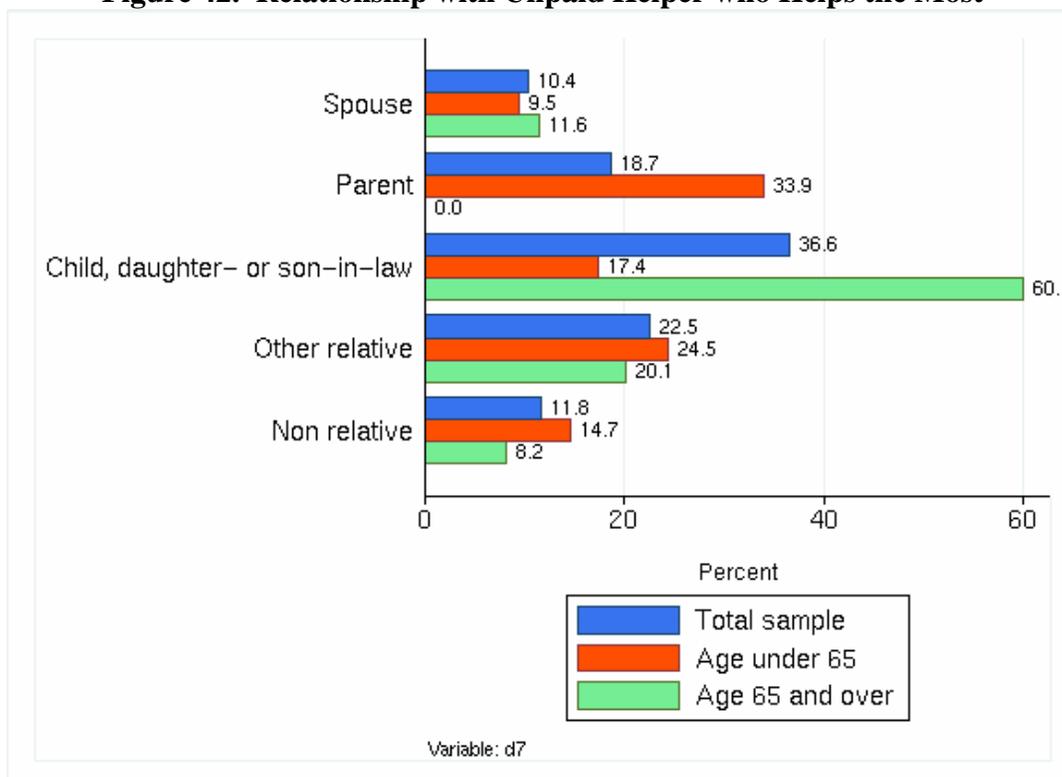
**Figure 40. Relationship with Secondary Unpaid Helper**



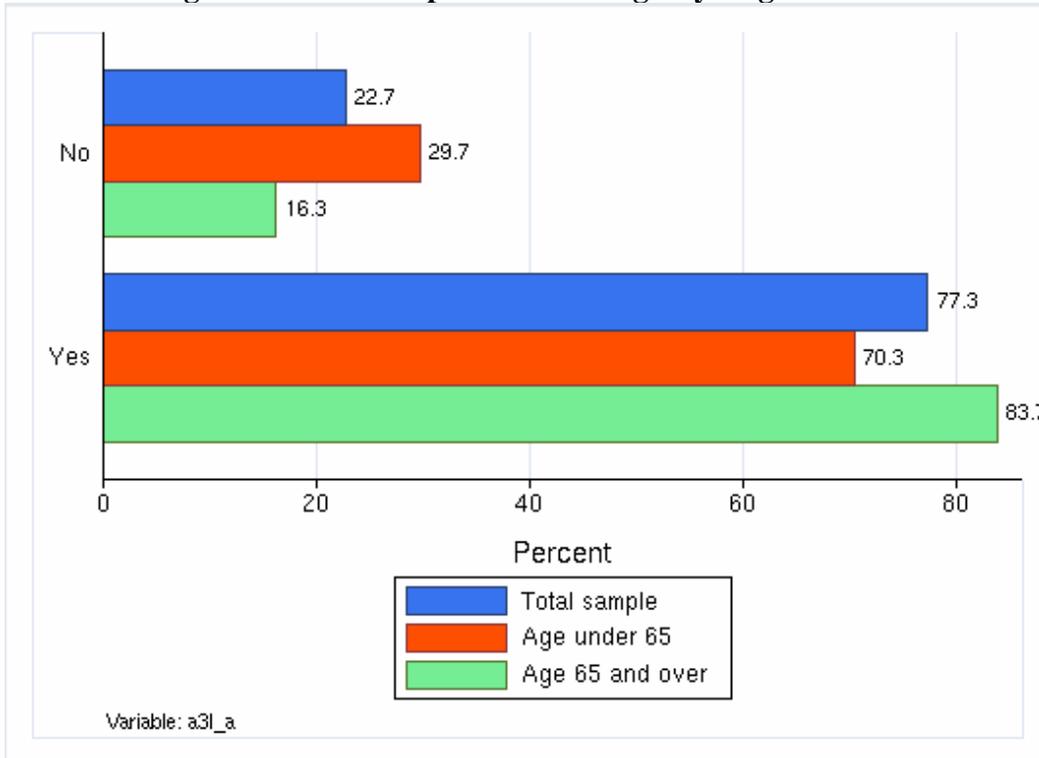
**Figure 41. Is There a Main Unpaid Helper?**



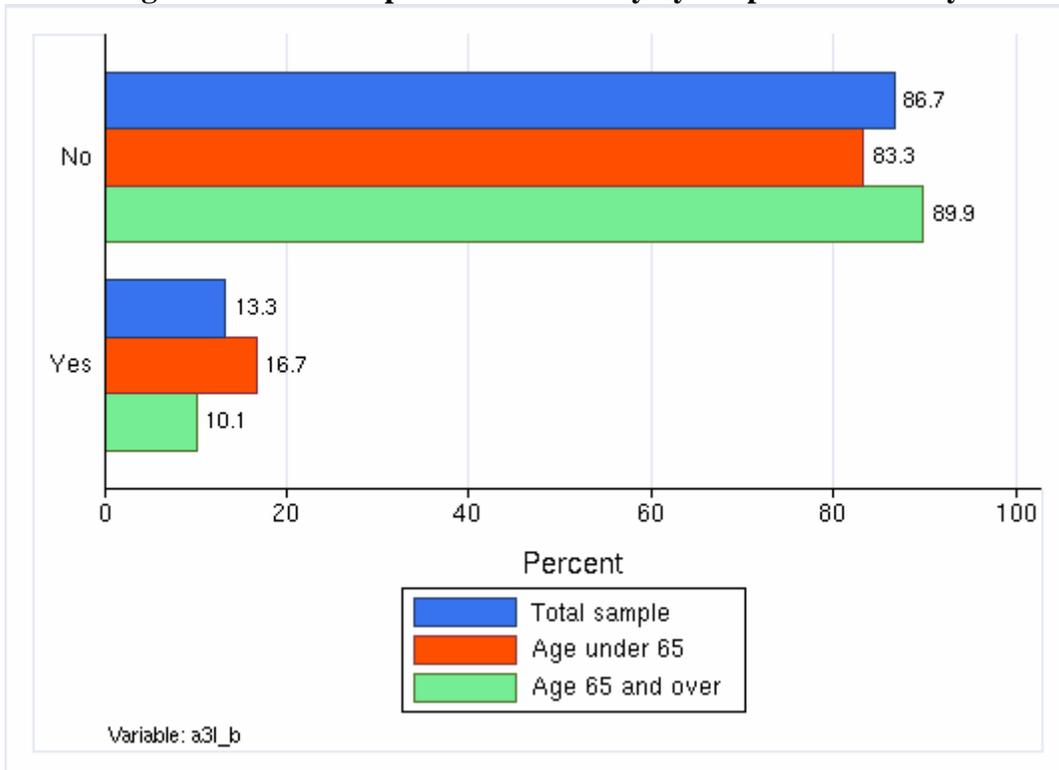
**Figure 42. Relationship with Unpaid Helper who Helps the Most**



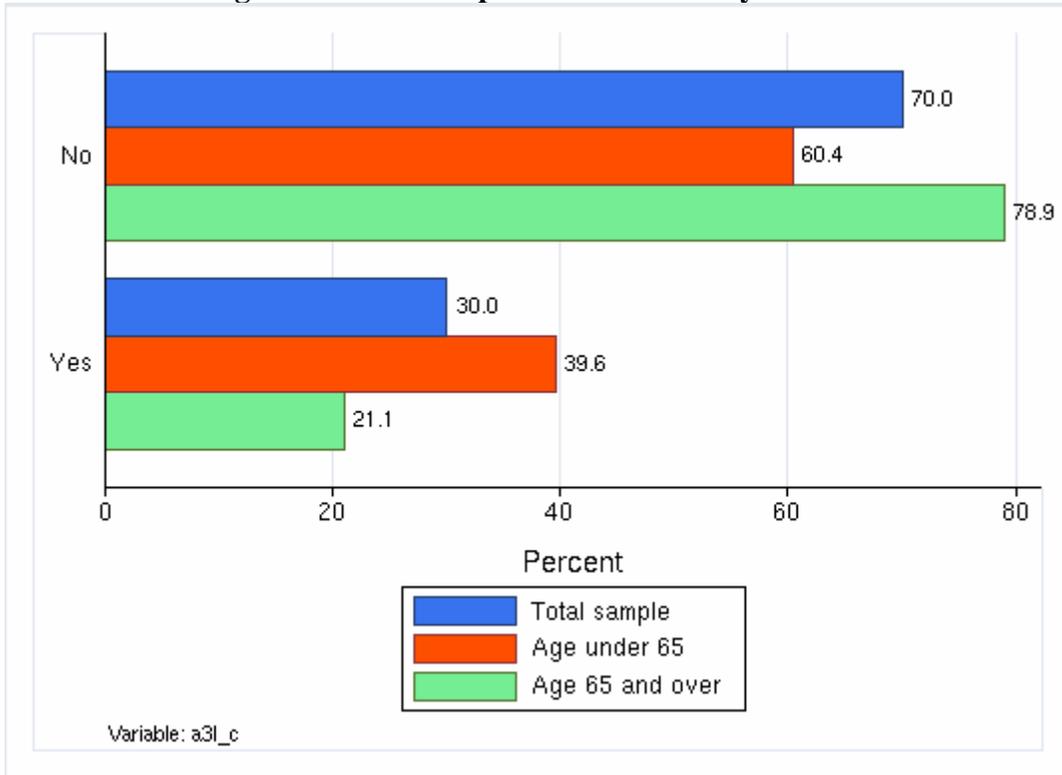
**Figure 43. Paid Helpers from an Agency/Organization**



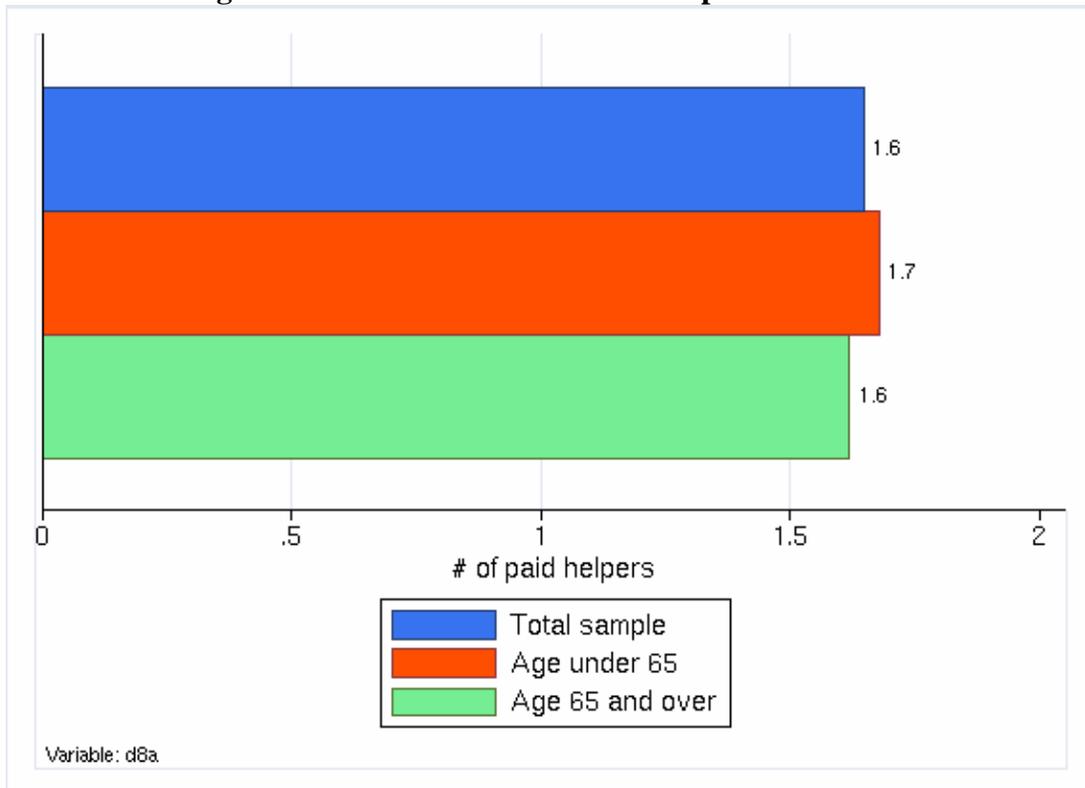
**Figure 44. Paid Helpers Hired Directly by Respondent/Family**



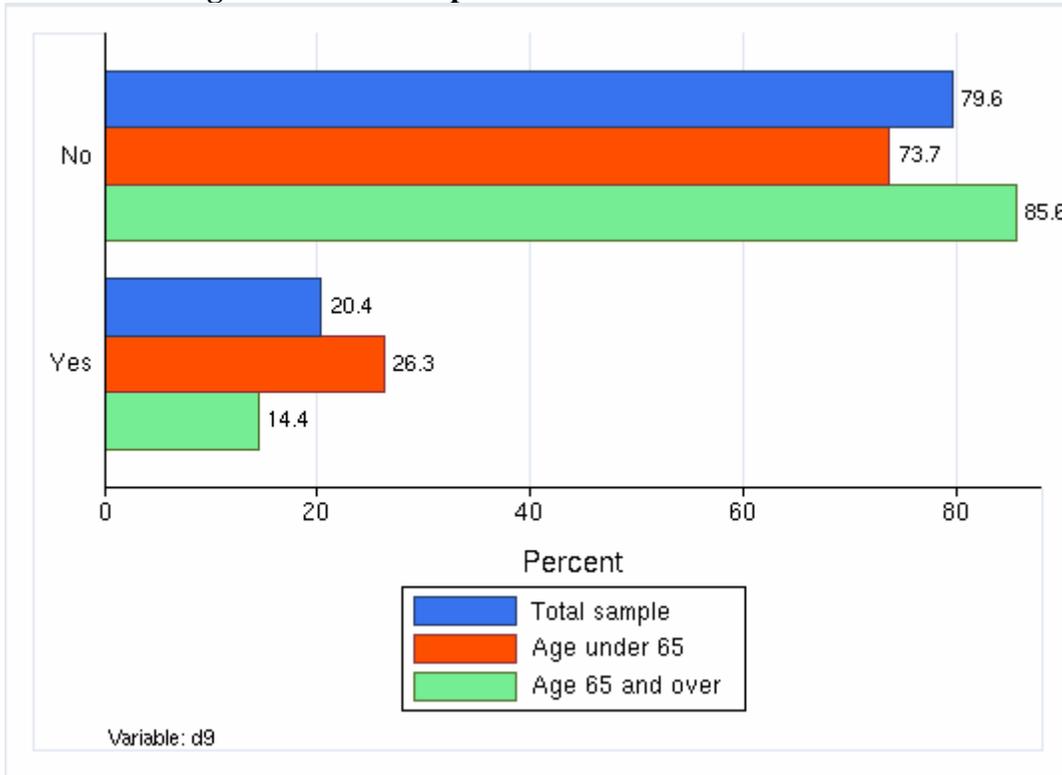
**Figure 45. Paid Helpers who are Family/Friends**



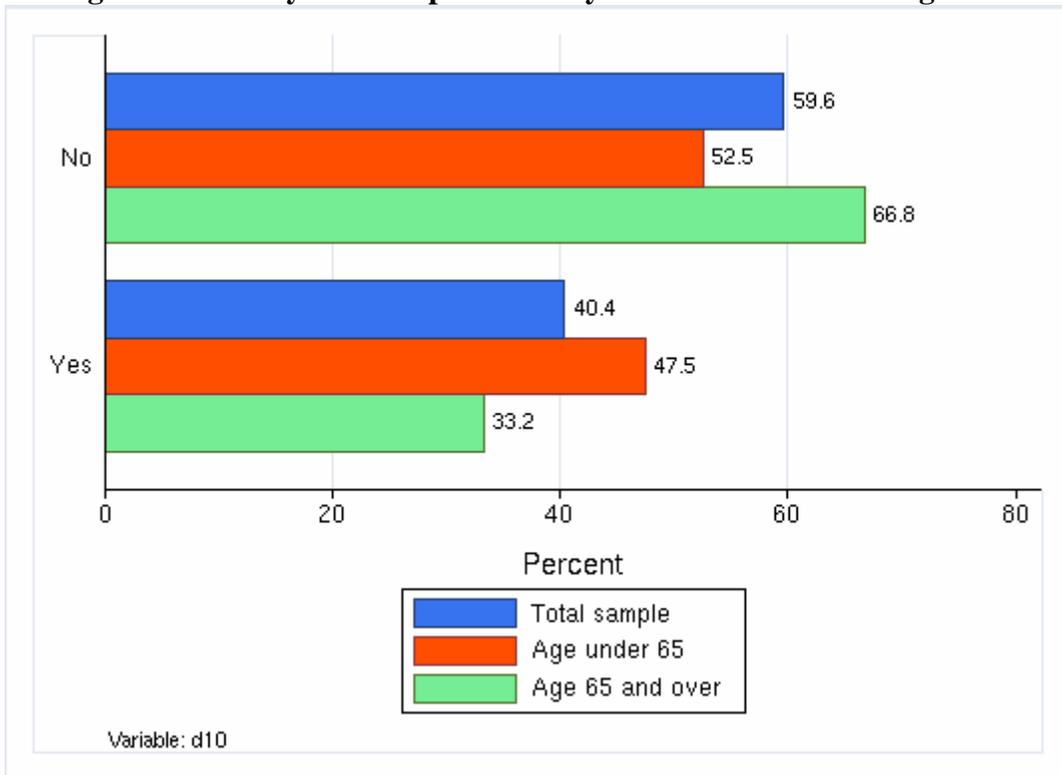
**Figure 46. Mean Number of Paid Helpers Last Week**



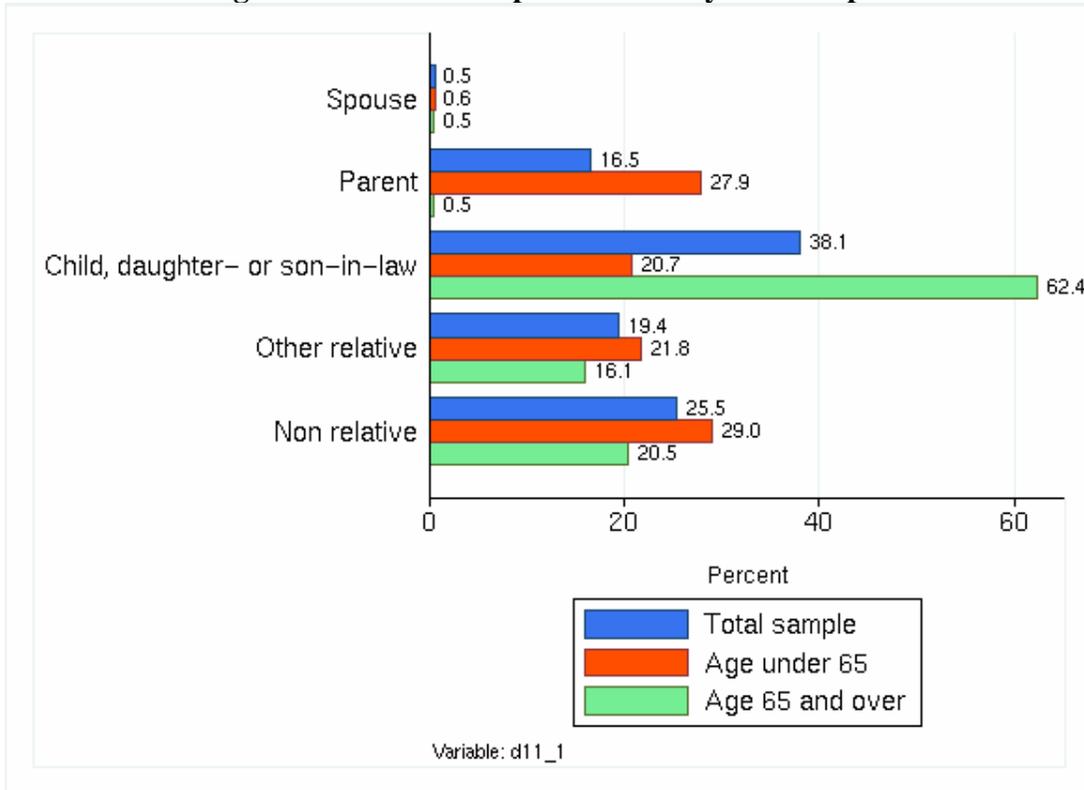
**Figure 47. Paid Helper Lives in the Same Household**



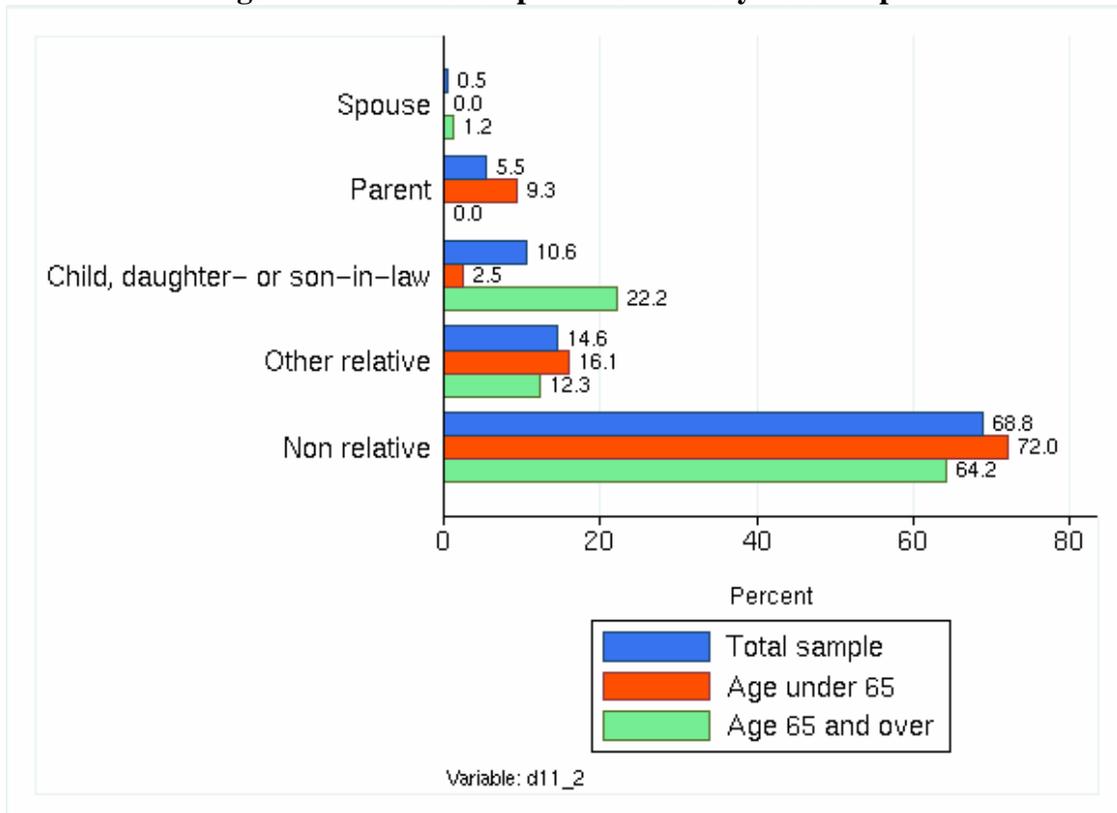
**Figure 48. Is Any Paid Helper a Family Member/Friend or Neighbor?**



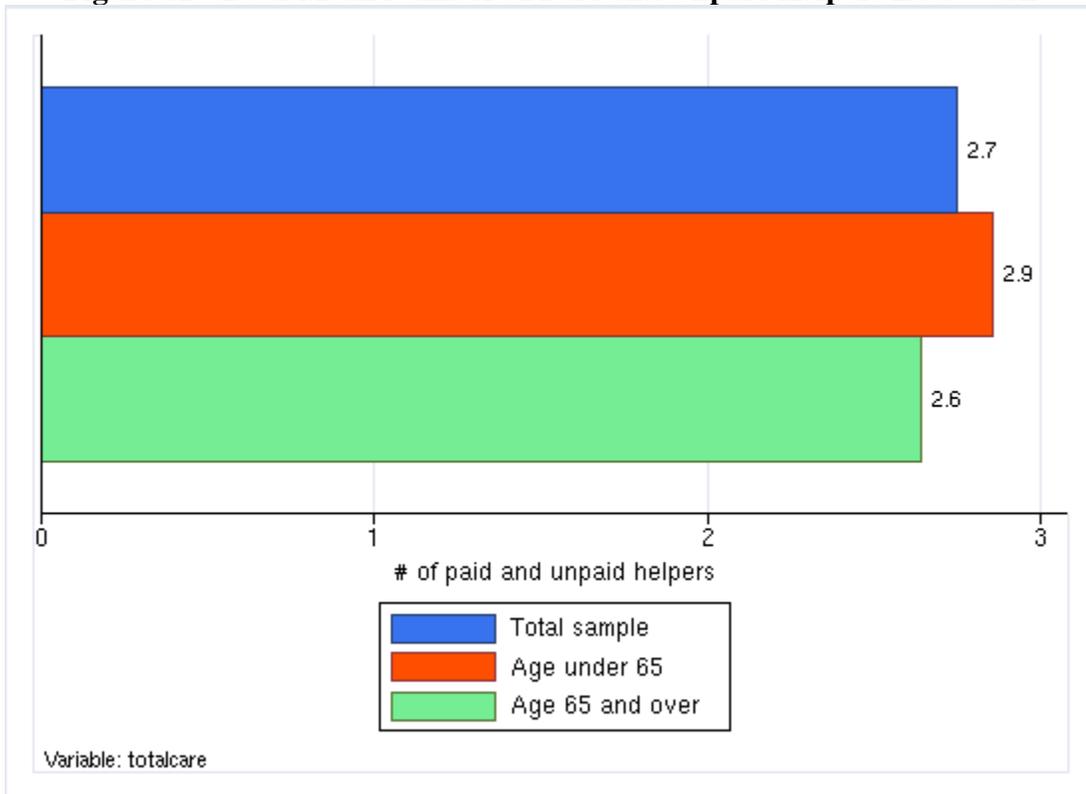
**Figure 49. Relationship with Primary Paid Helper**



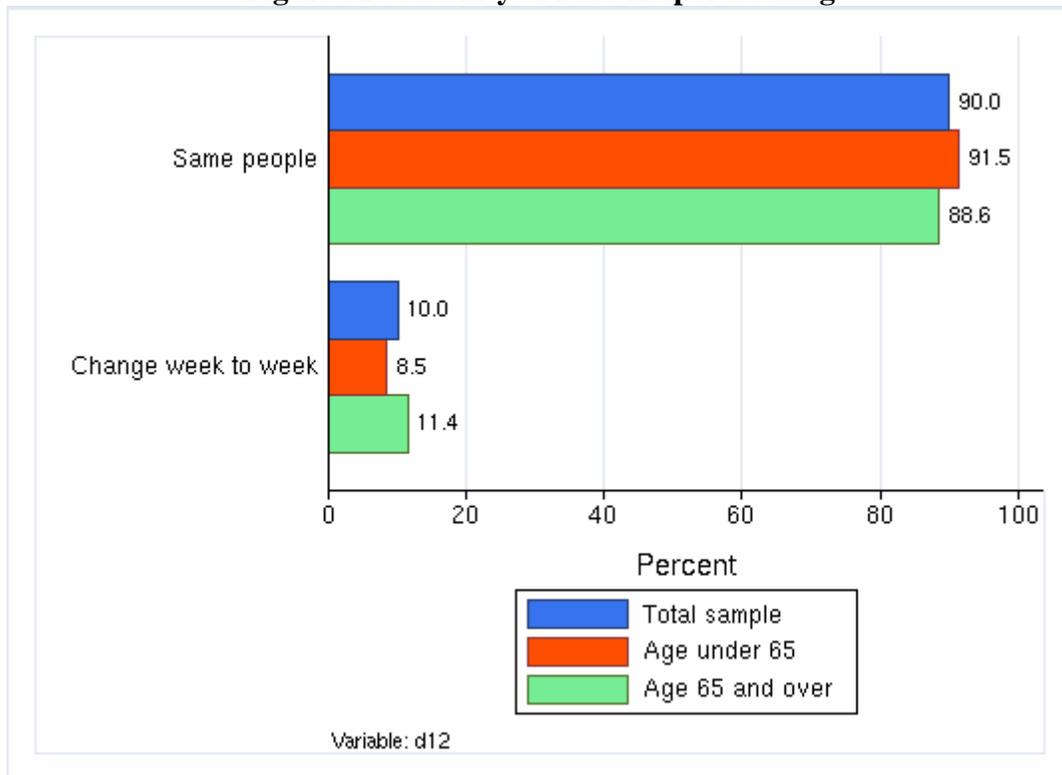
**Figure 50. Relationship with Secondary Paid Helper**



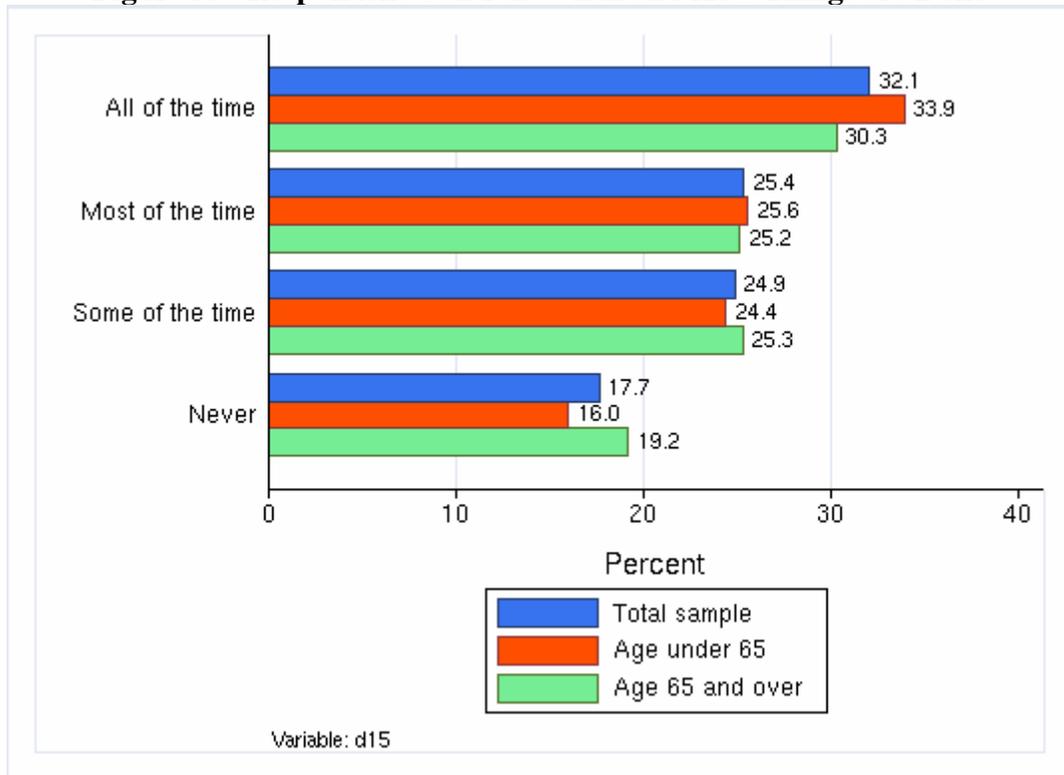
**Figure 51. Total Mean Number of Paid and Unpaid Helpers Last Week**



**Figure 52. Stability of Paid Helper Staffing**

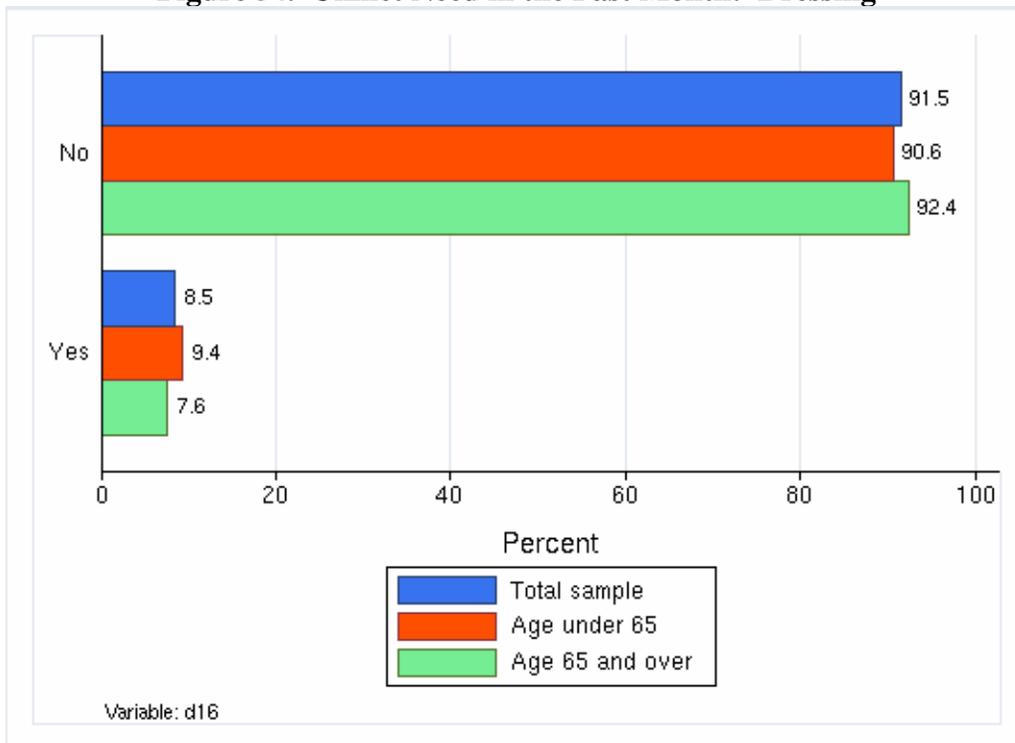


**Figure 53. Respondent Controls When and How Things are Done**

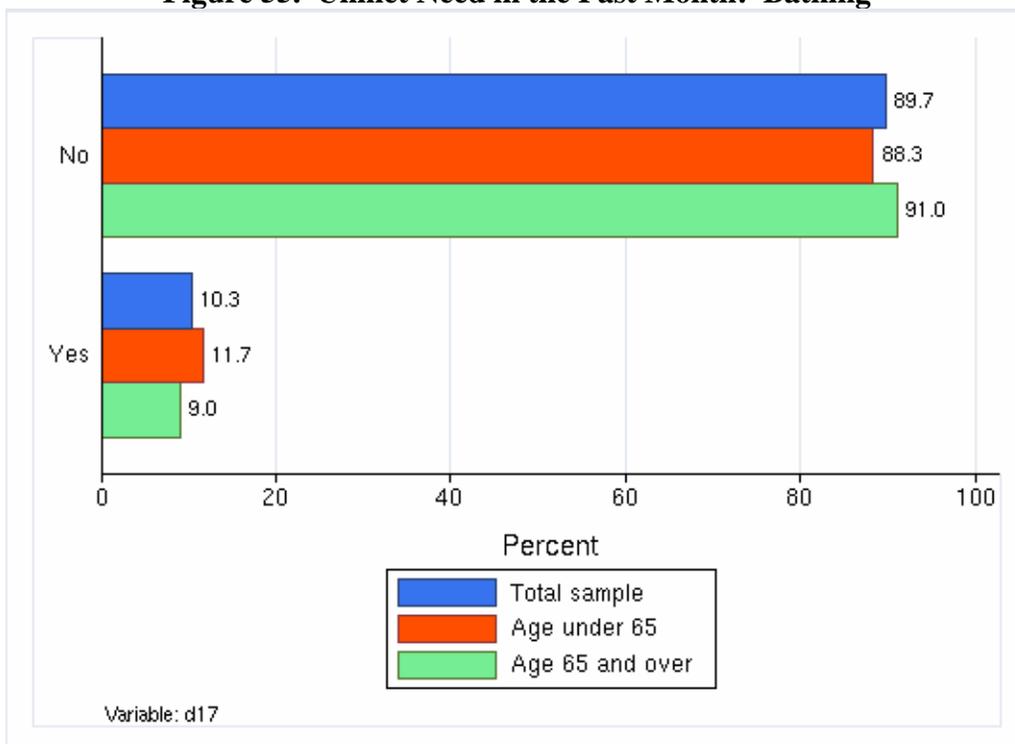


**6. UNMET NEED FOR ADL/IADL ASSISTANCE IN THE PAST MONTH**

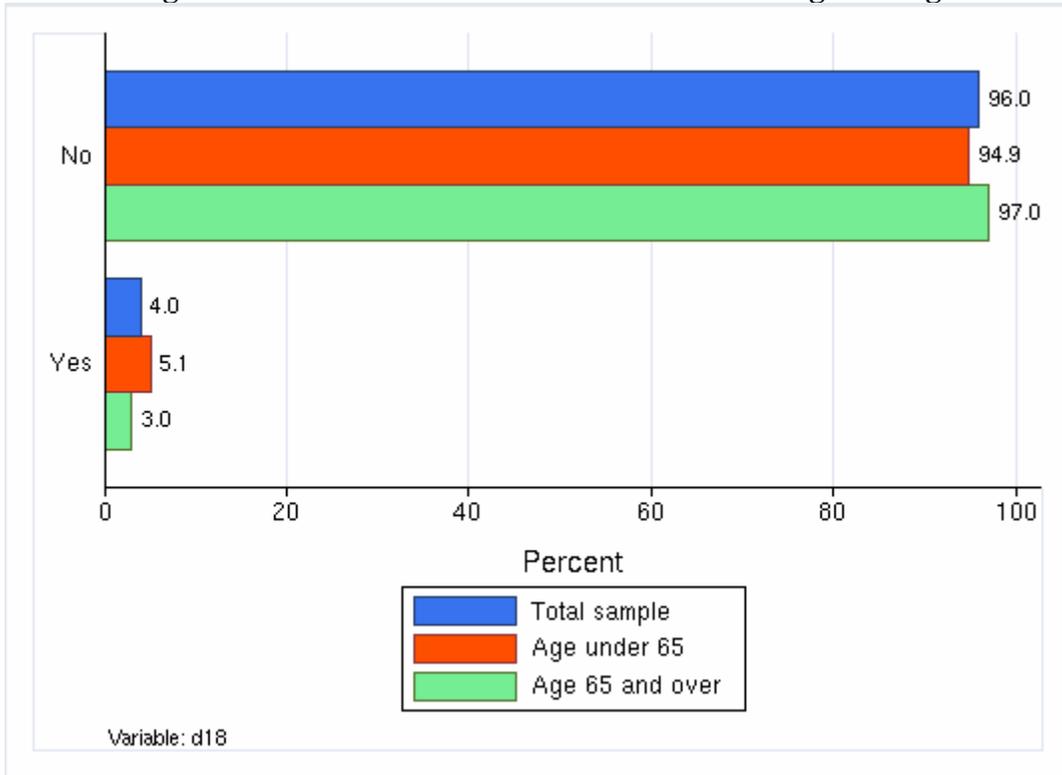
**Figure 54. Unmet Need in the Past Month: Dressing**



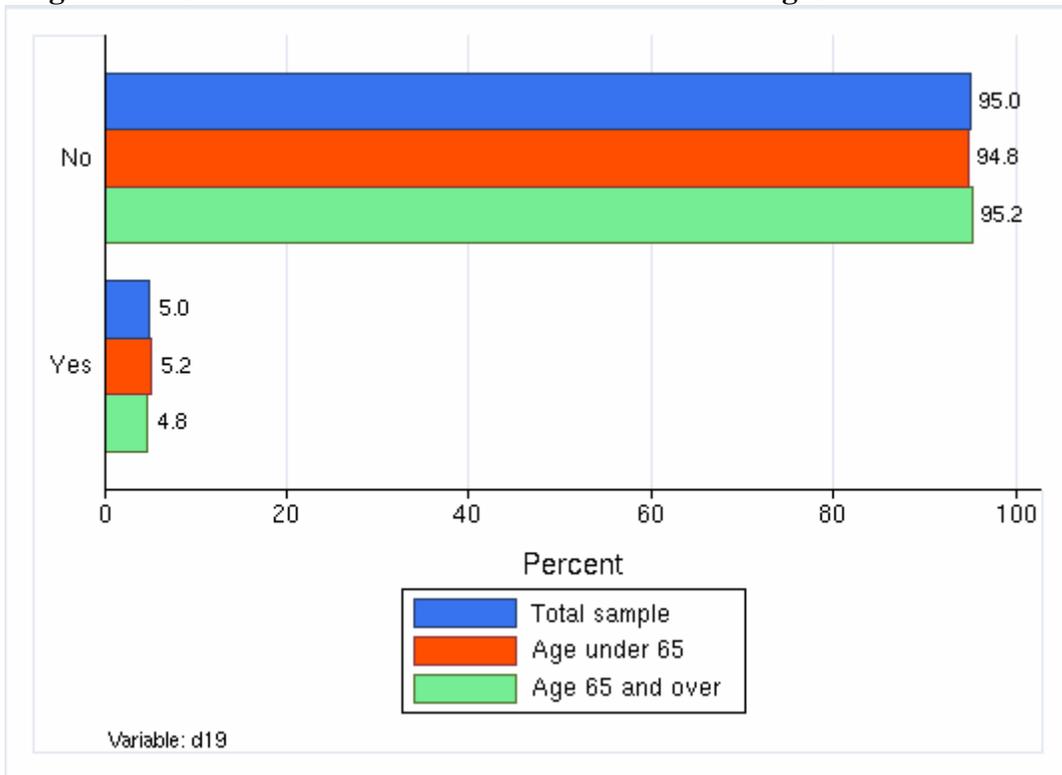
**Figure 55. Unmet Need in the Past Month: Bathing**



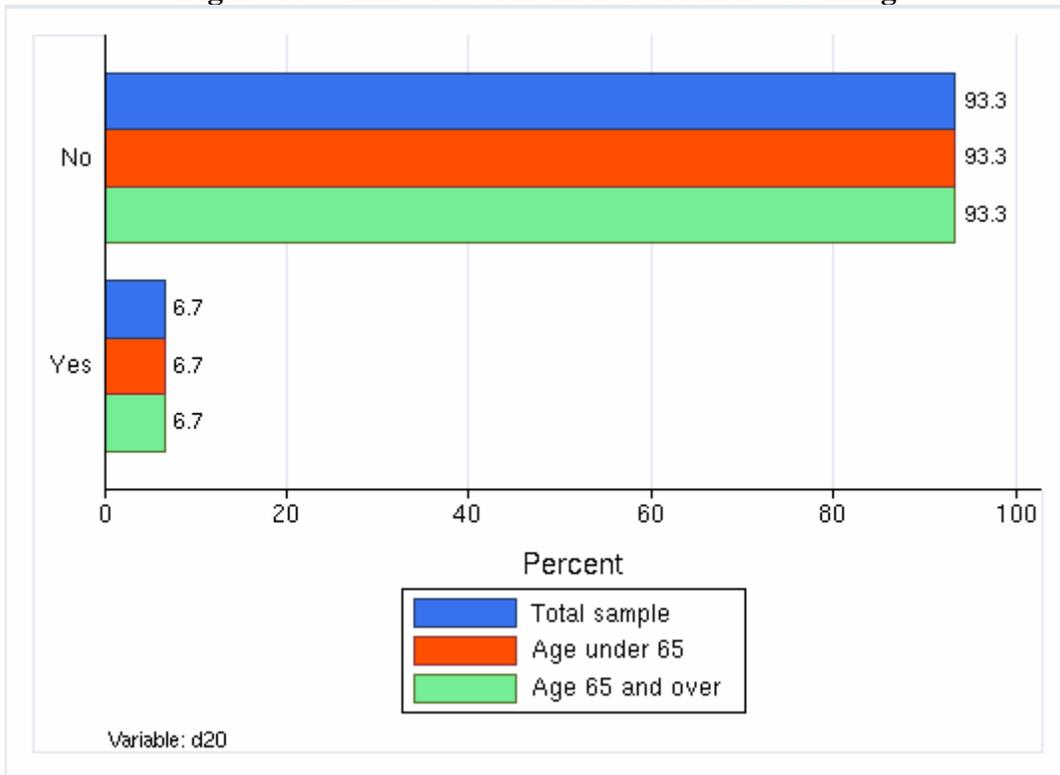
**Figure 56. Unmet Need in the Past Month: Eating/Feeding**



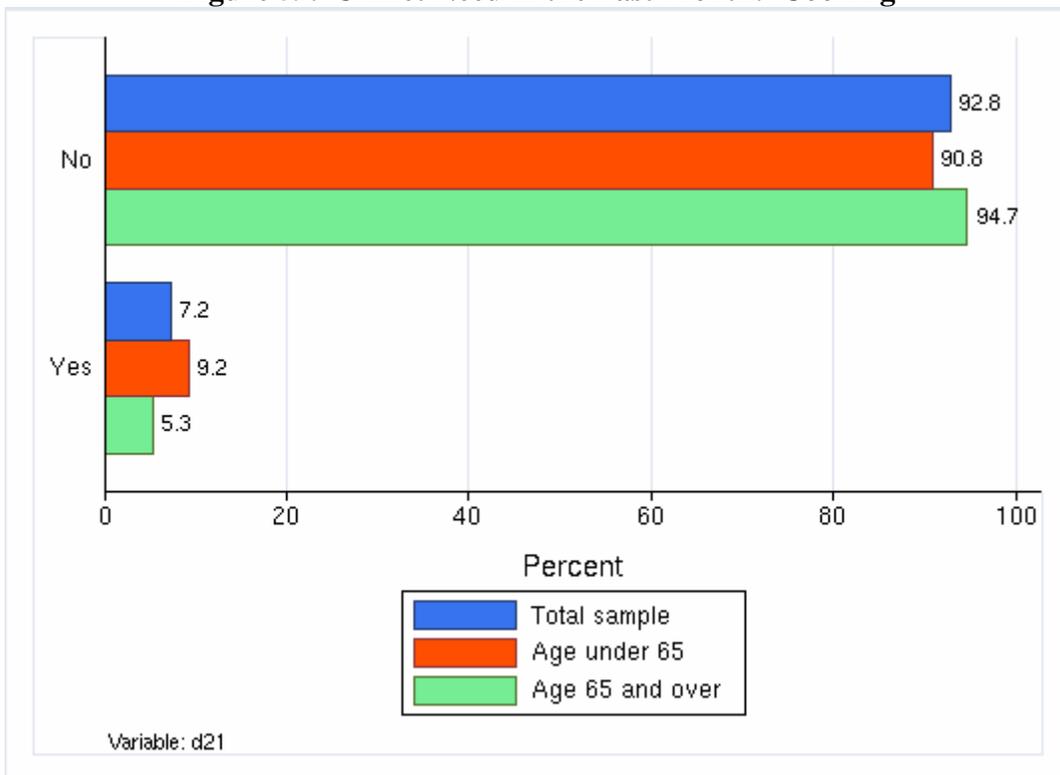
**Figure 57. Unmet Need in the Past Month: Transferring Out of Bed/Chairs**



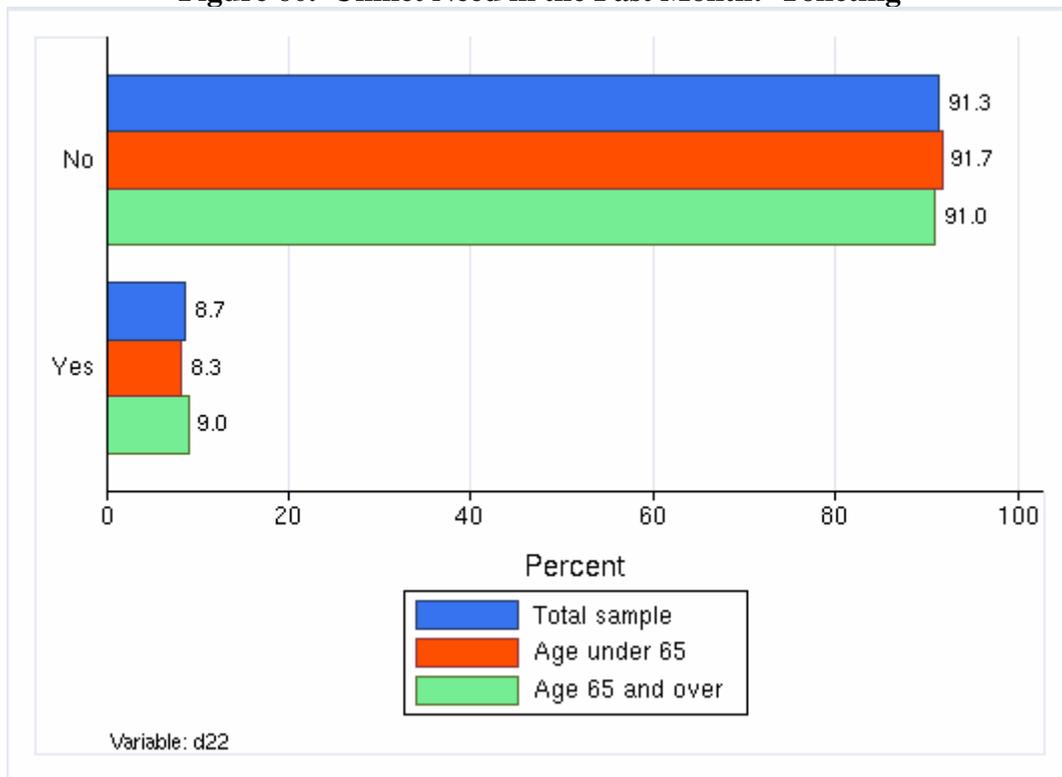
**Figure 58. Unmet Need in the Past Month: Walking**



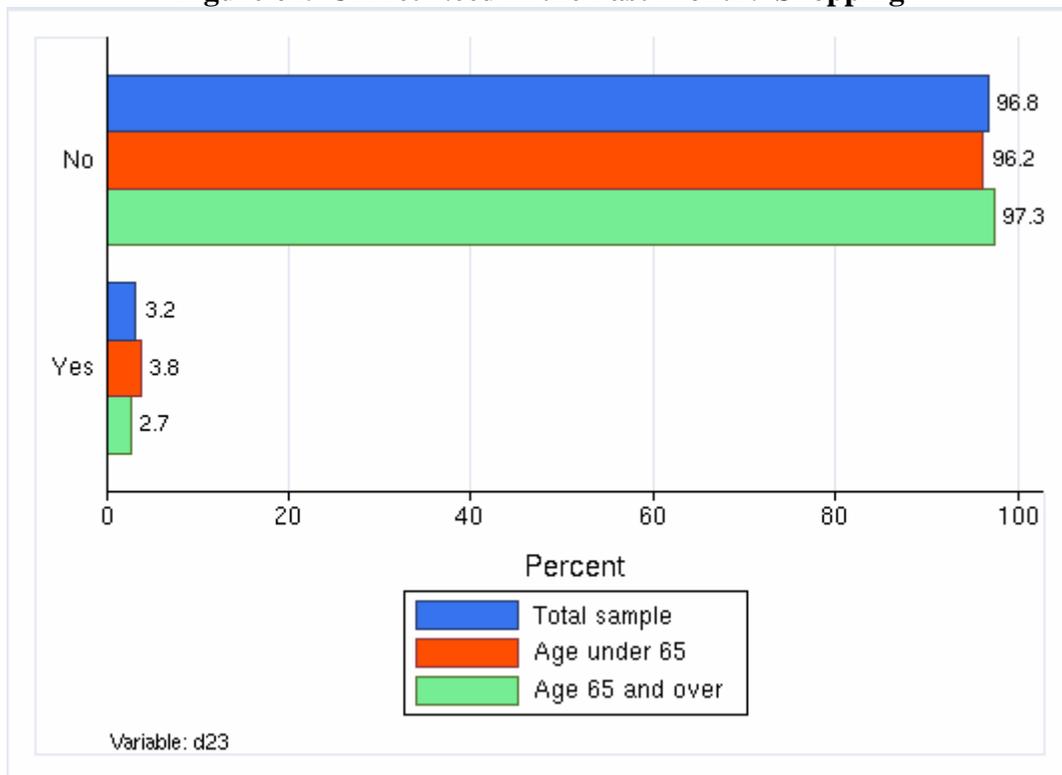
**Figure 59. Unmet Need in the Past Month: Cooking**



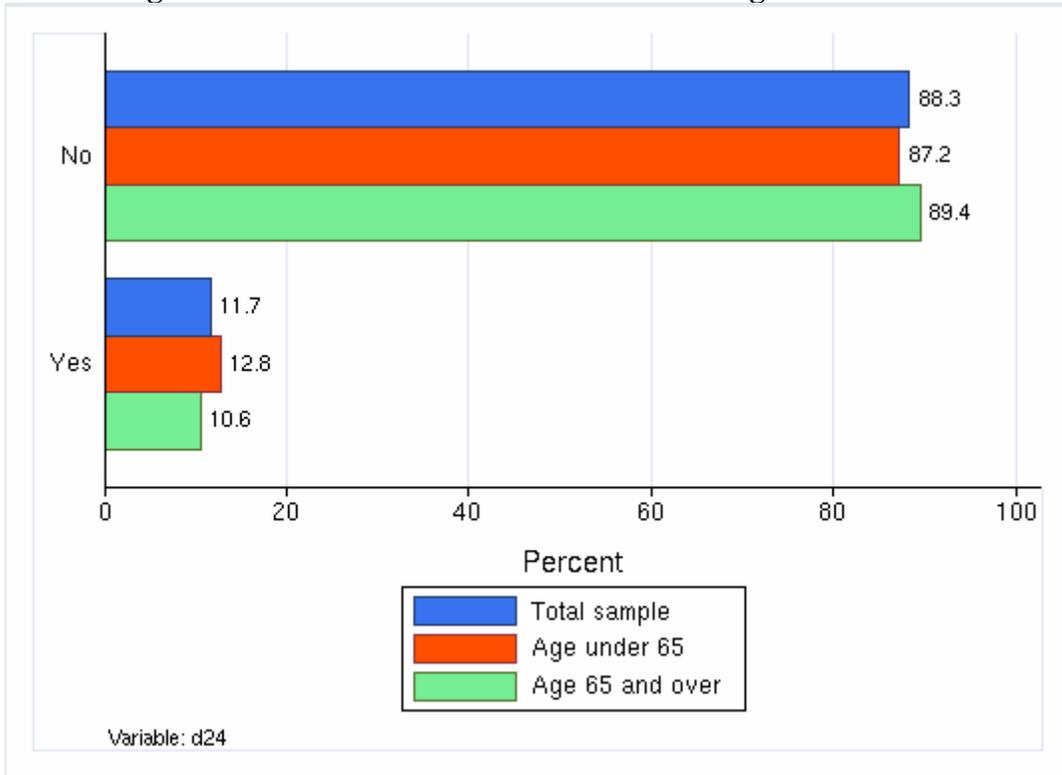
**Figure 60. Unmet Need in the Past Month: Toileting**



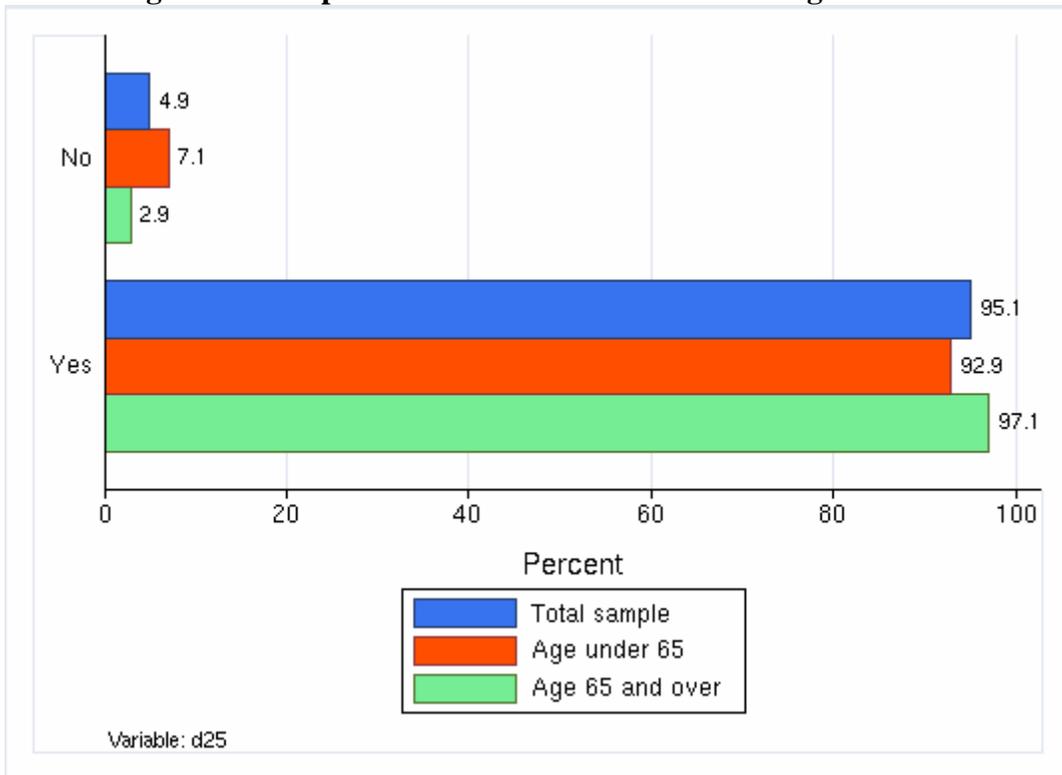
**Figure 61. Unmet Need in the Past Month: Shopping**



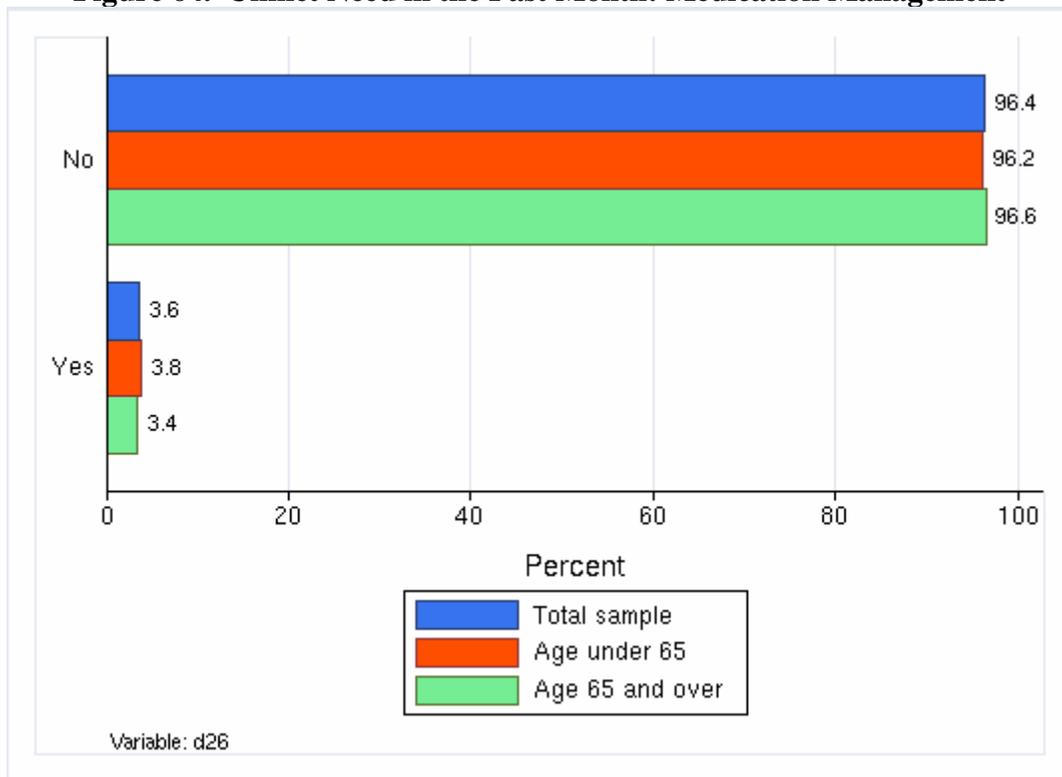
**Figure 62. Unmet Need in the Past Month: Light Housework**



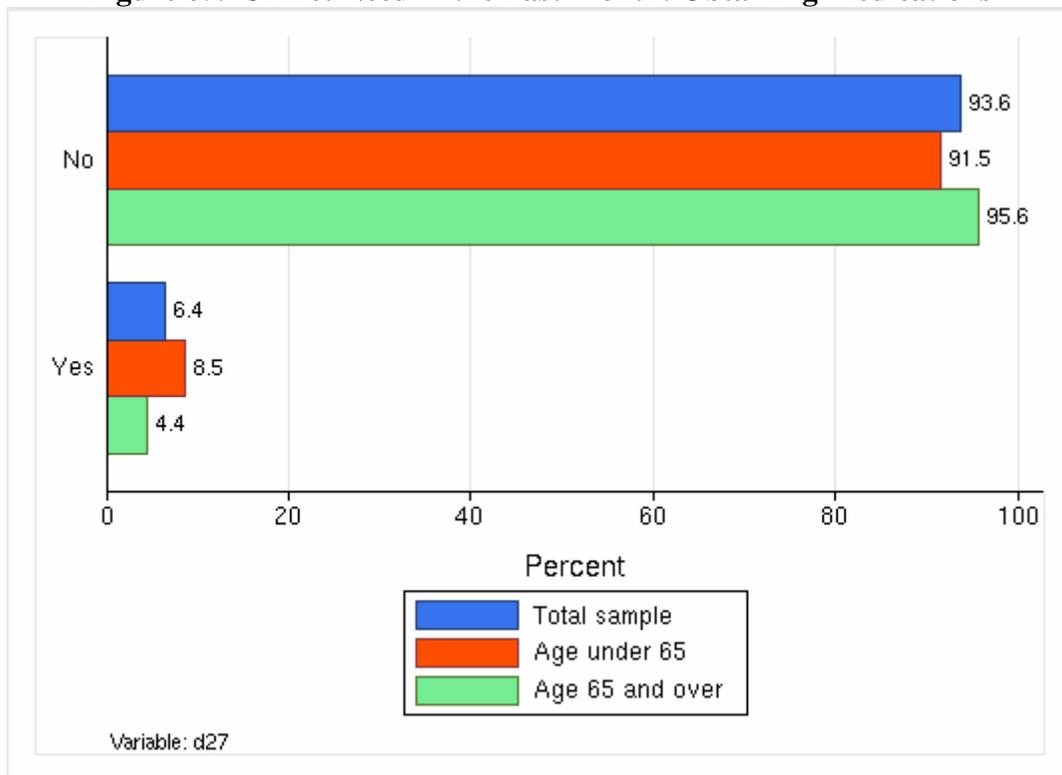
**Figure 63. Respondent Takes Medications on a Regular Basis**



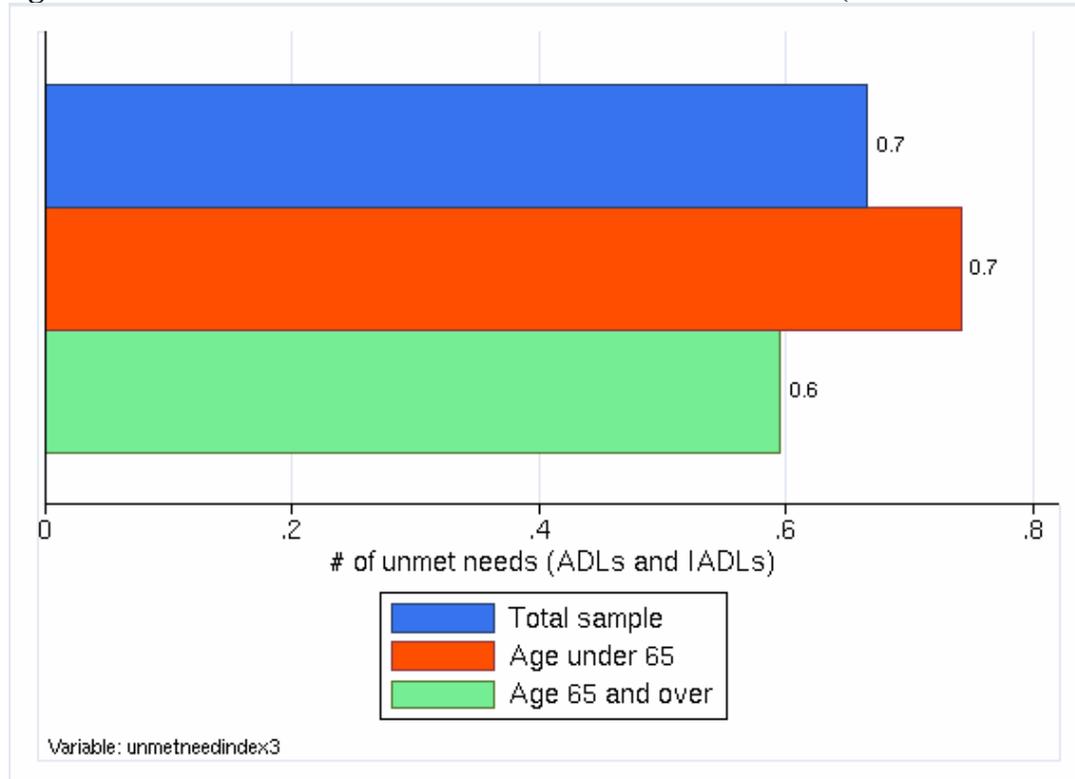
**Figure 64. Unmet Need in the Past Month: Medication Management**



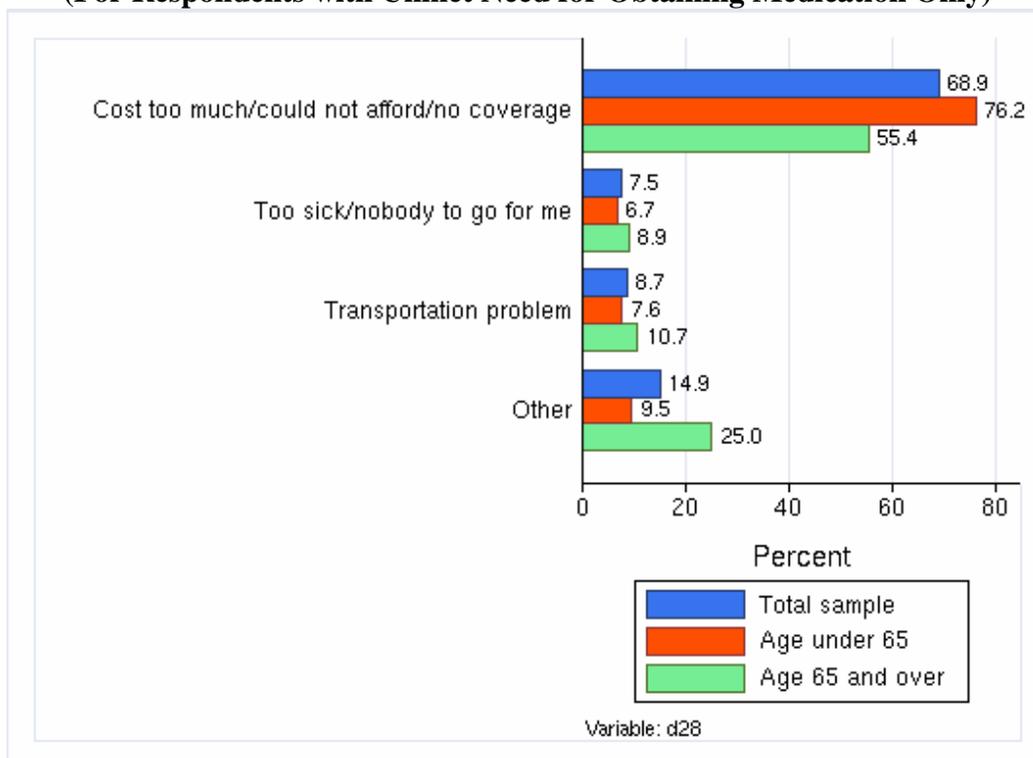
**Figure 65. Unmet Need in the Past Month: Obtaining Medications**



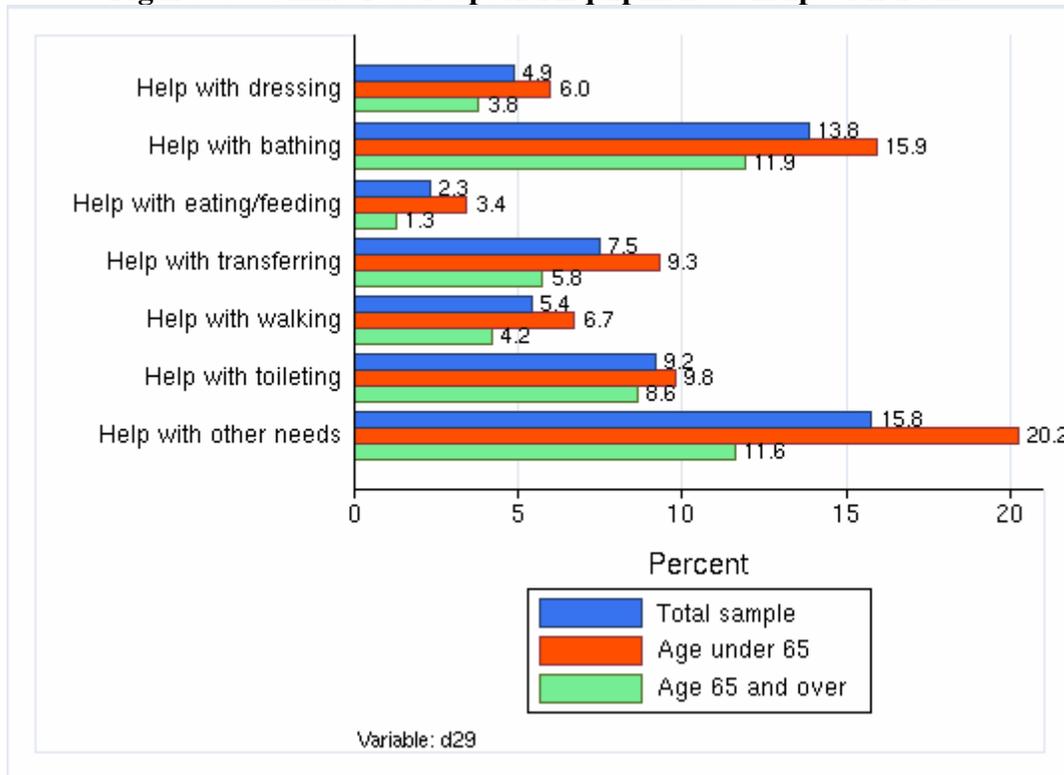
**Figure 66. Mean Number of Unmet Needs in the Last Month (ADLs and IADLs)**



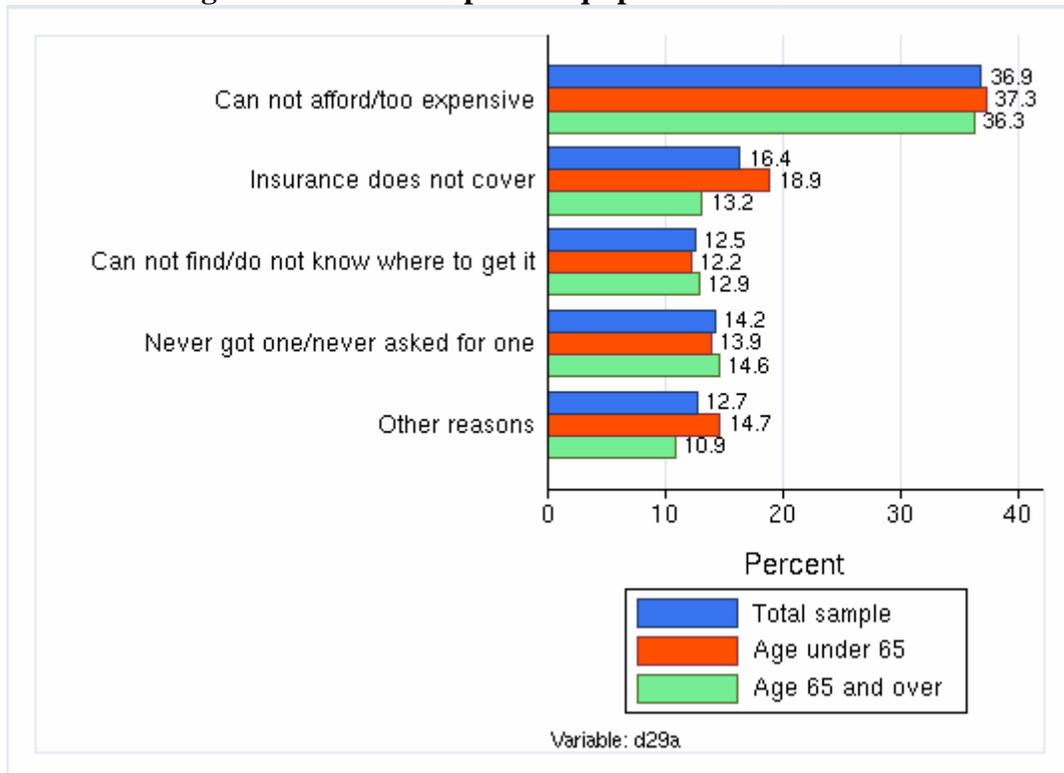
**Figure 67. Main Reason Respondent Didn't Obtain Medicine in the Last Month (For Respondents with Unmet Need for Obtaining Medication Only)**



**Figure 68. Unmet Need: Special Equipment to Help with Task\***

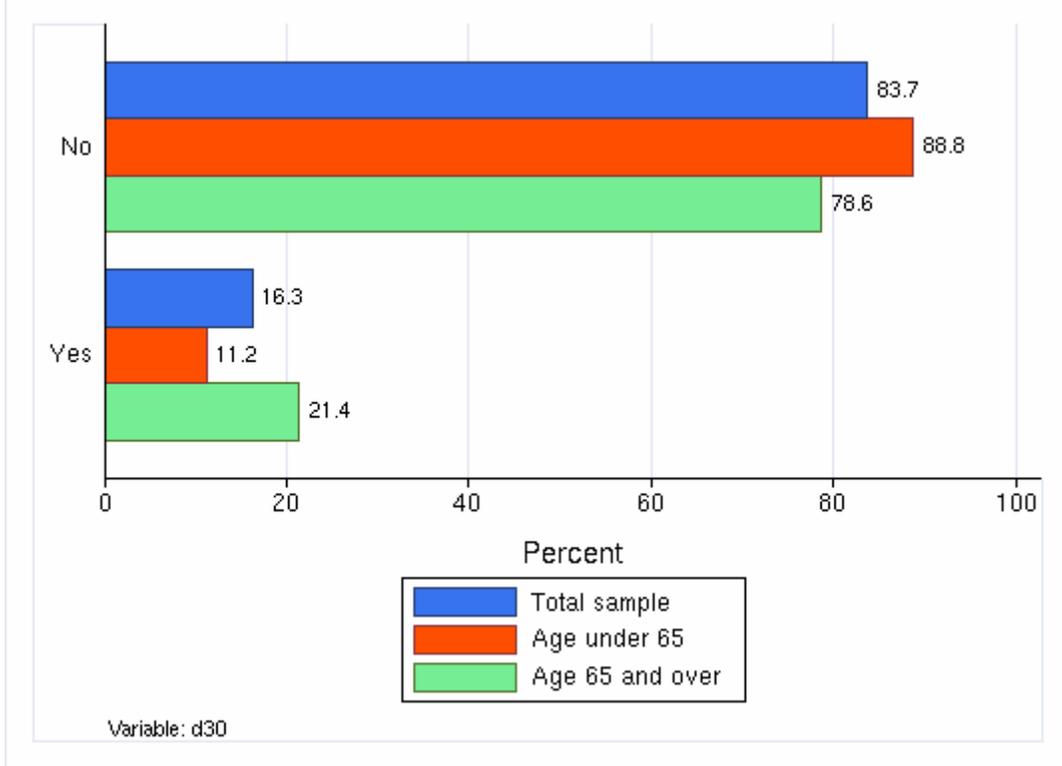


**Figure 69. Reasons Special Equipment Not Obtained\***

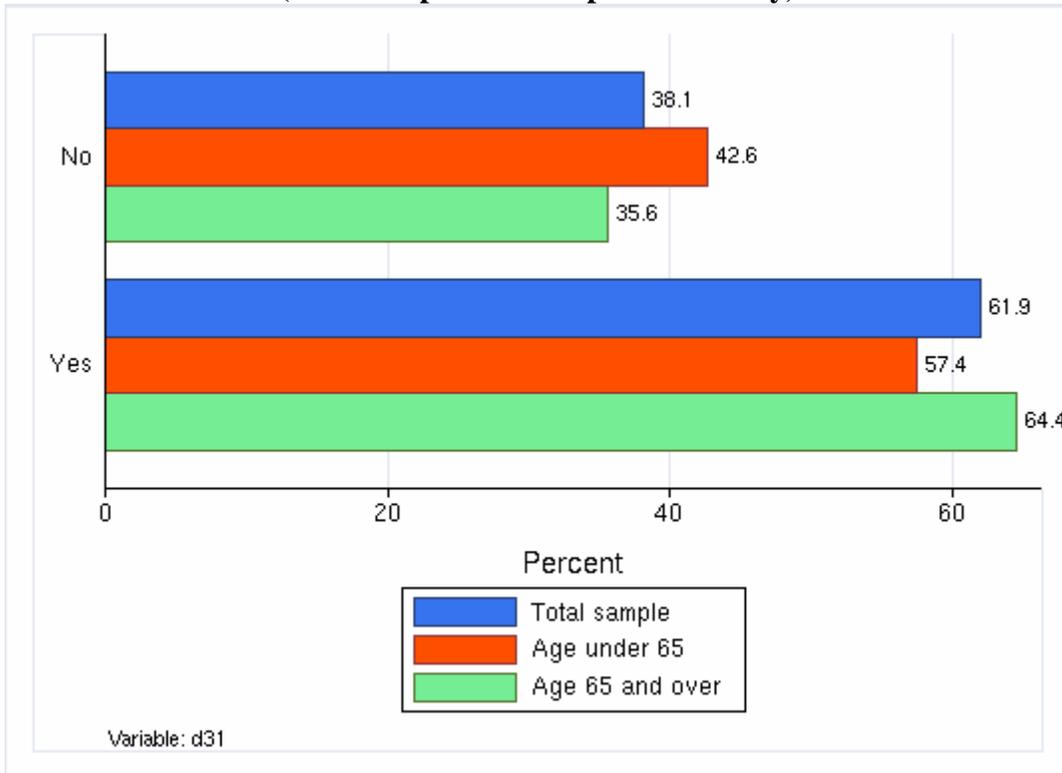


\* Respondents answered "all that apply" so categories do not add up to 100%

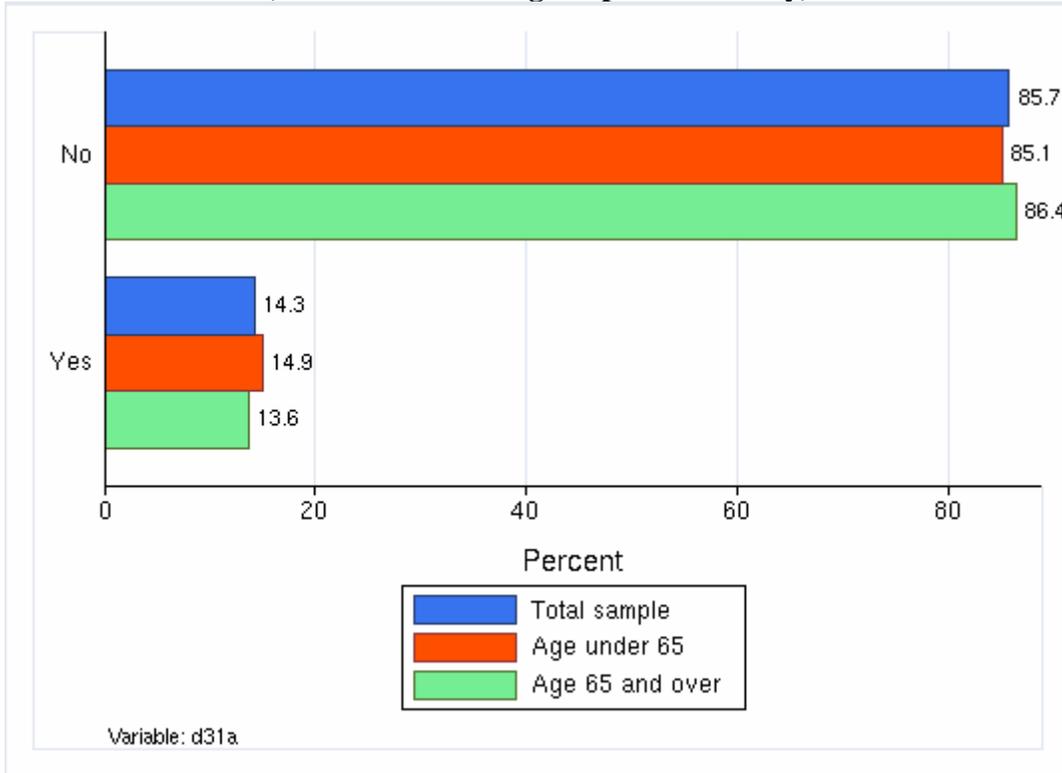
**Figure 70. Receiving Home Delivered Meals (For Home-Dwelling Respondents Only)**



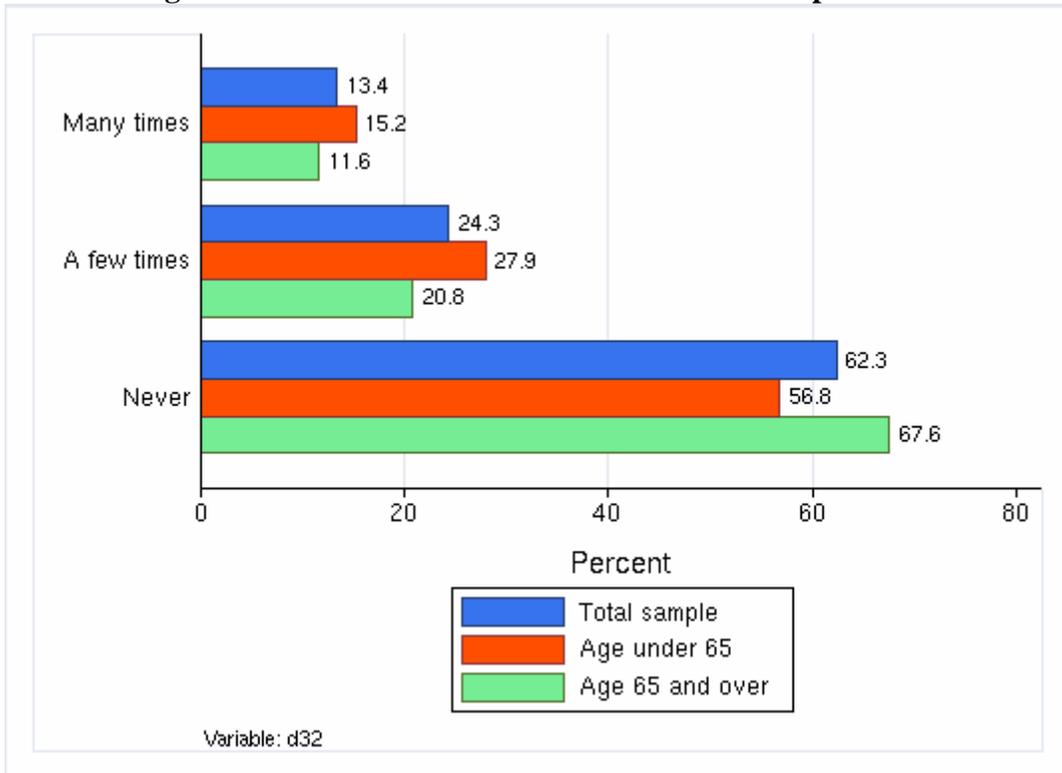
**Figure 71. Receiving Meals in Residence's Dining/Lunch Room (For Group-Home Respondents Only)**



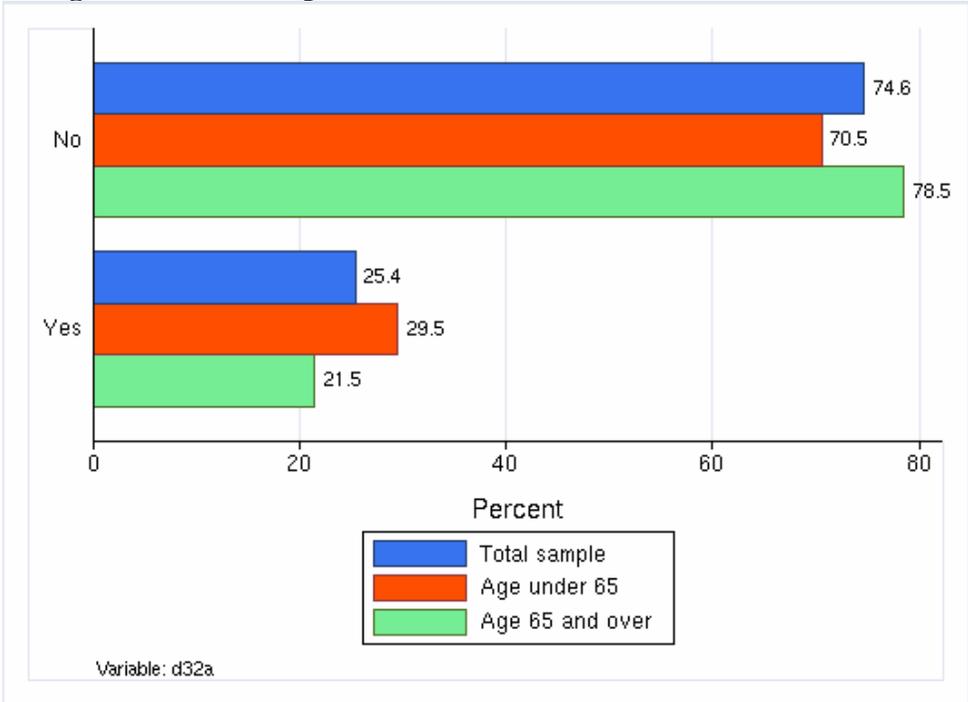
**Figure 72. Receiving Meals at an Adult Day Care Facility/Other Program  
(For Home-Dwelling Respondents Only)**



**Figure 73. Unmet Need in the Last Month: Transportation**

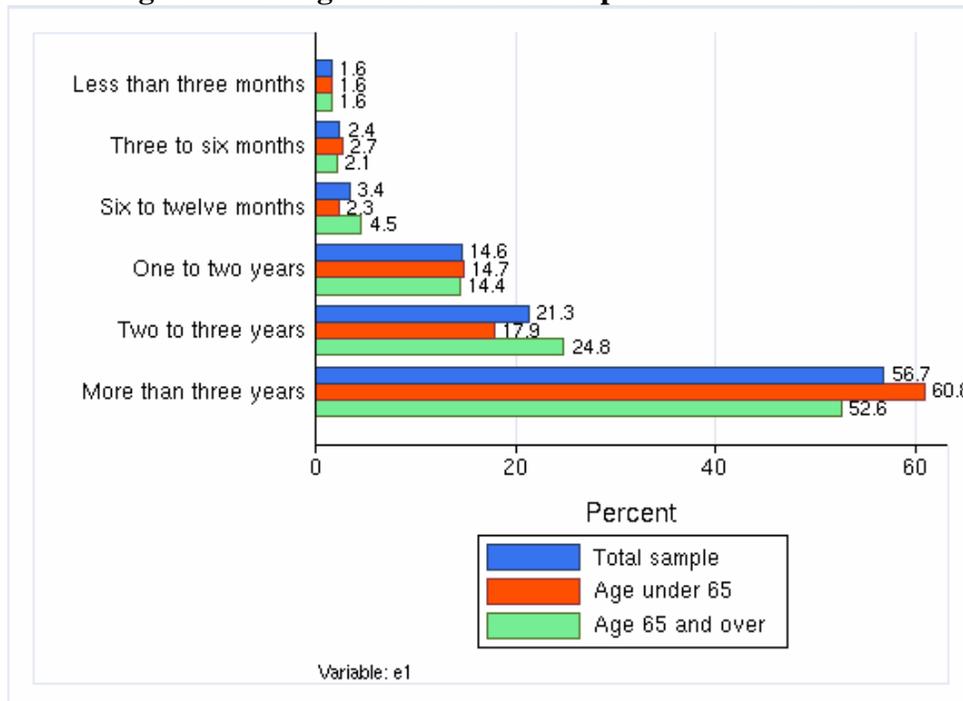


**Figure 74. Use of Special Bus/Cab/Van Service in the Past Month**

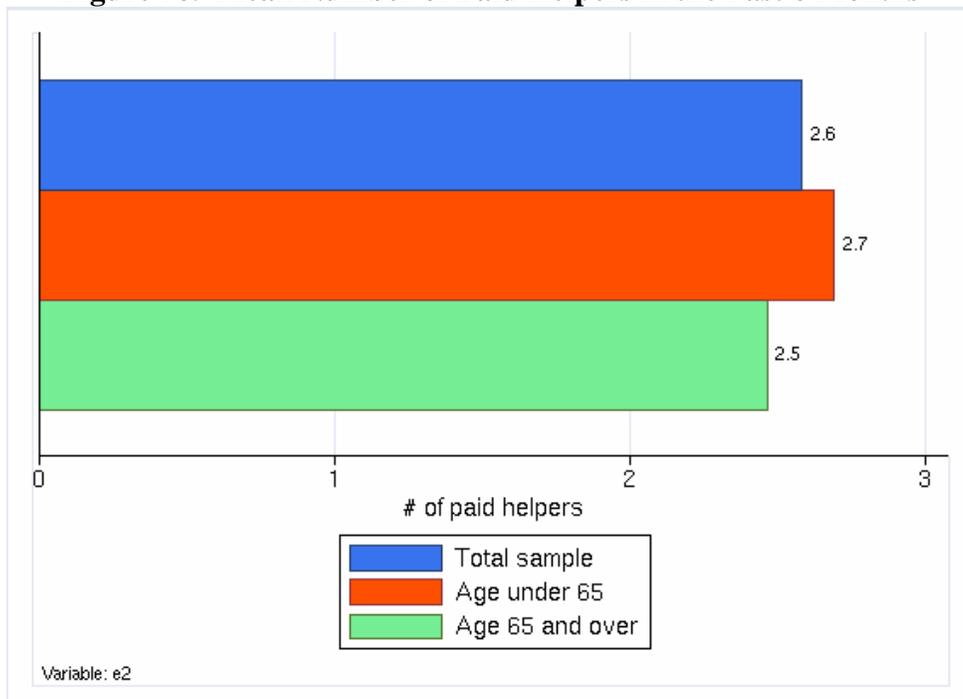


## 7. PERSONAL ASSISTANCE<sup>5</sup>

**Figure 75. Length of Time Paid Help Received at Home**

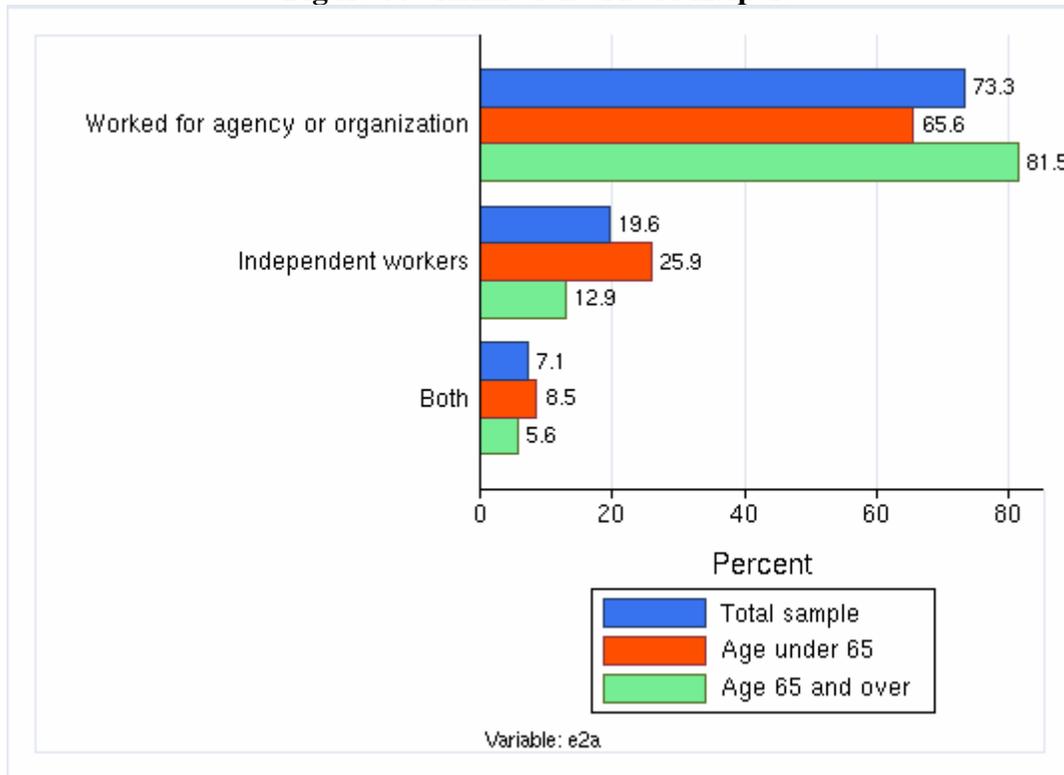


**Figure 76. Mean Number of Paid Helpers in the Past 6 Months**

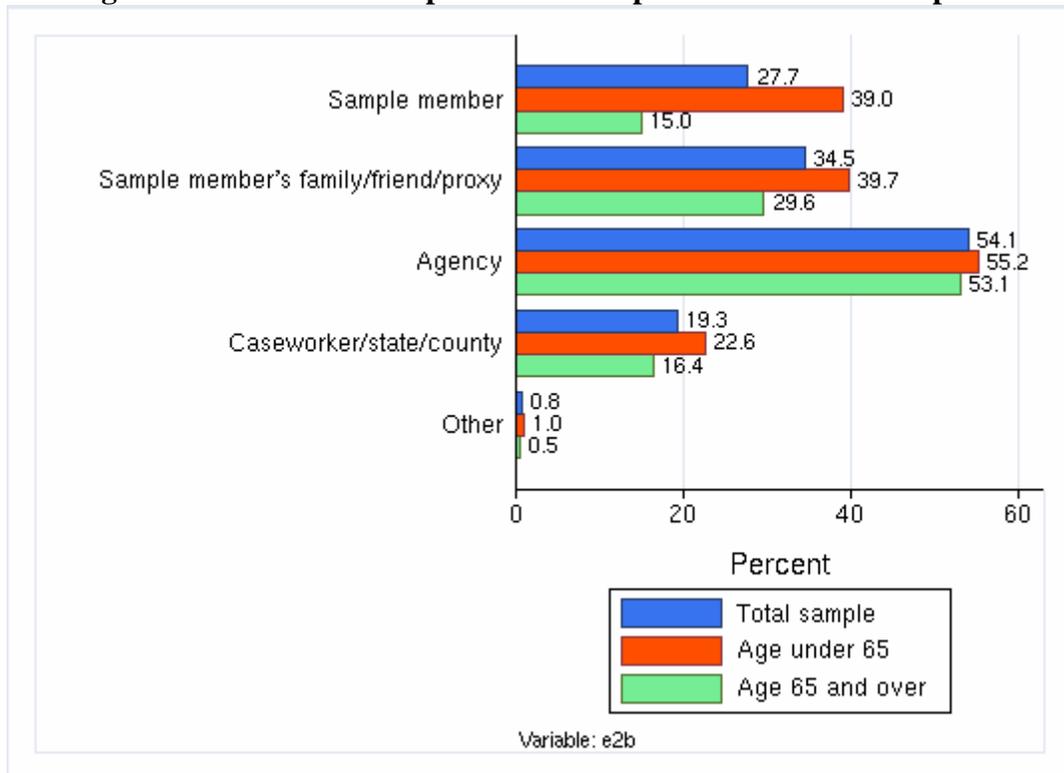


<sup>5</sup> This section was not asked of sample members in assisted living environment or other group residential setting.

**Figure 77. Affiliation of Paid Helpers**

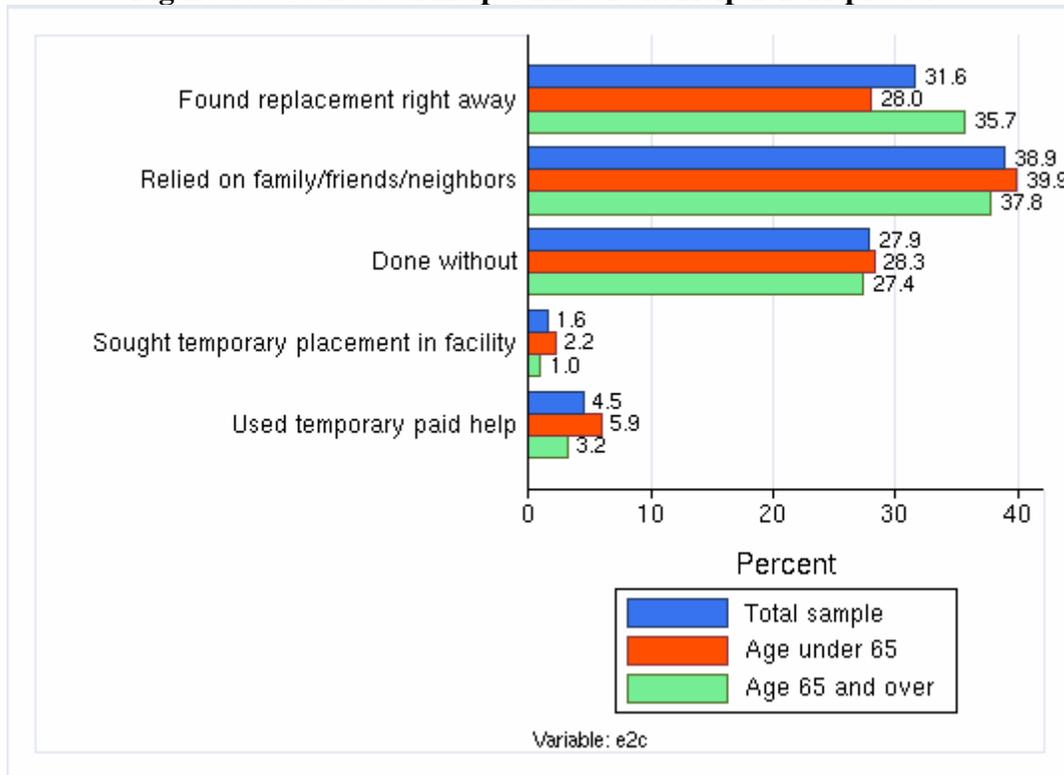


**Figure 78. Individual Responsible for Replacement of Paid Helpers\***

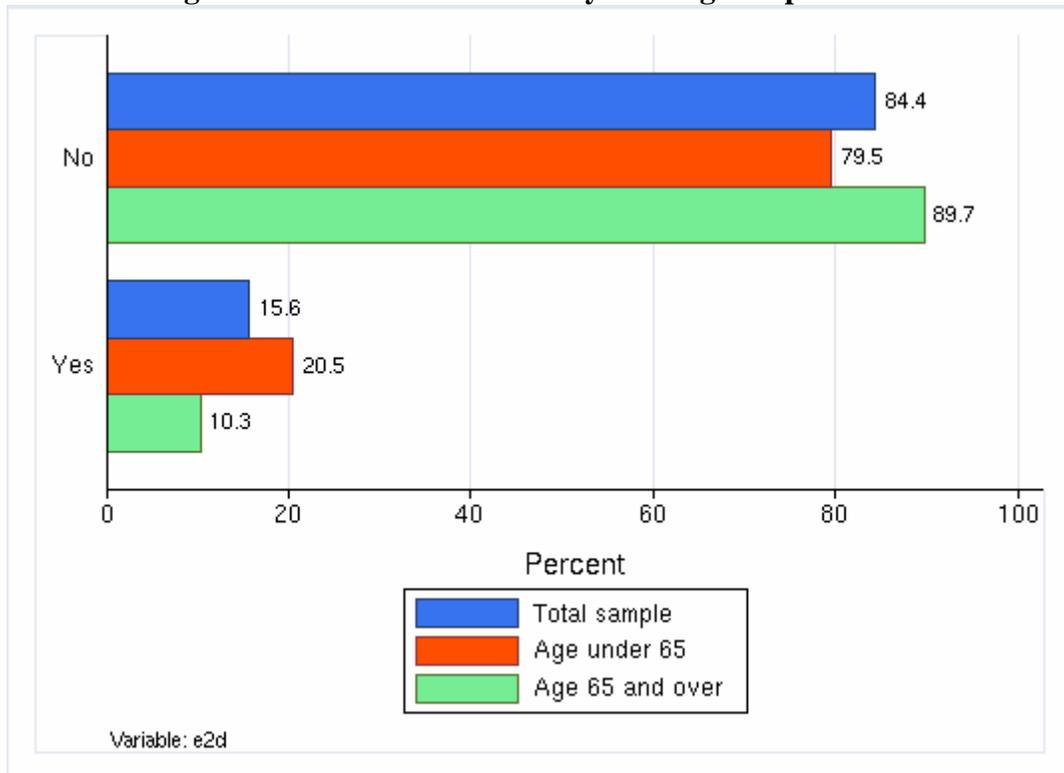


\* Respondents answered "all that apply" so categories do not add up to 100%

**Figure 79. Sources of Help Until a Paid Helper is Replaced\***

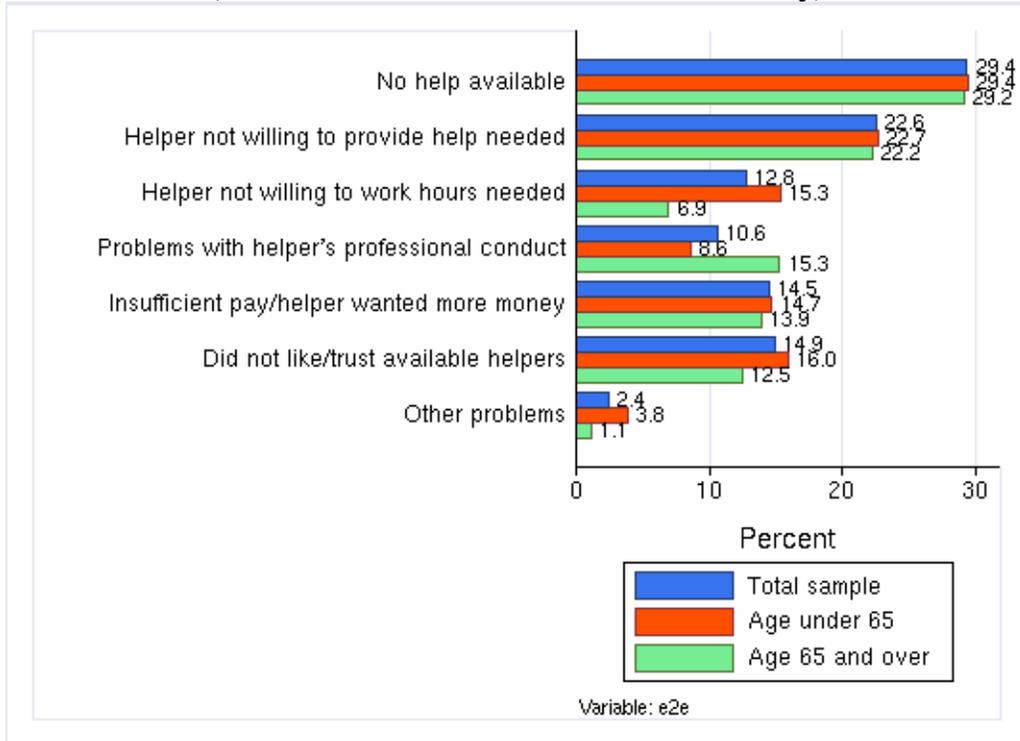


**Figure 80. Problem or Difficulty Finding a Replacement**

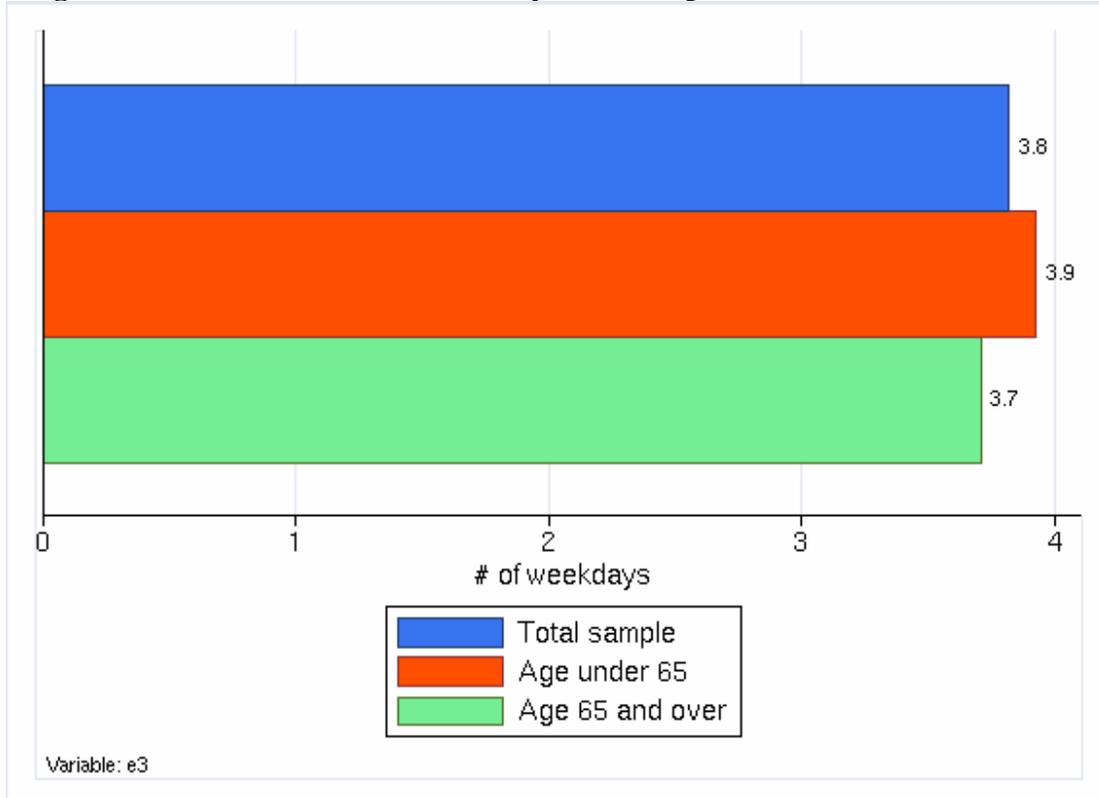


\* Respondents answered "all that apply" so categories do not add up to 100%

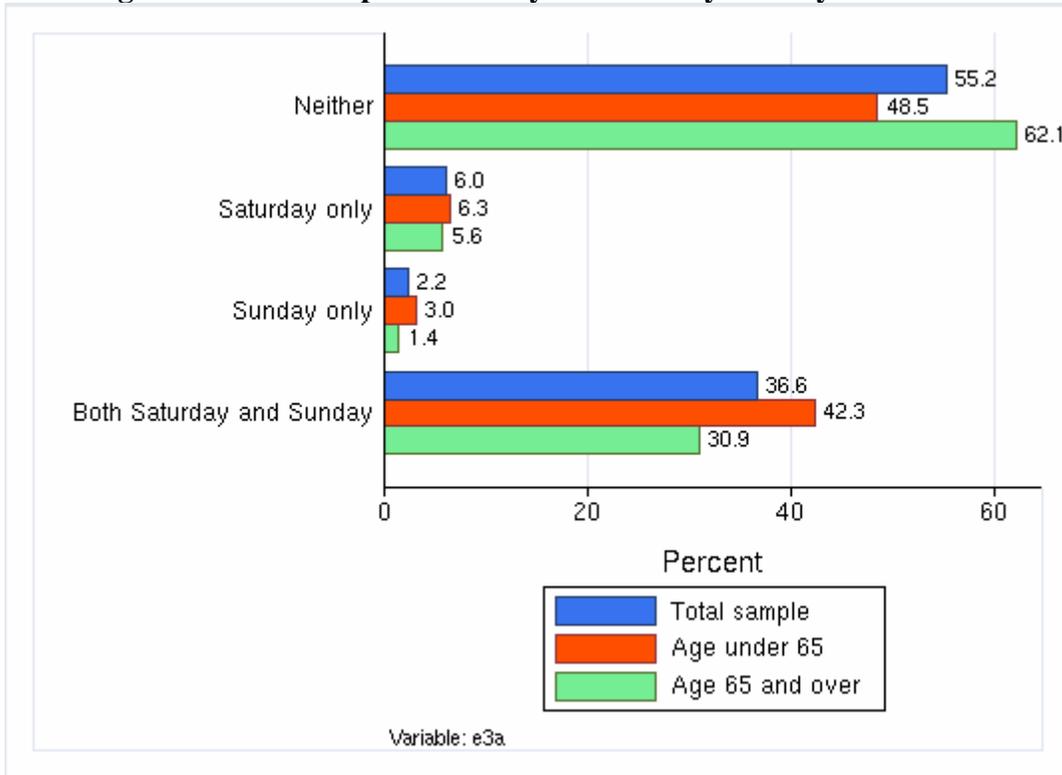
**Figure 81. Types of Problems/Difficulties Finding Replacement Paid Workers  
(For Those Who had a Problem or Difficulty)**



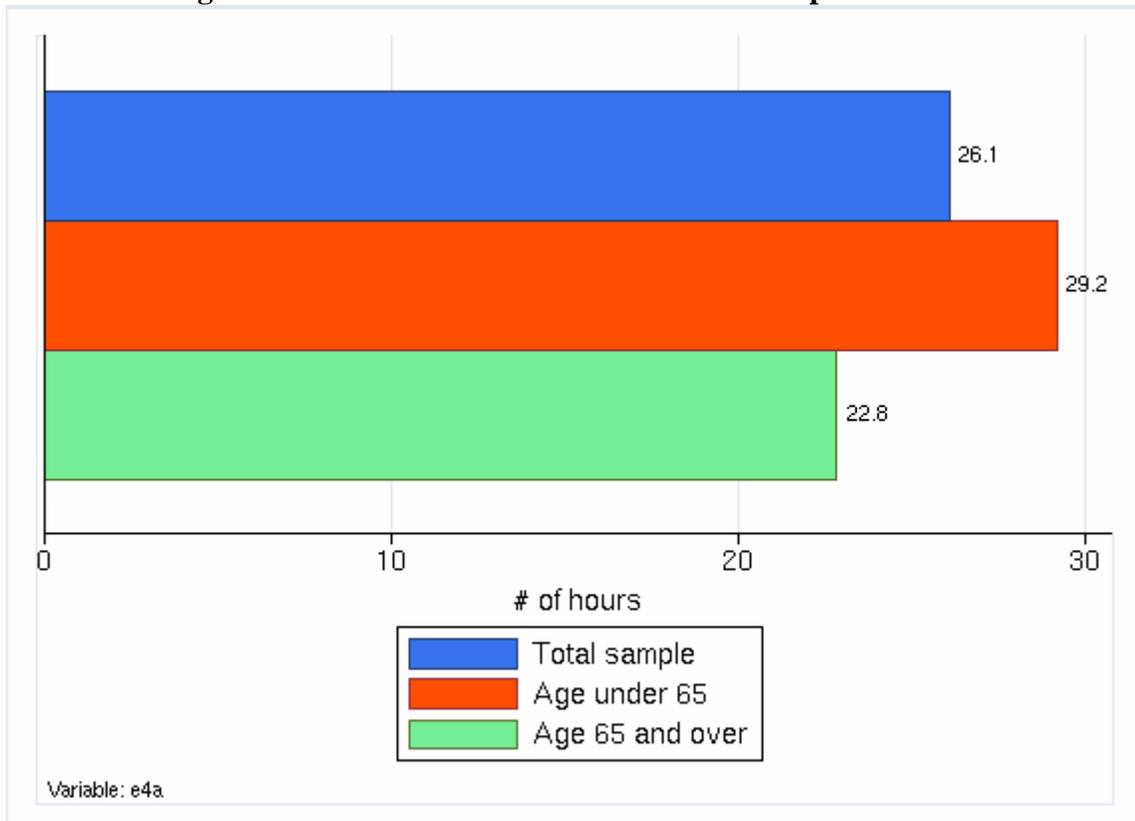
**Figure 82. Mean Number of Weekdays Paid Helper Provided Care Last Week**



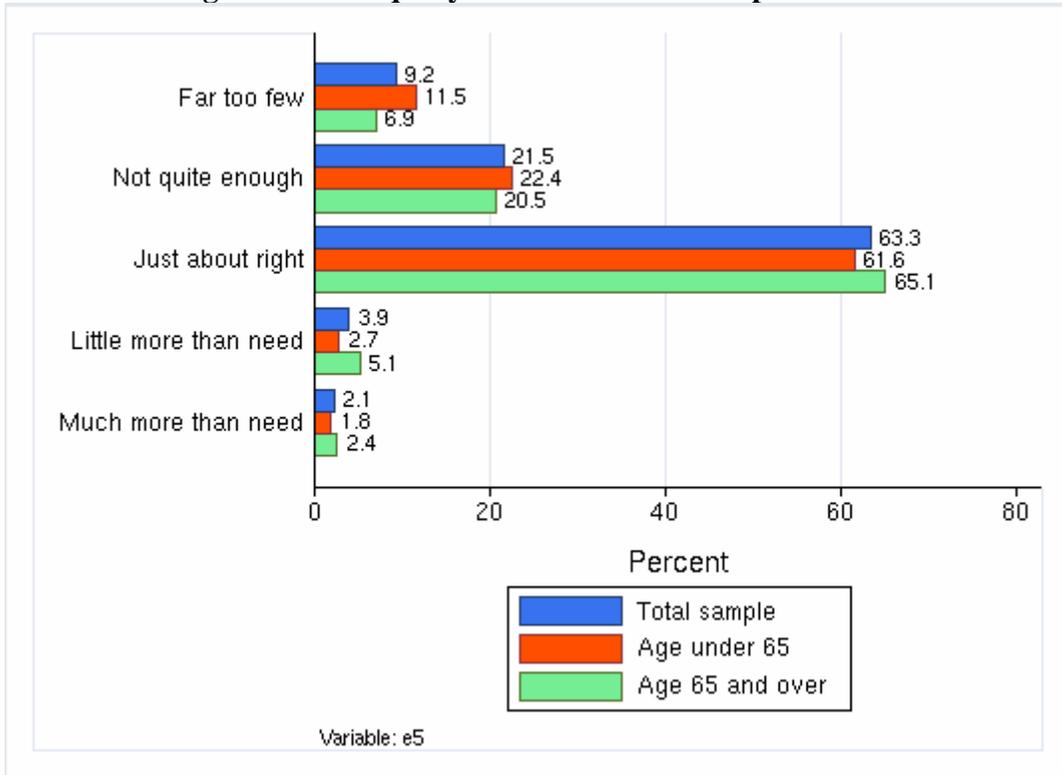
**Figure 83. Paid Help Availability on Saturday/Sunday Last Week**



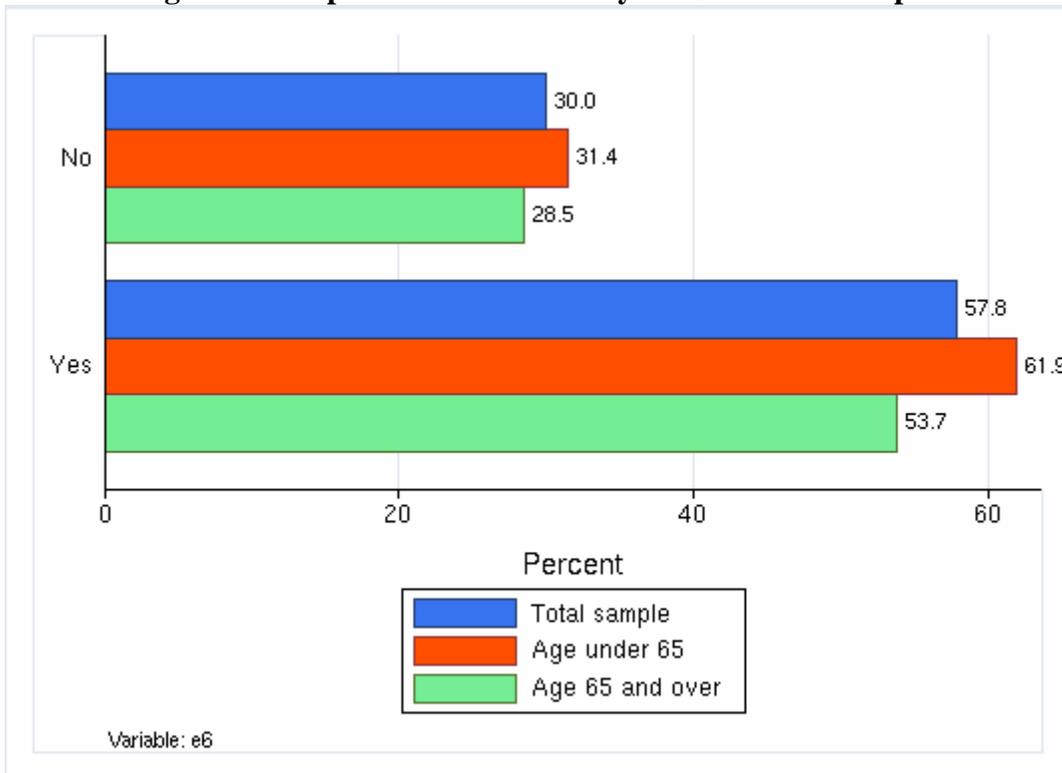
**Figure 84. Mean Number of Hours of Paid Help Last Week**



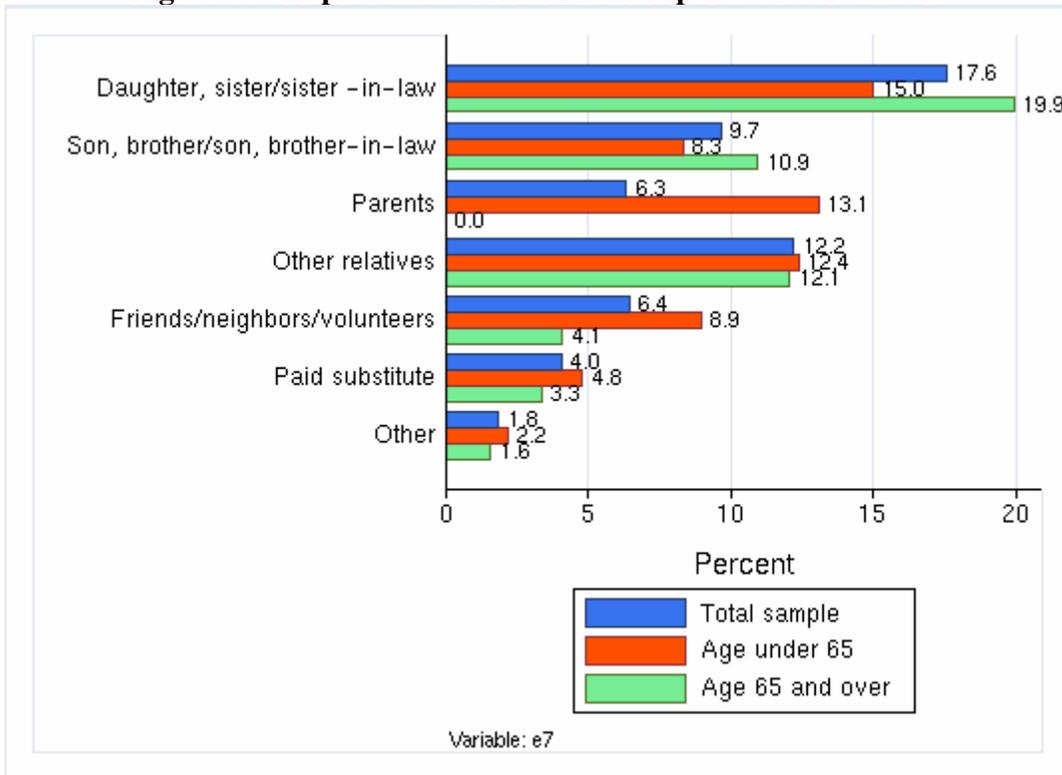
**Figure 85. Adequacy of Hours of Paid Help Provided**



**Figure 86. Replacement Availability for Usual Paid Helper**

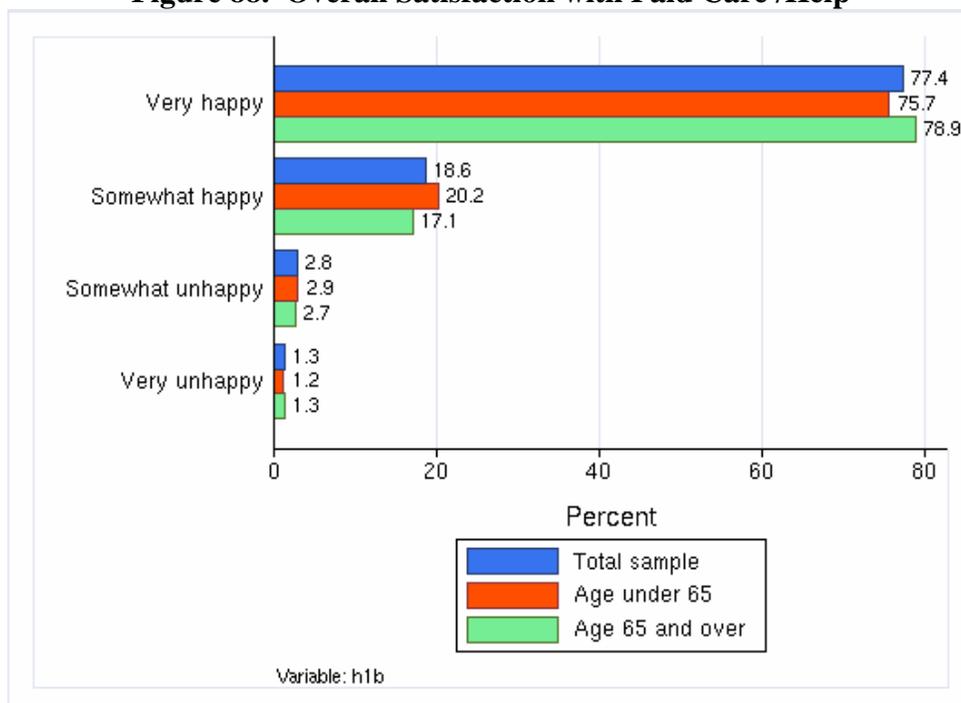


**Figure 87. Replacement When Paid Helper is Not Available**

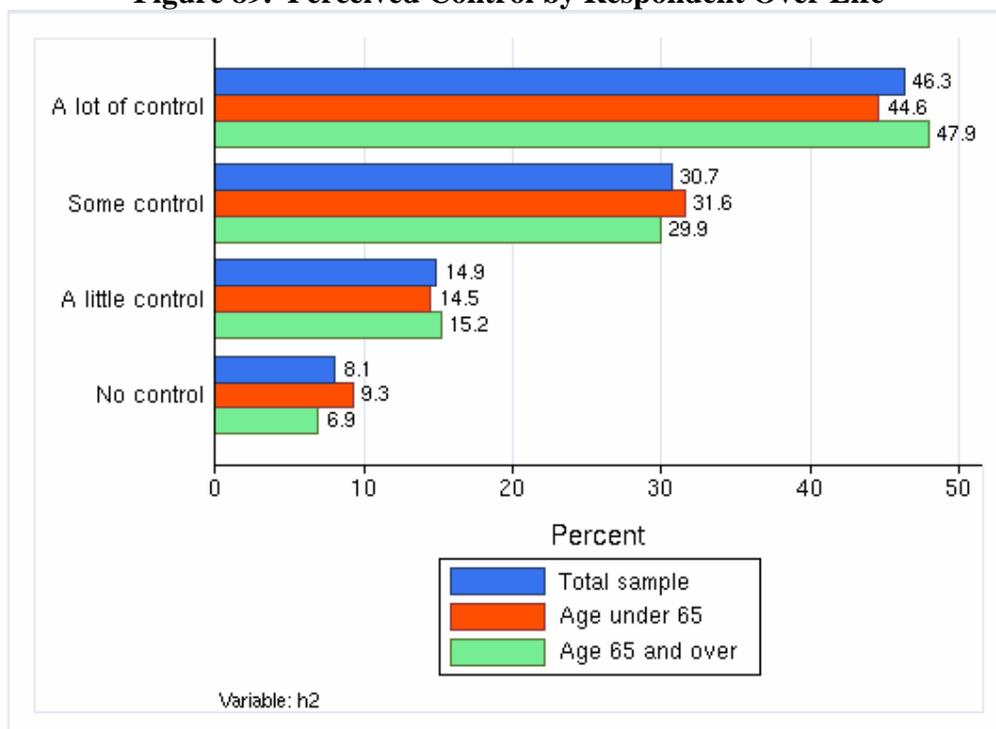


## 8. SATISFACTION WITH CARE<sup>6</sup>

**Figure 88. Overall Satisfaction with Paid Care /Help**

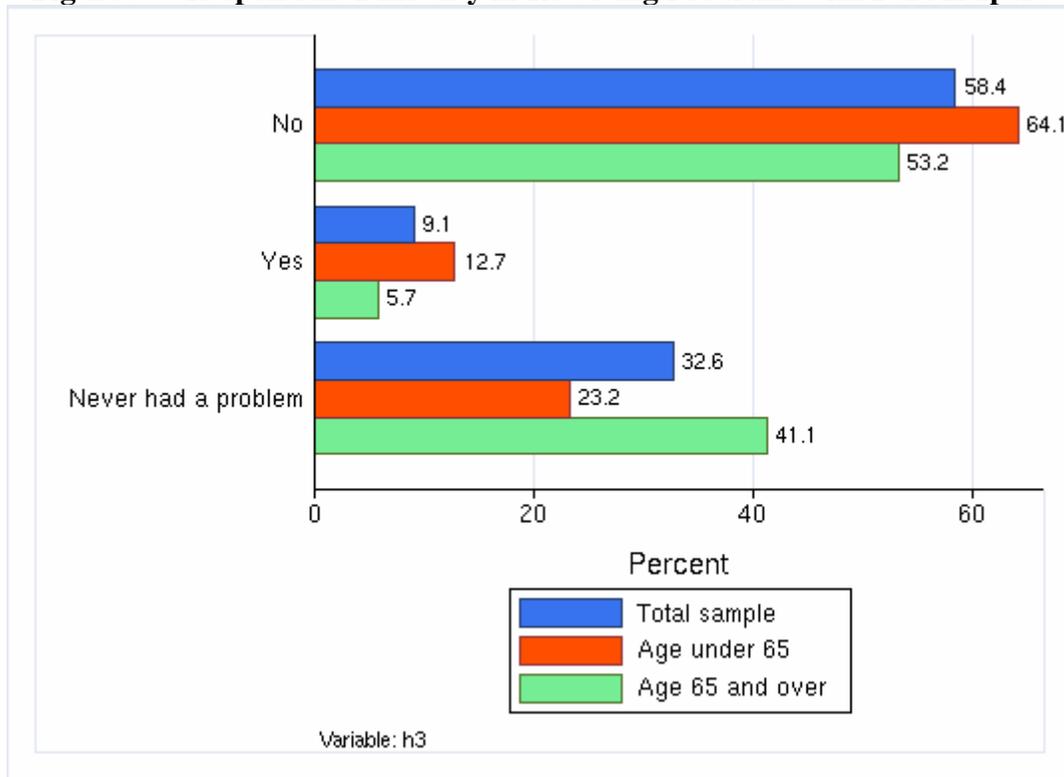


**Figure 89. Perceived Control by Respondent Over Life**

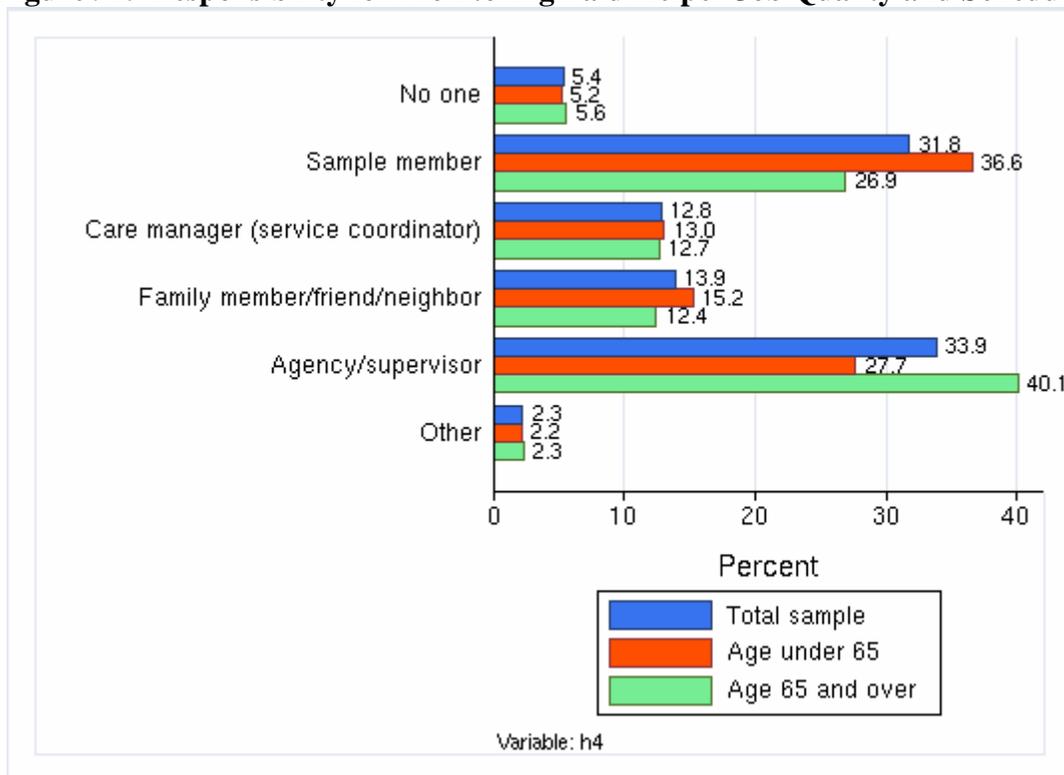


<sup>6</sup> This section was only asked of sample members and unpaid caregivers who serve as proxies

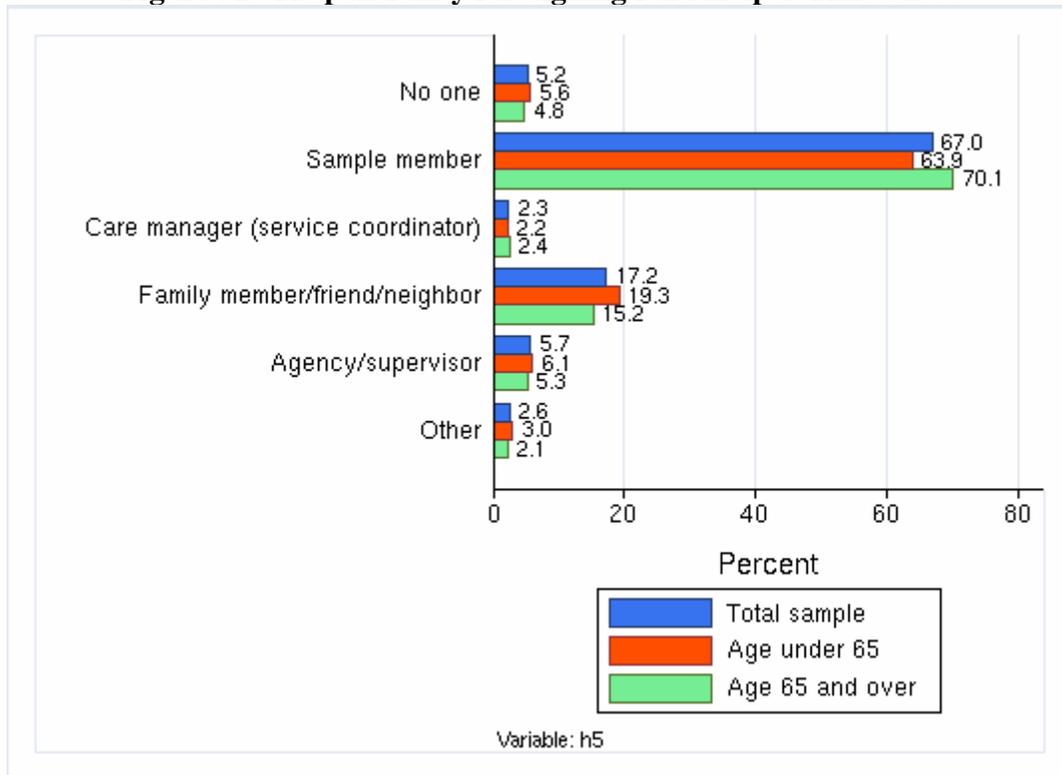
**Figure 90. Respondent Difficulty in Resolving Problems with Paid Helpers**



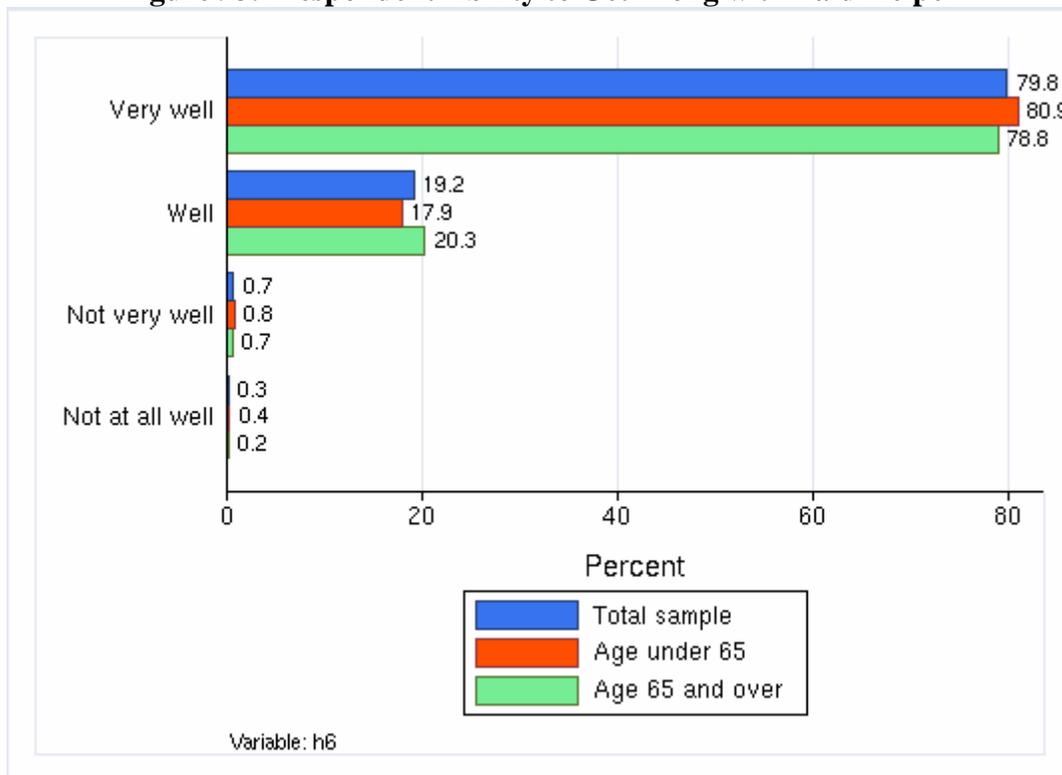
**Figure 91. Responsibility for Monitoring Paid Helper Job Quality and Schedule**



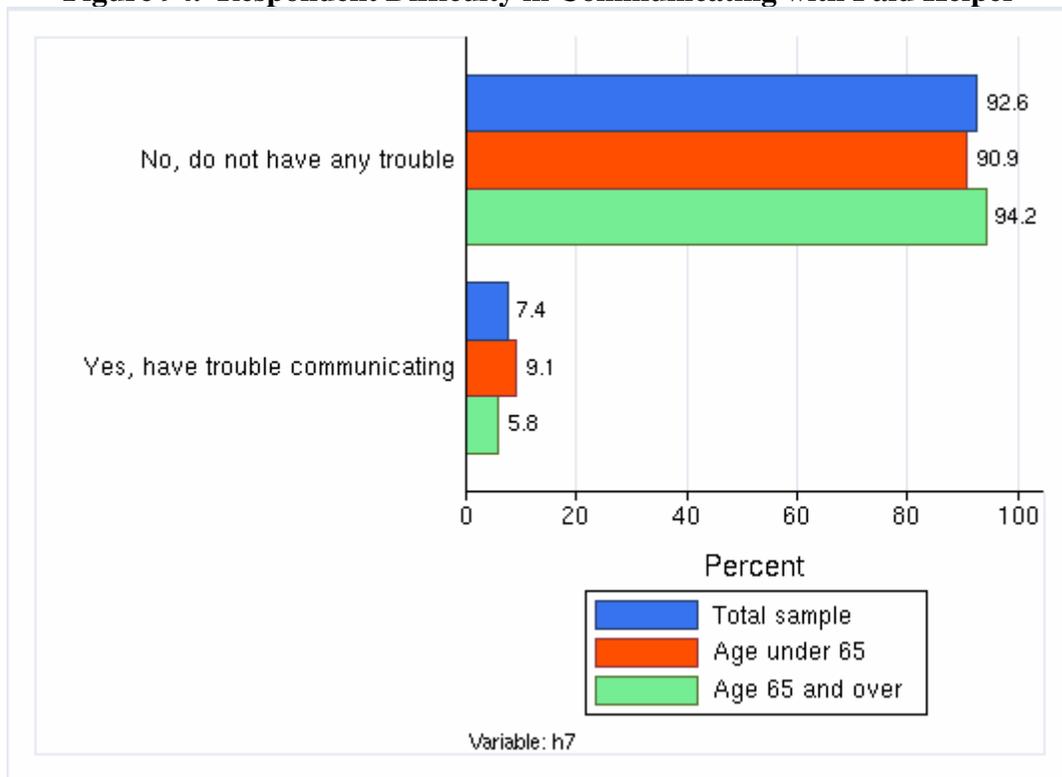
**Figure 92. Responsibility for Signing Paid Helper Time Sheet**



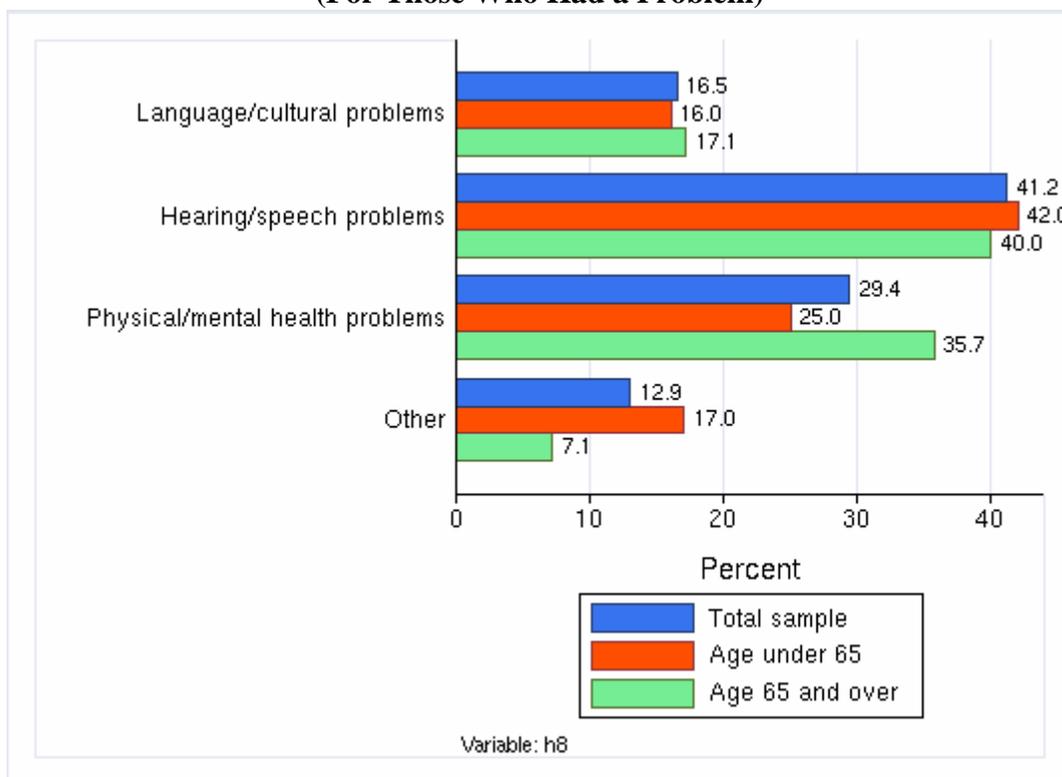
**Figure 93. Respondent Ability to Get Along with Paid Helper**



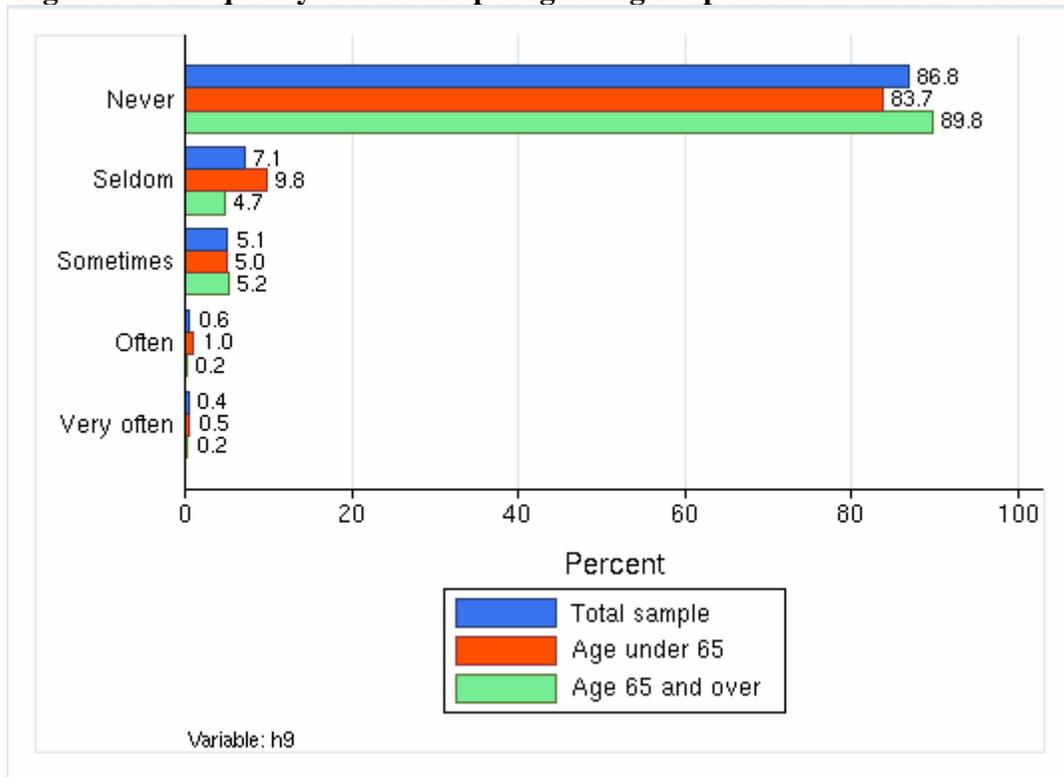
**Figure 94. Respondent Difficulty in Communicating with Paid Helper**



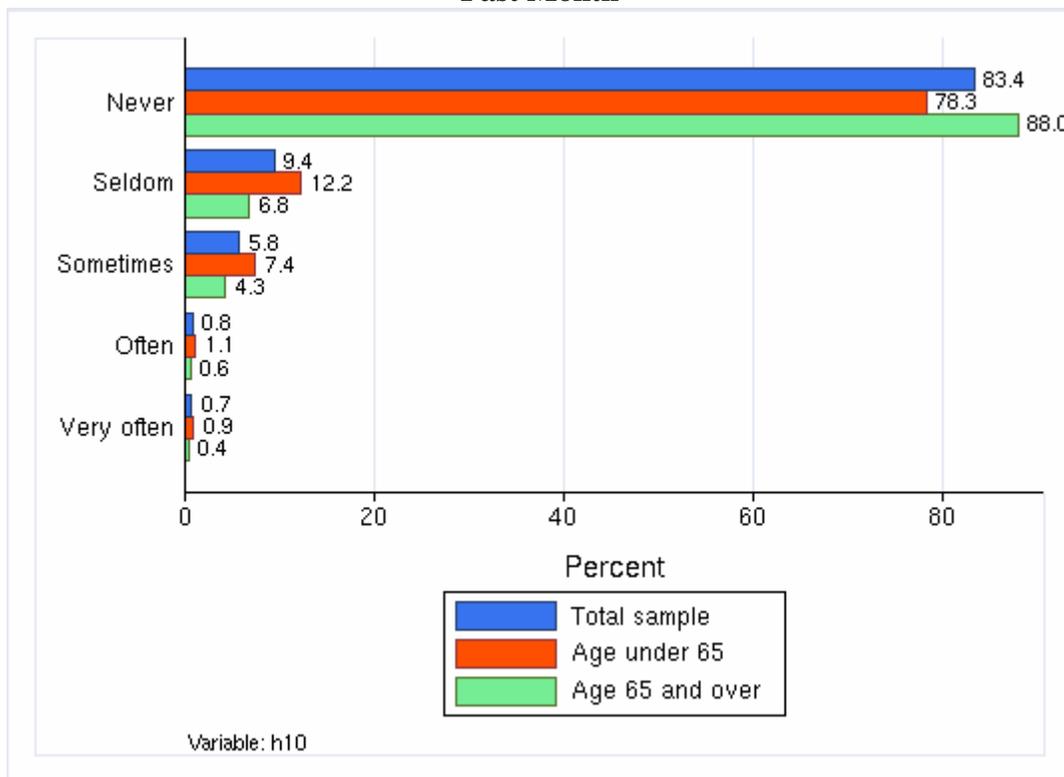
**Figure 95. Reasons for Communication Difficulties Between Respondent and Paid Helper (For Those Who Had a Problem)**



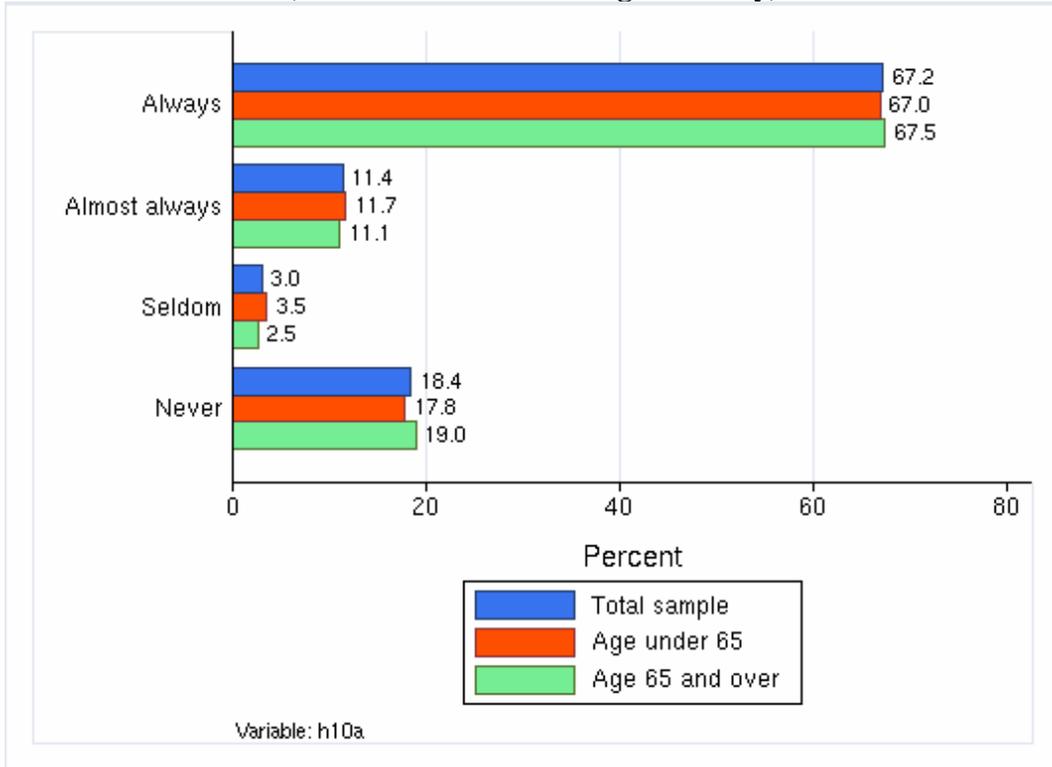
**Figure 96. Frequency of Paid Helper Ignoring Respondent in the Past Month**



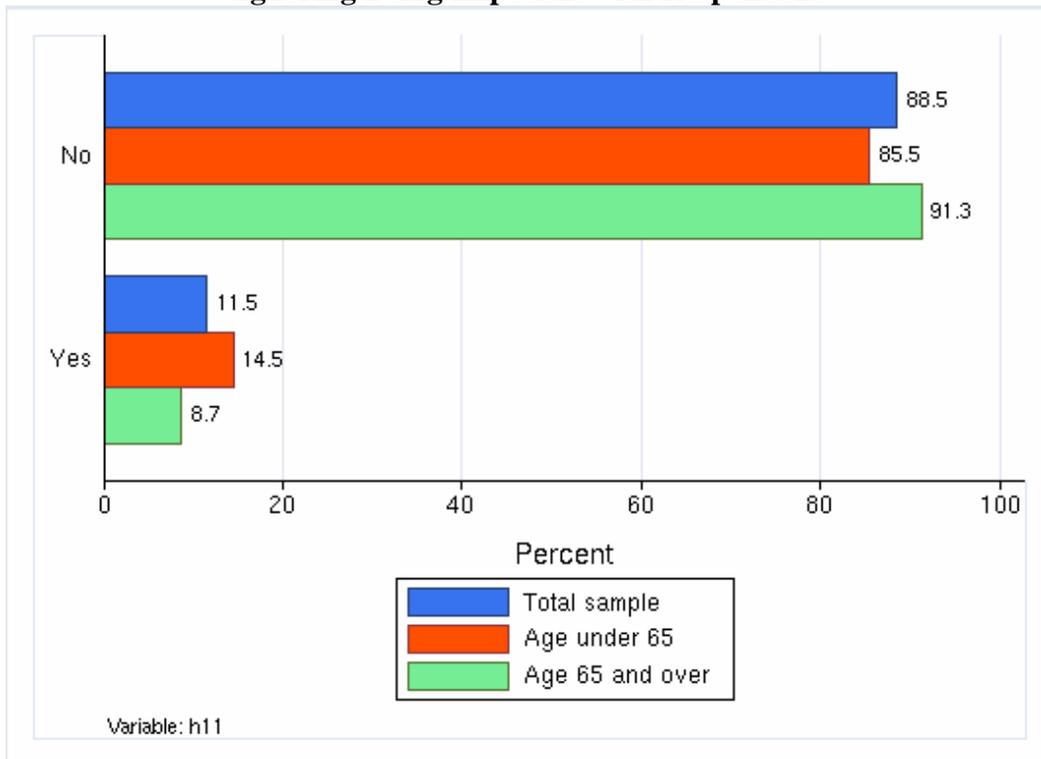
**Figure 97. Frequency of Paid Helper Being Impatient/Rushing Respondent in the Past Month**



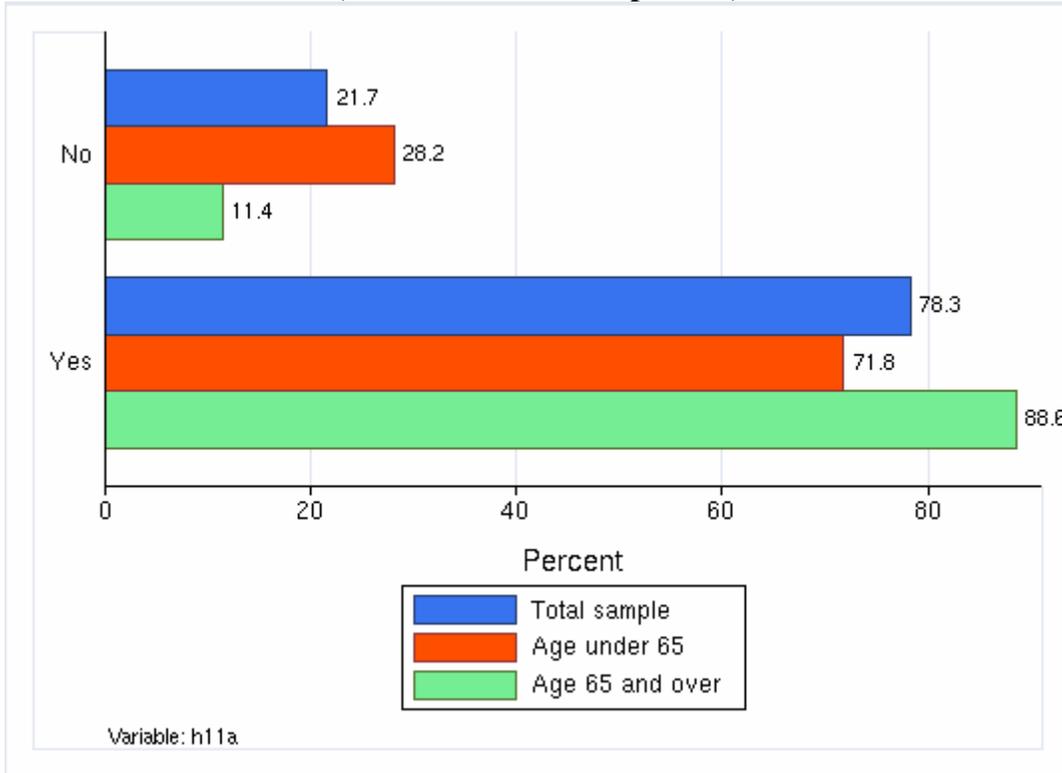
**Figure 98. Frequency of Paid Helper Assisting Quickly Enough with Toileting  
(For Those with Toileting Difficulty)**



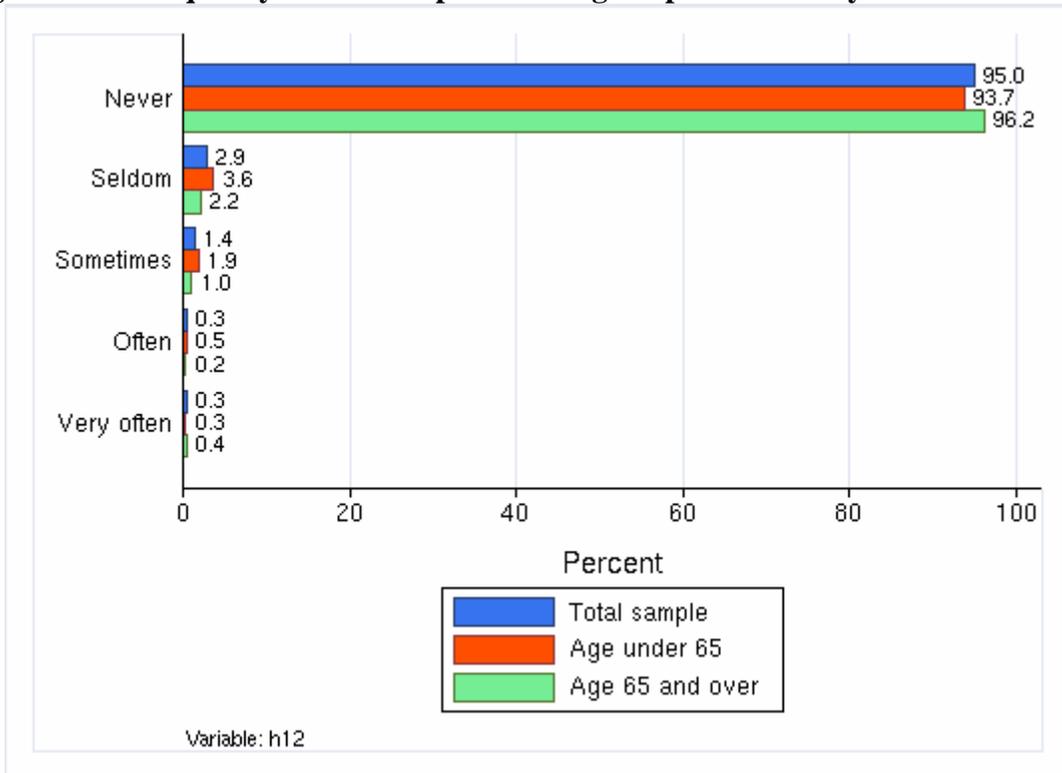
**Figure 99. Ever Complained to Care Manager/Service Coordinator of Paid Helper Ignoring/Being Impatient with Respondent**



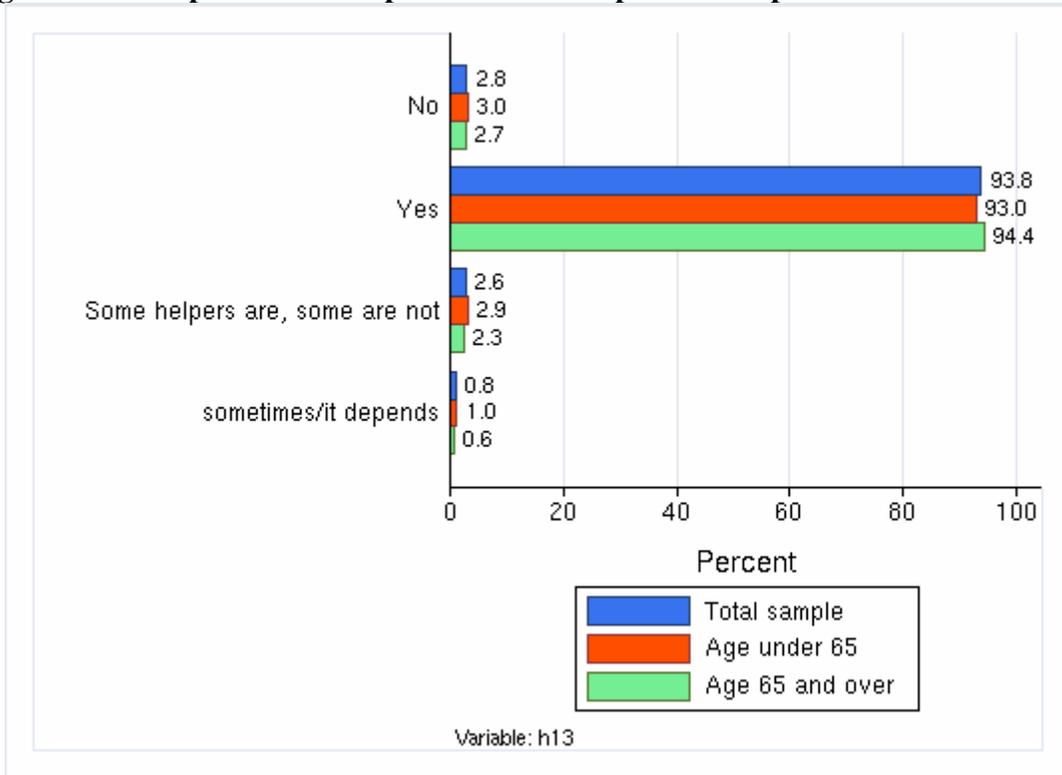
**Figure 100. Did Care Manager /Service Coordinator Resolve the Problem  
(For Those Who Complained)**



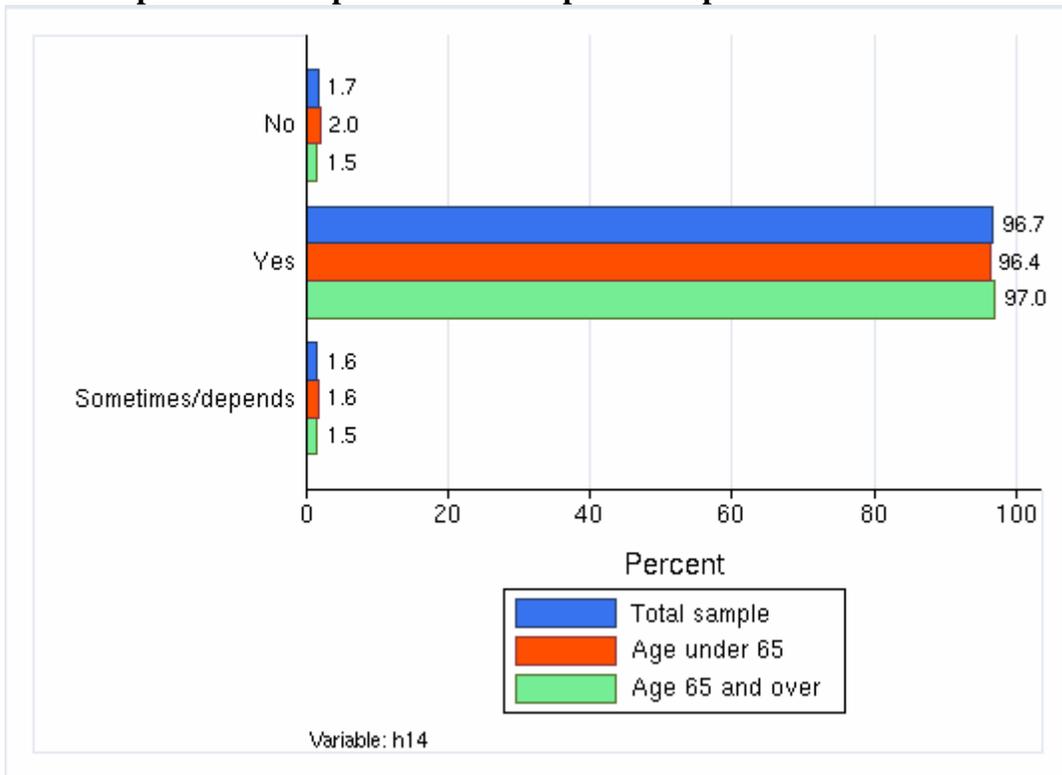
**Figure 101. Frequency of Paid Helper Treating Respondent Badly in the Past Month**



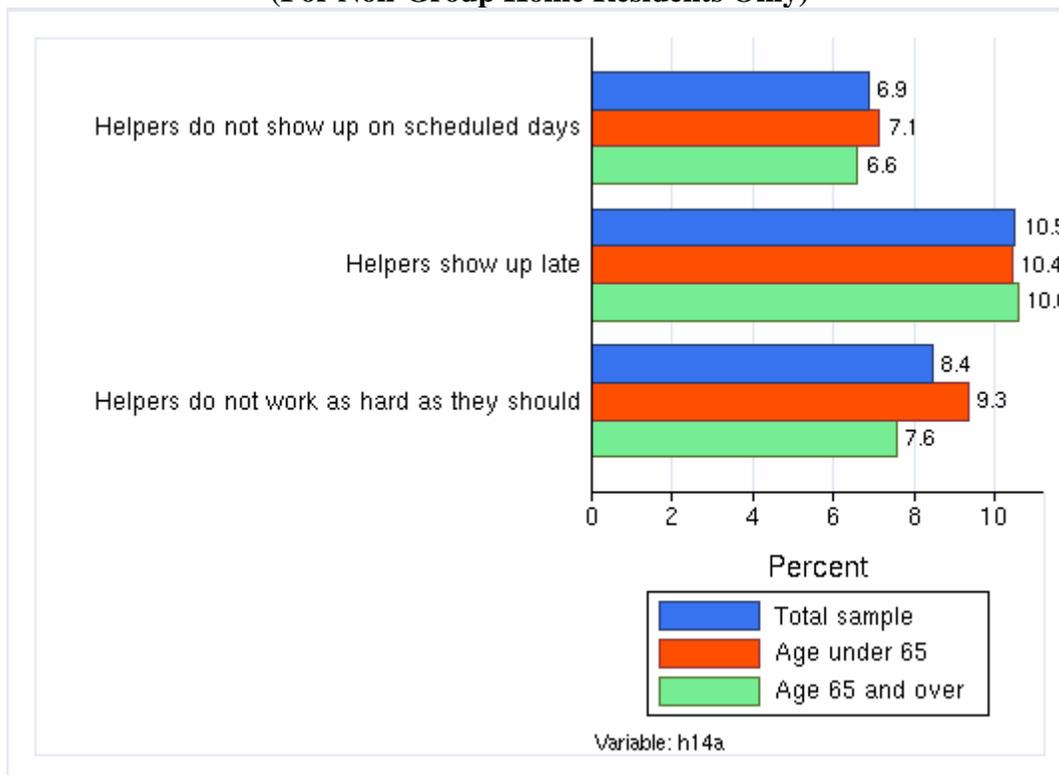
**Figure 102. Respondent Perception of Paid Helper as Competent and Well-Trained**



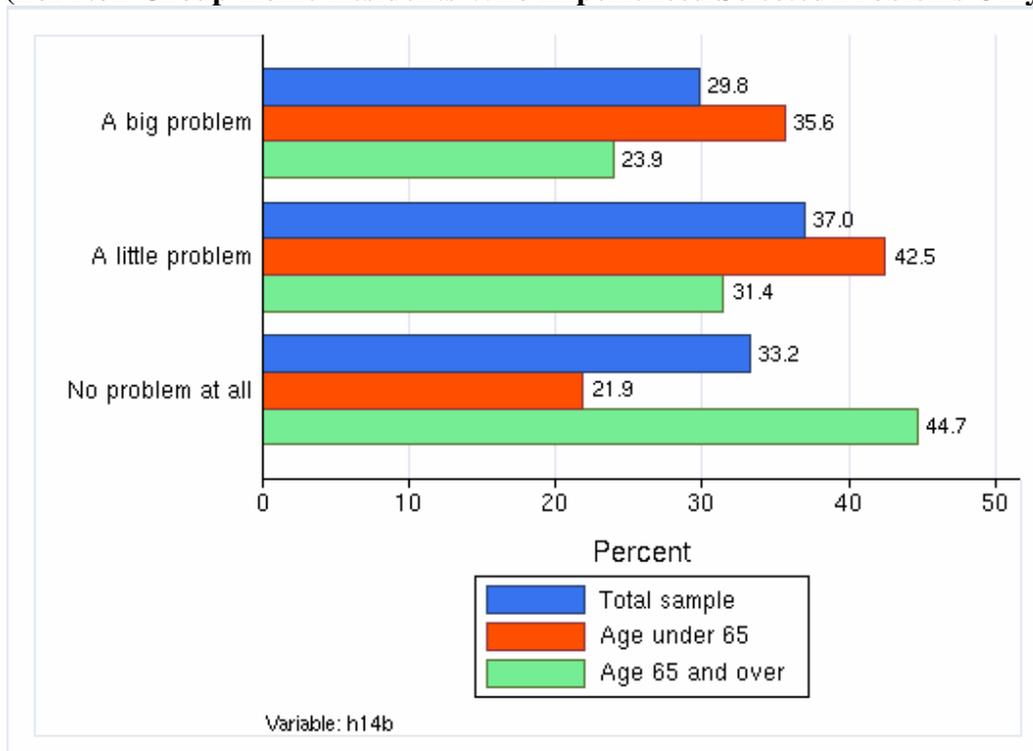
**Figure 103. Respondent Perception of Paid Helper as Respectful of Person and Preferences**



**Figure 104. Frequency of Selected Problems with Paid Helpers  
(For Non-Group Home Residents Only)**

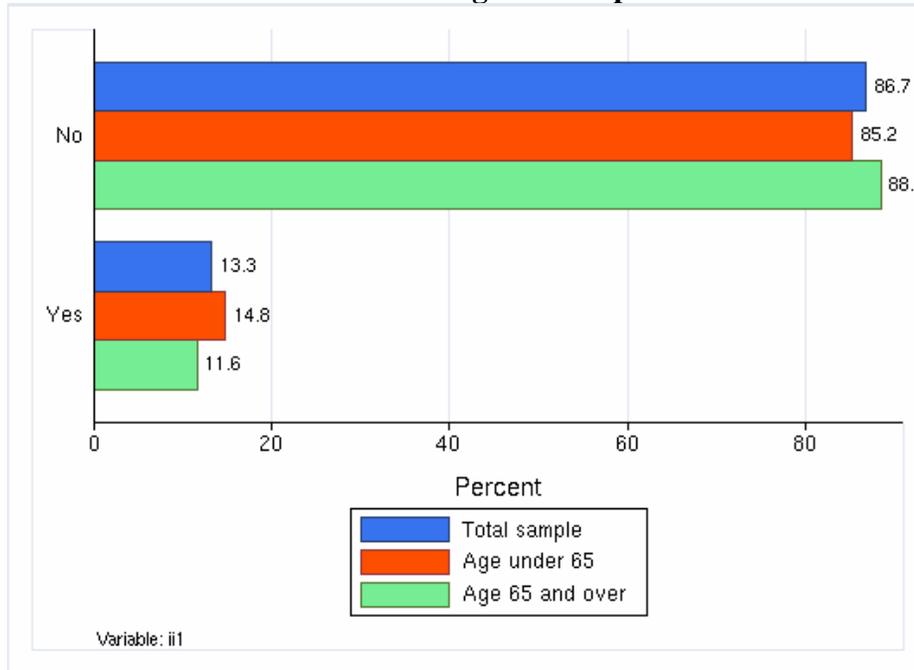


**Figure 105. Seriousness of Selected Problems with Paid Helper  
(For Non-Group Home Residents Who Experienced Selected Problems Only)**

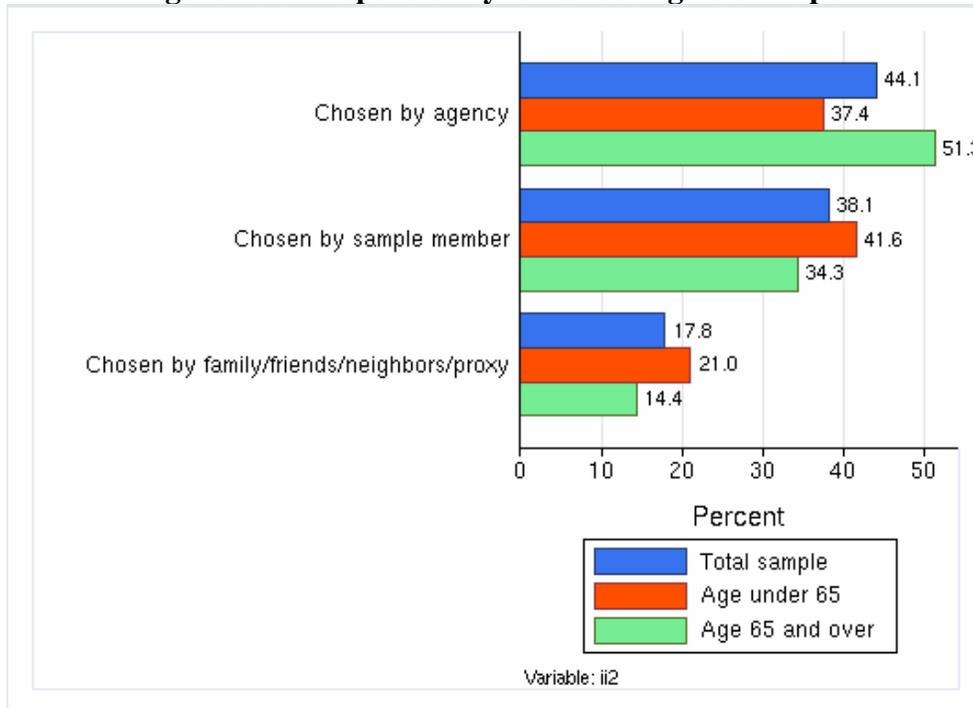


## 9. CONSUMER DIRECTION<sup>7</sup>

**Figure 106. Respondent Given a List of Agencies/Individuals to Choose from When Selecting Paid Helper**

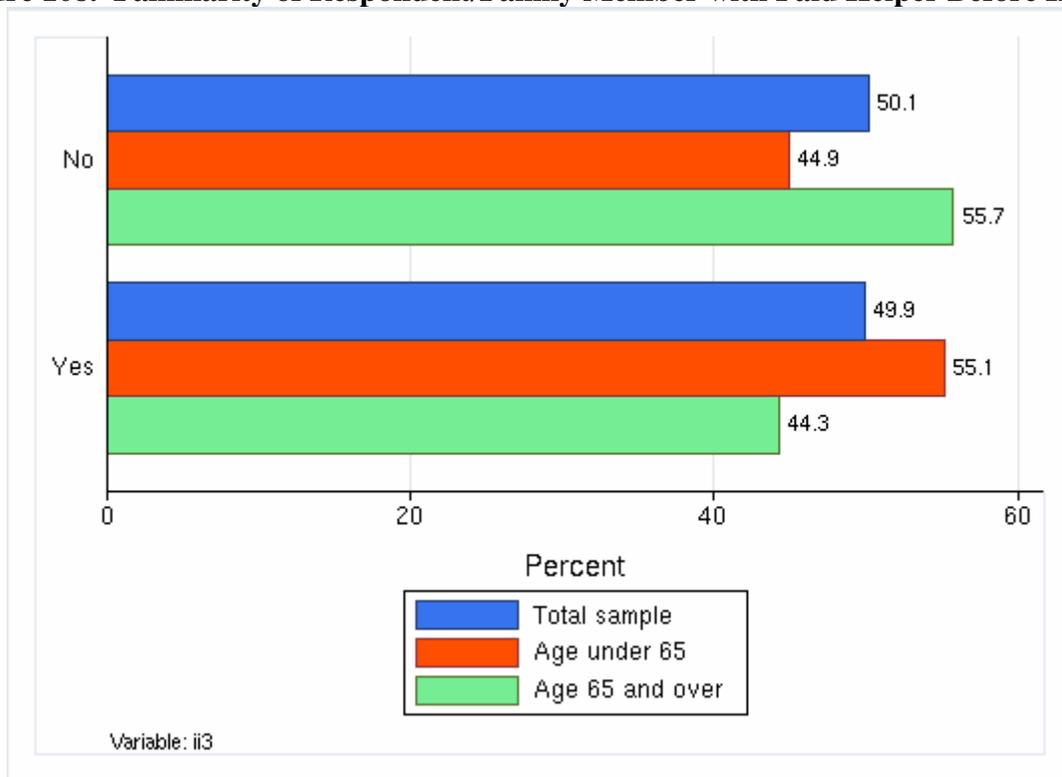


**Figure 107. Responsibility for Choosing Paid Helper**

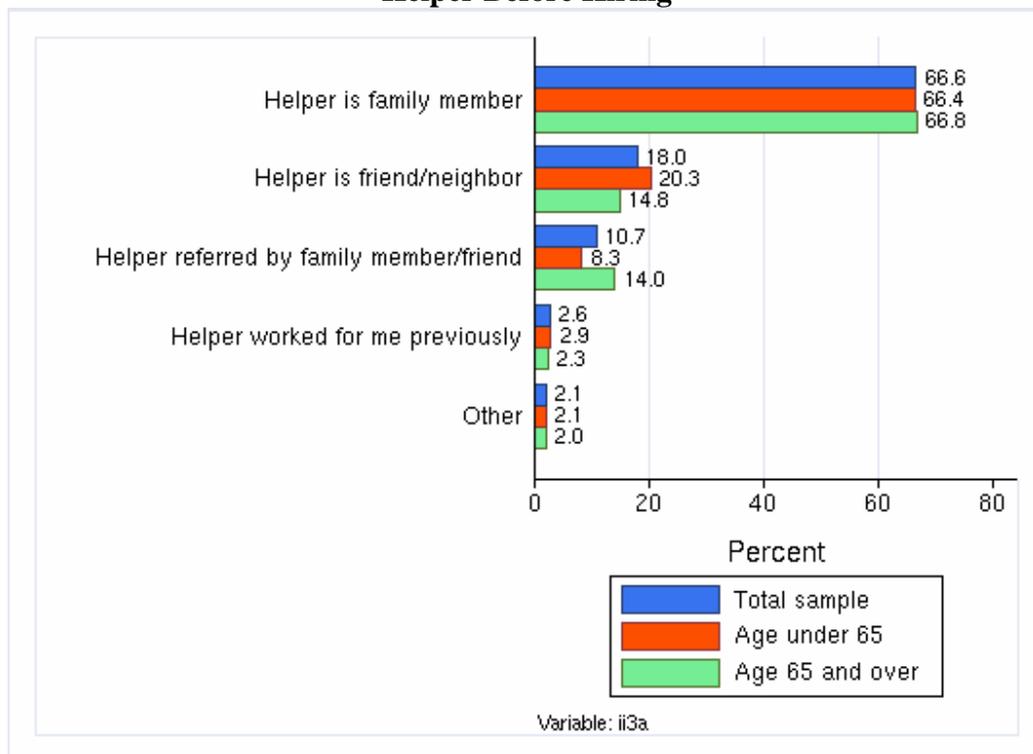


<sup>7</sup> This section was not asked of sample members in assisted living environment or other group residential setting.

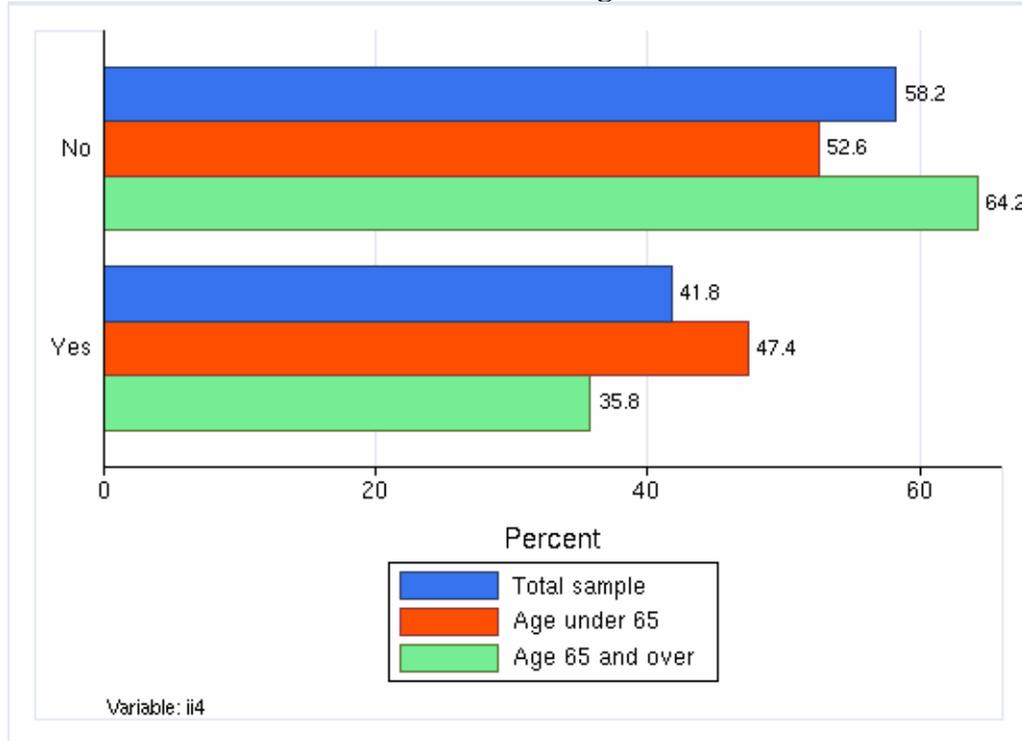
**Figure 108. Familiarity of Respondent/Family Member with Paid Helper Before Hiring**



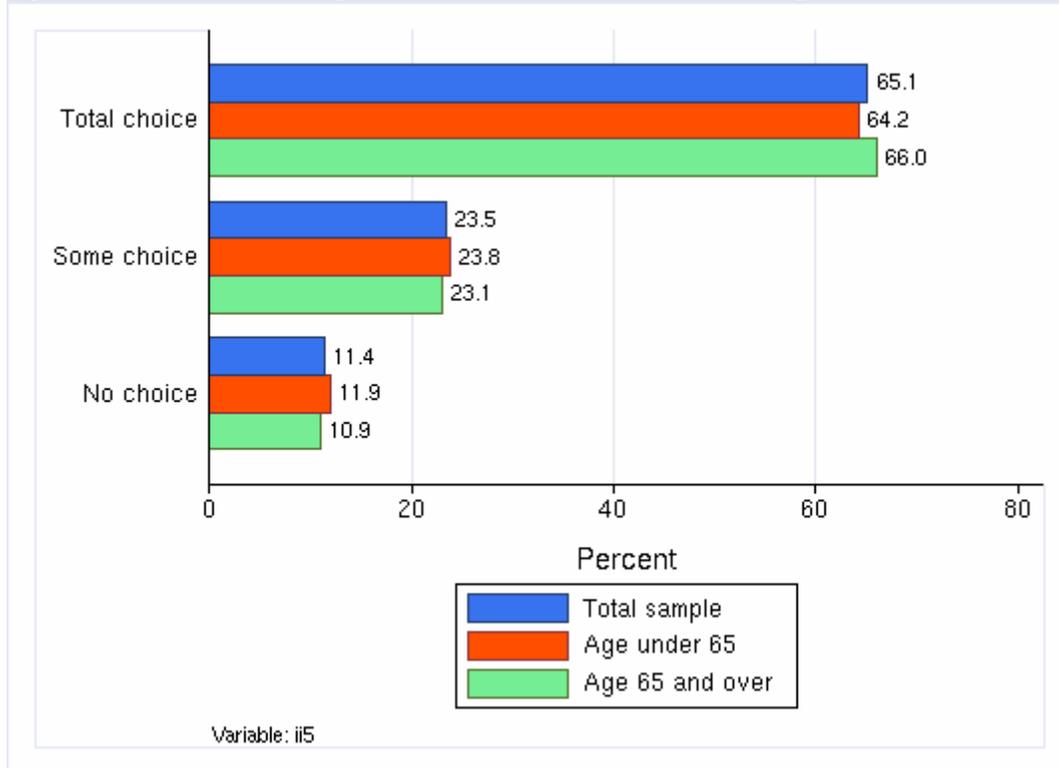
**Figure 109. Reason for Familiarity of Respondent/Family Member with Paid Helper Before Hiring**



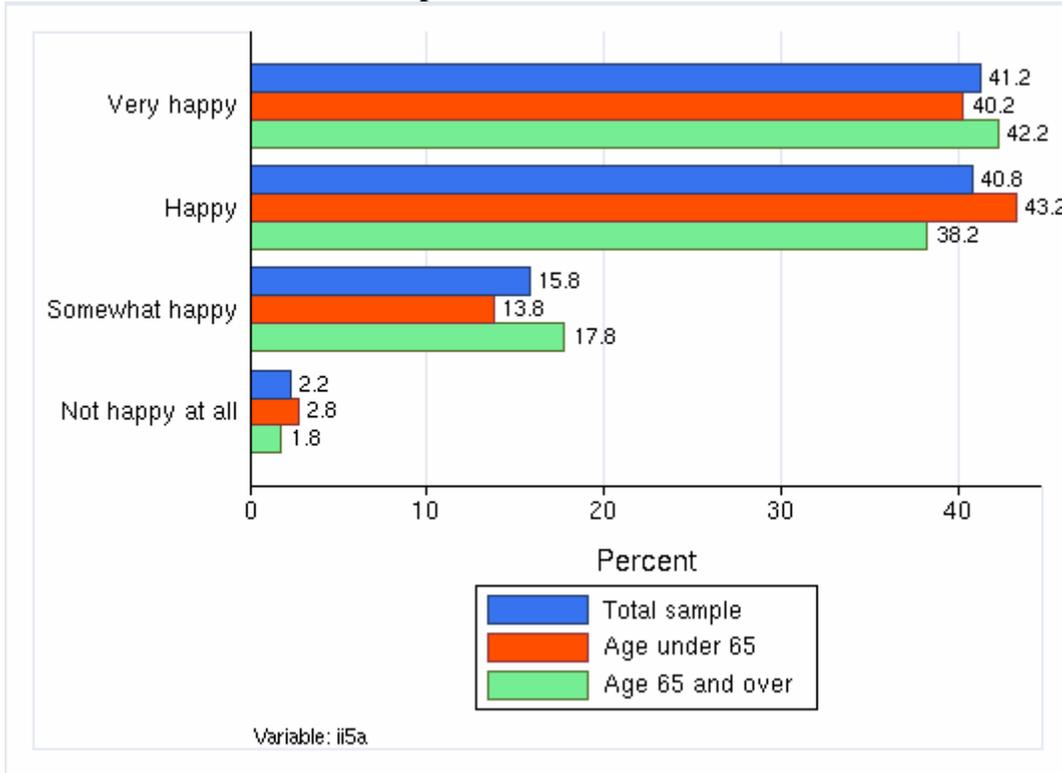
**Figure 110. Opportunity for Respondent/Family Member to Interview Paid Helper Before Hiring**



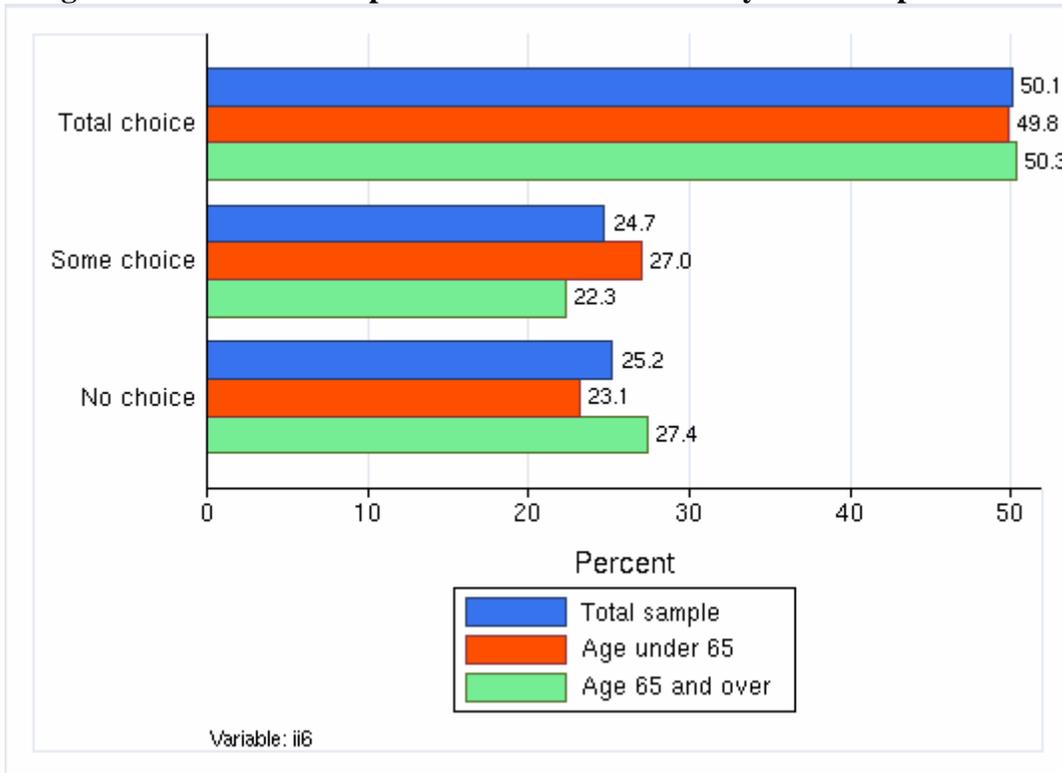
**Figure 111. Level of Respondent Choice of Tasks Paid Helpers Should Perform**



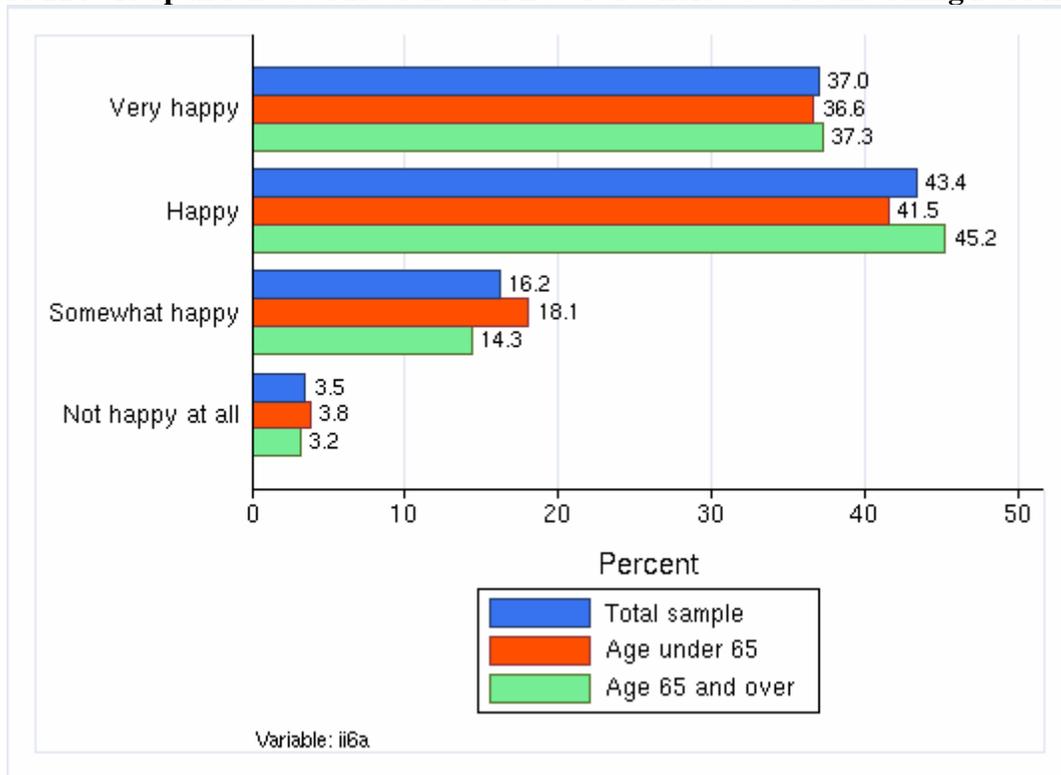
**Figure 112. Respondent Satisfaction with Level of Choice Over Tasks Paid Helpers Should Perform**



**Figure 113. Level of Respondent Choice of Time/Days Paid Helper Comes**

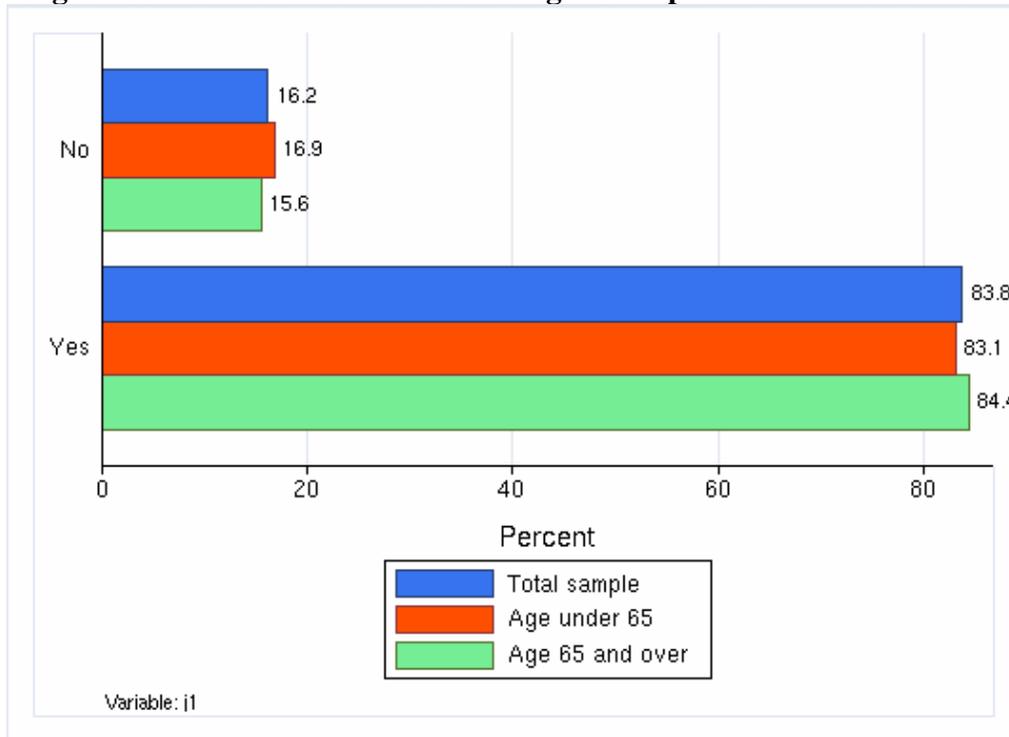


**Figure 114. Respondent Satisfaction with Level of Choice Over Scheduling Paid Helper**

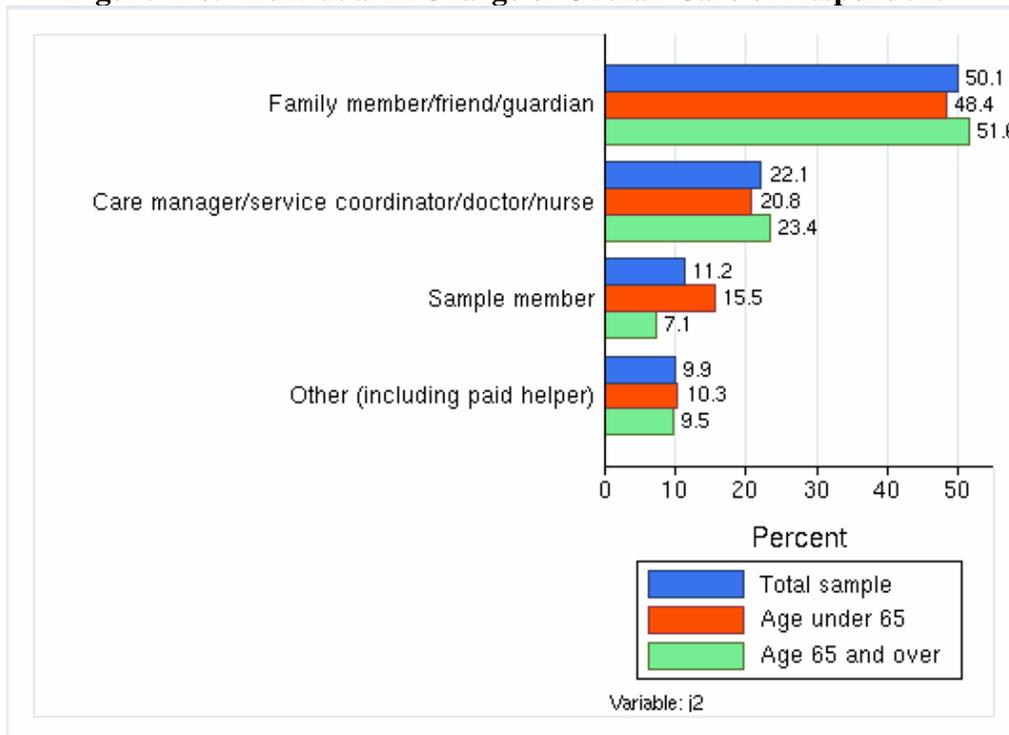


## 10. CASE MANAGEMENT

**Figure 115. Is One Individual in Charge of Respondent's Overall Care?**

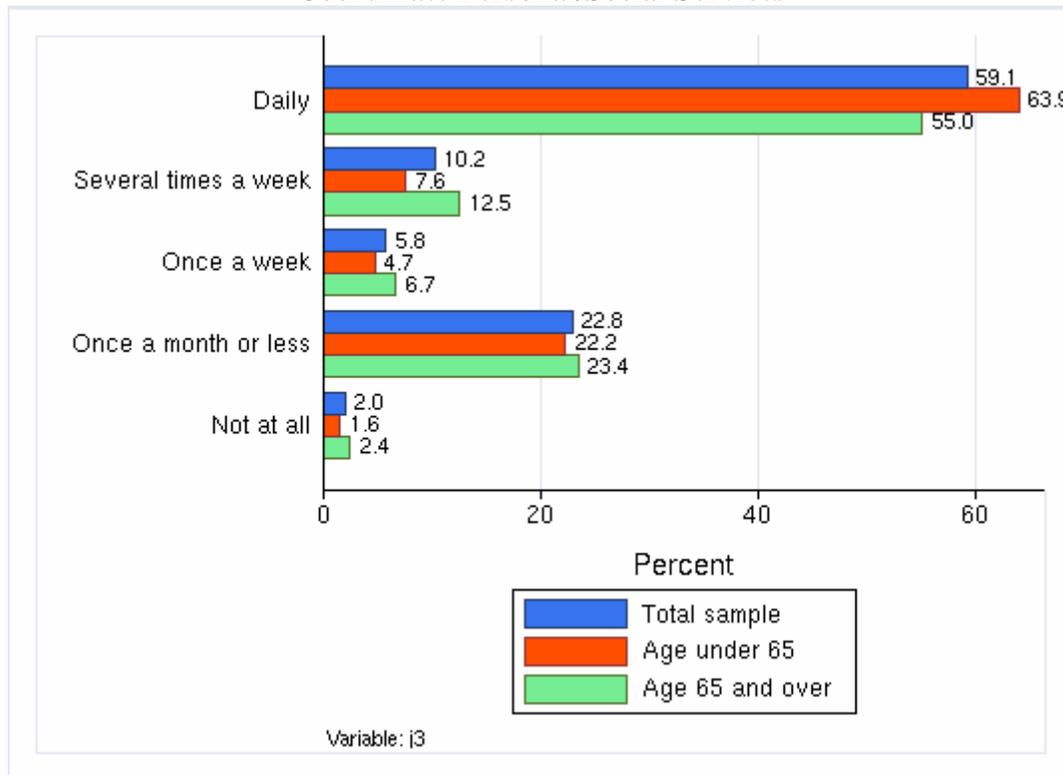


**Figure 116. Individual in Charge of Overall Care of Respondent\***

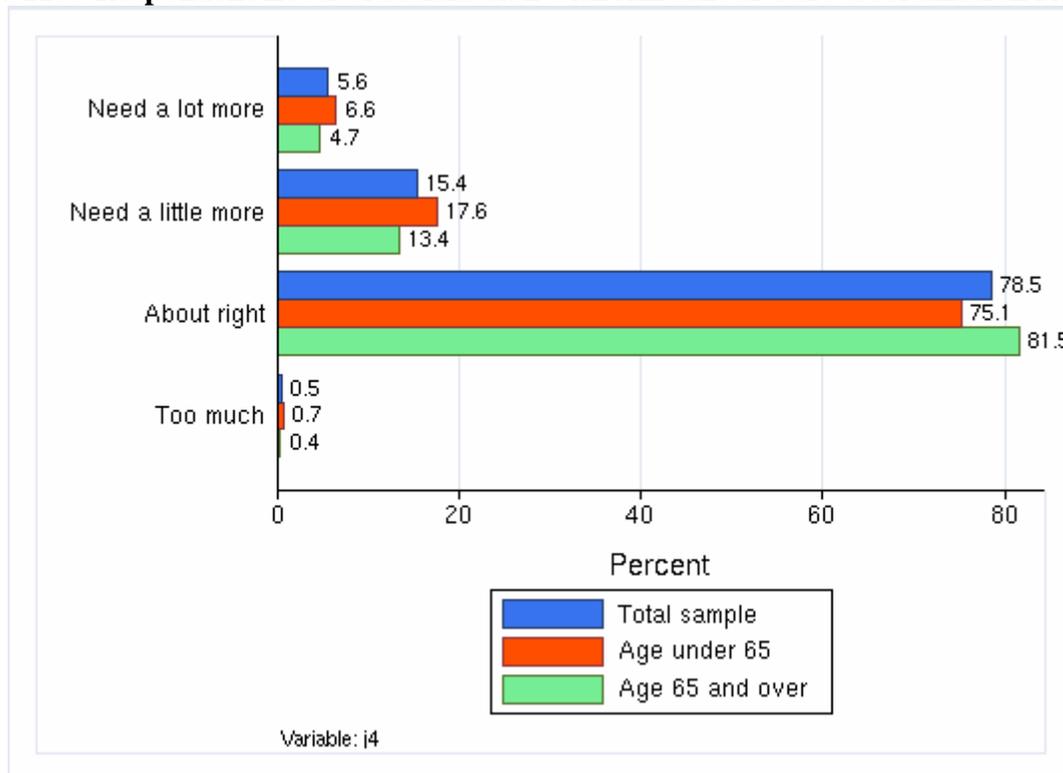


\* Respondents answered "all that apply" so categories do not add to 100%

**Figure 117. Frequency of Communication Between Respondent and Person Who Helps Coordinate Personal/Social Services**

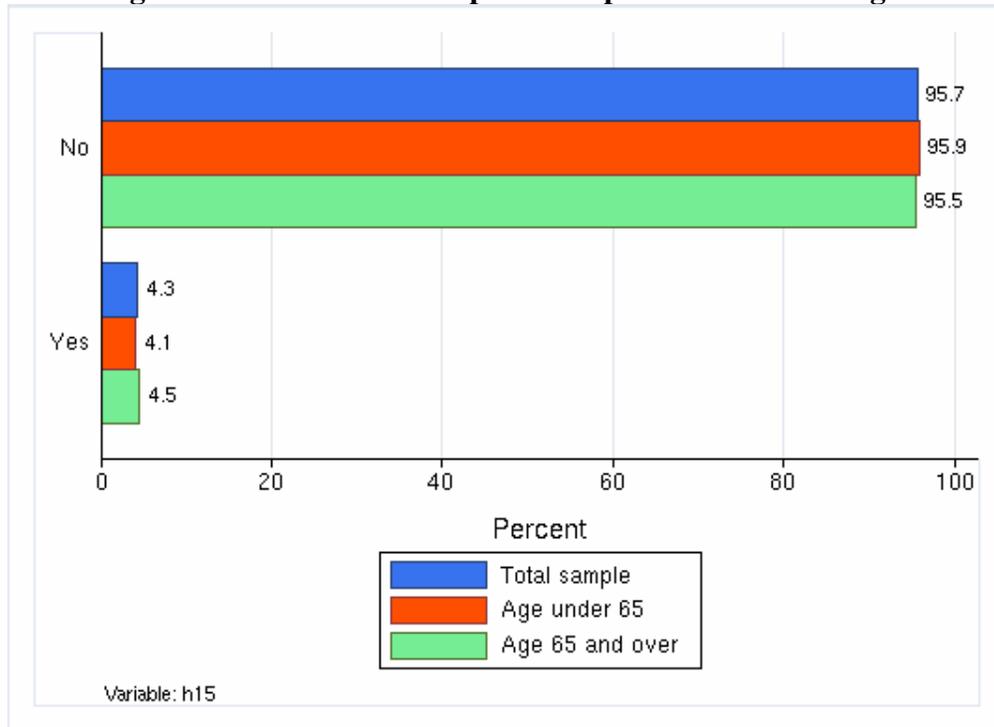


**Figure 118. Respondent Level of Satisfaction with Amount of Care Coordination Received**

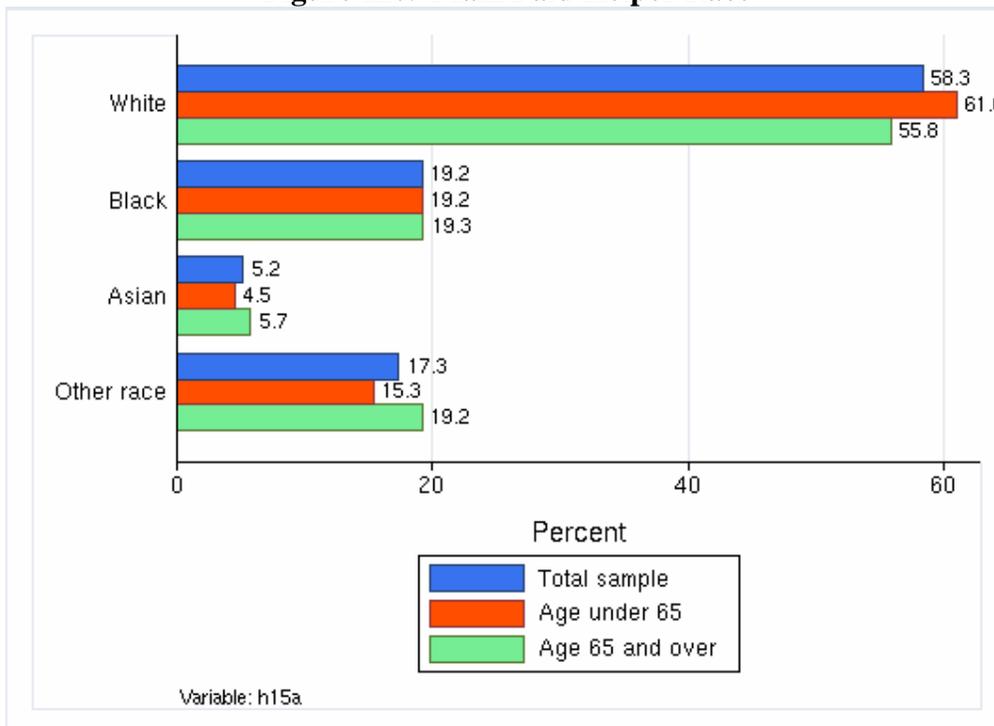


## 11. PAID HELPER DEMOGRAPHICS

**Figure 119. Main Paid Helper of Hispanic or Latino Origin**

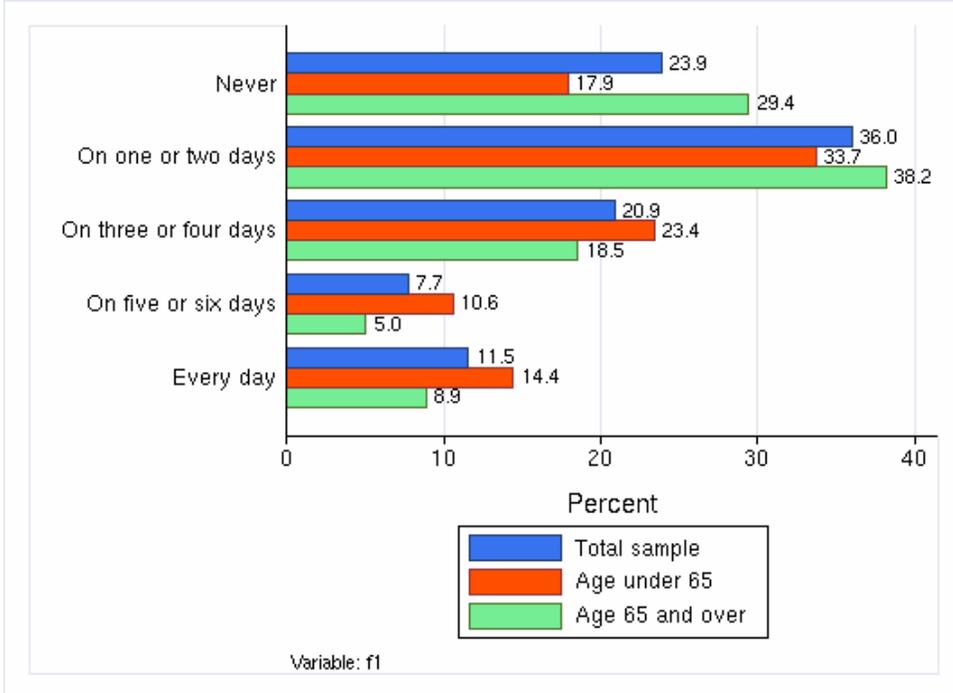


**Figure 120. Main Paid Helper Race**



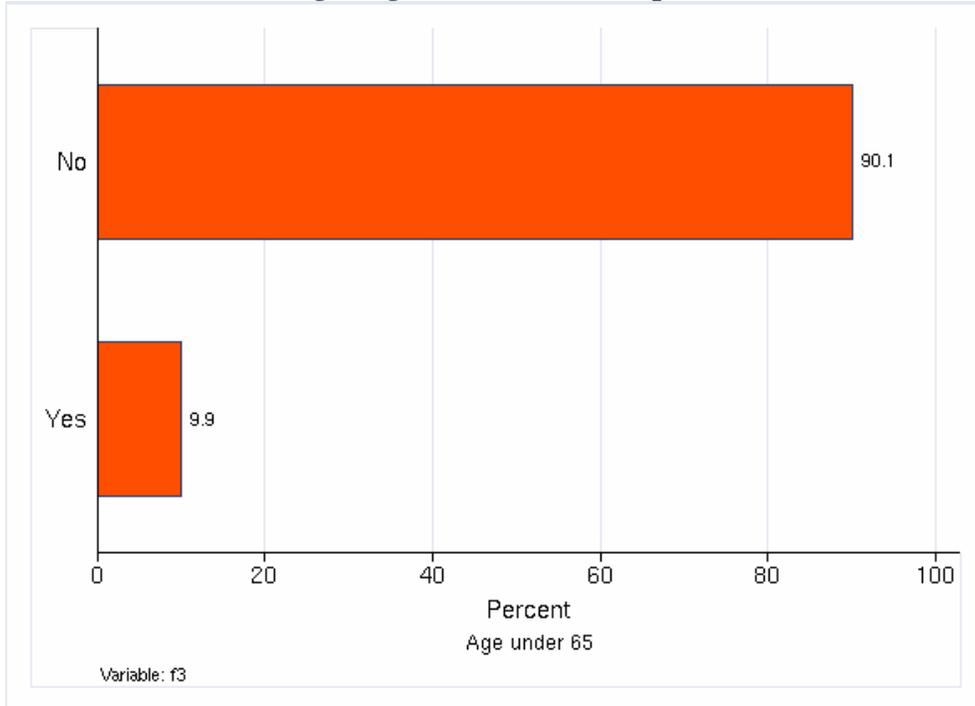
## 12. SOCIAL AND RECREATIONAL ACTIVITIES

**Figure 121. Mean Number of Days Going Out (Alone or with Someone)**

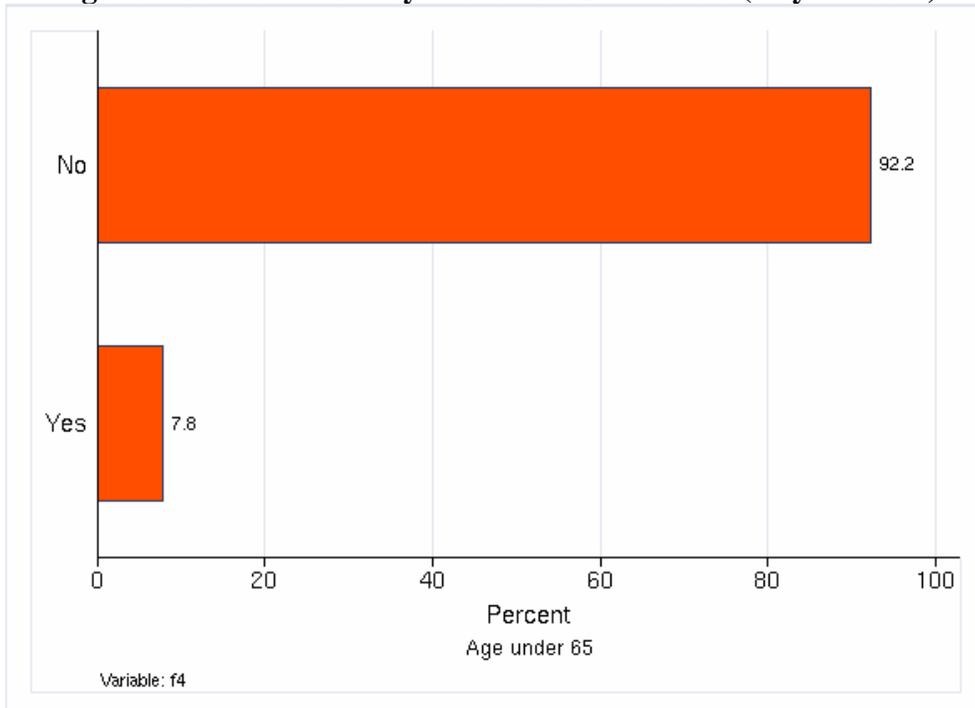


### 13. EDUCATION AND EMPLOYMENT<sup>8</sup>

**Figure 122. School/Training Programs/Class Participation in the Past Six Months**

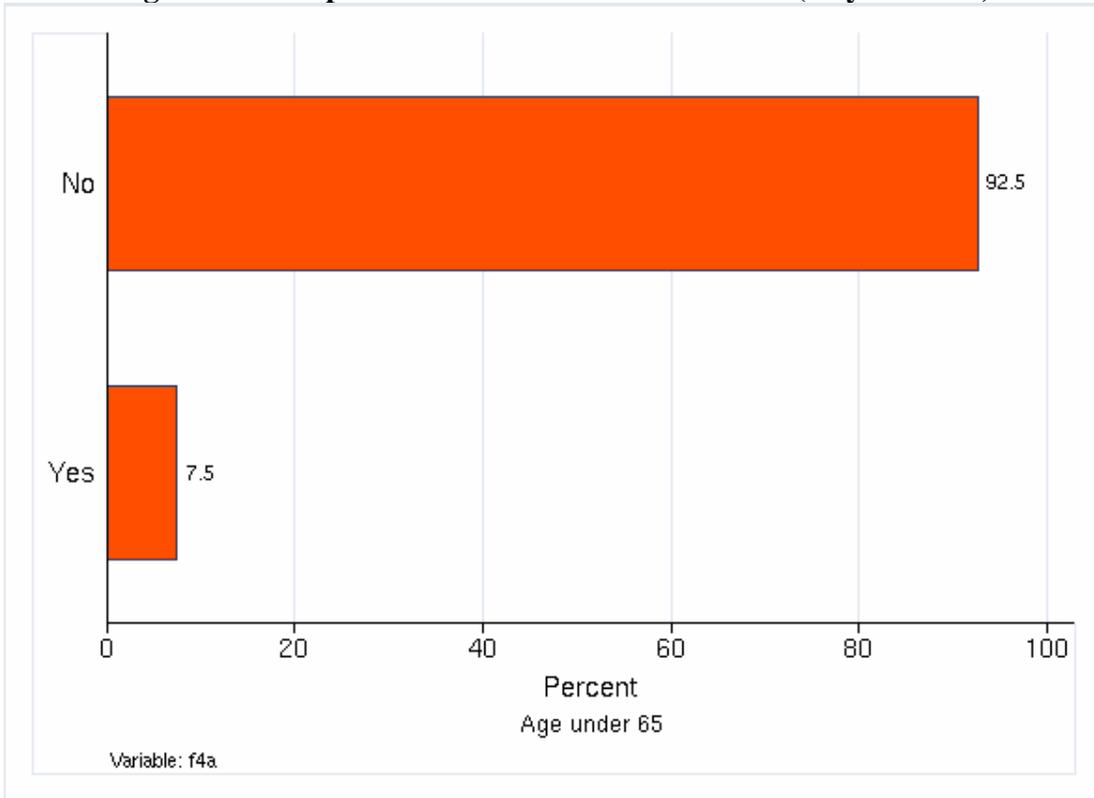


**Figure 123. Work For Pay in the Past Six Months (Any Amount)**

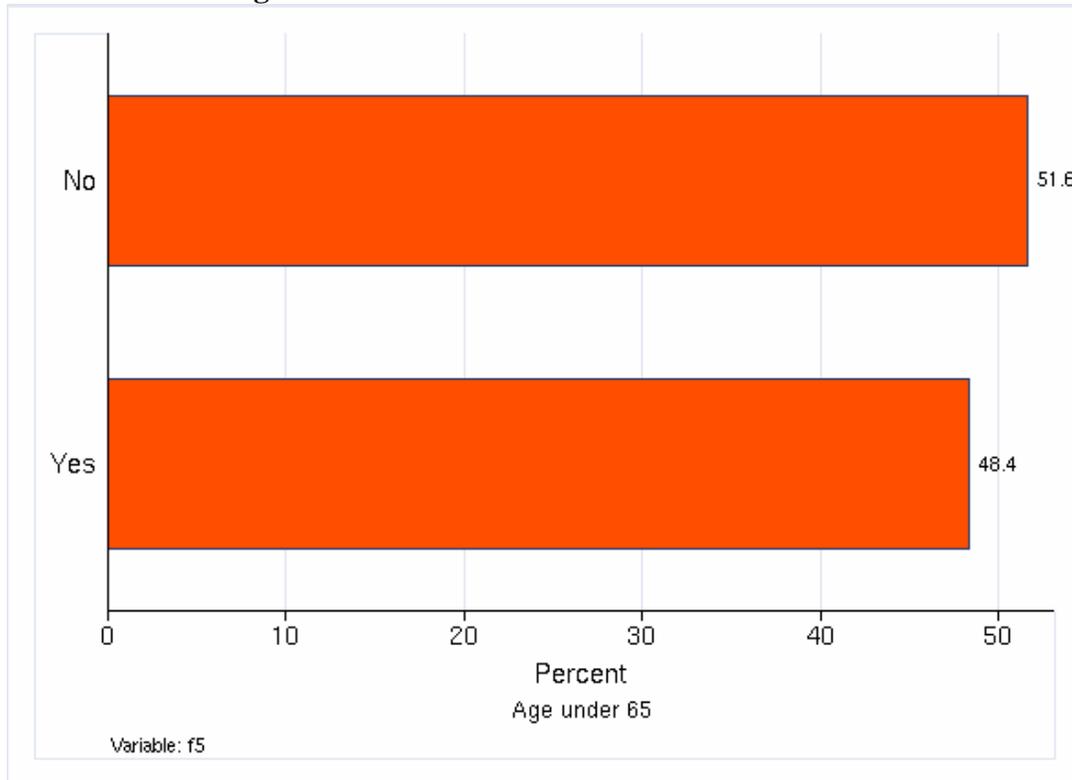


<sup>8</sup> This section was only asked of sample members under 65 years of age

**Figure 124. Unpaid Work in the Past Six Months (Any Amount)**

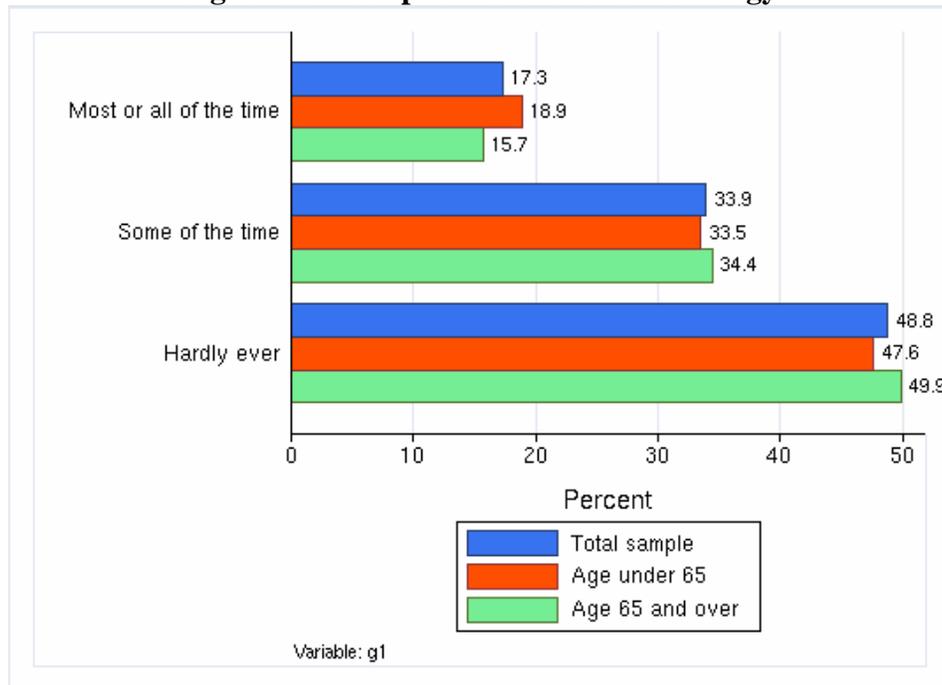


**Figure 125. Would Like to Work at a Paid Job**

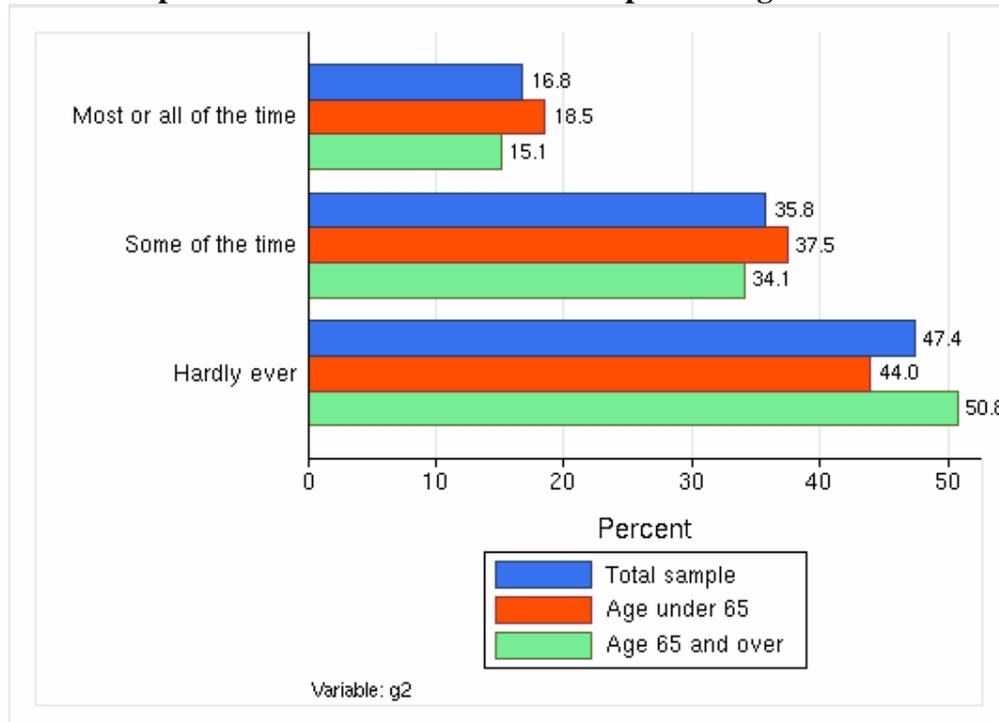


**14. SATISFACTION WITH LIFE DURING THE PAST MONTH<sup>9</sup>**

**Figure 126. Respondent Felt Full of Energy**

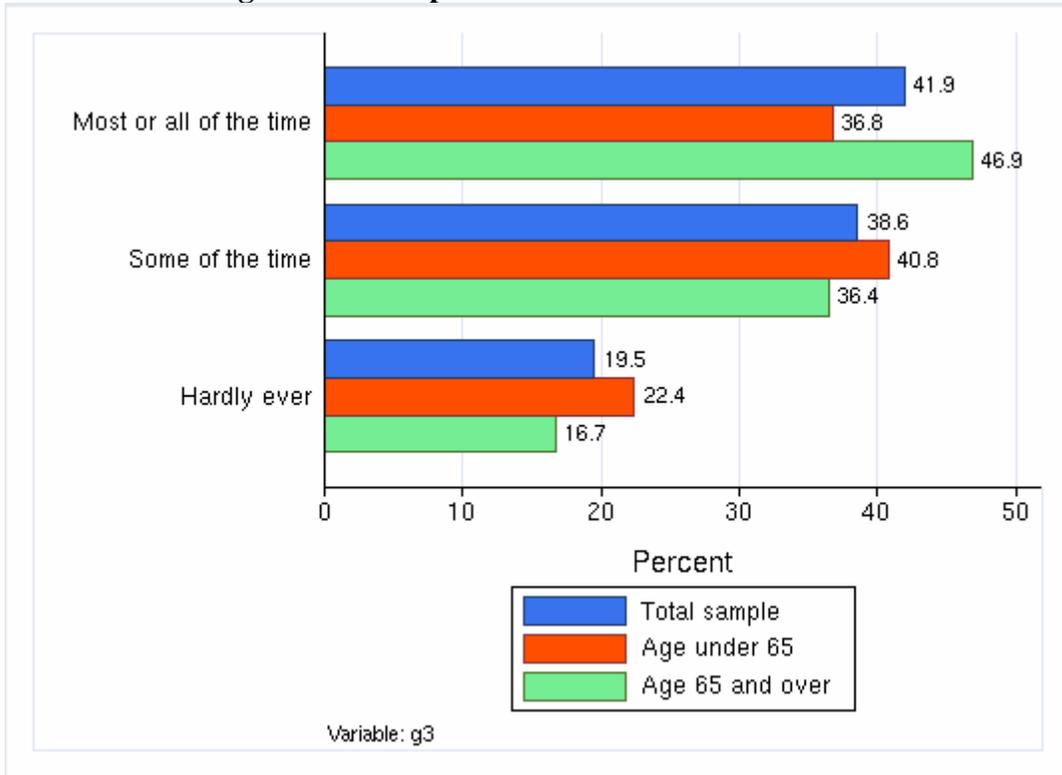


**Figure 127. Respondent Felt so 'Down in the Dumps Nothing Could Cheer You Up'**

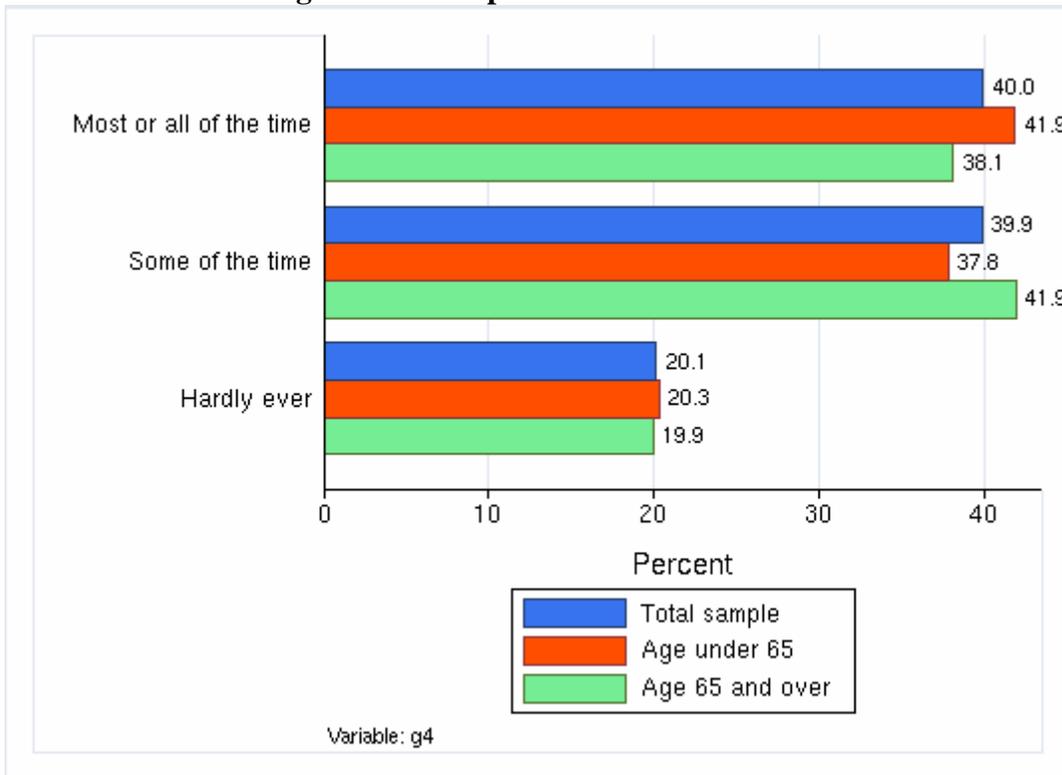


<sup>9</sup> This section was asked only of sample members who are self-respondents.

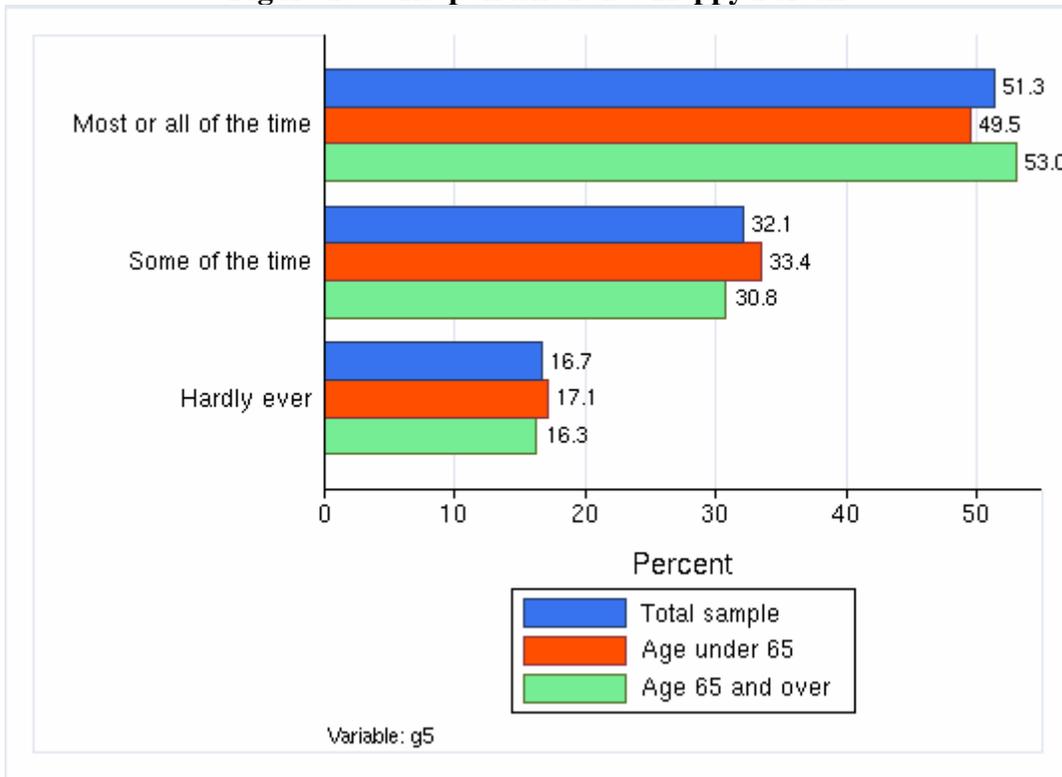
**Figure 128. Respondent Felt Calm and Peaceful**



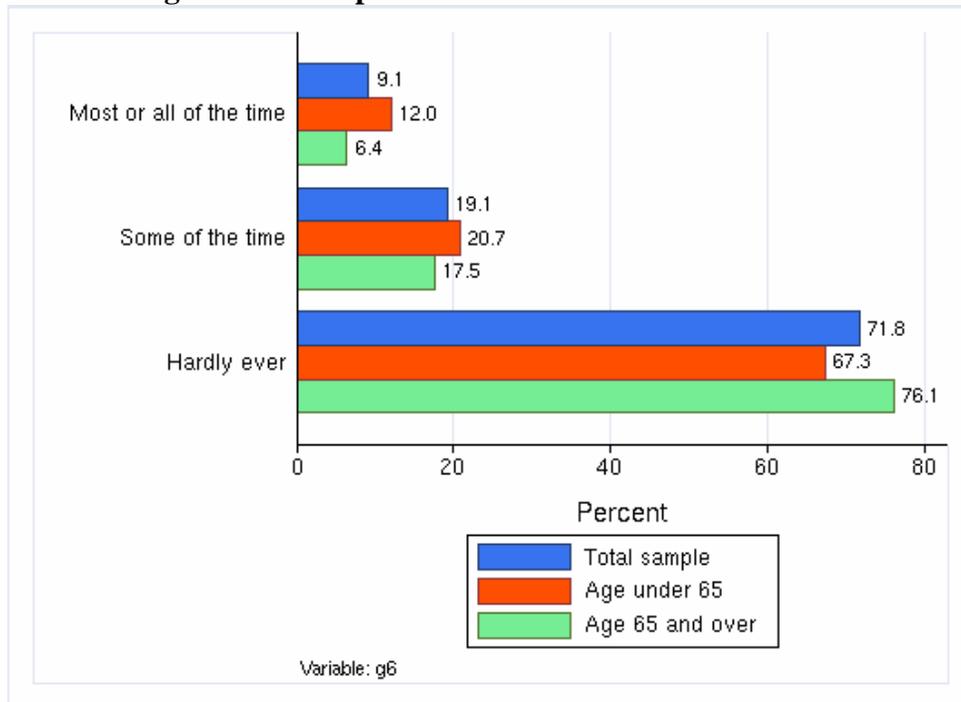
**Figure 129. Respondent Felt Worn Out**



**Figure 130. Respondent Felt a Happy Person**



**Figure 131. Respondent Felt Pushed Around in Life**



## REFERENCES

Wiener, J. M., Tilly, J., & Alecxih, L. M. B. (2002). Home and community-based services for older persons and younger adults with disabilities in seven states. *Health Care Financing Review*, 23(3):89–114.

Snell, L. P., Zhao, Z., Lu, C., Potter, F., & Ciemnecki, A. B. (2005). Evaluation of home and community-based Services waiver program: Survey methodology. Princeton, NJ: Mathematica Policy Research, Inc.