FACTORS INFLUENCING FUNCTIONAL ABILITY AMONG COMMUNITY-
DWELLING ADULTS AGING WITH DEVELOPMENTAL DISABILITIES

by

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A dissertation submitted to the
Graduate School-New Brunswick
Rutgers, The State University of New Jersey
in partial fulfillment of the requirements
For the degree of
Doctor of Philosophy
Graduate Program in Social Work
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May 2011
Adults with developmental disabilities are increasingly reaching old age in significant numbers while living in community-based, non-institutional settings. The overlay of cognitive and physical age-related impairments onto existing intellectual and physical disabilities, a paucity of informal social relationships, and a limited education and low income levels place this generation at risk for premature behavioral limitations and dependency.

The purpose of this study was to explore the relationships between individual functional ability in the performance of typical self-care and household activities, personal expectations of competency, and the physical and social environment of the home to better understand how these factors contribute to both the autonomy and dependency of people aging with developmental disabilities. This study hypothesized that physiological impairment, the built environment, and personal expectations would
be among the factors impacting individual functional ability level. Using a combination of qualitative and quantitative methods, this study gathered data from adults with developmental disabilities through individual in-person interviews and self-care/household task observations conducted in the participants' homes. A small sample of the consumers' direct care staff were also interviewed.

Results from the study revealed that both levels of participation and competency in the performance of self-care activities varied widely. Physical impairments, and particularly severe mobility impairments, had a stronger impact on functional ability than the cognitive impairments of the participants. Those who used wheelchairs for all mobility both reported and were observed to have very limited person-environment fit. Settings that offered a higher degree of supervision were also more likely to physically support a wide range of activities. Ninety percent of the interview participants expected to perform less well than they did during the task observation assessment. Qualitative data revealed that participants valued privacy, safety and a physically and socially supportive environment. These data also suggested factors that may have inhibited functional ability, such as an over-concern with the risks involved in participation, low perceptions of ability, and staffs' habitual caregiving behaviors. Methods of encouraging and fostering independence and autonomy in the home are discussed. Behavioral methods included having high expectations of consumers, encouraging consumers to attempt tasks that they previously may have considered too challenging, and supporting consumers to take calculated risks in order to develop judgment and increase skills.
Environmental methods included providing supportive physical environments, modified to meet individual needs, and appropriate and timely home maintenance.
ACKNOWLEDGEMENTS

There are many people who have provided support, encouragement, and camaraderie throughout this process whom I would like to thank.

Dr. Allison Zippay, Dr. Donald Dickson, Dr. Yvonne Johnson, Dr. Carol Turner and Dr. David Axelrod provided me with a stellar dissertation committee. Their guidance, patience, and thoughtful instruction throughout the writing and revising process were crucial to the project’s completion. I am grateful for the mentoring, support, and encouragement that each provided. Their generosity of time and expertise have provided a model that I will emulate throughout my teaching career.

I was privileged to have had Dr. Allison Zippay as my chairperson. Her positive approach to providing feedback, her willingness to review draft after draft and give thoughtful consideration to both overarching and minor issues helped me to maintain my stamina and determination to complete this project. Dr. Donald Dickson provided critical expertise regarding disability legislation and served as source of wise counsel. Dr. Yvonne Johnson offered valuable insights and suggestions from a social work strengths and ecological perspective that helped compensate for my missing MSW. Dr. Carol Turner helped immensely in formulating my methodological approach to the project. Dr. David Axelrod provided astute methodological and statistical advice, as well as intellectual insight and challenging feedback.

Dr. Graham Staines has broadened my analytic skills and contributed immeasurably to my quantitative analysis. Graham continues to help me to be both a better scholar and a more effective teacher. He has been unfailingly generous with his
time and availability, often beckoned with very little notice. He has served as a constant source of intellectual insight and friendly encouragement. I value both his friendship and collegiality. Had I met him earlier in the dissertation process, its completion would have been timelier.

Dr. Kathleen Pottick’s Dissertation Seminar gave me critical motivation, instruction and encouragement at a time when it was most needed.

Wayne Anderson provided both expertise and camaraderie as he helped me review, code, recode, cross-reference, and make sense of realms of qualitative data. His patience and willingness to spend long hours helping with the qualitative data analysis, his sense of humor and easy-going nature are most appreciated.

My colleague, Richard Olsen, nurtured my love of research and guided me through many research projects, teaching me the “nuts and bolts” of the process.

Zoë, Daphne, Ives, Pekoe and Henry have gotten me through long days working at home alone, and have provided much-needed diversions, as well as a measure of sanity when my own was in short supply.

My family has provided immeasurable encouragement and support. My sister, Katherine Porter, helped with her computer expertise and as a supportive and encouraging presence who was always only a phone call away, and, on many occasions, dropped whatever she was doing to help me solve the most tedious and intractable computer problems. My brother and sister-in law, Bill and Mike Hutchings, have been supportive in countless ways throughout the dissertation process. My parents, David and Esther Hutchings instilled in me the value of education and a love of learning that
will always enrich my life. Over the years they have given me so much and asked for little in return. Throughout my graduate career they have been generous with both financial and emotional support. This dissertation is dedicated to them.

Finally, John Semmlow has lived through the entire PhD program with me. He has been a constant source of intellectual challenge and emotional support. John has encouraged me to persevere when I was unsure of my own ability, challenging my self-doubt and helping me to replace it with confidence. He has been a dedicated sounding board, figure-maker and advisor. John's humor, his delightful sense of adventure, camaraderie and, most of all, his love have sustained me throughout this process and continue to enrich my life.
# Table of Contents

Abstract of the Dissertation  ii  
Acknowledgements  v  

**Chapter One**  
Summary  1  
Statement of the Problem and Historical Context  6  
Theories that have Informed Prior Research  15  
Research Questions  23  

**Chapter Two - Literature Review**  
The Impact of Less Restrictive Environments on Functional Ability  27  
The Role of Expectations in Disability  32  
The Role of Environment in Disability  35  
The Role of Mobility Limitations in Disability  48  

**Chapter Three - Methods**  
Research Paradigm  56  
Sampling Procedures  60  
Data Collection  63  
Measures  66  
Content Validity  73  
Data Analyses  75  

**Chapter Four - Quantitative Results**  
Hypothesis One  89
<table>
<thead>
<tr>
<th>Hypothesis Two</th>
<th>93</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesis Three</td>
<td>98</td>
</tr>
</tbody>
</table>

### CHAPTER FIVE – QUALITATIVE RESULTS | 104
---|---
| Qualitative Responses from Consumers | 104 |
| Qualitative Responses from Staff | 123 |
| Person-Environment Fit and Its Relationship to Self-Report | 128 |
| Maintenance Issues | 132 |
| Issues of Consumers who Relyed on Wheelchairs for Ambulation | 133 |
| The Don’t Do Respondents | 138 |
| Participant Sketches | 141 |

### CHAPTER SIX – DISCUSSION | 154
---|---
| Risk versus Safety | 160 |
| Physical Barriers to Functional Ability | 172 |
| Property Maintenance to Support Functional Ability | 176 |
| Implications for Practice | 179 |
| Recommendations for Further Research | 182 |
| Limitations of the Study | 188 |
| Conclusion | 191 |

### APPENDIX A | 195
---|---

### APPENDIX B | 203
---|---

### APPENDIX C | 239
---|---

### APPENDIX D | 241
---|---
LIST OF TABLES

Table 1: Characteristics of the Sample 84
Table 2: Characteristics of the Participants' Homes 86
Table 3: Transformed Variables 87
Table 4: Correlations 88
Table 5: Regression of Mean Observed Functional Ability Score on Accumulated Overall Impairments and Control Variables 89
Table 6: Regression of Mean Observed Functional Ability on Accumulated Physical Impairments and Control Variables 90
Table 7: Regression of Mean Observed Functional Ability Score on Uses a Wheelchair Full-time and Control Variables 91
Table 8: Regression of Mean Self-Reported Functional Ability Score on Accumulated Overall Impairments and Control Variables 91
Table 9: Regression of Mean Self-Reported Functional Ability Score on Accumulated Physical Impairments and Control Variables 92
Table 10: Regression of Mean Self-Reported Functional Ability Score on Uses Wheelchair Full-time and Control Variables 92
Table 11: Correlations between Self-Reported and Observed Functional Ability 94
Table 12: Mean Functional Ability Scores by Home Accessibility Level – 4 Levels 101
Table 13: Mean Functional Ability Scores by Home Accessibility Level – 2 Levels 102
Table 14: Activities Not Supported By Home Supervision Level 102
Table 15: Number of "Don't Do" responses for Functional Assessment Ability Variables 138
LIST OF FIGURES

Figure 1: The World Health Organization Model, 1980 16

Figure 2: Transactional model 18

Figure 3: Ecological Theory of Aging 21

Figure 4: Participants’ Self-Reported Functional Ability Compared To Observed Functional Ability 97

Figure 5: Comparison of functional ability scores and home accessibility level with and without full-time wheelchair use 99
CHAPTER ONE: INTRODUCTION AND BACKGROUND

SUMMARY

This study investigated correlates of functional ability in self-care activities among people who are aging with developmental disabilities, defined for the purposes of this study as people forty years of age or older, except in the case of four people who were experiencing the effects of aging in their 30s. Developmental disabilities were defined, in this study, according to the definition used by the United States Government's Division of Health and Human Services:

A severe, chronic disability of an individual that is attributable to a mental or physical impairment or a combination of both; manifested before the age of 22; likely to continue indefinitely; and resulting in severe limitations in three or more of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. These limitations reflect the individual's need for a combination

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1 Although “aging” is literally and technically what every living being is doing from birth until death, “aging” is also the term used to describe older people and the process of getting older that is ongoing in their lives. The term, “aging” is, likewise, widely applied to people with developmental disabilities who are in the latter stages of their lives. For example, the International Association for the Scientific Study of Intellectual Disabilities’ (IASSID) special interest group for older intellectually impaired adults is called “The Aging Roundtable.” The American Journal on Mental Retardation (AJMR), in March 2004, published a “Special Issue on Aging” devoted to the subject of adults 30 years of age and older.

2 Sweeney, in 1979, reported a lack of consensus on what is considered “aging” among the population of adults with intellectual disabilities. This lack of consensus does not seem to have resolved itself in the twenty-six years since Sweeney’s observation. The AJMR issue listed above included eight papers reporting on research, three of which were devoted to Down syndrome. These three reported on samples of “older” adults aged 30 and above. Among the other five papers, samples began at age 30 in one, age 45 in another, age 50 in a third, and age 65 in a fourth. The fifth paper included two sub-samples, one with Down syndrome beginning at age 45, and a second, with mental retardation but without Down syndrome beginning at age 65. One author, in a recent edited text on community supports for people aging with developmental disabilities states, “Beginning when a person is in his or her 50s, an age span of 30 years or more defines being an “older” person with intellectual disability” (Bigby, p. 61). The National Survey of Programs Serving Elderly Mentally Retarded Persons focused on programs serving people age 55 and over (Seltzer and Krauss, 1987). In their survey of “Cutoff Points used in the Literature on Aging and Mental Retardation, these points range between age 40 and 75 (Seltzer and Krauss, 1987, p.12). A number of reasons have been suggested for the wide variety in lower age limits in research and surveys of this population: 1) the lack of good data about true life expectancy for this population, not confounded by factors such as the quality of health care received, and 2) the recent rapid progress in extending the length of life for various subgroups of people with intellectual disabilities (Seltzer and Krauss, 1987).
and sequence of special, interdisciplinary or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated." (Developmental Disabilities Assistance and Bill of Rights Act, 2000)

It is estimated that there are currently about three million people with this diagnosis living in the United States, and that one-half million elderly persons in the United States are developmentally disabled (Overeynder & Bishop, 2005). This population is expected to double by 2030 (Heller, Janicki, Hammel & Factor, 2002).

The current generation of older people with developmental disabilities is the first to outlive their parents and reach old age in significant numbers (Bigby, 2007). More people with developmental disabilities are, for the first time, reaching old age while living in small, non-institutional houses and apartments (Ansello, 1988a; Ansello & Rose, 1989; Heller, Factor & Hsieh, 1998; Janicki & Wisniewski, 1985). Members of this population are experiencing a set of unprecedented issues that they themselves, their families and caregivers, and our society are ill-equipped to address. Like the general population, people aging with developmental disabilities experience an increase in health conditions associated with aging such as arthritis, cardio-vascular conditions, diabetes, dementia, osteoporosis, and visual and hearing impairments (Anderson, 1993; Ansello, 1988a; Ansello & Rose, 1989; Kapell, Nightengale, Rodriguez et al., 1998). They are at high risk for poor health largely due to lifestyle factors such as lack of exercise and poor diet (Bigby, 2007). The overlay of cognitive and physical age-related impairments onto existing intellectual and/or physical disabilities places this graying population at magnified risk for accidents, restricted mobility, premature behavioral limitations, and a loss of independence (Mughal, 2000), and presents overwhelming challenges to
professionals in the gerontology field (Ansello, 1988; Pierce, 1992). Unlike the generic elderly, people with developmental disabilities often have very little education, have been isolated, to varying extents, from normal life experiences, and have had few relationships outside those that have taken place within their immediate families, or with their disabled peers (Ansello & Rose, 1989). When compared to younger people with developmental disabilities, they are less likely to be employed, attend a day program, or have opportunities for meaningful leisure. Their long-term relationships are likely to be disrupted due to their parents' death, residential mobility, and retirement from formal day programs (Bigby, 2007). As this growing population crosses the threshold into old age, they need additional social, medical and environmental supports to remain in their homes. This includes a pressing need for viable housing options for these individuals, many of whom are experiencing decreasing functional abilities (Heller & Factor, 2000).

This line of inquiry is of paramount interest to social work. The social work profession's values focus on the worth, dignity and uniqueness of each individual. The National Association of Social Workers (NASW) advocates fostering people's rights, self-determination, and access to resources and opportunities (NASW, 1996). The NASW Code of Ethics states that, “The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. An historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of
society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living” (Code of Ethics of the National Association of Social Workers, Preamble). The proposed research focuses on people with developmental disabilities in the environmental context of their homes. By definition, they are vulnerable because of their limitations in self-care and independent living activities. They are also vulnerable for all the reasons mentioned in the preceding paragraph. The overarching goal of this research is to identify forces, or variables – personal and environmental – that enhance as well as detract from the individual’s ability to function as independently as possible for as long as possible. The identification of these forces and variables is the first step in being able to manipulate them to optimize their impact on the individual.

The current study draws on data collected for a primary study on home modifications during individual, in-home assessments of 129 adults with developmental disabilities. Data were examined to determine the relative importance of personal and environmental characteristics that correlate with functional ability. The impact of impairment (the physiological), the built environment with its barriers and supports (the physical), and personal expectations (the psychological) are expected to have an effect on functional ability. Stronger relationships carry increased potential for future research investigating predictors of functional ability.

The data used for this study were collected during an individual multifaceted, in-home assessment of each participant, sometimes in the presence of and, at times, with the assistance of, a member of their direct-care staff. These data were originally
collected for an applied research study exploring aspects of the physical environment of the homes of people aging with developmental disabilities that either reinforced or undermined each person’s ability to age in place. Subjects were selected using a multistage strategy that included criterion, purposeful and pragmatic approaches, from among a population of 194 adults, living in small, community-based residential settings. This study included a sample of 129 adults who volunteered to participate in the study.

During the assessment, quantitative and qualitative data were collected including basic demographic information regarding each consumer and her or his home environment, a face-to-face interview with consumers, and a directed observation of everyday home-based tasks. A small number of interviews with consumers' direct-care staff were completed to supplement the data by adding a caregiver perspective. The goal of the original study was twofold:

1) Evaluate the person-environment relationship for each subject and to then make recommendations as to how the home could be made safer, more convenient and more conducive to autonomous behavior for the individual.

2) To compile, evaluate and use the data to create a manual to help family caregivers, provider agencies, and individuals with developmental disabilities make home modifications to create safer, more convenient home environments that would facilitate as much independence as possible for as long as possible, and allow consumers to age in place, rather than be moved to a more restrictive setting.
The goal of the current study was to use the quantitative data to gain a better understanding of the correlates and predictors of functional ability among these adults who are aging with developmental disabilities, and, in many cases, experiencing additional age-related problems. The qualitative analysis provides an opportunity for a more layered investigation of the participants’ experience of everyday life in a supported-living, community-based, residential setting. Participants’ observations help to elucidate and characterize the quantitative findings.

**STATEMENT OF THE PROBLEM/HISTORICAL BACKGROUND**

Three fundamental changes have occurred simultaneously that have had a profound effect on people with developmental disabilities and those who provide services for them. The first is the longevity of this population which, in tandem with that of the general population, has increased dramatically (Bittles, Petterson & Sullivan et al., 2002; Connolly, 1998; Lubin & Kiely, 1985; Nevins 2003-4). Historically, most people with developmental disabilities were cared for by their parents in the familial home, and did not outlive their parents, much less survive to old age (Ansello & Rose, 1989; Janicki & Wisniewski, 1985). Now the majority of adults within this population are outliving their parents (Ansello, 1988a; Bigby, 2007). The second phenomenon is the dramatic increase in our cognizance and protection of the human rights and needs of people with disabilities. This understanding has been expanding with ever-increasing momentum through numerous legal and legislative actions (Dybwad, 1999). The third development is the deinstitutionalization movement that has taken place over the last forty-plus years, and resulted in a mass move from large segregated institutions (often called
developmental centers, despite their somewhat custodial approach to care) to small-scale, community-integrated, residential settings. I will now discuss these three changes more fully and in turn.

LONGEVITY

The increase in life-expectancy has been particularly dramatic. In the 1930s the mean life expectancy for people with developmental disabilities was 19 years; by the 1970s it had risen to 59 years, and reached 66 years in 1996. The trend has been even more dramatic for people with Down syndrome, whose life expectancy increased from age nine in the 1920s to age 56 in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999). This increased life expectancy can be attributed to several factors that fall under the general category of improvements in health care and in living conditions (Ansello, 1988a; Lubin & Kiely, 1985; Sison & Cotton, 1989). There is also agreement that the demographic impact of this trend will only increase as the large baby boom cohort continue to age. Estimates place the number of older people with developmental disabilities in the United States at 1,242,800 by the year 2030 (Heller, Janicki, Hammel & Factor, 2002).

DISABILITY RIGHTS

The second phenomenon is the dramatic changes in and expansion of our understanding of the needs of people with disabilities. This is a direct result of the convergence of a number of often-related factors that have influenced the treatment of and opportunities available to this population. Disillusioned by the second-class citizenship and lack of opportunity available to their family members with intellectual
disabilities, a number of advocacy groups such as the National Association of Retarded Citizens (now known as the Arc) and the President's Commission on Mental Retardation, begun in the 1960s by President John F. Kennedy, mobilized their forces (Scheerenberger, 1987; Shorter, 2000). These advocacy groups were instrumental not only in promoting research into the causes and treatment of mental retardation, but also in legislation that promoted inclusion and opportunity for people with developmental disabilities. Much of the landmark legislation that has been passed during the previous four decades is the direct result of the work of these advocacy groups, and has resulted in better medical treatment, a more inclusive (“mainstreamed”) education, increased legal rights and improved quality of life (Croser, 2002; Dybwad, 1990).

In 1971, the Wyatt-Stickney federal court action, a landmark class action suit, established the right of people with mental illness living in residential facilities in some jurisdictions to treatment rather than mere custodial care. The final judgment allowed that the rights of people with mental illness as well as those with intellectual disabilities were being violated, stating that patients “unquestionably have a constitutional right to receive such treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition” (Wyatt v. Stickney, 1971, p. 784). It went on to define specific minimum treatment standards to be met by the state institution (Willer, Scheerenberger, & Intagliata, 1979). Following this Alabama decision similar litigation occurred in a number of other states, including New Jersey, which adopted parts of the appendix as statutory requirements (American Psychological Association, 2004). Rather
than face the costly standards imposed by the court, states deinstitutionalized many of those who had been living in their hospitals. For this reason, Wyatt was the seminal case in achieving widespread deinstitutionalization of previously committed individuals (Hooper, 2004).

Eleven years later in a related case, Youngberg v. Romeo (Youngberg v. Romeo, 1982), the Supreme Court ruled that people with mental retardation, involuntarily committed to state institutions, have substantive rights under the due process clause of the Constitution’s Fourteenth Amendment. These include the right to safe conditions of confinement, freedom from bodily restraints, and the minimal training or habilitation necessary to ensure those interests. Any infringement upon a patient’s rights, it was ruled, must be based on professional judgment and must be consistent with accepted professional judgment, practice, or standards.

In 1975, the Education for the Handicapped Act (PL 94-142, now known as the Individuals with Disabilities Education Act) was passed by Congress, guaranteeing the appropriate education of all children with mental retardation and developmental disabilities from school age through age 21 (Wiegerink & Posante-Lord, 1977). In 1986, the law was amended to cover children beginning at age three and incentives were given to states to provide infant and toddler programs (Pelka, 1997). The 1994 reauthorization of the Individuals with Disabilities Education Act (IDEA) guaranteed the right of every child to be included in a free, appropriate, publicly supported educational system that is deemed the least restrictive appropriate educational placement for each individual (Turnbull & Turnbull, 1998).
Concurrently, the disability rights movement emerged during the 1960s and was modeled after the civil rights movement. People with disabilities viewed themselves, and were increasingly viewed by others, as a minority group whose difficulties were caused by societal discrimination and prejudice. It was gradually recognized that society erected both physical and social barriers to the pursuit of opportunities by people with disabilities. Proponents of the disability rights movement sought to free themselves from oppressive social biases such as segregation and unequal treatment (Percy, 1989; Shapiro, 1993). This movement promoted (and still promotes) legislation that opens opportunities for people with disabilities to participate more fully in the everyday life of our society. In 1973, the disability rights movement was instrumental in the passage of Section 504 of the Rehabilitation Act, which promised people with disabilities non-discriminatory participation in any program or activity that received federal financial assistance (Pelka, 1997). The Americans with Disabilities Act [ADA] is another landmark civil rights law advocated by the disability rights movement. The Act calls for making all aspects of public life accessible to, and inclusive of, people with mental, physical and sensory disabilities (Dart & West, 1995), and was further supported by a move toward ‘normalization' (Nirge, 1969).

The original principle of the normalization movement was to promote the idea that people with disabilities deserved to participate in patterns and conditions of everyday living that are as close as possible to the norms established by mainstreamed society, and to make such settings and conditions available (Nirge, 1969; Pelka, 1997; Wolfensberger, 1970). The normalization movement, begun after World War II in
Scandinavian countries, was instrumental in providing additional momentum to the disability rights movement. Wolf Wolfensberger (1970) is largely responsible for transferring the principle of normalization to the United States and generalizing it to all sectors of human services and to all socially devalued groups (Heller, Spooner, Enright, Haney & Schilit, 1991; Trent, 1994). Wolfensberger also suggested replacing the medical model of disability, which emphasizes developmental limitations, with what he referred to as the 'developmental model' of disability, which emphasizes developmental potential. In later years, he refined this model, replacing the concept of human deviancy with the concept of social devaluation, and proposed that positive social roles were necessary to reverse social devaluation. In 1983, Wolfensberger renamed this more evolved principle of normalization “social role valorization,” and defined it as, “the enablement, establishment, maintenance and/or defense of valued social roles for people, particularly for those at value risk, by using as much as possible, culturally valued means” (Wolfensberger, 1991, p.36). As a result of this increased emphasis upon the importance of social factors in maintaining disability, the inadequacies in clinical models of disability became increasingly apparent (Llewellyn & Hogan, 2000).

Deinstitutionalization

The third factor, the deinstitutionalization movement, has been, in part, a direct outgrowth of our deepened understanding of the needs of this population and the subsequent legal and human rights they have gradually been granted during the last four decades. Disillusionment with residential "training schools" that had begun as educational institutions, but had spiraled downward to become custodial living centers,
began as early as the late 1950s (Scheerenberger, 1987). Although a minority of the population were living in public institutions at the time\(^3\), Dybwad (1964), then a firm believer in institutional care, noted in an address at the Annual Convention of the National Association for Retarded Citizens in 1959, that, “Institutional care in general is not well accepted these days. ... Some people have maintained that as far as the future of state institutions for the mentally retarded is concerned there is no basis to think of such a future since ‘institutions are on the way out.’” (p. 83). The deinstitutionalization movement began concurrent with a series of largely unfavorable critiques involving neglect and abuse of people with disabilities living in a variety of institutional settings. In a series of court cases in the 1970s, federal judges ruled that the prevailing cruel conditions at institutions for the developmentally disabled were unconstitutional, and that people with psychiatric disabilities who were not dangerous to themselves or others could not be incarcerated against their will. These decisions increased not only the difficulty of continuing institutionalization, but also the expense, since facilities were then required by law to offer safety, education, recreation and rehabilitation (Pelka, 1997). The Nursing Home Reform Amendments contained in the Omnibus Budget Reconciliation Act of 1987 required that persons with mental retardation who are not in need of skilled nursing care, be transferred from nursing homes to community-based settings (Braddock, Hemp, Parish, Rizzolo, & Pomeranz, 2002). State agencies responsible for the welfare of this segment of the population were prompted -- by both the rationale of normalization and the law -- to de-institutionalize the people relegated

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\(^3\) Dybwad (1964) states that, “…federal figures for 1957 indicate that for the 5,000,000 retarded persons in the United States, only 150,000 reside in public institutions.” (p. 14)
to development centers and move them to community-based settings. In June 1999, the Supreme Court ruled that it is a violation of the ADA for states to keep individuals with disabilities in institutions when they could be more appropriately served in the community (Olmstead v. L.C., 1999). The majority opinion states:

Specifically, we confront the question whether the proscription of discrimination may require placement of individuals with developmental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. In so ruling, we affirm the decision of the Eleventh Circuit in substantial part. We remand the case, however, for further consideration of the appropriate relief, given the range of facilities the State maintains for the care and treatment of persons with diverse mental disabilities and its obligation to administer services with an even hand. (L.C. & E.W. vs. Olmstead, p. 588)

With this decision the Supreme Court noted that unnecessary segregation and institutionalization constitute discrimination and violate the ADA’s mandate to integrate, into the wider society, those with developmental disabilities unless certain defenses are established. The court stated that a state may have a defense to lawsuits challenging the state's failure to serve individuals in an appropriate and integrated setting if it has a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings. The Court conceded that states may maintain a waiting list of individuals appropriate for community services, in conjunction with their comprehensive work plan (The Arc of the United States, 2000). A major legal defense to implementation has continued to be lack of resources. The Olmstead decision includes the statement,
In evaluating a State’s fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State’s obligation to mete out those services equitably. (L.C. & E.W. vs. Olmstead, 1999)

This ruling also marks the first time the concept of "least restrictive setting," until then usually associated with education of children with disabilities, was applied to residential environments for adults with developmental disabilities.

Following this Supreme Court decision, the Clinton administration issued a policy statement informing states that in order to comply with the Olmstead v. L.C. case ruling, they would almost certainly have to shift people out of institutions and into small group homes or apartments. The Clinton administration told states that they would be expected to evaluate all individuals with disabilities living in institutional settings to determine if their needs could be better met in the community. The administration made it clear that the ruling also applies to people living at home who are at risk of institutionalization if the supports they need to live in the community are not made available to them (Pearson, 2000).

In 2001, President George W. Bush announced the New Freedom Initiative – a plan to eliminate the barriers to full integration faced by people with disabilities. Its aims include promoting full access to community life. As part of this initiative, President Bush issued Executive Order 13217 calling for swift implementation of Olmstead, and requiring coordination among the numerous Federal agencies that administer programs affecting community access for people with disabilities. The Department of Health and Human Services has awarded nearly $160 million in Real System Change Grants since

Consequently, the twenty-first century is witnessing a boom in a population that was sparse in the previous century -- people with developmental disabilities in their forties, fifties and older, such as those in this study, who are living increasingly longer in small-scale, community-based settings. While this population has characteristics and needs that overlap with those of the general aging population, it also has characteristics that distinguish its circumstances and needs. Provider agencies are grappling with the problems of keeping this population safe, productive, integrated with their community, and as independent as possible while they 'age in place' rather than face unnecessary or premature institutional placement and the social deprivation and custodial care with which they are associated.

THEORIES THAT HAVE INFORMED PRIOR RESEARCH

As our understanding of the human rights and needs of people with disabilities expanded, our appreciation of their relationship to the environment also has undergone dramatic change. Just as societal discrimination and prejudice can be manifested in socially biased practices and legislative disregard, it can also be revealed by a physical environment that is unresponsive to its residents' needs.

For many years, the medical model of disability defined the dominant view of the disablement process, and informed and directed disability research (Steinfeld &
Danford, 1999). The prevailing model during this time -- the International Classification of Impairments, Disability and Handicap (ICIDH), also known as “the WHO (World Health Organization) model” (World Health Organization, 1980) -- is notable for its lack of attention to the environment. In this model, an individual’s health condition leads to an impairment, which is defined as a disturbance at the level of the organism. This impairment then leads to disabilities, which are defined as limitations in activities. Finally the disability leads to handicaps, defined as limitations in social participation. (See Figure 1.)

![Diagram of ICIDH model]

**Figure 1**

**The World Health Organization Model, 1980**

Aside from the fact that this model is an oversimplification – health conditions, such as pregnancy, can lead to functional limitations without leading to impairment, while the stigma of any number of conditions can cause handicaps that are unrelated to abilities or disabilities – it is most notable for its complete disregard of the environment, the relationship of the environment to disability, and ways in which environments contribute to or even create disability. With this model, environmental interventions were considered an extension of prosthetics implemented to deal with personal pathology or imperfections (Steinfeld & Danford, 1999).

In the wake of the inadequacies of the WHO model, there have been a number of perspectives and models that speculate as to the role played by the environment, and the interactive relationship between people and the setting or context in which they
conduct their lives. The medical model has been largely replaced by a new set of theories termed the "transactional" model.

Transactional theories are, in part, an outgrowth and adaptation of the eco-systems perspective in social work, which focuses on the way that people and environmental forces interact (Grief & Lynch, 1983). Ecology is defined as, “the study of complex reciprocal and adaptive transactions among organisms and their environments” (Grief & Lynch, p. 36). The unit of attention is the person-in-situation, and the person is perceived as both affecting and being affected by their ecological milieu or environment.

Germain (1973) cites William Gordon (1969) with the idea that the social work profession need recognize the interface between the person and the environment, “thus making use of the ecological metaphor to address the "goodness of fit" between the two" (Greif & Lynch, p.39). Germain (1978) addresses the ecology of space and the effect of the arrangement of space on the individual and group. She points out that the social work profession has a record of concern for the microenvironment – the physical and social settings where people live and work, and this concern is consistent with the transactional model of stress and coping (Germain, 1983). This model proposes that a good fit between people and their environments is of benefit to both entities. It benefits the person by supporting and promoting growth, health and social functioning and bringing about social satisfaction. Reciprocally, the environment benefits from the growth, health and satisfaction of its inhabitants. Conversely, inadequate transactions are likely to impair personal development and functioning and defile environments,
prompting what can become a downward spiral of maladaptation. Transactional interventions consider the qualities of both the person and the environment (Germain, 1983).

Proponents of the “transactional” perspective argue that a fundamental knowledge about the relationship of disability to the environment, and the ways in which environments contribute to disability and handicap, is needed. They point out that non-medical interventions in the context of a person’s life may be just as significant as medical care.

**Figure 2:**
Transactional model (adapted from Steinfeld and Danforth, 1999, p. 4)

Steinfeld and Danford (1999) propose a model in which the environment and personal abilities mediate both functional ability and social participation. In this model, the focus is on abilities and how they are supported or limited by physical and social factors. (See Figure 2.) Impairment, defined as “disturbances at the level of organism” (p. 2) lead to disability or limitations in activities, which in turn leads to handicap which is defined as “limits in societal participation” (p. 2) At the time that this model was
proposed, environment was not generally taken into account. By including the environment as a factor influencing disability and handicap this model departed from earlier models.

This approach is consistent with the strengths perspective in social work practice, which also arose as an alternative to the WHO, or the diagnostic model's inadequacies, and builds on the values of the profession by emphasizing the individual's resources and strengths, rather than focusing on their limitations (Weick, Sullivan & Kisthardt, 1989). This perspective advocates empowering individuals by helping them gain more control in their lives, through the recognition of their strengths and assessing these strengths in the context of their environment (Cowger, 1997; Rappaport, 1981; 1990; Russo, 1999; Saleebey, 1997, Weick et al., 1989).

Steinfeld and Danford suggest that the transactional model of fit (also called the “transactional multi-method approach”) better reflects the process through which individuals experience and adapt to their environment. They point out that because transactional processes are complex, multi-method research strategies are necessary to measure fit. For example, research should incorporate both professional and consumer perspectives, and utilize both global and fine-grained measures (Steinfeld & Danford, 1999).

Other transactional models have been proposed, most notably by Lawton and Nahemow. In 1973, Lawton and Nahemow developed the environmental docility hypothesis, a theory related to the individual's level of adaptation, based upon the work of Harry Helson. Helson defined adaptation as a “mechanism for acquainting us with
changes in the environment” (1964, p. 43). An adaptation process experienced by the person gradually neutralizes her or him to a temporal stimulus so that a constant degree of intensity is maintained by the environmental stimulation. Eventually, after an initial rapid change in activity and sensitivity, the stimulus is no longer perceived and “adaptation level” has been obtained. While Helson used the adaptation level to explain psychophysical phenomena, Lawton and Nahemow extended it into other realms of experience, and called this phenomenon the “ecological theory of aging” (Lawton & Nahemow, 1973; Nahemow, 2000). They suggested that the environment exerts “press” upon a person – either supporting or challenging a person to act within her or his environment. The consequences of “environmental press” upon a person are dependent upon the competence of the person. Mismatches between the press of an environment and the functional capabilities that a person may possess can lead to situations where the person’s functional independence and performance are seriously compromised. This compromised condition can be caused by either an environmental press exceeding a person’s coping capacity, which results in a condition referred to as “overload”, or the environment presenting only features or situations that are well below an individual’s capabilities, leading to a condition of “deprivation”. Coping capacity is defined as individual resources to and mechanisms to minimize the threat. Fit has variously been defined by some objective performance criteria developed by an outside observer, created by the individual, or imposed by one’s social milieu. Lawton and Nahemow define fit as the point of equilibrium where an individual’s capabilities are in balance with the press of the environment. Equilibrium is defined as the “zone of
adaptation” within which individuals are sufficiently challenged to ensure that they will continue to find that they have the ability to adapt, yet they are not so challenged or deprived that they are under pathological stress. (See Figure 3.)

**Fit** is socially defined as a situation that represents congruence between the desired presentation of self and the reflected self as perceived by others.

There are several ways that a fit is achieved. When the elderly or the disabled are relocated to a more supportive setting, such as a nursing home or developmental center, they are insulated from challenges as their mastery declines. Conversely, an individual with a high level of competence will often maintain a high exposure to challenge by simultaneously performing several challenging roles. With its emphasis on

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**Figure 3**

**Ecological Theory of Aging (adapted from Lawton & Nehemow, 1973, p. 661)**
autonomy and independence, current rehabilitation practice aims to compensate for declining abilities and to reduce environmental press by providing environmental supports, including home modifications, to help people achieve or maintain competence (Faletti, 1984).

**STUDY PURPOSE**

An important consequence of transactional theory is the elevated importance of the environment. This motivates researchers to assess the impact of environmental interventions on behavior. The proposed study's purpose is to look at correlates of functional ability and examine hypotheses about predictors of functional ability, as well as to explore the perceptions of consumers and staff regarding the experience of supported living environments in settings designed to allow consumers to integrate into the community mainstream. A major reason to understand the factors that correlate with and predict autonomy and independence among people aging with developmental disabilities is to help them remain as safely independent as possible for as long as possible.

**RESEARCH QUESTIONS**

The research questions were based on a review of the literature on the interconnection between environment and behavior, and intellectual and developmental disabilities. The questions guiding this research were derived from theoretical models previously described that indicate the importance of person-environment fit in adaptation, satisfaction and autonomous behavior in daily-living activities. By definition, it was assumed that developmental disability is related to
observed function. However, people may under-perform relative to their actual capabilities; and people with developmental disabilities may have negative self-images that limit their personal goals and prevent them from engaging in specific activities (Gargiulo & O'Sullivan, 1986; Glick, 1999; Rholes, Blackwell, Jordan & Walters, 1980; Weisz, 1979; 1999).

In this study, descriptive variables including accumulated overall impairments, accumulated physical impairments, environmental accessibility level of the home, and supervision level of the housing-type, were examined to investigate relationships between impairment and two measures of functional ability. Qualitative and quantitative data eliciting consumer and caregiver perspectives on the relationship between self-care and the home environment have been used to explicate empirical findings. The primary research questions were:

1. How are impairment and functional ability related?
2. a. What is the relationship between consumer self-report of functional ability and observed functional ability?
   b. What are consumer and staff perceptions about the relationship of aging with a disability, staff supported, community-based living and functional ability?
3. How are environmental accessibility and functional ability related?

The corresponding hypotheses were:

1. People with fewer physical impairments will demonstrate greater functional ability, while those with the greatest degrees of physical impairment, such as quadriplegia, will demonstrate less functional ability.
2. People with greater observed functional ability will have greater self-reported functional ability.
3. Physical ability will be inversely related to the degree of accessibility of the living environment. For those with mobility impairments, home modifications to improve physical accessibility will not compensate for the physical impairment of the individual.
CHAPTER TWO: LITERATURE REVIEW

Previous research on people aging with developmental disabilities has dealt largely with issues related to population characteristics, health and the impact of age-related changes on health, aging parents of adults with developmental disabilities, and, to a lesser extent, retirement and lifestyle choices (Heller, Janicki, Marks, Hammel & Factor, 2008; Hogg, Lucchino, Wang & Janicki, 2001; O’Brien & Rosenbloom, 2009; Salvatori, Tremblay & Tryssenaar, 2003). When reviewing the literature on people with developmental disabilities, it is quickly apparent that children with developmental disabilities have received a disproportionate amount of attention compared to their adult counterparts, and even less attention has been directed to the elderly. Among the literature on adults, there are many descriptive articles outlining and elucidating overarching issues such as population characteristics, health issues, general service provision, particularly as it relates to expenditures, leisure activities and social life, residential settings and outcomes, and deinstitutionalization and adaptive behavior (e.g., Bigby, 2007; Campbell and Herge, 2000; Lakin & Stancliffe, 2007; Lifshitz & Merrick, 2004; Stancliffe, Emerson & Lakin, 2000; Sutton, 1997). Many of these report the results of surveys: percentages of people within a given category, such as experiencing specific health conditions, having a plan for future care, displaying challenging behaviors, or the extent of informal supports needed and/or received by a given cohort (e.g., Bigby, 2004; Campbell and Herge, 2000). There are also a number of review articles that summarize and assess past reports and studies on similar and other specific issues, also with the goal of clarifying and consolidating existing information.
(e.g., Campbell and Herge, 2000; Felce & Emerson, 2001; Heller, 2002; Kim, Larson & Lakin, 2001; Kozma, Mansell & Beadle-Brown, 2009; McCallion & McCarron, 2004; Walsh, 2002). While there are many articles of tangential and background significance to the current study, a review of the literature revealed less empirical research of direct significance. For this reason, the search was broadened to examine environmental research with populations beyond those with intellectual and developmental disabilities. For example, a study on adolescents and young adults with cerebral palsy is included because it elucidates findings on the caregiver expectations of people with and without physical disabilities. A study of people who have recently suffered a stroke has been included because it elucidates the relationship between environmental factors and impairment. Despite the fact that some bear a tangential relationship, they all address issues that are of sufficient bearing to warrant inclusion in this review.

Most of the research that does exist is found in disability, psychology and occupational therapy literature. It is surprising what scant attention the social work literature has to offer in this area to which so many social workers devote their energies and careers.

**Prior Research**

The literature reveals some key predictors of positive functional outcomes for people with disabilities, including smaller, community-based housing environments, organizational policies and staff attitudes that reflect values of consumer empowerment and inclusion, residents' self-perceptions, appropriate person-environment fit including
both supportive home modifications and assistive technology, and an absence of severe mobility limitations.

**The Impact of Less Restrictive Environments on Functional Ability**

While adults with mild intellectual impairments or developmental disabilities that cause solely physical limitations may be able to live independent of caregivers and service providers, the majority of adults with moderate and severe intellectual disabilities who are not cared for by their families, live some portion of their lives in residential settings provided by service agencies and offering staff support (Felce & Emerson, 2001). In the previous chapter, the court decisions leading up to the deinstitutionalization movement, and the movement itself, were briefly outlined (see pages 10-12). In addition to the impetus to put an end to custodial care and the additional momentum provided by the normalization movement, there was a strong sense that community-based settings offered the least restrictive environment appropriate to many adults with developmental disabilities. Low-support settings were deemed preferable, in part because of the increased flexibility and opportunities for self-determination at a lower cost to provider agencies and families that they offer (Blumberg, Ferguson & Ferguson, 2001). The philosophy of and movement toward community living has been seen as favoring independence, physical and social integration and inclusion, individualized consumer-based services, community-based employment, and empowerment to make life decisions (Henry, Keys, Balcazar & Jopp, 1996). High support settings, conversely, were then, and continue to be, viewed as more restricted and regimented (Blumberg, Ferguson & Ferguson, 2001).
Deinstitutionalization has been a major policy initiative over the past four decades not only in the United States but throughout developed countries, much research has been undertaken in order to evaluate its impact (Emerson & Hatton, 1994; Felce & Emerson, 2001; Hatten & Emerson, 1996; Heller, 2002; Kim et al., 2001; Larson & Lakin, 1989; Young, Sigafoos, Suttie et al., 1998). This research focused, to a large extent, on setting type and size. Overall findings revealed more positive outcomes for people living in smaller, community-based settings. Many researchers have found that people with developmental disabilities exhibit significant strides in adaptive behavior shortly after moving from an institutional to a community-based setting (Emerson & Hatton, 1994; Hatten & Emerson, 1996; Heller, Miller & Hsieh, 2002, Larson & Lakin, 1989; Kim et al., 2001; Young et al. 1998). It has been suggested that the improvement may be a reflection of the increased opportunities individuals are provided to display their existing skills in community-based settings (O’Neill, Brown, Gordon et al., 1985). It has also been noted that there are many exceptions to this positive trend (Cullen, Whoriskey, Mackenzie et al., 1995; O’Neill et al., 1985; Wing, 1989). Many authors of longer term studies have reported a "plateau effect" after the initial increase in skills (Hemming et al., 1981; Klienberg & Galligan, 1983; Lowe et al., 1993; Lozano, 1993; Cambridge et al., 1994). Research has shown that technical and educational support usually accelerate functional skills and adaptive behavior (e.g., Iwata, Bailey, Neef et al., 1996; Reid, Phillips & Green, 1991). Less institutional environments have been accepted as more likely to offer the enriched atmosphere in which training and teaching occur (Felce & Emerson, 2001). Furthermore, research reveals that community-based housing
has resulted in greater staff: resident interaction and increased engagement among residents (Felce & Perry, 1995).

There is evidence, however, that many direct care staff lack the proficiency to implement training (Parsons, Reid and Green, 1993), and that they often give less attention to individuals with lower abilities or more challenging behavior (Felce & Perry, 1995; Felce, Jones, Lowe & Perry, 2003). Felce and Perry found, in a study of staff:resident interactions and resident engagement in activity in 15 housing services, that residents who scored lower on the Adaptive Behavior Scale (ABS; Kushlick, Blundell & Cox, 1973) had "virtually no opportunities provided for participation in domestic activities" (Felce & Perry, 1995; p. 808). The authors go on to state, "As meal preparation, clearing away, cleaning, laundry and other household maintenance tasks need to be done, the clear inference is that these were achieved largely by staff independently of resident involvement" (p. 808). This division of labor, the authors point out, not only deprives the residents of learning and participation opportunities, but also preoccupies the staff and lessens the amount of time they have to spend with the residents.

Another study examined associations between staffing levels, staff activity and staff attention to residents in 29 group homes in the south of Wales, and analyzed their relationship to resident and setting characteristics (Felce, Lowe & Jones, 2002b). The investigators looked specifically at the reported range and frequency of social and community activities engaged in by consumers, the reported extent of participation in domestic activities, and the reported extent of engagement in activity within the
residences. A convenience sample was recruited by asking senior social service personnel to identify three or four community-based, staffed group homes in each of three categories: statutory, voluntary and private community provision schemes. Among these, 29 group homes agreed to participate: ten in the statutory, ten in the voluntary and nine in the private sectors. These accommodated a total of 97 residents with a mean age of 45 years (range, 21-86 years). Resident abilities were measured by the Adaptive Behavior Scale and had a wide range, with those in the private sector being disproportionately less able. There were no significant differences between sectors in the presence of challenging behaviors, measured by the Aberrant Behavior Checklist (Aman & Singh, 1986). Data on staffing intensity, qualifications and experience was obtained in an interview with each house manager. Descriptive information on the internal organization and management practices of each setting was also obtained during this interview using the Residential Services Working Practices Scale (Lowe et al., 1998; Emerson et al., 2000b) and the Group Homes Management Scale (Raynes et al., 1994). The extent of planned activities was assessed from interviews with direct-care staff and weekly diaries, which tracked the time and length of activities and where they took place (home or community). Staff activity was recorded by observers who conducted observations from 4 to 7 pm during two weekdays at each participating house. Surprisingly, the results revealed that higher staff to resident ratios was associated with less assistance to residents, staff doing more household activities and lower resident participation in household tasks. However, the researchers found that number of years of staff experience had a positive correlation with staff spending more
time with consumers, less time doing 'other activities' such as office and administrative work, and more time spent assisting consumers.

In a study of the level of functional independence and self-determination in daily care tasks among 54 consumers with developmental disabilities, Saloviita and Aberg (2000) compared subjects living in an institutional setting, community group homes, and apartments. Participants' mean age was 43 years, and varied between 19 and 72 years. Participants' level of disability was rated as mild, moderate, or severe/profound. No consumers categorized as having a severe/profound level of disability lived in apartments. Direct-care staff acted as proxies for the consumers and rated their daily care abilities undertaking 22 activities on a three-point scale. Topics addressed included housekeeping tasks; food selection, procurement and preparation; and decision-making about everyday activities and planning. Self Determination Scores (SDS) were calculated as the sum total of the scale, and mean scores were calculated for each housing type. Predictably, the researchers found that the highest rate of self-determination was among the apartment dwellers. The SDS level between group home dwellers and institution dwellers was not significantly different, although the former was slightly higher. There was a statistically significant association between the level of disability and the level of self-determination. Within all housing categories, there was considerable variation in scores. Examined alone during separate analyses with disability level held constant, disability level of the participants explained differences between the housing types, because people with higher levels of impairment are placed in residential

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4 It is interesting to note that in a study of self-determination, defined by Wolfensberger as free choice of one’s own acts without external compulsion, proxies were used as spokespersons for the consumers.
settings with higher levels of supervision. The authors comment that, "...at least in some aspects, it is the type of residence which generated the care observed rather than the characteristics of the residents" (p.27). Nevertheless, the similar scores of residents of the institution and the group homes is interesting. The authors explain this, in part, by the fact that the institution is a small, progressive establishment where wards are divided into small units similar to the size of group homes. By contrast, the group homes in the study were fairly large, housing an average of 8.5 participants. The authors conclude that the self-determination of people with developmental disabilities living in supported housing can only be guaranteed by organizing supports based on consumers' individual choices.

**THE ROLE OF EXPECTATIONS IN DISABILITY**

There has been a paucity of research in both self-expectations and self-images of people with intellectual disabilities (Glick, 1999). The reasons for the lack of research in this area have been posited to include perceived difficulties with self-report and measurement, given the cognitive and communication limitations among this population (Zetlin, Heriot, & Turner, 1985), and a preoccupation with cognitive functioning (Zigler, 1971).

Researchers have observed that people with intellectual disabilities often have low expectations of personal success, which undermine and inhibit their task performance. They attribute their low expectations to attempts to complete tasks correctly that repeatedly result in failure, thereby extinguishing the expectation of success. Studies have shown that one of the consequences of a lifetime characterized by
frequent confrontation with tasks that are beyond the intellectual ability of the individual is lowered motivation to achieve success (Zigler & Balla, 1982; Zigler & Hodapp, 1986). In situations perceived as challenging, it has often been observed that people with intellectual disabilities give up without trying (Bennett-Gates & Kreitler, 1999). Repeated experiences of failure interact with cognitive, developmental and situational factors, contributing to and confounding environmental press. The main motivation shifts from achieving success to avoiding failure (Bennett-Gates & Kreitler, 1999; Bennett-Gates & Zigler, 1999; Bybee & Zigler, 1998; Cromwell, 1963.)

Magill-Evans et al. (2001) compared families of 90 adolescents and young adults with cerebral palsy to families of a control group of 75 of their peers without physical disabilities. Each subset was divided into two age groups: adolescents (mean age of 14.2) and young adults (mean age of 20.6). The subset of the sample with cerebral palsy was further divided into two groups: CP1, composed of individuals able to actively participate in all phases of the research and CP2, those unable to answer for themselves because of communication and/or cognitive limitations (approximately half the subset). Parents acted as proxies for the latter group. Using a variety of measures, including The Futures Questionnaire (FQ; Arnold & Chapman, 1992), an instrument designed for people with disabilities and evaluating their future expectations, the study investigated participants’ anticipation of success in future relationships, postsecondary education, employment and independent living. When scores of the CP1 group were compared with the control group’s scores, the researchers found that young adults with cerebral palsy had significantly lower expectations for their future achievements in all of the
measured areas, compared both to the subset without disabilities and also, perhaps counter-intuitively, to the adolescents with cerebral palsy. Parents of both adolescents and young adults in the CP1 group also had lower expectations for their children than those in the control group. For the CP2 group – the most severely involved members of the sample, parents had the lowest expectations for their children’s futures. The authors suggest that families of individuals with cerebral palsy need to be aware of the positive changes in social, work and living arrangements that are impacting outcomes for people with disabilities.

In a study measuring the differences between self-reported disability and observed functional limitations among 1453 community-dwelling (defined as not living in nursing homes) men and women between the ages of 63 and 94, subjects were asked to complete a disability questionnaire prior to an exam conducted by a trained nurse measuring participants' ability to complete specific tasks in a clinical setting (Kelly-Hayes, Jette, Wolf et al., 1992). The disability questionnaire, mailed to participants one week before their exams, included questions on each subjects' perceived ability in six basic activities of daily living [ADLS]: dressing, walking, grooming, feeding, chair transfers, and stair climbing. These same ADLS were rated during subject exams conducted by a nurse-practitioner. Both participants and the nurse-rater used the same 4-point scale. The vast majority (92%) did not report any disability and were not observed to have any limitations. Differences occurred between reported disability and functional limitations in 3.1% to 6.6% of the cohort, and were most prevalent in the walking and stair-climbing tasks. At least 89% of the time when a difference between
self-report and observed limitations occurred, the self-reported disability was greater than the observed limitation. Furthermore, in all six tasks, those with cognitive impairment and those who were among the older members of the sample demonstrated significantly larger differences. Those with cognitive impairments demonstrated the largest disparity between the two scores. The authors conclude that physical functional limitations and reported disability are two distinct concepts, particularly among high-risk subgroups, such as the cognitively impaired. This study, however, is limited by the fact that it was conducted at a clinic and not 'in situ' at the participants' homes. Participants' ratings as to how well they could complete activities in their home and, then, at the clinic are assumed, in this study, to be the same, while, in reality, the setting is likely to have impacted their ability. Furthermore, those unable to get to the clinic due to disability were excluded from the study, further limiting its generalizability.

THE ROLE OF THE ENVIRONMENT IN DISABILITY

Theories that posit that the environment plays a major role in handicap, impairment, and functional abilities have gained considerable support in the past thirty years. These theories suggest that the interaction between the environment and the person can be improved through environmental modification (Iwarsson, Isacsson & Lanke, 1998; Lawton, 1980; Nordenfeldt, 1993; Rousseau, Potvin, Dutil, & Falta, 2001). However, to confirm or refute such broad theoretical statements with solid evidence has proven challenging and most research studies have focused on a very limited aspect of the environment.
In the past three decades there has been an increase in research that focuses on how different environmental characteristics of residential settings affect the well-being of people with developmental disabilities. Most of this research has dealt with how size and type of residential setting influence the adaptive behavior of their occupants (Conroy, 1996; Emerson, Robertson, Gregory et al., 2000; Heller, Factor & Hsieh, 1998; Heller, Miller & Factor, 1999; Hill, Rotegard, & Bruininks, 1984; Stancliffe, 1997; Stancliffe & Aber, 1997; Stancliffe, Aber & Smith, 2000; Wehmeyer & Bolding, 1999). Recently researchers in the field of developmental disabilities have begun to look at other aspects of the physical environment (Heller, Factor, & Hsieh, 1998). However, gerontologists and psychologists have a slightly longer history of engaging in environmental and behavioral research.

Positive physical qualities of housing environments have been associated with enhanced resident functioning, activity level and social contacts on the part of residents (Lawton, 1977; Moos & Lemke, 1980). Many of these findings may also apply to people aging with developmental disabilities.

In an exploration of the relationship between environmental factors and impairment following a stroke, Rochette, Desrosiers, and Noreau (2001) conducted a cross-sectional study among 51 stroke rehabilitation patients. Along with demographic variables, they measured the influence of perceived environmental barriers and facilitators, and the level of handicap, defined as "performance in the accomplishment of daily activities and social roles [the dependent variable]" (P. 561). They found that
perceived social and physical environmental obstacles, together with age and the level of impairments, explained 58.9 percent of the variation in handicap level.

Two descriptive studies, both conducted by the Chicago-based Research and Rehabilitation Training Center on Aging with Mental Retardation, have evaluated the functional effects of assistive technology and environmental interventions on people aging with developmental disabilities. The first study screened the functional abilities of 35 persons with cerebral palsy and mental retardation and provided referrals to assistive technology – environmental intervention [AT-EI] services as needed (Hammel, Heller & Ying, 1998). Subjects were classified into two groups – those to whom AT-EI was provided, and those for whom AT-EI was never present or present but had been removed. Participants were rated twice – once at the time of screenings, and again, 18 months later. Results showed that those with AT-EI support improved or maintained their functional ability, while those without this support did not (Hammel & Heller, 2000; Hammel, Heller & Ying, 1998).

The second study examined the long-term impact of AT-EI on the performance of 32 ADLs and instrumental activities of daily living [IADLs] by 109 adults with developmental disabilities (Hammel, Lai & Heller, 1999). Over a four-year time period, 90 percent of those who used AT-EI had improved or maintained task performance abilities, while only 10 percent declined. Among those without AT-EI, 27 percent experienced functional losses, while 73 percent improved or maintained their abilities.

In an effort to determine the specific environmental information that enables and disables the individual with a disability, Finkel (1999) examined "wayfinding", that
is, “the process of moving from one location to another predetermined location” (p. 332). Wayfinding generates a foundation for information and behavioral responses within the built environment. Finkel’s sample was comprised of 60 adults, 15 of whom were sighted, and 45 of whom had visual impairments. The individuals with visual impairments were divided into three subgroups: 15 with low vision and no assistive devices, 15 with white canes, and 15 with guide dogs. In this study, participants were guided through a prescribed interior route, and then asked to retrace the route as the researcher followed, explaining as they went, why they were making particular decisions. After retracing the route, participants were asked to create a tactile map of the route using magnified wood strips. Finally, participants were interviewed regarding their experiences finding their way through public buildings. Although the sighted participants made fewer errors and took less time to navigate the route, their ratings of the accessibility of public buildings were not significantly different from the visually impaired subgroups. Participants in all of the subgroups (including the sighted group) frequently described a lack of landmarks as a problem area in wayfinding. Findings indicated that both the functional and psychological implications of design – namely the belief that the environment does not pose barriers – are components of a truly accessible environment.

A study of the impact of assistive devices and environmental modifications on everyday activities and caregiving for young children with cerebral palsy, reported findings that may be relevant to older adults with cerebral palsy and other physical mobility-related disabilities (Ostensjo, Carlberg & Vollestad, 2005). Because of the
relative dearth of similar studies among a population comparable to those in the current study, it has been included in this review. Ninety-five children with cerebral palsy were assessed in three areas: functional independence, defined as their ability to perform essential tasks in the area of self-care, mobility and social function; the amount of caregiver assistance needed to perform these tasks; and environmental modifications, defined as alterations to support performance in performing these same tasks. Much of the data were obtained through parent/caregiver-report. The Gross Motor Function Classification System (GMFCS: Palisano et al., 1997) was used to categorize the severity of physical disability into five levels of limitations. The Pediatric Evaluation of Disability Inventory (PEDI: Haley et al., 1992) was used to measure functional skills, caregiver assistance and environmental modifications. Findings showed that 980 of 1075 environmental modifications were in regular use among 84 (88.4%) of the children included in the study. Predictably, those categorized within the two most severe levels on the GMFSC used 80% of the modifications. It was also found that environmental modifications and adaptations to motor vehicles facilitated the use of assistive devices. When parents estimated, on a 5-point scale, to what extent the modifications had improved the child’s functional independence and supported their own role as caregivers, 50% rated the modifications to have a moderate to very large impact on the child’s mobility, 25% felt that they improved self-care skills, and 20% felt that they improved social function. (It should be noted that the mean age of the children in the study was 58 months, an age at which any child’s self-care and social skills are in the early phases of development.) Sixty-five percent of parents felt that the impact of the
modifications on mobility eased their role as caregivers, 75% felt the modifications’ impact on self-care eased their caregiver burden, and 25% felt their impact on social function made it easier for parents in their caregiver role. The nine percent of the modifications that were not helpful included those deemed not preferred to a specific more appropriate modification (toilet modifications are the example provided), and modifications or devices that the children did not need (modified eating utensils are provided as an example). Modifications which were less practical than other methods, such as a transferring board for a child who was easy to lift, were also not helpful. Large devices, such as power wheelchairs that took up so much space that they got in the way of other activities were also not favored. The authors conclude that comprehensive assistive technology assessments and increased attention to home and vehicle modifications to support the use of assistive devices are warranted. Again, it is important to note that the average age of the children who participated in this study was less than five years. At this stage, most children can easily be lifted and carried. If a similar study were conducted with adult subjects, the results could reasonably be expected to be more powerful and demonstrative. With an older population, it would be interesting to see the degree to which the modifications supported independence among the people with disabilities and eased caregiver burden varied.

In a Swedish study of 114 people aging with disabilities, 73 subjects whose referrals for home modifications had been approved (intervention group) were compared to 41 subjects who were still awaiting approval (comparison group) (Petersson, Lilja, Hammel & Kottorp, 2008). The measurement instrument utilized for
This study was the Swedish version of the Client-Clinician Assessment Protocol (C-Cap) Part 1 (Lilja, 2002), which consists of 18 home-based, self-care tasks. All of the subjects rated their ability to do self-care tasks independently, easily and safely at two points in the study – once at baseline, and again at follow-up, approximately two months after the intervention group had received home modifications. The rating scale for level of difficulty was a five point scale very similar to the one used in the current study: 5=no difficulty, 4=a little difficulty, 3=difficulty, 4=a lot of difficulty, 1=unable to do. Unlike the current study, safety and level of dependence were rated separately from difficulty so that each of the 18 self-rated items had three actual ratings. The rating scale for independence was a 4 item rating: 4=independent, 3=used technical devices and/or home modifications, 2=uses only help from another person, 1=uses both personal assistance and technical devices and/or home modifications. Safety was rated on a three-point scale: 3=feel safe; 2=feel a little unsafe; 1=feel unsafe. Data were collected in the participants' homes by a visiting occupational therapist. The mean levels of the comparison group did not change significantly between baseline and follow-up. Those in the intervention group reported less difficulty and increased safety, particularly in tasks related to bathroom activities, and getting in and out of the house. The level of independence did not change significantly, although, by definition, it could be said that all of the participants in the treatment group who reported less difficulty and greater safety, became increasingly dependent on home modifications. This would suggest that dependence, as it was operationalized for this study, should have increased. Perhaps it would have been more appropriate to define independence as the ability to do the tasks
without assistance from another person, and to not include home modifications as an indicator of dependence, since the researchers are measuring their impact on ability, which includes independence.

Thompson, Robinson, Dietrich, Farris, and Sinclair (1996a) studied the perceived characteristics of homeliness in 108 photographs of 20 group homes occupied by adults with intellectual disabilities. Homeliness was defined as having qualities associated with single family living rather than characteristics associated with buildings that do not typically function as homes, such as hospitals, schools offices, etc.. They found that people with mild intellectual disabilities, family members of people with intellectual disabilities, group home administrators, architects and college undergraduates all rated the degree of homeliness in photographs of residences for people with intellectual disabilities with a high rate of correlation.

The researchers then used hierarchical multiple-regression analysis to examine the influence of residential homeliness on resident behavior measures (Thompson, Robinson, Dietrich, Farris and Sinclair 1996b). They controlled for staff variables, program philosophy and preexisting consumer characteristics which could all confound the outcome. The researchers found that people living in more homelike residences were more likely to be involved in independent household chores; those living in more institutional appearing homes were more likely to display stereotypic movements. Residential homeliness was found to be associated with positive residential behaviors in adults with intellectual disabilities.
To investigate the influence of residential homelikeness on the number of activities performed in the community, the authors conducted a subsequent analysis, constructing models depicting the possible influence of residential homelikeness, staff philosophy, staff-initiated interactions with consumers, and consumer IQ on consumer community activities using hierarchical multiple regression analysis (Thompson et al., 1996b). Controlling for the effects of resident admission characteristics, staff to consumer ratios, and program philosophy, they found that perceived homelikeness was positively correlated with positive staff-to-consumer interactions and, again, negatively correlated with stereotypic movements and physical aggression.

In a later investigation of residential homelikeness, Egli, Feurer, Todd and Thompson (2002) constructed models depicting the potential influence of homelikeness, staff philosophy, staff-initiated interactions with consumers, and consumer IQ on consumer community activities using path analysis. The authors hypothesized that the way direct-care staff interacted with consumers would affect the number of community activities in which consumers were engaged. Observations of staff and consumer activity were videotaped in 18 group homes and the frequency and duration of staff-initiated social interactions with two target consumers in each residence were measured. These variables were examined in relation to residential homelikeness, consumer IQ, and staff members’ attitudes about people with intellectual disabilities. The latter was measured using the Community Living Attitudes Scale – Mental Retardations (CLAS-MR), an instrument designed to assess attitudes about community inclusion of people with intellectual disabilities (Henry, Keys, Jopp, &
The effects of these three variables were modeled both as direct effects and as effects mediated by staff initiated social interactions, on the number of community activities consumers participated in over the period of one month. Community activities were counted using the Residential Lifestyle Inventory (RLI) which was completed by the staff for each participating consumer. The number of activities performed in the community by each participating consumer was the primary dependent variable.

Statistically significant positive correlations were observed between residential homelikeness, staff-initiated interactions and community activities. Consumer IQ did not correlate with any of the other measures. To address possible causal relationships, a path model was constructed. The researchers evaluated the plausibility that residential homelikeness, consumer IQ and positive staff attitudes each had an influence on the number of community-based activities in which consumers were engaged, and that this influence was mediated by staff-initiated social interactions. Residential homelikeness and client IQ were each found to have a similar direct effect (approximately .2) on community activities. Both of these variables along with positive staff attitudes also had an indirect effect, mediated by staff-initiated interactions, on community activities, although the indirect effect of client IQ was not significant (.07). A second model, eliminating client IQ, revealed that residential homelikeness and positive staff attitudes independently exerted a statistically significant, comparable (.41** and .48***, respectively) influence on staff-initiated interactions, which, in turn, had a statistically significant impact on community activities (.55**). Although residential homelikeness,
and characteristics of the built environment in general, are rarely studied in relationship to consumer behaviors, this study, along with its predecessors, illustrates that its potential relationship to consumer community involvement is comparable to the effects of the more commonly studied variables such as IQ and direct-care staff characteristics. This study, however, did not measure provider agency philosophy, staff competency and knowledge about community resources, or community characteristics which all have the potential to influence the outcome.

Hammel et al. (2008) report on the proceedings of the Environmental Barriers and Supports to Health, Function and Participation Work Group convened at the "State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Living Symposium." The group's aim was to provide a research and policy agenda targeting the evaluation and assessment of environmental factors on people with developmental disabilities. Four environmental areas were addressed: the built/physical environment; assistive and information technology design and use; the social and community environment; and system/policy level environmental factors. The work group looked at the relationship of these factors on the physical and emotional health, functional activity, community participation and qualities of life outcomes for adults with intellectual and developmental disabilities. Methods included a systematic literature review across MEDLINE, CIHAHL, Rehab-Data, PsychInfo, and other related data bases. Similar to the current review, the search was broadened to examine environmental research with populations beyond those with intellectual and developmental disabilities. The numbers of articles actually reviewed is
not specified and there is report of any statistical analysis of the article content and no indication that effect size was calculated. The participants found that physical environment research fell into two focus areas: adapting or modifying existing environments to improve function; and designing new environments that promote universal and equitable access. Gaps in knowledge identified by the group included an analysis of how environmental modifications, assistive technology, and functional/behavioral strategizing influence a range of outcomes including emotional and physical health, functional ability, community and social participation. The group observed that environmental modifications have historically been under-funded and consequently, small in scope. A need to target which environmental attributes and interventions are most effective, for whom they are effective, and under what conditions they are effective, was identified as especially important for people with long-term cognitive disabilities. In this way modifications might be better prioritized throughout the lifespan. The authors stress the importance of conducting research across housing and community environments, in a broad range of settings including institutional settings, and throughout the lifespan.

Another high-priority environmental research area cited by this work group was what constitutes a “healthy home” and a “livable community” for a person aging with developmental disabilities. Beyond the need for supportive housing, it is essential to know what type of communities and environmental characteristics promote full participation, while aging in place. The authors suggest expanding the notion of “accessibility” to include not only physical, but also sensory, cognitive and social
accessibility. Exploring how these attributes relate to health, function and participation would "enable rigorous, multivariate research on the relationship between the environment, participation and health" (p. 146).

Access to assistive and information technology and the impact of technology on function was another area the group cited as a research priority. Making technology intuitive and user friendly to people with intellectual and developmental disabilities will allow studies on its role in supporting people in home, community and employment environments. Ways to bridge the gap between access and full participation was another focal area cited by the authors that needs program and intervention research. Suggestions for interventions include peer mentoring and self-advocacy.

In the area of policy research the work group advises focusing on the policy initiatives related to least restrictive living choice and full community participation. They cite the numerous system change initiatives that relate to environmental issues (e.g., the New Freedom Initiative, home and community-based waivers, Money Follows the Person Initiative), and suggest comparing implementation across different states and its impact on participation and function.

While the work group’s recommendations are similar to those that the current study suggests, the wide range of suggestions represents a smorgasbord of ideas and approaches. It would have been useful if the work group could have articulated priorities within this framework and potential funding for investigators. Nevertheless, the article provides a breadth of research options, and identifies the areas where information has the most potential to inform practice.
THE ROLE OF MOBILITY LIMITATIONS IN DISABILITY

Bussmann and Stam (1998) have defined the term mobility as moving from place to place. Mobility limitations is a term that is typically used to describe the status of people who are unable or have a high level of difficulty completing specific mobility-related tasks. While the prevalence of mobility limitations increases with age, people aging with developmental disabilities are more likely to experience mobility limitations than their typically developing age-related peers (Cleaver, Ouellette-Kuntz & Hunter, 2008). With the predicted growth of the population of older people with developmental disabilities, the impact of mobility limitations will have substantial repercussions. Several studies have examined the impact of limited mobility on people. These include people with and without developmental disabilities.

In an investigation of the relationship between mobility limitations and the place of residence of adults with intellectual disabilities, a telephone survey of proxies for 128 adults, age 45 and older, was conducted (Cleaver et al., 2008). Residents were divided into two categories: those offering integrated support structures (indicative of high support), such as group homes and institutional placements, and those categorized by separation of formal support structure from the place of residence and judged to offer low support (living alone, with a family, or with roommates). Similar to the current study, mean age was 56.3 and a majority of the participants were living in high-support settings. Mobility was measured using the Rivermead Mobility Index and those receiving a score of 12 or lower were considered to have mobility problems. Using a multivariate logistical regression, and controlling for the impact of general health, seizure disorders,
visual impairment, expressive communication difficulties, Down syndrome, and behavioral issues, findings revealed that individuals with mobility problems had 3.6 times the likelihood of living in a high support setting than those without mobility issues. Statistically significant associations were also found between living in a high support setting and having a behavior problem or impaired verbal communication. The authors conclude that the identification of barriers to people with mobility limitations could contribute to broadening the residential options available to this cohort.

In a study of home modifications and routine task performance among individuals with mobility impairments, Connell, Sanford, Long, Archea, and Turner (1993) surveyed 486 subjects about their difficulty and dependence in performing bathroom, kitchen and entry/egress activities. Respondents were also asked to indicate whether they had made modifications to their homes in any of these areas. The sample was recruited from the North Carolina State University's Center for Accessible Housing's Design Advisory Network. The Network had over 1,300 members, 935 of whom had mobility impairments. Fifty-two percent of these participated in the study. Data were collected by a mailed survey and were the self-reported assessments of the participants. The researchers found that overall difficulty and dependence in activities of daily living (ADLs) and IADLs was higher among power wheelchair users than among those who used manual wheelchairs or assistive walking devices. Ambulatory individuals had the least difficulty and were the most independent. Although the impact of home modifications varied as a function of level of disability, results indicated that home modifications helped to reduce difficulty and dependence in task performance.
Galambos, Darrah and Magill-Evans (2007) compared subjective age (how old participants felt) in 148 adults, ages 20 to 30. Participants were volunteers recruited through service providers from one Canadian province. Roughly half the sample had a motor disability such as cerebral palsy or spina bifida, while the other half did not. The authors speculated that experiences associated with physical limitations may lead to a lower subjective age. This did not prove to be the case, however. While people with motor disabilities reported having a significantly lower number of role transitions (i.e., living away from parents or getting a job), significantly less fostering of autonomy by their fathers, and felt they were treated younger than their actual age by their parents, there were no significant difference in subjective age between the groups. There was, however, a difference in subjective age between participants with more severe disabilities and greater mobility limitations and their less mobility-impaired peers. Having increased mobility limitations was a significant predictor of an older subjective age. This study has the inherent limitations associated with all non-experimental research. Because the sample was a purposeful sample of volunteers, people who did not participate could have elected this option because of their increased autonomy and role transitions. This is speculative, but mentioned to illustrate the potential confounding factors.

In a month-long pilot study of 28 adult, full-time wheelchair users, researchers measured participants' ability or inability to reach specific neighborhood destinations, and both numbers and types of facilitators and barriers encountered and whether the latter were or were not surmounted (Meyers, Anderson, Miller et al., 2002). The
purposeful sample consisted of volunteers recruited by the researchers. Selection criteria included 'chronic' wheelchair use, and a self-reported wide range of social participation. Participants had an age range of 24 to 79 years with a mean age of 47. The study began with a baseline interview on personal demographics and history, and included items on health/impairment, disability, assistive technology use, wheelchair use, and the physical environment of the participant, which was measured on a scale of 0-3 (most confining to most unconfining). Each participant completed a daily phone interview regarding the barriers and facilitators they encounter in their activities for each of 28 consecutive days. At the end of the study (day 30) a retrospective, exit interview was conducted. Researchers tested for reliability between participants' daily reports and their retrospective reports. T-tests and analysis of variance were used to determine if whether the numbers of destinations reached, and barriers and facilitators encountered were related to subjects' gender, age, length of time with impairment, type of impairment, wheelchair type (manual or motorized), or study site (Boston and Durham). Analysis of variance was also used to examine participants' environments and their experiences. Destinations that the participants had the most difficulty reaching included drug stores, friends' and relatives' homes, restaurants, and work-places. Reported barriers and facilitators included personal, interpersonal and environmental factors. Examples include lack of will or motivation (a personal barrier), lack of personal assistance (an interpersonal barrier), and the natural (bad weather, air quality) and built environment (inaccessible buildings, broken elevators, etc.). Facilitators included good health (physical), encouragement from others (interpersonal), good weather and
accessible buildings (environmental). Consistency between daily and retrospective reports was high. Respondents over 50 years of age reported fewer destinations reached successfully and fewer barriers overcome. There were many more barriers than facilitators reported by participants. Environmental barriers were more frequently impossible to overcome than personal or interpersonal barriers. The data suggest that efforts to mitigate and eliminate barriers and facilitate social and community participation by wheelchair-users should focus upon the built environment, mentioning that, even among this opportunistic sample of highly active and engaged participants, access remains elusive.

The fact that the participants all agreed to daily interviews and detailed record-keeping, were highly active, and socially engaged, indicates that they may be among the more motivated and able people who use wheelchairs for all mobility. A more representative sample of wheelchair users might have perceived even more barriers and impediments, or might have had problems simply leaving their homes. Additionally, the study did not take into account the limitations related to weather and climate. The authors suggest a clear need for social policy interventions including personal assistance and assistive technology. They also cite a need for programs that teach people to provide assistance to people with impairments without conveying condescension or dislike.

**SUMMARY AND GAPS IN RESEARCH**

The lack of experimental designs, and the preponderance of purposeful samples limit the generalizability of previous research. Nevertheless, results from previous
studies indicate that many factors including the social/interpersonal and built environments have a significant impact on the ability of people with disabilities to function independently or quasi-independently. Research has shown that functional ability for people with disabilities is related to living in smaller, community-based settings that support a high level of staff-resident interaction and emphasize training and teaching residents to participate in domestic activities. Conversely, lack of participation in activities and role-segregation between staff and residents have both been shown to lead to lower functional ability for people with disabilities. Not surprisingly, people with more significant impairments tend to be among the lowest functioning. The literature reveals that functional ability, or handicap, is a more complex issue than extent of impairment or degree of person-environment fit. It is also a function of expectations both of oneself and of one's parents, staff and/or caregivers (Kelly-Hayes et al., 1992, Magill-Evans et al., 2001, Zigler & Balla, 1982, Zigler & Hodapp, 1986). While home modifications and assistive technology help to stem functional losses and improve abilities, the act of providing an enabling tool or setting is itself an expression of confidence in the person.

The literature reveals that not only is functional ability impacted by the expectations of oneself and others, and the physical and social environment of the home, but that these factors interact to further influence functional ability. Research supports the interaction between functional ability and self-perceptions, expectations, mobility limitations and both the physical and social environment (Egli et al., 2002, Finkel, 1999, Rochette et al., 1999, Thompson et al., 1996a and 1996b, Zigler & Balla,
1982, Zigler & Hodapp, 1986). The finding that residential homeliness and positive staff attitudes and interactions had a significant positive impact on consumer involvement in community activities further demonstrates the interdependence of what could easily be conceived as unrelated constructs (Egli et al, 2002). Mobility restrictions have been shown to limit residential options and access to community resources. This provides the impetus for the proposed study to further investigate the influence of both personal and environmental factors on individuals aging with developmental disabilities.

As previously mentioned, people aging with developmental disabilities and their relationship to the microenvironment has received increasing attention from researchers, largely because of their recent increases in life expectancy, their presence in community-based settings, and their growing visibility as a result of the disabilities movement. When people with developmental disabilities are studied it is usually via caregiver proxies. Very few studies get their information from directly interviewing and observing/interacting with the consumers themselves.

The research to date reports trends and correlations between environmental settings and consumer behaviors. The current study confirms these findings and examines them in greater depth. It also opens a curtain to reveal the lives behind these data, to consider individuals, their reasoning and the feelings they have for their environment. This study will fill a gap in research, and generate questions for further research on these issues.
CHAPTER THREE: METHODS

OVERVIEW

This study analyzed both quantitative and qualitative data to explore the functional ability of adults aging with developmental disabilities and living in community-based settings. The study represents a secondary analysis of data that were collected during in-home assessments.

This chapter begins with an overview of the research paradigm, followed by a discussion of the study's constructivist foundation and multiple methods. Sampling methods, including the difficulties inherent in sampling this vulnerable population, the specific sampling procedures, and sample criteria are explained. Data collection methods for the consumer interview and directed observations are then discussed. The section on measures begins with a discussion of the key descriptive and predictor variables and the two dependent variables, observed and self-reported functional ability. It explains how each key variable was measured and how mean (aggregated) variables were created from each subject's data. Methods of handling missing data are discussed. A discussion of the content validity of the instruments follows. Finally the data analysis methods are delineated for both qualitative and quantitative investigation. Qualitative data include participant responses to open-ended questions and spontaneous comments from participants as they took part in the task observation component of the assessment process.
RESEARCH PARADIGM

Research paradigms help the researcher define his/her view of the world (Guba and Lincoln, 1994). Although this research included quantitative methods to examine hypotheses for further study, it rests on a constructivist foundation. The data serve as the roots and the springboard of the research analysis. The study investigated people's perceptions and interpretations (constructions) about their ability to perform self-care and independent living skills in their home environment in order to better understand and interpret the relationship between people aging with developmental disabilities and their socially constructed experience of, and relationship to, the physical and social environment in which they live. It is acknowledged that a person's ability to perform these tasks is dependent not only on their actual physical and intellectual competence but also on their perceptions about their own competence which are likely to be at least partially based on other people's constructs – or perceptions regarding their competence and ability. The research used multiple strategies. It made use of data triangulation by intermixing both open-ended and fixed-choice interview data, and observational analysis. The study triangulated methodologically by using both quantitative and qualitative components. It was context-bound and, in its methodology, attempted to be responsive to specific situations, and adaptive to individual characteristics and needs. For the sake of practicality, study methods depended on a pragmatic approach that had the flexibility to adapt to both a population that can be somewhat eccentric, and research limitations that include less funding and time than one would prefer.
OVERVIEW OF RESEARCH METHODS

Data collection methods included face-to-face structured interviews with consumers (the primary research subjects); 20 supplemental phone interviews with consumers’ direct care staff; an extensive task observation component where consumers were asked to demonstrate how they performed everyday self-care activities; and ethnographic notes collected and compiled by the researcher.

These data were collected using both inductive and deductive processes. That is, the study protocol began with observations of specific activities in the context of the home environment and went “from grounded results through inductive logic to general inferences (or theory) [people with these characteristics are likely to be able to perform these tasks with some relatively high or low degree of autonomy], through deductive logic [correlation] to tentative hypotheses or predictions of particular events/outcomes” (Tashakkori & Teddlie, 1998, p.24). “Grounded results” refer to the data, which is grounded in context-specific phenomena – the routine self-care activity in the context of the individual’s home environment. This cycle has been complemented by the incorporation of qualitative information gleaned from open-ended questions posed during the consumer interview, by subjects’ comments as they participated in the observed functional assessment component of the study and by a smaller number of structured interviews with direct-care staff of 20 of the subjects.
DIFFICULTIES INHERENT IN SAMPLING THIS AT-RISK POPULATION

Researchers have noted the difficulty in identifying, accessing and recruiting adults with developmental disabilities as research subjects for both medical and noninvasive psychological and behavioral research studies (Beange, McElduff & Baker, 1995; Lennox, Beange, & Edwards, 2000; Lennox et al 2005; Siegal & Ellis, 1985).

Problems identifying and recruiting minority and at-risk populations have been well-documented (Anderson, Fogler, & Dedrick, 1995; Lewis, George, Fouad et al., 1998; Neufeld, Harrison, Margaret, et al, 2001). Difficulties gathering samples of people with intellectual disabilities in particular have been attributed to substituted decision-making and the ethical necessity of obtaining guardian or parental consent, the limited literacy of the population, anti-intellectualism and insistence upon immediate application, the threat of litigation against service providers, and organizational gate-keeping practices (Siegel & Ellis, 1985; Lee, 1993; Lennox et al, 2005; McDonald & Keys, 2008). Difficulties are less apt to be encountered when the researcher has access to a captive pool, such as institutionalized persons or clients of a state-wide human services agency (Siegal & Ellis, 1985). However, for the independent or university researcher, recruitment is often dependent upon the goodwill of organizations (Lennox et al, 2005). Researchers not only need the consent of an organization’s most senior staff, but also more than token cooperation from subordinates (Lee, 1993). Since many of the staff at community provider organizations face complex and overwhelming workloads, research may not be their priority, or even a concern (Lennox, 2005). Likewise, familial caregivers of adults
with developmental disabilities, often their elderly parent(s), are likely to find the daily challenges associated with caregiving overlaid on their own age-related limitations overwhelming, and simply lack the energy to participate in activities that are not essential to their daily well-being (Todd & Shearn, 1996; Schofield, Bloch, Nankervis, et al., 1999; Lennox et al., 2005). Because many of the members of this population are not their own guardians, dual consent is necessary – first from a guardian and secondly from the research participant. The fact that the guardian often does not play a role in the daily activities of the person they are charged to protect, can further complicate and delay the consent process (Lennox et al, 2005). If adults with developmental disabilities live with their families, and have not accessed ongoing funding or support, such as Medicaid or Supplemental Security Income they are likely to be unknown to service provider organizations, and "invisible" (Lennox et al, 2005). Finally, ethical limitations prevent the direct recruitment of potential participants. While this safeguard protects this population from the possibility of harm through researcher abuse, as Lennox et al. (2000) point out, it may inadvertently deny them the opportunity to be included as research participants.

This consumer sample was unique because it was composed entirely of people over age 30 with developmental disabilities – an at-risk population which is difficult to sample. Eighty percent of the sample members were fifty years of age or older – an age that people with disabilities rarely reached a half-century ago. The sample included people living in a variety of community-based settings where goals of autonomy, independence and self-determination are the norm – another condition that has only
recently existed. It also included people with a variety of typical age-related conditions such as arthritis, osteoporosis, adult-onset diabetes, and dementia – all conditions that have an impact on a person's relationship to their environment.

SAMPLING PROCEDURES

The population domain consisted of New Jersey residents who were adults with developmental disabilities residing in New Jersey and over 30 years of age. Many of the younger subjects in the sample were included because they were prematurely experiencing age-related deficits due to a disability such as Down syndrome, where the life expectancy is currently age 56 (Janicki, 1996). Subjects ranged in age from 32 to 91, with a mean age of 56 years.

During the original applied research study, sampling methods employed a multistage strategy and followed procedures approved by the Human Subjects Institutional Review Board at New Jersey Institute of Technology. Initially, criterion sampling was used to identify an eligible pool of adults: The New Jersey State Division of Developmental Disabilities and the Arc of New Jersey and its statewide affiliates generated lists of all known provider agencies for people with developmental disabilities living in community-based settings within the state of New Jersey.

A letter was sent to each of these 129 agencies, located throughout the state, explaining the research study and asking them if they would be willing to participate by 1) helping with sample recruitment, 2) facilitating the consent process, and 3) facilitating the interview/home visit. The criteria for study participation were people 50 years of age or older, having a developmental disability, and living in a community-based setting.
It was also stated that people who were younger than the age 50 cutoff would be considered for participation if they were experiencing limitations associated with aging prematurely, such as arthritis, dementia, and muscle weakness. Sixteen of these 129 agencies agreed to participate.

Each participating agency identified an eligible pool of adults. The agencies were each sent a packet consisting of letters of invitation and corresponding consent forms. One letter/consent form was written for legal guardians and another was specifically for consumers. Both of these letters of invitation explained the nature and terms of the study. Those who agreed to participate signed consent forms and returned them to the provider agency or, in a few cases, directly to the researcher. (In cases where consumers had designated legal guardians, both the consumer and the legal guardian provided written consent to participate in this study if the consumer was capable of so doing. In cases where written consent from the consumer could not be obtained, the consumer was asked to provide verbal consent both prior to, and again, at the time of the assessment.) The provider agency, in turn, forwarded the signed consent forms with relevant contact information to the researchers. This usually was the name and phone number of the consumer’s direct support staff or familial caregiver, but occasionally the phone numbers of the consumers themselves.

The researchers received a total of 194 signed consents, and completed 129 assessments. Although the initial sampling guidelines distributed to provider agencies and families was based on general eligibility criteria, at this second stage of the selection process interviewees were sometimes selected for specific reasons. Sample members
were selected to obtain maximum variation in geographic location (rural, urban and suburban) and by living situation (family homes, group homes, supported or supervised apartments). Every effort was made to work with provider agencies to select subjects from diverse racial and ethnic backgrounds among those who had consented to participation. Provider agencies were also asked to identify subjects with secondary diagnoses common to aging adults (for example: arthritis, diabetes and dementia), so that these subjects would be included among those selected for the study.

Following this purposive sampling stage, subjects were finally selected for pragmatic reasons. In five cases staff advised against conducting assessments with consumers due to behavioral issues, or refused to facilitate the process, in three cases consumers did not return phone calls, in 13 cases staff did not return phone calls, five consumers were moved to other settings, such as hospitals or rehabilitation facilities, and one consumer died before the assessment was scheduled. The researcher scheduled interviews by phone with caregivers/support staff of selected members of the research pool. After appointments had been scheduled the sampling pool was again reduced when one consumer repeatedly missed appointments, five consumers refused to participate at the time of the assessment itself, and two consumers were physically unable to participate in any activities of daily living.

The final volunteer sample for this study included 129 adults who were aging with developmental disabilities and living in community-based settings, such as group homes, supervised and supported apartments, and family homes in the state of New Jersey. Because the sample was composed of people who were willing to participate in
the study, who had the physical capability of moving around their home with at least a minimal degree of independence, and were known to provider agency personnel, other study subjects or their caregivers, and lived in the state of New Jersey, it is not generalizable to the broad population of adults aging with developmental disabilities living in community-based settings. The normal problems of generalizing from a purposeful sample are somewhat upset by the fact that the invitation to participate was extended to all 129 New Jersey agencies known by the State Division on Developmental Disabilities and The Arc of New Jersey, and study subjects came from the 16 agencies who agreed to participate. As previously explained, people with developmental disabilities are a unique and vulnerable population and, for this reason, sampling poses difficulties that limit research.

**DATA COLLECTION**

This proposed study was approved by the Rutgers Internal Review Board for the protection of human subjects in March 2004 and was approved for continuation between March 2005 and 2008. It was a secondary analysis of data.

The objective of the original study was to provide information and strategies for modifying the living environments of older persons with developmental disabilities in order to facilitate “aging in place” safely, productively, and as independently as possible. The data were collected between July 2000 and July 2004. Human subjects approval was obtained from New Jersey Institute of Technology prior to contacting provider agencies. During the original study, data were collected using four methods: consumer interviews, directed observations, photographs, and interviews with caregivers. At the request of
the IRB, after the interview of the consumer, and before the directed observation, the researcher reviewed the consumer's capabilities with the caregiver to ensure that consumers were not asked to perform any activity that might be dangerous for them to complete on their own. The researcher omitted directives the staff advised against for specific consumers and these were coded as "not asked" missing data.

**Consumer Interviews**

Assessments took place in the participants' homes and began with a structured consumer interview. [See Appendix A.] Data collected during the consumer interview included descriptive information, qualitative information (when the subject was willing and able to provide it) to characterize global feelings about the home environment, and 32 fixed choice questions about subjects' ability to perform specific self-care activities in and around their homes. An open-ended series of questions was added after data collection had begun when it became clear that a deeper understanding of consumers' attitudes toward their homes would enhance the research effort.

**Directed Observations**

Each consumer was asked to demonstrate 61 typical activities of daily living in the home environment so that the researcher could observe and rate the participant's performance and recommend home and/or behavioral modifications to make the activity easier, safer and/or more convenient. Sample activities included entering and exiting the home, using the kitchen, bathroom, bedroom and living room, going up and down stairs, doing the laundry, opening and closing windows, getting the mail, turning on lights, etc. Subject performance was rated for each activity on a five-point scale,
indicating degree of difficulty in task completion. [See Appendix B.] One other researcher and the author completed all of the assessments, with the vast majority completed by the author. Inter-rater reliability was .87.

CAREGIVER INTERVIEW

Structured phone interviews with caregivers of 20 consumers were conducted at a later date. The caregiver interview is a written questionnaire designed to elicit information from the person most directly involved in the subject’s care, supervision, or monitoring. The instrument includes open-ended questions about changes in the subject’s functional abilities as a consequence of aging; identification of barriers in the environment that affect safety, independence, productivity and inclusion in everyday residential activities; discussion of what the person and the home would need in order for the person to age in place, and questions asking what prevents the subjects from completing the tasks they are unable to perform. It also includes items that address the individual’s physical limitations; the individual’s cognitive or intellectual limitations; behavioral characteristics (e.g., refusal); personal preference regarding the task itself; barriers/limitations in the physical environment; or something else. In this way the researcher may gain additional insight into the likely barriers to functional independence in self-care activities. These interviews were conducted by two researchers: the author and an occupational therapist/doctoral student at Columbia University. [See Appendix C.]
MEASURES

The variables in this study included various descriptive items, (i.e., both consumer and environmental characteristics), and two dependent variables (i.e., consumer self-reported functional ability and observed functional ability).

DESCRIPTIVE VARIABLES

Subject Variables

The following information was used to describe subject characteristics: age in years, sex, race, accumulated overall impairments, accumulated physical impairments, and mobility device(s) usage. Subjects using wheelchairs or scooters were categorized according to extent of dependence on the mobility aid: 1) for all mobility and regular seating/positioning, 2) during the assessment, but can ambulate without the device, and 3) for extended travel only (for example, at shopping malls or to cover outdoor distances). It was also noted if consumers were classified as having autism, epilepsy, dementia or Alzheimer's disease, having a non-developmental chronic or degenerative physical disability (i.e., arthritis), a mental illness or diabetes, and being unable to participate in the verbal interview (being minimally or non-verbal). These categories were derived from the diagnostic information recorded during the in-home interviews/assessments. Because it was suspected that the data on mental illness were not reliable (under-reported) this variable was dropped from the analysis.5

5 Total psychoactive medication use for older adults with developmental disabilities residing in the community has been reported to be between 36 percent and 48 percent (Anderson & Polister, 1993; Intagliata & Rinck, 1985; Radinsky, 1984). Since only 17.1 percent of the sample were reported to have a mental illness, it is likely that this variable was underreported.
Accumulated overall impairments and accumulated physical impairments were transformed (aggregate) continuous variables that were calculated by summing the number of impairments, or subsets of physical impairments, each consumer was reported and/or observed to have.

An accumulated overall impairment score, with a possible range from one (since they all had a developmental disability) to twelve, was calculated for each of the study participants. A higher score indicated a higher level of impairment. Scores were calculated by giving each subject one point for each of the following items: 1) having an intellectual developmental disability, 2) having a physical developmental disability, 3) not having the communication ability and/or cognitive skills to participate in the verbal interview (referred to in this study as "non-verbal"), 4) having a chronic or degenerative physical disability that is not developmental, 5) having quadriplegia, 6) ambulating only with the use of a wheelchair or scooter, 7) using a mobility device during the assessment, 8) using a mobility device at all, 9) having epilepsy or seizures, 10) having age-related dementia including Alzheimer's disease, 11) having diabetes, 12) having autism.

Similarly, an accumulated physical impairment score, with a possible range from zero to seven, was calculated as a subset of the accumulated overall impairment score, by giving each subject one point for each of the following: 1) having a physical developmental disability, 2) having a chronic or degenerative physical disability (often these were age-related) that is not developmental, 3) ambulating only with the use of a wheelchair or scooter, 4) use of a mobility device during the assessment, 5) use of a
mobility device at all (usually for strenuous occasions), 6) being quadriplegic (there were no paraplegics in the study), and 7) having epilepsy or a seizure disorder. The physical impairment score was treated as a continuous variable in the quantitative data analysis.

It should be noted that diagnoses were obtained from available consumer records, staff-report and self-report. Some consumers did not provide records, and some consumers may have had conditions that did not appear in the records. The amount and reliability of diagnostic information varied between consumers and its accuracy is not easily gauged. The heterogeneity of these aggregate measures (e.g., combining diagnostic and behavioral items) is addressed by controlling for relevant sets of variables in the regression analysis.

*Environmental Variables*

The home environment of each subject was described by two variables: the accessibility level of the dwelling and the supervision level of the home.

The physical environment of each subject’s home was given an accessibility level ranging from one to four, with four being more accessible and one, less accessible. A score of four was given to purpose-built (to be physically accessible) homes or apartments, or to existing housing stock that had received extensive modifications to make it physically accessible. These included houses designed or modified to be accessible to people with mobility impairments, and apartments especially designed for seniors or for people with mobility impairments. A score of three was given to existing, largely unmodified one story homes without steps at the entrance or to the laundry. These included ranch-type dwellings, many built on slabs, or without full basements,
and one level apartments either on the ground floor, or in buildings with elevators. A score of two was given to existing, unmodified, one-story homes with stairs at the entrance and/or to the laundry. These included raised ranch houses, bungalows, and some one-level garden-type apartments. A score of one was given to homes with two or more stories. The one two-story home that had an elevator was included in this category, since the consumer still frequently used the stairs.

The supervision level of each subject's home was given a rating from one to three with a higher number indicating increased supervision. A score of one was given to supported living settings in which consumers lived in their own homes or apartments with supportive services but without supervision. Usually referred to as "supported apartments," services are not linked to the residence, and consumers usually have a direct relationship with a landlord or leasing agency. A score of two was given to supervised apartment settings in which consumers had their own apartment units but were supervised by provider agency staff who had units in the same building or complex and were on call 24 hours per day. A score of three was given to group homes or family homes, in which staff or family were in the same home in a supervisory capacity 24 hours a day.

**Dependent Variables**

There were two dependent variables that both measured functional ability. One was the participants' self-reported functional ability, and the second was the researcher's observed assessment of each participant's functional ability.
Consumer estimates of functional ability were elicited using the fixed choice portion of the consumer interview. Each verbal subject (N=108) was asked whether or not they could perform 32 activities of daily living. Responses were scored, (3) can perform the task easily – no problems, (2) has some difficulty performing the task, (1) needs help to perform the task or has major difficulty, and (0) cannot perform the task.

Self-reported functional ability scores were averaged to provide a continuous estimate of functional ability. Higher scores indicated greater functional ability and lower scores indicated less functional ability. Missing data were imputed using the subject's mean score on non-missing items. One hundred and eight of the 129 subjects were able to participate in the interview and express their estimates of their own functional ability, while 21 could not. Possible scores ranged from zero to 3. Actual scores ranged from .06 to 3, with a mean score of 2.94, and a median score of 2.78. Consumers who were unable to communicate could not be included in this analysis.

Observed functional ability was assessed using data collected with the Consumer Self-Care Assessment Instrument, which was an observational assessment tool that included a comprehensive list of 61 household tasks and activities. Seventeen of these were excluded from the final analysis because the physical environment of a large number of the subjects did not support the activity. Forty-six tasks remained in the final assessment analysis (See Appendix D).

The functional ability activity assessment began at the main approach to the home – usually a driveway or front walkway. It continued through the front door to the coat closet where consumers were asked to hang up their coats. Next consumers were
asked to demonstrate use of the stairs. They were then requested to demonstrate doing
(or pretending to do) the laundry, which involved a series of eleven tasks including
ironing one small item. Consumers completed this phase of the assessment by returning
to their bedrooms with their laundry. The assessment then explored bedroom activities:
getting clothes in and out of dressers and closets, getting in and out of bed,
opening/closing a window and turning on/off a light, and taking shoes off and putting
them back on. From here the assessment moved to the bathroom where consumers
were asked to demonstrate turning on a light, using the sink, sitting down on and
going up from the toilet, reaching the toilet paper, flushing the toilet and getting into
and out of the bathtub and/or shower, and simulating drying oneself with a towel. The
assessment now turned to the kitchen where consumers were again asked to switch the
light on and then use the sink to wash their hands. Here they were also asked to retrieve
dinnerware from its cabinet or drawer and set a place at the table, fill a glass with water
and bring it to the table, and get something from the refrigerator. The assessment
included sitting down at and getting up from the table (those in wheelchairs had to
position themselves at the place where they normally ate), washing a dish or loading it
into the dishwasher, putting water in a pan and setting it on the stove, adjusting the
heat on the stove, stirring the water in the pot, pouring out the water and drying off the
pot. Finally the assessment moved to the living room or communal space where the
consumer was asked to turn on a light, sit down, demonstrate using the television and
the video cassette player, open and close a window, respond to an imaginary knock at
the front door, and call a prescribed phone number. The entire assessment, not including the interview, usually took at least an hour and sometimes several hours.

Each task the consumer performed or considered performing received a score from one to five, one for "can't do", two for "great difficulty; needs assistance", three for "moderate difficulty", four for "minimal difficulty" and five for "no difficulty". The mean value of these data describing the researcher's ratings of consumers' functional ability was calculated to provide a continuous estimate of observed functional ability: higher scores represented greater functional ability and lower scores represented less functional ability.

There were more activities in the observed scale than in the self-report interview instrument because observers were able to disaggregate tasks into more specific steps than the subjects could distinguish during the interview. Similarly, as the difference between rating scales indicates, the observers made slightly finer discriminations in ratings of ability level.

**Missing Data**

Additional categories were developed, as needed, to describe the reasons, in addition to "can't do", for not undertaking a task. Any reason for not undertaking a task, other than the fact that the subject lacked the ability, was considered missing data. Early in the assessment process, it became clear that the reasons for not undertaking a task were many, varied and often, unclear. Four categories were added to describe missing data. Two of these categories were consumer-driven – "consumer refused" and "consumer doesn't do". One was researcher driven – "consumer was not asked". As
previously explained, one was dictated by the physical environment of the home, and was called "irrelevant", meaning the home did not support the activity (such as homes without laundry facilities, linen closets, etc.). The 15 tasks that many of the consumers' homes did not support were dropped from the analysis. These were tasks that 7 to 28 percent of the participants did not have the possibility of performing because their environments did not provide the prerequisite facilities, such as laundry machines, secondary entrances and linen closets.

In order to complete the analysis without list-wise deletions, missing data were replaced with the subject's mean score on the non-missing items. The number of missing data and the reason for their absence were recorded as separate variables for each consumer in order not to lose this information. This generated four additional variables for each participant: 1) number of "don't do" responses, 2) number of refusal responses, 3) number of activities omitted at the researcher's discretion, 4) number of activities the home did not support.

**CONTENT VALIDITY**

It was important that the measures used in the original study be responsive to the characteristics of adults with developmental disabilities; geared to assessing the need for changes in, or modifications to, the physical environment; and aimed at assessing the congruence of the physical environment of the home with those residing there. Because there were no measurement instruments available that met these criteria, existing instruments designed for rehabilitative and geriatric assessment were reviewed and
portions were adapted for use in developing measures specific to the study’s goals. The assessment instruments that were reviewed and utilized include:

- The Gerontologic Environmental Modification Assessment Forms (GEM) developed by Bakker at the Weill Medical College of Cornell University. This instrument was developed for elders who are undergoing the normal process of aging, with the goal of improving home safety (Robinson, 2001).

- Tellerehabilitation Housing Assessment Tool Draft (1998) developed by Jon Sanford with Shepherd Center. The instrument was developed as a comprehensive housing inventory.

- Canadian Mortgage and Housing Corporation (CMHC) Assessment form: Maintaining Seniors’ Independence Guide to Home Adaptations (no year available). This instrument was developed to enable frail older people to undertake daily activities more independently.

- Philadelphia Corporation for Aging Housing Department Occupational Therapy Evaluation.

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6 No year was found on or associated with this document. At the time of this writing, it was been expanded into a series of documents that are available from the Canadian Mortgage and Housing Corporation via their website: https://www.cmhcschl.gc.ca:50104/b2c/b2c/init.do?language=en&shop=Z01EN&areaID=0000000017uctID=&prod 00000000170000000015.

7 This is an internal document used by the Occupational Department at the Philadelphia Corporation for Aging Housing Division. It has been developed and modified over time. The version we used was given to us in 1999, but the evaluation is not associated with a particular date.
The content validity of the instruments was verified by consultations with experts in the aging and environment behavior fields, a review of existing instruments designed to assess self-care performance skills, and piloting the instruments with 46 subjects. Laura Gitlin, Ph.D, director of the Philadelphia Geriatric Institute, was consulted for her expertise in measurement and assessment of the task performance of aging adults. Jon Sanford, M. Arch., was consulted for his expertise in assessment of environments for the elderly and disabled. Task performance assessment instruments mentioned above were reviewed and used to determine the applicable domains and to insure the instrument's inclusiveness. It should be noted that these instruments were used as a resource and were adapted and not verbatim, thus the reliability of these instruments is not germane to this study.

DATA ANALYSES

QUANTITATIVE DATA ANALYSIS

Participant Description/Demographics

Frequency distributions, range and mode are presented to summarize the categorical variables, sex, race, developmental disability (assumed to be the primary diagnosis), secondary diagnoses, provider of residential facility, mobility devices used, supervision level of the home, and accessibility level of the home. Means, standard deviations and range were reported to summarize the following continuous variables: subject age in years, consumer accumulated overall impairments, consumer
accumulated physical impairments, consumer self-reported functional ability score and observed consumer functional ability score (See Tables 1 and 3, Chapter 4.)

Reliability of Measures

All the measures used in this study were developed by the researcher to suit the unique needs of this population. The reliability and (concurrent) validity of the measures were evaluated as a part of this study. Each dependent variable was evaluated using coefficient alpha, an estimate of internal consistency. For self-reported functional ability alpha = .96; alpha for observed functional ability = .98. Alpha greater than .70 is considered acceptable for research purposes (Nunnally, 1972). Validity of measures is reported under hypothesis two in Chapter Four: Quantitative Results.

Hypothesis Testing

Bivariate and multivariate analyses were used to test the current hypotheses and to suggest areas for subsequent research. The analyses included outcome variables that were mean ratings for both self-reported and observed items concerning functional ability, and ratings for individual items as previously described. The correlation table lists both transformed (aggregate) measures and explanatory variables, including demographics and descriptive variables: age, accumulated overall impairments and accumulated physical impairments, supervision level of the home, and accessibility level of the home.

Quantitative Data Analysis

Research Question and Hypothesis 1 (Functional Ability and Impairment)
The first research question that guided this study addressed the relationship between impairment or disability level of the subjects and their ability to carry out self-care activities in the home. The resulting hypothesis was:

\[ H_1: \text{People with fewer physical impairments will demonstrate greater functional ability, while those with the greatest degrees of physical impairment, such as quadriplegia, will demonstrate less functional ability.} \]

To test the first hypothesis regression analyses were run in parallel for two dependent variables, namely, mean observed functional ability and mean self-reported functional ability. These two dependent variables, that is, were regressed on various combinations of predictors.

**Control Variables**

The regression analyses used two control variables: accessibility level of the home and supervision level of the home. Accessibility was included as a control because homes that are less accessible are less function-friendly, and present barriers to functional ability. Supervision level was included as a control because people with lower functional ability are routinely placed in more highly supervised settings where staff are present on a continuous basis and may facilitate or limit consumer function. All regressions included these two control variables as predictors.

**Predictor Variables**

The first regression added an overall measure of impairment (i.e., accumulated overall impairments) to the two control variables. To identify the most relevant aspects of impairment, the second regression substituted accumulated physical impairments for
accumulated overall impairments. In the third regression, the focus on impairment was further narrowed by substituting wheelchair status (i.e., whether or not people use wheelchairs as their main mode of seating and only means of ambulation) for accumulated physical impairments. As a result, the analysis included three regressions for each dependent variable or a total of six regressions.

**Research Question and Hypothesis 2 (Observed and Self-Reported Functional Ability)**

The second research question that guided this study was, “What can be learned about the relationship between consumer self-reported functional ability and observed functional ability?” The corresponding hypothesis was,

\[ H_2: \text{People with greater observed functional ability will have greater self-reported functional ability.} \]

To test the second hypothesis, the product-moment correlation (i.e., Pearson r) between the two measures of mean functional ability (i.e., self-reported and observed) was calculated. To explore the relationship between observed and self-reported measures of comparable discrete activities (using the correlational strategy), the ratings were standardized to 4-point scales and 37 individual task correlations were run. The results were also presented in a histogram.

**Research Question and Hypothesis 3 (Home Accessibility Level and Functional Ability)**

The third research question that guided this study was, “What can be learned about the relationship between environmental accessibility and functional ability?” The corresponding hypothesis was,
H₃: Physical ability will be inversely related to the degree of accessibility of the living environment. For those with mobility impairments, home modifications to improve physical accessibility will not compensate for the physical impairment of the individual.

Home accessibility, used as a statistical control in the regressions, was also of substantive interest as a correlate of functional ability. Because observed and self-reported functional ability were highly correlated and the former included a slightly larger sample and more individual items, this hypothesis was tested using observed rather than self-reported functional ability. Correlations between home accessibility level and other relevant variables (i.e., mean observed functional ability level, accumulated overall impairment level, accumulated physical disability level, and using a wheelchair full-time) were run. Individual functional ability levels and home accessibility levels were graphed to visually present the difference between participants who used wheelchairs full-time and the other members of the sample. Mean observed functional ability levels were calculated for each of the four accessibility levels of the home. Based on the results of this calculation, the sub-sample of participants living in the most accessible housing level were compared with those living in the three less-accessible housing type levels, using a two-tailed T-test. Because one of the missing data categories recorded activities not supported by the home that were included in the observation instrument, these data were available. The mean number of unsupported activities for each of the three housing supervision level was calculated and compared empirically. An ANOVA was run to test the significance of these results.
QUALITATIVE DATA ANALYSIS

Qualitative data included responses by both consumers and staff to open-ended questions, comments made by consumers and, to a lesser extent, staff, during the other phases of the assessment process, and ethnographic notes recorded by the researcher. These data were collected to further elucidate consumer’s perspectives on, and attitudes toward, personal functional independence or dependency and the home environment.

Initially, qualitative data were coded according to the question to which consumers were responding. All responses were recorded by the researcher-developed questions used in the instrument. During this process it became clear that several themes were emerging from these responses. Initial themes included broad categories such as social relationships with peer, staff and neighbors, the built environment of both the home and the neighborhood, and general likes and dislikes. Within and between these categories other dimensions emerged, including participants’ feelings of autonomy versus dependency, belonging or isolation, residential permanency or transience, and privacy and social inclusion. Categories for these dimensions found within the data were created and relevant comments were cross-coded under both the question that generated the consumers' response and, when applicable, the recurrent theme(s) the response addressed. This was completed using Microsoft Word and making cross-referenced lists of comments. Once all the interviews were coded, the researcher examined the similarity and diversity of responses within both categories in order to identify significant patterns. The data were transferred into Microsoft Excel to
expedite this process. In this way, data were further categorized. For example, feelings of residential permanency could be grouped according to the supervision and accessibility level of the home, whether the feelings were positive or negative, and if they stemmed from interpersonal or physical environment issues or both. Once this process had been completed, it became easier to see connections between categories and the ways in which themes overlapped and related to each other. The data were also transferred into Microsoft Access in order to cross reference quantitative and qualitative data (e.g., reviewing the comments of consumers who expected to be able to the most activities versus those who expected to be able to do very little). The data could, at this point in the process, be used to generate an increased understanding of the relationship of the physical, social and attitudinal environment of the home environment to observed functional ability and consumer self-report of functional ability. Cross tabulations were used to examine differences among age groups, sexes, mobility device users, and supervision levels of the home. In this manner, the data were synthesized, analyzed and possible interpretations were proposed.

**Primary Data Limitations**

The study had a major limitation. The data were originally collected for a parent applied research project on home modifications. Therefore descriptive data that would have been useful during the current analysis were not collected. For example, there were no data collected on intellectual levels of the participants, or on individuals’ medications that may have impacted their functional ability. Descriptive data on participants had to be integrated from multiple sources, including researcher
observation, participant self-report, staff-report, charts and records. Different sources were available for different participants and sources varied in their reliability.
CHAPTER FOUR: QUANTITATIVE RESULTS

This chapter begins with a summary of the descriptive results which include the characteristic of the sample participants and their home environments. It goes on to describe the bivariate and multivariate analyses beginning with correlations between the key variables of the study. The findings for each of the three hypotheses are discussed in turn, as outlined in the analysis plan at the end of Chapter Three.

UNIVARIATE RESULTS

As illustrated in Table 1, the sample consisted of 129 adults between the ages of 32 and 91, with a mean age of 56.09 (s.d. = 10.08) years and a median age of 55. Approximately half were female. The majority (n=108, 83.7%) were Caucasian; 16 were black; four were Hispanic; and one was Asian-American. All but four members of the sample had an intellectual development disability. Twenty-two participants had physical developmental disabilities. Eighteen individuals had both physical and intellectual developmental disabilities.

Fifty individuals (38.8 percent) reported no physical disabilities, while 52 reported non-developmental, chronic or degenerative physical disabilities. Thirty-four subjects (26.4 percent) reported one physical disability, 28 subjects (21.7 percent) reported two or three physical disabilities, and 17 subjects (13.2 percent) had scores ranging from four to six. It should be noted that medical diagnoses were obtained from available consumer records, staff-report and self-report. Some consumers did not provide records, and some consumers may have had conditions that did not appear in the records. The amount and reliability of diagnostic information varied between
consumers and its accuracy is not easily gauged. Other impairments could be observed by the researcher and confirmed by records, and/or staff or participant report.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th><strong>CHARACTERISTICS OF THE SAMPLE (N=129)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>n</td>
</tr>
<tr>
<td>Male</td>
<td>64</td>
</tr>
<tr>
<td>Female</td>
<td>65</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>CAUCASIAN</td>
<td>56.09</td>
</tr>
<tr>
<td>BLACK</td>
<td></td>
</tr>
<tr>
<td>HISPANIC</td>
<td></td>
</tr>
<tr>
<td>ASIAN</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>108 (83.7%)</td>
</tr>
</tbody>
</table>

**Disability Characteristics**¹

<table>
<thead>
<tr>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifelong intellectual developmental disability</td>
<td>125</td>
</tr>
<tr>
<td>Lifelong physical developmental disability</td>
<td>22</td>
</tr>
<tr>
<td>Both physical &amp; Intellectual developmental disabilities</td>
<td>18</td>
</tr>
<tr>
<td>Non-developmental physical disability</td>
<td>52</td>
</tr>
<tr>
<td>Non-verbal/minimally-verbal</td>
<td>21</td>
</tr>
<tr>
<td>Epilepsy/seizures</td>
<td>21</td>
</tr>
<tr>
<td>Diabetes</td>
<td>16</td>
</tr>
<tr>
<td>Dementia</td>
<td>5</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>5</td>
</tr>
<tr>
<td>Autism</td>
<td>2</td>
</tr>
</tbody>
</table>

**Mobility Device Use**

<table>
<thead>
<tr>
<th>n</th>
<th>CUMULATIVE TOTAL</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Required wheelchair as only mode of ambulation</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Used a mobility device during the assessment</td>
<td>+19</td>
<td>31</td>
</tr>
<tr>
<td>Used a mobility device at all</td>
<td>+10</td>
<td>41</td>
</tr>
</tbody>
</table>

¹Ss could display more than one disability characteristic
Almost one-fifth of the participants were not able to communicate more than the most rudimentary responses (i.e., yes, no) verbally. Twenty-one were reported as having epilepsy although no data were collected on the frequency or control of seizures. Diabetes, dementia, quadriplegia and autism were also represented among the sample. Twenty-two consumers reported having a mental illness, however the researcher questions the reliability of the reporting of this variable (see footnote 1, Chapter 3). Furthermore, psychotropic and psychoactive medication use, which is likely to significantly impact mental health, was not gathered during the original study. For these reasons having a mental illness was not included in the results or in the accumulated overall impairment score.

Almost one-third of the sample used a mobility device at times, although only twelve needed to use it for all ambulation.

As noted in Chapter 3, accessibility level of the home was coded into four categories ranging from very accessible purpose-built or retrofitted homes to the most inaccessible category, two-plus story homes. As summarized in Table 2, about one-fifth of the participants lived in homes where the built environment had been purposefully planned for people with physical disabilities. Another fifth lived in one-story dwellings with no more than three steps (usually at the front entrance). A similarly sized group (20.2%) lived in dwellings that were primarily confined to one level but had a significant number of stairs used by the residents, usually either at the entrance or to the basement laundry. The others (30.2 percent) lived in homes with two or more stories. One consumer lived in a group home with an elevator and this home was included in
this final categories since the consumer still used the stairs regularly and the home had few other modifications.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Characteristics of the Participants’ Homes (N=129)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home Accessibility Level</strong></td>
<td>n</td>
</tr>
<tr>
<td>Purpose-built/extensive modifications</td>
<td>27</td>
</tr>
<tr>
<td>1 story without stairs</td>
<td>37</td>
</tr>
<tr>
<td>1 story with stairs</td>
<td>26</td>
</tr>
<tr>
<td>2+ stories</td>
<td>39</td>
</tr>
<tr>
<td><strong>Home Supervision Level</strong></td>
<td>n</td>
</tr>
<tr>
<td>Supported Apartment (weekly visits by staff)</td>
<td>27</td>
</tr>
<tr>
<td>Supervised Apartment (24/7 on site staff)</td>
<td>19</td>
</tr>
<tr>
<td>Group/Family Home (24/7 in home staff/caregiver)</td>
<td>83</td>
</tr>
</tbody>
</table>

Again as noted, supervision levels of the home were coded into three categories. Twenty-seven consumers (20.9 percent) lived in supportive living settings, often referred to as "supported apartments." Nineteen consumers (14.7 percent) lived in supervised living settings, usually referred to as "supervised apartments." The majority of the sample members (n=83, 64.3 percent) lived in group homes, including the one sample member who lived in his father's home and also received 24/7, in-home supervision.

As displayed in Table 3, accumulated overall impairment scores ranged from one to seven, of a possible range of zero to twelve, with a mean of 2.81 (s.d. = 1.63) and a
median of 3.0. Accumulated physical impairment scores ranged from zero to six, of a possible range of zero to seven, with a mean of 1.43 (s.d. = 1.59) and a median of one. Forty-nine participants (38 percent of the sample) had a score of zero (no recorded physical disabilities). Mean self-reported functional ability scores ranged from .6 to three, with a mean of 2.56 (s.d. = .48) and a median of 2.78. Twenty-one subjects were not able to report on their abilities. Mean observed functional ability scores ranged from one to five with a mean of 4.59 (s.d. = .69) and a median of 4.83.

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>TRANSFORMED VARIABLES (N = 129, except as noted)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Accumulated overall impairment level</td>
<td>129</td>
</tr>
<tr>
<td>Accumulated physical disability level</td>
<td>129</td>
</tr>
<tr>
<td>Mean self-report functional ability score</td>
<td>108</td>
</tr>
<tr>
<td>Mean observed functional ability score</td>
<td>129</td>
</tr>
</tbody>
</table>

* Defined under variables, pp. 70-72

**BIVARIATE AND MULTIVARIATE ANALYSES**

**CORRELATIONS**

Table 4 presents correlations between the study variables. The correlations of each of the (i.e., functional ability) with both participant descriptors and home environment descriptors roughly mirrored each other. There were significant positive correlations between mean observed functional ability and: mean self-reported functional ability, accumulated overall impairments, accumulated physical disabilities, home accessibility level, home supervision level, and all mobility device use levels.
Mean self-reported functional ability correlated significantly with these same items in addition, it correlated significantly with having a non-developmental physical disability.

### TABLE 4
**CORRELATIONS (N=129 except as noted)**

<table>
<thead>
<tr>
<th></th>
<th>Mean Observed FA Score</th>
<th>Mean Self-Reported FA Score (N=108$^+$)</th>
<th>Accumulated Overall Impairments</th>
<th>Accumulated Physical Disabilities</th>
<th>Home Accessibility Level</th>
<th>Home Supervision Level</th>
<th>Wheelchair Fulltime</th>
<th>Non/Minimally Verbal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Observed FA Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Self-Reported FA Score (N=108)</td>
<td>$0.893^{**}$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accumulated Overall Impairments</td>
<td>$-0.535^{**}$</td>
<td>$-0.525^{**}$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accumulated Physical Disabilities</td>
<td>$-0.623^{**}$</td>
<td>$-0.630^{**}$</td>
<td>$0.924^{**}$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Accessibility Level</td>
<td>$-0.314^{**}$</td>
<td>$-0.434^{**}$</td>
<td>$0.374^{**}$</td>
<td>$0.369^{**}$</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Supervision Level</td>
<td>$-0.215^*$</td>
<td>$-0.219^*$</td>
<td>$0.187^*$</td>
<td>$0.085$</td>
<td>$0.054$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheelchair Fulltime</td>
<td>$-0.813^{**}$</td>
<td>$-0.839^{**}$</td>
<td>$0.597^{**}$</td>
<td>$0.671^{**}$</td>
<td>$0.360^{**}$</td>
<td>$0.178^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used Mobility Device During Assessment</td>
<td>$-0.459^{**}$</td>
<td>$-0.469^{**}$</td>
<td>$0.754^{**}$</td>
<td>$0.857^{**}$</td>
<td>$0.266^{**}$</td>
<td>$-0.010$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used Mobility Device At All</td>
<td>$-0.387^{**}$</td>
<td>$-0.381^{**}$</td>
<td>$0.761^{**}$</td>
<td>$0.846^{**}$</td>
<td>$0.244^{**}$</td>
<td>$-0.016$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-developmental Physical Disability</td>
<td>$-0.091$</td>
<td>$-0.232^*$</td>
<td>$0.547^{**}$</td>
<td>$0.517^{**}$</td>
<td>$0.197^*$</td>
<td>$0.028$</td>
<td>$0.145$</td>
<td>$-0.063$</td>
</tr>
<tr>
<td>Non/Minimally Verbal</td>
<td>$-0.150$</td>
<td>--</td>
<td>$0.210^*$</td>
<td>$0.087$</td>
<td>$0.077$</td>
<td>$0.201^*$</td>
<td>$0.016$</td>
<td>--</td>
</tr>
<tr>
<td>Age</td>
<td>$-0.003$</td>
<td>$-0.110$</td>
<td>$0.030$</td>
<td>$0.014$</td>
<td>$0.138$</td>
<td>$0.121$</td>
<td>$-0.016$</td>
<td>$0.120$</td>
</tr>
<tr>
<td>Sex$^+$</td>
<td>$-0.063$</td>
<td>$-0.077$</td>
<td>$-0.061$</td>
<td>$-0.056$</td>
<td>$0.052$</td>
<td>$-0.137$</td>
<td>$0.025$</td>
<td>$-0.066$</td>
</tr>
</tbody>
</table>

$^*$ p < .05  ** p < .01

$^+$ Only 108 of the 129 subjects were able to report on their own functional ability so the sample size for this variable is slightly smaller.

$^8$ Age and sex were not correlated.
**Hypothesis 1 (Functional Ability and Impairment)**

The first research question that guided this study addressed the relationship between impairment or disability level of the subjects and their ability to carry out self-care activities in the home. The corresponding hypothesis was:

\[ H_1: \] People with fewer physical impairments will demonstrate greater functional ability, while those with the greatest degrees of physical impairment, such as quadriplegia, will demonstrate less functional ability.

**Quantitative Findings for Hypothesis One**

Hypothesis one was tested using a planned sequence of regressions. Specifically, in a multivariate regression analysis using the dependent variable, mean observed functional ability score, and the independent variable, accumulated overall disabilities, and controlling for the accessibility and supervision levels of the home, a significant model emerged (\( F_{3,125} = 15.497, p < 0.000, R^2 = .271, \) Adjusted \( R^2 = .254 \)). Accumulated overall impairments was negatively related to observed functional ability. The model accounted for 25.4 percent of the variance in mean observed functional ability score. Variables are shown in Table 5 below:

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Regression of Mean Observed Functional Ability Score on Accumulated Overall Impairments and Control Variables (Accessibility Level and Supervision Level); ( N=129 )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unstandardized Coefficients</td>
</tr>
<tr>
<td></td>
<td>B</td>
</tr>
<tr>
<td>Accessibility Level</td>
<td>-.102</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-.112</td>
</tr>
<tr>
<td>Accumulated Overall Impairments</td>
<td>-.181</td>
</tr>
</tbody>
</table>
Dependent Variable: Mean Observed Functional Ability Score

In a parallel multivariate regression analysis substituting the variable accumulated physical impairments for accumulated overall impairments, again, a significant model emerged ($F_{3,125}=24.263$, $p < 0.000$, $R^2 = .368$, Adjusted $R^2 = .353$). The model accounted for 35.3 percent of the variance in mean observed functional ability score, which is approximately 10 percent more of the variance than the model using the variable, accumulated overall impairments, explained. Again, the relationship was negative. Variables are shown in Table 6 below:

Table 6

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility Level</td>
<td>-7.38E-02</td>
<td>.050</td>
<td>-1.14</td>
<td>1.483</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-.142</td>
<td>.064</td>
<td>-1.59</td>
<td>-2.221</td>
</tr>
<tr>
<td>Accumulated Physical Impairments</td>
<td>-.240</td>
<td>.035</td>
<td>-5.20</td>
<td>-6.780</td>
</tr>
</tbody>
</table>

Dependent Variable: Mean Observed Functional Ability Score

In another parallel multivariate regression analysis substituting the variable, uses a wheelchair full-time, and still controlling for supervision and accessibility levels of the home, a significant model again emerged ($F_{3,125}=83.279$, $p < 0.000$, $R^2 = .667$, Adjusted $R^2 = .659$). This model accounted for 65.9 percent of the variance in observed functional ability and indicates that fulltime wheelchair users have a greatly diminished level of observed functional ability. (See Table 7.)
The same three regressions were then repeated, substituting the dependent variable, mean self-reported functional ability score for mean observed functional ability score. When the model was run using the most inclusive impairment measure, accumulated overall impairments, a significant model emerged \((F_{3,104} = 18.570, p < 0.000, R^2 = .349, Adjusted R^2 = .330)\). The model accounted for 33.0 percent of the variance in self-reported functional ability and the relationship was negative. (See Table 8 below.)

<table>
<thead>
<tr>
<th>Table 7</th>
<th>Regression of Mean Observed Functional Ability Score on Uses a Wheelchair Full-time and Control Variables (Accessibility Level and Supervision Level); N=129</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unstandardized Coefficients</td>
</tr>
<tr>
<td>Accessibility Level</td>
<td>-1.666E-02</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-5.953E-02</td>
</tr>
<tr>
<td>Uses a Wheelchair FT</td>
<td>-2.072</td>
</tr>
<tr>
<td>Dependent Variable: Mean Observed Functional Ability Score</td>
<td></td>
</tr>
</tbody>
</table>

Again using the dependent variable self-reported (rather than observed) functional ability, and the predictor variable, accumulated physical (rather than overall) impairments, a significant model again emerged \((F_{3,104} = 18.570, p < 0.000, R^2 = .349)\). The model accounted for 33.0 percent of the variance in self-reported functional ability and the relationship was negative. (See Table 8 below.)

<table>
<thead>
<tr>
<th>Table 8</th>
<th>Regression of Mean Self-Reported Functional Ability Score on Accumulated Overall Impairments and Control Variables (Accessibility Level and Supervision Level); n=108</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unstandardized Coefficients</td>
</tr>
<tr>
<td>Accessibility Level</td>
<td>-.113</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-7.656E-02</td>
</tr>
<tr>
<td>Accumulated Overall Impairments</td>
<td>-.114</td>
</tr>
<tr>
<td>Dependent Variable: Mean Self-Reported Functional Ability Score</td>
<td></td>
</tr>
</tbody>
</table>
.453, Adjusted R Square = .437). This model accounted for 43.7 percent of the variance in self-reported functional ability in a negative relationship. Variables are shown in Table 9 below:

**Table 9**

**Regression of Mean Self-Reported Functional Ability Score on Accumulated Physical Impairments and Control Variables (Accessibility Level and Supervision Level); n=108**

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>Accessibility Level</td>
<td>-8.415E-02</td>
<td>.034</td>
<td>-.198</td>
<td>-2.457</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-8.887E-02</td>
<td>.041</td>
<td>-.159</td>
<td>-2.178</td>
</tr>
<tr>
<td>Accumulated Physical Impairments</td>
<td>-.159</td>
<td>.024</td>
<td>-.527</td>
<td>-6.494</td>
</tr>
</tbody>
</table>

Dependent Variable: Mean Self-Reported Functional Ability Score

When the regression was run substituting uses wheelchair fulltime as the impairment measure, the overall model was again significant \(F_{3,104}=90.024, p < 0.000, R\ Square = .722, Adjusted R\ Square = .714\). This model accounted for 71.4 percent of the variance in self-reported functional ability in a negative relationship.

**Table 10**

**Regression of Mean Self-Reported Functional Ability Score on Uses Wheelchair Full-time and Control Variables (Accessibility Level and Supervision Level); n=108**

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>Accessibility Level</td>
<td>-5.771E-02</td>
<td>.024</td>
<td>-.136</td>
<td>-2.428</td>
</tr>
<tr>
<td>Supervision Level</td>
<td>-3.320E-02</td>
<td>.030</td>
<td>-.059</td>
<td>-1.123</td>
</tr>
<tr>
<td>Uses a Wheelchair FT</td>
<td>-1.330</td>
<td>.098</td>
<td>-.775</td>
<td>-13.558</td>
</tr>
</tbody>
</table>

Dependent Variable: Mean Self-Reported Functional Ability Score
Hypothesis 2: Self-Reported Functional Ability and Observed Functional Ability

The second research question that guided this study was, "What can be learned about the relationship between consumer self-reported functional ability and observed functional ability?" The corresponding hypothesis was,

\[ H_2: \text{Consumers with greater observed functional ability will have greater self-reported functional ability.} \]

Quantitative Findings for Hypothesis Two

As predicted by hypothesis two, the correlation between mean observed functional ability and mean self-reported functional ability was very high \( (r = .89, \text{df}=106, p < .001) \).

An additional analysis was conducted to further explore the relationship between the observed and self-reported measures. Although the observed functional ability assessment and the self-reported functional ability interview were not designed to have a direct correspondence between individual items, some items are comparable and, using recoding of the rating scales to produce comparability, it is possible to look at the individual item correlation between consumers' self reports or expectations and their observed ability as rated by the researcher during the assessment. Though all of the correlations are significant at the .01 level and all are positive, the amount of variance each explains varies from a high of .71 to a low of .10. (See Table 11.)
### Table 11
**Correlations between Self-Reported and Observed Functional Ability; n=108**

<table>
<thead>
<tr>
<th></th>
<th>Mean Self-Reported Functional Ability Scores</th>
<th>0.893**</th>
<th>Mean Observed Functional Ability Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Do you have any difficulty using the toilet?</td>
<td></td>
<td>Flush the toilet.</td>
</tr>
<tr>
<td>2.</td>
<td>Do you have any difficulty getting into or out of your bed?</td>
<td></td>
<td>Show me how you get onto your bed and lie down.</td>
</tr>
<tr>
<td>3.</td>
<td>Do you have any difficulty sitting down in or getting up from any of the chairs or sofas in your house?</td>
<td>0.801**</td>
<td>[In the living/TV room], Let’s sit down.</td>
</tr>
<tr>
<td>4.</td>
<td>Do you have any difficulty getting into or out of your bed?</td>
<td>0.793**</td>
<td>Thanks, you can get off the bed now.</td>
</tr>
<tr>
<td>5.</td>
<td>Do you have any difficulty using the toilet?</td>
<td>0.788**</td>
<td>Get up off the toilet.</td>
</tr>
<tr>
<td>6.</td>
<td>Do you have any difficulty getting the mail?</td>
<td>0.759**</td>
<td>Go to the mailbox, get the mail and put it in the appropriate place.</td>
</tr>
<tr>
<td>7.</td>
<td>Do you have any difficulty getting things in and out of the refrigerator?</td>
<td>0.744**</td>
<td>Now put the food back in the refrigerator.</td>
</tr>
<tr>
<td>8.</td>
<td>Do you have any difficulty using the toilet?</td>
<td>0.738**</td>
<td>Sit down on the toilet and tear off a small piece of toilet paper.</td>
</tr>
<tr>
<td>9.</td>
<td>Do you have any difficulty taking a bath or shower?</td>
<td>0.721**</td>
<td>Take your towel, and pretend to dry yourself.</td>
</tr>
<tr>
<td>10.</td>
<td>Do you have any trouble opening or closing the front door?</td>
<td>0.706**</td>
<td>When you get to your front door, open it and go into the house or apartment.</td>
</tr>
<tr>
<td>11.</td>
<td>Do you have any difficulty with any of the inside doors or doorways?</td>
<td>0.687**</td>
<td>Now let’s go from the bathroom to the kitchen.</td>
</tr>
<tr>
<td>12.</td>
<td># missing of expectation items</td>
<td>0.670**</td>
<td># of missing functional ability items</td>
</tr>
<tr>
<td>13.</td>
<td>Do you have any difficulty getting things in and out of the refrigerator?</td>
<td>0.664**</td>
<td>Please get something out of the refrigerator and put it on the plate.</td>
</tr>
<tr>
<td>14.</td>
<td>Do you have any difficulty working at the kitchen sink or using the faucets?</td>
<td>0.660**</td>
<td>Show me how you go to the sink and wash your hands.</td>
</tr>
<tr>
<td>15.</td>
<td>Do you have any difficulty with any of the inside doors or doorways?</td>
<td>0.656**</td>
<td>Go from the kitchen into the living room (or wherever you sit and watch TV).</td>
</tr>
<tr>
<td></td>
<td>Mean Self-Reported Functional Ability Scores</td>
<td>.893**</td>
<td>Mean Observed Functional Ability Scores</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------</td>
<td>---------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>16.</td>
<td>Do you have any difficulty reaching things in the kitchen cabinets?</td>
<td>.651**</td>
<td>Take the dish out of the dish drainer or dish washer and put it away.</td>
</tr>
<tr>
<td>17.</td>
<td>Do you have any difficulty reaching clothes, coats, shoes, or other items in your closets?</td>
<td>.602**</td>
<td>Show me how you get something hanging on your clothes pole out of your closet and then return it to the closet.</td>
</tr>
<tr>
<td>18.</td>
<td>Do you have any difficulty reaching things in the kitchen cabinets?</td>
<td>.600**</td>
<td>Please get a dinner plate, silverware, and a glass from the cabinet and set a place at the table.</td>
</tr>
<tr>
<td>19.</td>
<td>Do you have any problems operating the TV, VCR, and/or CD player?</td>
<td>.595**</td>
<td>Show me how you turn on the TV.</td>
</tr>
<tr>
<td>20.</td>
<td>Do you have any difficulty going from one room to another?</td>
<td>.587**</td>
<td>Go from the kitchen into the living room (or wherever you watch TV).</td>
</tr>
<tr>
<td>21.</td>
<td>Do you have any difficulty working at the kitchen sink or using the faucets?</td>
<td>.584**</td>
<td>Wash one of the dishes and put it in the dish drainer or dishwasher.</td>
</tr>
<tr>
<td>22.</td>
<td>Do you have any difficulty working at the kitchen sink or using the faucets?</td>
<td>.575**</td>
<td>Fill the glass with water.</td>
</tr>
<tr>
<td>23.</td>
<td>Do you have any difficulty with any of the inside doors or doorways?</td>
<td>.561**</td>
<td>Show me how you walk from your bedroom to the bathroom and turn on a light.</td>
</tr>
<tr>
<td>24.</td>
<td>Do you have any difficulty using the stove's cook-top?</td>
<td>.531**</td>
<td>Stir the water in the pot with a spoon.</td>
</tr>
<tr>
<td>25.</td>
<td>Do you have any difficulty opening and closing your windows?</td>
<td>.529**</td>
<td>Show me how you open and close a bedroom window.</td>
</tr>
<tr>
<td>26.</td>
<td>Do you have any difficulty reaching clothes, coats, shoes, or other items in your closets?</td>
<td>.522**</td>
<td>Show me how you hang up your coat.</td>
</tr>
<tr>
<td>27.</td>
<td>Do you have any difficulty using the stove's cook-top?</td>
<td>.518**</td>
<td>Take out a saucepan and fill it with cool water and put it on the stove.</td>
</tr>
<tr>
<td>28.</td>
<td>Do you have any difficulty working at the kitchen sink or using the faucets?</td>
<td>.512**</td>
<td>Take the pot to the sink and pour out the water.</td>
</tr>
<tr>
<td>29.</td>
<td>Do you have any difficulty going from one room to another?</td>
<td>.509**</td>
<td>Now let's go from the bathroom to the kitchen.</td>
</tr>
<tr>
<td>30.</td>
<td>Do you have any difficulty using the stove's cook-top?</td>
<td>.502**</td>
<td>Turn on the stove and adjust the flame or heat from very low to very high. Turn off the stove.</td>
</tr>
<tr>
<td>31.</td>
<td>Do you have any difficulty taking a bath or shower?</td>
<td>.492**</td>
<td>Show me how you turn on and turn off the bathtub/shower faucet (just pretend).</td>
</tr>
<tr>
<td></td>
<td>Mean Self-Reported Functional Ability Scores</td>
<td></td>
<td>Mean Observed Functional Ability Scores</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------</td>
<td>---</td>
<td>-----------------------------------------</td>
</tr>
<tr>
<td>32.</td>
<td>Do you have any difficulty using the stove's cook-top?</td>
<td>.893**</td>
<td></td>
</tr>
<tr>
<td>33.</td>
<td>Do you have any difficulty using the faucets, shower controls or drain plugs?</td>
<td></td>
<td>Move the pot from the stove to the counter.</td>
</tr>
<tr>
<td>34.</td>
<td>Do you have any difficulty going from one room to another?</td>
<td>.432**</td>
<td>Walk from the living room to the front door, as if responding to the doorbell.</td>
</tr>
<tr>
<td>35.</td>
<td>Do you have any difficulty opening and closing your windows?</td>
<td>.430**</td>
<td>Open a living room window.</td>
</tr>
<tr>
<td>36.</td>
<td>Do you have any difficulty sitting down in or getting up from any of the chairs or sofas in your house?</td>
<td>.422**</td>
<td>Sit down at the table and get back up again.</td>
</tr>
<tr>
<td>37.</td>
<td>Do you have any difficulty stepping in and out of the bathtub or shower?</td>
<td>.392**</td>
<td>Show me how you step into the bathtub or shower.</td>
</tr>
</tbody>
</table>
When the observed functional ability rating scale and the self-reported functional ability rating scale are made comparable (via recoding) on a 4-point scale, where 0 = can't do; 1 = great difficulty; 2 = some difficulty; 3 = no difficulty, the mean difference between each consumer's self-reported and observed functional ability scores can be compared for the sample of 108 verbal participants. (See Figure 4.) Seventy-three percent of the subjects were within .5 points and 38 percent were within .25 points of their ability as rated by observers.
Scores on mean observed functional ability significantly exceeded scores on self-reported functional ability (p<.001). More specifically, the mean differences in individual participant scores (i.e., observed functional ability score minus self-reported functional ability score) range from a low of −1.03 to a high of .89. Working from 0, which would be the score for a perfect fit between self-reported and observed ability, there are a total of 99 positive mean scores, indicating that mean observed functional ability exceeds mean self-reported functional ability for 91.6 percent of the 108 verbal study participants. In other words, over 90 percent of the sample underestimated their task performance as observed by the researcher.

The individual differences among the positive scores ranged from .01 and to .89. There were only nine negative scores, meaning self-reported ability exceeded observed ability. Among the negative scores, the mean differences ranged from −0.08 to −1.03. The mean individual difference in score for the sample was .28 (SD = .33) and the median score was .30.

**HYPOTHESIS 3: FUNCTIONAL ABILITY AND ENVIRONMENTAL ACCESSIBILITY**

The third research question that guided this study was, "What can be learned about the relationship between environmental accessibility and functional ability?" The corresponding hypothesis was,

H₃: Physical ability will be inversely related to the degree of accessibility of the living environment. For those with mobility impairments, home modifications to improve physical accessibility will not compensate for the physical impairment of the individual.
Quantitative Findings for Hypothesis Three

There was a weak but significant negative correlation between mean observed functional ability and home accessibility level ($r = -.314$; df = 127; p<.01), meaning those with greater functional ability lived in less accessible housing and, conversely, those with less functional ability lived in more accessible housing. (See Figure 5.)

![Figure 5](image)

**Figure 5**
Comparison of Functional Ability Scores and Home Accessibility Level with and without Full-Time Wheelchair Use

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9 To test this hypothesis, the variable Observed Functional Ability will be used because 1) Observed and Self-Reported Functional Ability were very highly correlated, and 2) Observed Functional Ability includes the full sample of 129 subjects, while Self-Reported Functional Ability includes only the 108 subjects able to self-report.
In Figure 5, the wheelchair users are symbolized by the red squares, while the other subjects are symbolized by the blue squares. Accessibility is measured on a scale from 1 (purpose built, barrier-free housing) to 4 (two or more story dwellings). The graph shows that full-time wheelchair users live in housing that is among the most accessible, although even wheelchair users with more functional ability tend to live in slightly less accessible housing (one story homes without accessible, barrier-free features) than their cohorts living in purpose-built homes. Non-wheelchair users, by contrast, have a greater degree of functional ability and live in a wider array of housing accessibility levels.

Although some non-wheelchair users live in purpose-built, accessible homes, the majority live in dwellings that include a significant number of stairs or two or more levels. Also, while wheelchair users who live in less accessible homes tend also to have higher functional ability, the same is not true for the non-wheelchair users. Their functional ability tends to remain high, compared to the full-time wheelchair users, whether their home has a high or low accessibility rating.

Similarly impairment level (r = .37; df = 127; p<.01), physical disability level (r = .37; df = 127; p<.01), using a wheelchair full-time (exclusively for ambulation and regular seating) (.36; df = 127; p<.01) all have a significant positive correlation with accessibility level of the home. People with the greater impairment live in more accessible homes.

To further explore the relationship between home accessibility and mean observed functional ability, mean functional ability scores were calculated for each of the four housing accessibility levels. Subjects living in the most accessible housing
(N=27) had the lowest mean observed functional ability score (4.03, sd = 1.27, on a scale of 1-5), and as housing levels became less accessible, mean observed functional ability scores of the housing’s residents increased (See Table 12). The mean scores for those not living in purpose-built housing were clustered together. The mean observed functional ability score for those not living in purpose-built housing was 4.74 (sd = .29) (Table 13). The three less accessible housing levels were collapsed. This created two levels of housing accessibility: barrier free/retrofitted housing and all other housing. A two-tailed t-test conducted between these two mean functional ability scores (4.03 (sd = 1.27), for retrofitted versus 4.74 (sd = .29) for non-retrofitted housing) revealed the difference to be significant at the level of .007 assuming unequal variances.

Table 12

<table>
<thead>
<tr>
<th>Home Accessibility Level</th>
<th>n</th>
<th>Mean Observed Functional Ability Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>purpose built barrier-free</td>
<td>27</td>
<td>4.03</td>
<td>1.27</td>
</tr>
<tr>
<td>existing unmodified 1-story</td>
<td>37</td>
<td>4.68</td>
<td>.37</td>
</tr>
<tr>
<td>1-story with stairs</td>
<td>26</td>
<td>4.74</td>
<td>.32</td>
</tr>
<tr>
<td>2+ storey</td>
<td>39</td>
<td>4.81</td>
<td>.16</td>
</tr>
<tr>
<td>Total</td>
<td>129</td>
<td>4.59</td>
<td>.69</td>
</tr>
</tbody>
</table>

When the mean scores for the number of activities not supported by the home environment was calculated for each of the three supervision levels of the homes (supported living, supervised apartments/homes, and group/family homes), it was found that housing that had less supervision (implying higher functioning inhabitants) did not support the greatest number of activities, and that the number of activities not
supported by the home decreased as the supervision level of the home increased. (See Table 14.) An F-test, with degrees of freedom 2 and 126 was calculated to test the significance of the mean differences among the three groups. The ANOVA had an F score of 7.40 and was significant at (p< .001).

**Table 13**
**MEAN FUNCTIONAL ABILITY SCORES BY HOME ACCESSIBILITY LEVEL (2 LEVELS)**

<table>
<thead>
<tr>
<th>Home Accessibility Level</th>
<th>n</th>
<th>Mean Observed Functional Ability Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>purpose built barrier-free</td>
<td>27</td>
<td>4.03</td>
<td>1.27</td>
</tr>
<tr>
<td>existing unmodified 1-story, 1-story with stairs, and 2+ storey</td>
<td>102</td>
<td>4.74</td>
<td>.29</td>
</tr>
<tr>
<td>Total</td>
<td>129</td>
<td>4.59</td>
<td>.69</td>
</tr>
</tbody>
</table>

Activities most likely to be not supported by the home included going up and down stairs, using a VCR, ironing, and washing/crying clothes, using a kitchen counter, getting mail from a mailbox, opening and closing a bedroom and then a living room window, and dialing a phone number.

**Table 14**
**ACTIVITIES NOT SUPPORTED BY HOME SUPERVISION LEVEL**

<table>
<thead>
<tr>
<th>Supervision Level of the Home</th>
<th>n</th>
<th>Number of Activities not Supported by the Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1: Supported Living</td>
<td>27</td>
<td>3.48</td>
</tr>
<tr>
<td>Level 2: Supervised Living</td>
<td>19</td>
<td>2.63</td>
</tr>
<tr>
<td>Level 3: Group/Family Home</td>
<td>83</td>
<td>1.24</td>
</tr>
<tr>
<td>Total</td>
<td>129</td>
<td>1.91</td>
</tr>
</tbody>
</table>

10 “Not supported” means that the home did not provide the physical facilities necessary to complete the activity.
In summary, the data show that mobility impairment has a significant impact on functional ability; the greater the loss of mobility, the fewer self-care and household tasks the participants were able to complete independently.

Participants able to participate in the verbal interview gauged their own abilities very similarly to the researcher’s observational assessments of their task performance. However 90 percent of those interviewed underestimated their abilities when compared to the observational data. This finding is statistically significant at the .001 level.

Individuals with greater overall physical impairment levels were more likely to live in purpose-built homes or homes that were substantially modified to make them physically accessible. By contrast people living in settings with less supervision tended to also live in homes that supported fewer of the self-care and home-care activities included in the assessment.
CHAPTER FIVE: QUALITATIVE RESULTS

The purpose of the qualitative analysis was to further explore and explicate the relationships between individual functional ability, personal expectations of competency and attitudes toward the social and physical environment of the home. Analyzing the responses and comments made by participants in the study enables the researcher to draw inferences about the participants' perspectives.

QUALITATIVE RESPONSES FROM CONSUMERS

People with developmental disabilities have few opportunities to have their voices heard. As evidenced by many of the articles that were included in this study's literature review, researchers tend to interview proxies, sometimes staff, often parents or some other spokesperson, instead of directly speaking with and observing the person who actually is living life with a developmental disability. Despite the fact that a major portion of the consumer interview consisted of fixed-choice questions and the prescribed task assessment, the opportunity to give the participants a chance to express their own views about their abilities, and about their lives as only they know them, was a valued component of this research. Analyzing the responses and comments made by participants in the study enables the researcher to draw inferences about the participants' perspectives. To this end, consumers' verbal comments and observations about these activities and their home life, in general, were recorded in writing by the interviewer on the interview and assessment forms. A smaller number of direct-care staff also participated in qualitative interviews with the researcher. This chapter describes these qualitative findings through summaries of the consumers' responses.
illustrated by selected quotations. It also includes personal sketches of a small number of consumers to better elucidate the findings and to connect those findings to the lives of the individual participants.

The intention of the researcher to record consumer comments, however, does not mean that all consumers had a lot to say. People with developmental disabilities are often not verbose, especially when confronted with a stranger who is assessing their abilities. In the current study, there were 21 consumers who were unable to indicate fixed-choice responses to the consumer interview, and an additional 17 consumers for whom there are no recorded comments – a total of 29.5 percent of the sample. The 91 consumers for whom qualitative data was recorded made from two to 43 comments each. Among these 91 consumers, the mean number of comments per consumer was 13.65; the median was 11. A total of 1,242 consumer comments were recorded.

In addition to the comments recorded during the fixed choice consumer interview and the task performance assessment, an open-ended series of questions was added after data collection had begun when it became clear that a deeper understanding of consumers’ attitudes toward their homes would enhance the research effort. Qualitative data were collected to access and explore how participants regarded their homes, what they liked and disliked about their residences, and what aspects of their homes and their lives in the context of the home environment mattered to them. This qualitative data also elucidated and expounded on the quantitative findings by probing issues such as feelings of independence/dependence, feelings of belonging or loneliness, and reactions to the support participants received from providers and staff.
Because many consumers gave one word responses when asked for their feelings about their current home (e.g., okay, fine, good), they were also asked to compare their current residence with their previous home. This proved to be a better prompt for a more thoughtful and individual response. This often helped to establish a conversational, as opposed to interrogational, climate. The interviewer went on to ask about problems performing everyday self-care tasks in the home environment. Respondents were asked what activities had become more difficult with age. While many consumers continued to give one-word responses, others were more expansive. Their answers, combined with the other recorded comments, provide insights into the participants’ lives and experiences from a uniquely personal point of view that no proxy could replicate. The participants explain what the quantitative data cannot, and in doing so, give us the rare opportunity to glimpse the minds of people who have live with developmental disabilities, and increase our insights into their lives. During the process we can also begin to identify issues that make a difference to their individual lives and impact their functional ability. The qualitative data reveal that accessibility and independence were not only a concern of full-time wheelchair users, but had a broader meaning and impact for participants without major ambulatory issues. Social participation and engagement were influenced in multiple ways by both the social and physical responsiveness of the home environment to consumer needs.

**CONSUMERS’ PERSPECTIVES ABOUT INDEPENDENCE, ACCESSIBILITY AND THEIR HOMES**

Themes that arose when consumers were asked about their homes included issues related to independence/dependence, privacy, housemate and staff interactions,
social relationships, neighborhood and community involvement and maintenance issues.

Living Situation: Impressions

The first open-ended question consumers were asked was the inductive and intentionally neutral: “What do you think about it here?”. Most verbal consumers answered this question, and the majority provided positive responses about their living situation. Many of these positive comments were short answers, such as “I like it,” “It’s fine”, “I love it,” and “good.” A few were less wholehearted, answering, ”It’s okay,” “It’s all right,” or “I manage.” Several consumers who liked their homes qualified their comments: “I like it, but I want a wife,” or, “I like it, but sometimes I want to go to home too,” (a reference to the parental home). And others simply didn’t like where they lived, but seemed unable to determine or unwilling to share their reasons. These consumers made statements such as “I want to move out. I don’t want to live here in the future,” or “I don’t belong here.” Others specified something about what they liked or disliked.

From those who were able to express something of their reasoning, several topics arose. These included independence and autonomy, privacy or the lack of privacy, social connections to the neighborhood or town, social issues within the home setting, support issues and maintenance issues.

Several people expressed feelings associated with the impact of their home on their feelings of independence and dependence. Two, who lived in supported apartments, mentioned that they liked being on their own. One stipulated that she wanted to die in this home, rather than in a group home or nursing home. “You can
hold your money," another remarked, drawing a distinction between settings, such as developmental centers, where residents deposit their money at a central location, and his current residence. Another mentioned appreciating challenges and not wanting things to be easy.

Others spoke of wanting more ownership of their home, or wanting to live by themselves. One woman who lived in a group home confided, “There's a program I was looking into before I came here where you hire your own staff and have your own apartment.” Another wanted the state to buy him his own home. Another group home resident flatly stated, “This is not my home. This is the Arc's home. I want my own home.” One consumer wistfully remarked, “Sometimes I’d like to go walking down a street and come back on my own.”

Others mentioned a connection to the neighborhood or town, saying, “The people are nice,” “the neighborhood is quiet,” and “I’ve found a lot of new friends – neighbors.” Two respondents mentioned nearby employment. One respondent who used a wheelchair for all mobility proudly described her job delivering mail at a local suburban mall. Another declared, “I love my apartment. I can get to church. As long as I can get to church that's all I care about.”

Support was often mentioned in a positive context. Three mentioned staff/caregiver support. “It's better here [than previous residence],” critiqued one consumer. “People try to help you – take you to the bank, buy us clothes.” One non-ambulatory woman said, “[The staff] keeps me clean. They keep the house clean. They
keep my clothes clean.” One person who said she liked her home “a lot” mentioned a supportive physical environment: “There’s no stairs. I can’t be on stairs.”

Several consumers living in group homes mentioned a lack of privacy. “I have a personal friend I would like to have shared an apartment with. I don’t have privacy here,” one woman stated. She went on to explain, “People interrupt me on the phone. They don’t knock on the door. Sometimes I’d like to have a lock on my door.” Another woman commented, “I don’t want housemates—just me, myself, and my fiancé. They want me to throw things away and I don’t want to. I want a bigger house with a walk-in closet so I can put all my stuff in there.” Only one consumer, a woman living by herself, expressed a need for more companionship. “I don’t like it,” she confided. “I would like to move closer to a store and closer to my sister. It’s too lonesome and too quiet here. At night-time, I don’t sleep. I get up and walk and walk and walk.”

Connected to privacy, sharing a home with housemates was another issue that some consumers brought up immediately. Several complained about sharing their home and about their housemates. “Some of the people holler all the time. I stay outside when it’s nice weather,” commented a group home resident. Another explained that he had moved to his current home because he’d had problems with a housemate in his previous home. Yet another adamantly declared, “I have to get out of here because of the people – they bother me. They throw things at me. If they moved out all the people I would live here.” Another rather cryptically remarked, “People cause some problems. People come and break things.”
Finally, maintenance was an issue that was mentioned by two consumers living in supported apartments. “It’s not bad but they don’t take care of the place,” stated one man. “Maintenance is terrible. The ceiling needs to be replaced. The front of the drawer broke off. There are all kinds of little odds and ends. They [the apartment management] never do anything.” A woman, also living in her own apartment, felt similarly. “They don’t fix things when they’re broken,” she complained. “I have broken windows in the living room. The mats are coming apart on the front stairs. The paneling on the wall is buckled. It’s been like that since I moved in.”

Consumers’ Housing: Likes and Dislikes

Social activities, physical home amenities and accessibility, a sense of ownership, independence and positive social relationships were the major topics that arose when consumers were asked what they enjoyed. About two-thirds of the verbal respondents identified from one to eight things that they liked about where they lived and several said they liked everything. One person began by saying “not too much,” then listed some things he liked and summarized with, “I like everything.” One person said he could not answer the question because he was always out.

Among those who identified at least one positive characteristic of their home-life, many people talked about activities. Most often mentioned were agency-sponsored leisure activities such as dances, banquets, and bowling, but a handful of people also mentioned a job or a day program. Seven people said they enjoyed trips and outings and most specified places they enjoyed going, including sporting events, movies, and
visiting friends and family. Respondents often mentioned enjoying watching television or listening to radio. Other activities included crafts projects and meetings.

Some people, all experiencing age-related physical disabilities, commented on the accessibility of the home. One woman living in a compact but accessible first floor garden apartment remarked, “It’s easy to move around. It’s perfect for me.” A man who had recently moved from an apartment to a ranch-type house said, “I like living in a house better than in an apartment. I can move around more.” Another man who was having trouble walking and used a scooter for excursions explained, “I like being on the first floor and having a front door entrance. The apartment is nice and long. I like the long kitchen....I like having a folding ramp for my scooter.” One other person simply replied, “No stairs.” Another mentioned that she liked having her own bathroom.

Several people mentioned having a laundry room. Others mentioned that they liked their neighborhood.

A substantial number of people mentioned that they liked living in a quiet place. Quite a few mentioned a sense of ownership. “I have my own phone and my own TV – Everything’s your own,” explained a woman living in a supervised apartment. Others mentioned having their own room – an issue that also relates to privacy. One person replied, “Everybody leaves me alone.” Related to ownership, numerous people mentioned possessions that they were proud of, or enjoyed. Often this was a television. Others mentioned appliances and electronics (refrigerator, dishwasher, washer, dryer, phone), a cat, stuffed animals, an exercise bike, and paintings.
The issue of independence again arose. A group home resident explained, “I can do what I like.” A handful of people talked about the ability to do self-care activities. “I do my own laundry. I like to cook,” was one response. “I take my shower okay myself. Most of the time I don’t need anything,” replied another. Others mentioned cleaning and cooking. One person mentioned her ability to do the laundry, cook and entertain herself. Another mentioned putting a hot plate in the living room so he could watch television and cook simultaneously.

Related to both accessibility and independence, many people talked about their pleasure in being able to get to places on their own from their homes. “I can walk to the library,” one woman explained. Another said, “It’s closer to my job and to the bus stop. I can walk to the store. It’s easy to get to the beach. I have a lot of independence.” Another person who liked her apartment’s location noted, “It’s close to the train station, stores and restaurants. It’s not a bad town.” A number of people mentioned being able to walk on their own to stores and restaurants. Others mentioned proximity to public transportation. Respondents mentioned proximity to church, a grocery market, and the beach and boardwalk entertainment. Not surprisingly, all those who mentioned being able to get to places on their own were living in supported apartments.

Finally, many individuals mentioned social relationships. Some noted liking their roommates or housemates, others enjoyed their friends and one mentioned a neighbor. One person mentioned “being like a family” with other consumers served by the same provider agency who also lived in the apartment complex.
When consumers were probed about their dislikes, responses related primarily to the inadequacies and short-comings of the built environment, housemates and staff. Maintenance and privacy were again brought up, this time in a negative context. As with prior questions, about two-thirds of verbal consumers answered this question, and approximately a third of them said there was nothing they disliked. The others each identified between one and four things that they did not like, which closely reflected the things respondents had said they liked: the built environment, housemates, a lack of maintenance, supports, social life, location, neighbors, activities and a lack of privacy.

Many people mentioned that they did not like some aspect of the built environment. Over a third of these involved the lack of privacy in regard to housemates and neighbors. Thin walls, noisy housemates and noisy neighbors were mentioned by a number of people. Another person had upstairs neighbors that overflowed the tub and caused the consumer’s ceiling to fall down. Others mentioned that their space was too small and/or didn’t provide an adequate amount of storage space. One person disliked having to climb up and down stairs. Another did not have enough electrical capacity to operate several appliances simultaneously. Yet another consumer said he did not like the architecture of the houses in the neighborhood. A few people mentioned the home being too far from stores, friends or family.

Close to a dozen consumers mentioned problems with housemates, or sharing a house. “I’m not friends with the people that live here. I just know them,” one consumer explained. “I’d rather live on my own.” Another ruefully reported, “I’m living with the
town drunk, and my other housemate is nosey.” Other complaints included housemates who fought constantly or were reluctant to share.

Some mentioned concerns about the support they received from the staff. One person felt the staff should take him to the doctor more often, another resented the attention staff paid to her diet, and another didn’t appreciate the staff-enforced exercise regime. One older group home resident expressed a deeper staff-consumer rift, explaining, “The young staff members are careless and don’t really care about being here and don’t communicate with us too much.” Others just said that they didn’t like or get along with the staff at their homes and/or their day activity programs.

A number of people also mentioned maintenance problems. “This is roach heaven,” one consumer reported. Others complained about maintenance people that didn’t do their jobs, repairs that weren’t made, and things that didn’t work properly.

Again, the issue of privacy arose. One person who lived in a basement apartment complained that people looked in his windows. Another said, “I’d like to be by myself – that’s what I’d like.” Another person didn’t like sharing a bedroom.

Comparison of Current Residence to Previous Living Situations

Comparisons were made with prior living arrangements which included institutions and developmental centers, living with parents or families, or living in other provider-owned and/or supervised community-based group homes and apartments. Over a quarter of the sample members currently lived in supported apartments, another quarter in supervised apartments and almost half lived in group homes. Ten people said they had previously lived in institutions.
A majority of those who had lived in institutions had only negative comments about them; several noted both pluses and minuses and one preferred the developmental center. Negative comments included being abused and ridiculed by staff, and bad food, each mentioned several times; and a lack of freedom, mentioned occasionally. Not going on outings, being over-medicated, and the staff not having as much time for one to one relationships with the consumer, were also cited. Positive comments about the institutions included good social relationships with both staff and residents, mentioned by a few respondents; having one’s own room, good food and having a hairdresser. One person with quadriplegia explained,

I used to live in an intermediate care facility. It had 52 residents. Here we have six. You have much more interaction with the staff here than at the ICF. At the ICF they also treated you very well. [In current group home] they’re more interested in teaching you so you can learn a lot more here. At the ICF there were 16 residents on each unit so you had to interact with 15 other people. You felt close to the staff, but they didn’t have as much time as the staff here do. Before the ICF, I lived at home with my dad. That was the best place I ever lived. I have two sisters. One got married and one spent more time with me. My father built me my own room. It had a ramp so it was totally accessible. I lived in my father’s house until I was 41½.

Some had lived in multiple institutions and many had lived in a series of dwellings. One remarked, “I like the [supervised apartment]. The people won’t be moved around any more. I spent most of my life in institutions: first, New Lisbon, then Vineland Training School, then Maniko Colony – part of Vineland….At Budd Lake I lived with Mrs. Ames. It was a nice place because they were very good. Then I moved into an apartment.”

Nine people had previously lived with their families. Most mentioned positive memories of this experience, and about half mentioned regretting that it had become
too difficult for their parents to continue to provide care. “I lived with my Mom before she went to the Nursing Home. It was nice. She had to drive me to work and take care of my father and it was too much for her.” Others were less positive about living with family. “I lived in one room in a big building with my sisters,” one group home resident recalled. “It was a big room with a sheet dividing it. I had half and they had half. We cooked in the bedroom. It was terrible. People were drunk and there were lots of abused people. We only had one room. Then I had to sleep in my sister’s car because they kicked us out.” A few felt that their current living conditions were preferable to their families’ living situation. One explained, “I’ve lived in a lot of places – Hawthorne, New York in an institution, and before that with my mother and father. “I like it here. I go all over. I go to games. I go to New York.”

Some people had previously lived in group homes and slightly more had previously lived in apartments. Reasons for liking a location better included living in a spacious home, living in a convenient location (close to stores and transportation), having a washer and dryer inside the home, living in a quiet location, being able to do “normal things,” living in a safe location, having a nice view, being on their own, freedom to come and go as they pleased and do what they wanted to, having a “nice” place, an attic, a patio, having a “nice layout of rooms,” and living in “a regular house.” Conversely, reasons for disliking a place included not having enough space, not liking one’s housemates, having an irresponsible apartment manager, having to go outside to get to the laundry, having bug or rodent infestations, living in a bad neighborhood,
having staff around constantly, having poor air quality, and having a basement apartment.

_Problems Performing Tasks in the Home Environment_

When asked if there were tasks or activities that were particularly difficult for them to do in their homes, over half of the respondents cited one or more problems. These can be categorized as problems performing daily living and self-care tasks, and problems navigating the physical environment of the home.

Various activities of daily living were a focus of comments with doing laundry the most often cited problem. For example, respondents described difficulty carrying laundry to the laundry room, and reading the dials on the machines. In the kitchen, consumers had trouble reaching things in the cabinets, cooking, getting food out of the refrigerator and just “doing things in the kitchen.” In the bathroom, a number of people reported difficulty taking showers and taking baths. Using the sink and using the toilet were also mentioned. Doing chores around the house were referred to both generally and specifically. Taking out the garbage, getting the mail, and cleaning the cat litter were all brought up. Other activities, cited by a few people, included getting dressed, ironing, using the phone, opening blinds and unlocking doors.

Problems going up and down stairs were frequently reported. Carrying things also proved difficult for a large minority of the group. Reaching things was often a problem and more than a few said they had difficulties operating appliances. Problems with doors that were hard to open and/or close were commonplace.
Other problems that were not directly associated by consumers with the environment included problems balancing, mentioned by a number of consumers, and general physical weakness, referred to repeatedly. Medical problems were sometimes cited, including low blood sugar, a bleeding ulcer, arthritis, heart problems and diabetes. Ambulation problems were not rare. “Getting around [is a problem],” replied one person. “I have cerebral palsy. It’s hard to walk without using two canes, but I want to do things that I can’t do if I’m holding onto canes.”

Age-Related Issues

The majority of respondents identified numerous things that had gotten harder for them as they had aged. Ambulation was the most frequently mentioned difficulty, followed by loss of strength, problems on stairs, balance issues, and problems using their hands.

In terms of ambulation, several mentioned bad knees or bad legs and joint problems but many just said it was harder for them to walk. Some attributed the problem to a lack of stamina, saying they got winded or that it was difficult to walk any distance. One specified that she had trouble walking up hill. One speculated sadly, “It may get to the point where I can’t walk much.”

Approximately an eighth of the respondents mentioned having less strength now than they once had. “Standing up by myself [is harder],” said one person. “I can feel my body getting older,” said another.

It was not unusual for people to mention problems using stairs. “I have to go upstairs one step at a time,” remarked one. Another said that since his hip surgery stairs
had been hard and a third speculated that she might need an elevator in the future.

Several people described a lack of energy. “It’s hard to get going,” one observed.

A handful of people mentioned balance issues. One said he felt dizzy because of recently diagnosed diabetes. Another had switched from taking showers to taking baths so she could sit down in the tub, and avoid having to stand and balance. One said he had always had problems with balance, while another felt that it was a problem brought on by aging.

A handful of people mentioned problems using their hands. “It’s hard to turn the knob. I have a sickness in my left hand,” explained one elderly woman. “I don’t bother with the sliding glass door. The lock is too hard to turn,” another commented. “When they open it, I go out.” “My hands don’t work so well,” said another. “I can’t operate the controls on the radio.” One woman found putting her shoes on more difficult because her hands shook. Another respondent had trouble turning lamps on and off for the same reason.

Some specified a variety of other activities that had become more difficult with age. “Getting dressed;” “Getting the mail;” “Getting into the back seats of people’s cars;” “Reaching up to comb my hair;” were all mentioned at least once. Another respondent said she had trouble putting things back in her closet because reaching up was more difficult.

A few people mentioned issues with vision. “I have cataracts in both eyes. It’s harder to see to unlock the door,” one stated. “I can’t even see to read a Bible,” another lamented. “My eyesight and hearing are getting worse,” a third person observed.
Some mentioned the recent onset of illnesses including asthma, a bleeding ulcer, diabetes and arthritis, and the fact that these conditions influenced their health and feelings of well-being.

“I have no teeth so I have trouble eating,” said one person. “I wet myself. I have no control over my urination,” another replied. Another said that visiting friends was harder.

Two people said they missed being able to ride a bike and one missed going to the YMCA, which she was no longer allowed to use because she had had a pacemaker installed. One person mentioned that she forgot things more often, saying, ”Sometimes I can’t remember, but then it comes to me.”

Another spoke about his feelings associated with aging and having a disability: “I get frustrated and feel angry about getting older. I took an anger management course. Since my parents told me about my [intellectual disability] I always felt like a failure. I attempted suicide several times.”

Environmental Modifications, Physical Accessibility and Assistive Devices

Almost half the sample members mentioned ways that their homes could be changed to make it easier for them. Responses pertained to lighting, environmental modifications and assistive devices, maintenance and furnishings. Lighting was mentioned most frequently. While two consumers gave general responses (“better lighting”; “I need more light,”), most specified a room or an area where better lighting was needed and one person specified a task, vacuuming, that she needed more light to perform. One wanted a ceiling fixture to replace the tipsy lamp in the living room. Four
people mentioned that they needed better exterior lighting (i.e., “Improve the lighting on the driveway. It’s pitch black at night.”). A number of people mentioned more lighting in the bedroom; a few others specified the living room, a couple wanted more light in the hallway and one mentioned “a light next to the computer.” One wanted a touch lamp which she had seen advertised on television.

A substantial number of respondents mentioned modifications to the environment or assistive devices to make their lives easier. Several mentioned difficulties opening cans or jars and suggested that jar openers or electric can openers would be helpful. “Now, I only buy zip-top cans,” one added. One person wanted a computer keyboard with bigger letters and numbers, and a phone with bigger numbers and an amplifier. A handful mentioned changes to the bathroom. One wheelchair user reported, “The toilet is wedged in a corner too close to the wall. There’s no room to move. It needs more space around it.” Another wanted a higher sink, explaining, “It’s low compared to some other sinks and makes my back hurt.” Several wanted grab rails – one specified for the shower, another for getting into the tub and another just to hold onto because the bathroom floor got slippery. One wheelchair user mentioned wider halls, citing a difficult turn from a narrow hall. Another said the front sidewalk was too steep for her in her wheelchair. Doorbells came up several times. Some had trouble hearing the doorbell when it rang and another person wanted a doorbell at the back door. In one group home with a number of exterior doors, all were equipped with doorbells that sounded the same, so residents had trouble figuring out which door to go to. Other single mentions included a telephone jack in the bedroom, a lower bed,
“something to make cooking easier,” and replacing the dials on the washer and dryer with coin slots which the consumer found easier to use. Another person said he would like to have a washer and dryer in his apartment but couldn’t afford the charges for these extras. One person said he might need a cane when he was eighty or ninety.

Twelve people mentioned home improvements. Some cited the need for additional closets and/or storage space. Others felt they would benefit from larger bedrooms. Another suggested ramps to replace the exterior steps. A couple mentioned improvements in the heating/cooling system. Several thought that their refrigerators needed to be replaced, one saying that the existing refrigerator was wobbly and rolled, and another saying she couldn't climb high enough to clean the top of it anymore. A small group mentioned maintenance needs, making general statements such as, “Fix the things that are broken.” One observed that the house needed someone to come and clean it. One person suggested putting some windows in a closed bathroom. One individual wanted to move into a different group home.

A small group of people mentioned items related to furnishings. Some wanted rugs, and one complained that the rugs in the bedroom had been taken up and she was afraid, now, of falling and hurting herself on the bare floor. Another felt that his apartment was in dire need of refurbishing and wanted the walls painted, new blinds, new curtains and new rugs. He also wanted his stove replaced since the burners didn't work properly. Two people felt they would sleep better with new beds. Other single mentions included a couch, a new dresser, and an alarm clock.
Somewhat off topic, one person mentioned that he had no transportation and needed a car. The same respondent felt that learning to read would make a significant difference in his life. Another person felt that increasing the number of staff members at her group home would be helpful.

**QUALITATIVE RESPONSES FROM INTERVIEWS WITH STAFF**

As noted, direct care staff who worked with some of the consumers in the study were also interviewed to expand on consumers’ comments and to get staff perspectives on issues such as task performance and independence. The twenty interviews revealed some themes and threads common to the consumer interviews including age-related physical losses among consumers, accessible and inaccessible features of the home, and social relationships. The staff interviews also served to elucidate some of the reasons behind consumers’ both inability and reluctance to undertake various tasks.

Staff were asked if and how the consumers had changed over the time that they had worked with them, and if so, the reasons for these changes and how the individuals were impacted, particularly in performing self-care and household tasks. Staff members who felt that consumers’ abilities had deteriorated over the time they had worked with them generally attributed consumer losses to medical health issues that often had a domino effect. One example was the onset of diabetes, and the subsequent medications to control the disease. In one case, these medications not only caused liver problems, but also precluded the use of the consumer’s medications to control his paranoia, which meant that he was now experiencing serious mental health problems. In other cases a seemingly trivial injury, such as sprained ankle, set off a series of events that eventually
curtailed the consumer’s ability to walk independently. As the staff member expressed it, “The whole lower half of his body is out of whack.”

Conversely, when staff observed improvement, this change for the better was almost exclusively involving mental health. For example, anger issues had been resolved; consumers had worked through family concerns.

Staff were asked to rate how the physical environment of the home was working for the consumer, and to explain why they chose the specific rating. Most staff rated the environment favorably and frequently attributed the positive impact of the physical environment to the consumers’ familiarity with his or her surroundings, which enabled consumers to develop and settle into a routine that worked well for them. One distinctive comment, “When the fire alarm goes off he’s used to it,” was a reminder of the institutional vestiges requisite in group home environments. Suggestions for improving the physical environment of the home echoed consumers’ suggestions and generally dealt with making the home more physically accessible. Specific suggestions included front-loading washers and dryers, stoves with easily accessible and readable controls, less clutter, larger bedrooms, and one-level homes with more spacious layouts.

The staff also reiterated the consumers’ complaints about poor maintenance and the need for improvement in this area.

When asked about the social environment of the home, the most oft heard comments concerned the problems residents had getting along with each other, and were not unlike the problems any co-habitants might encounter – for example, using another’s personal belongings, or making too much noise. One staff member
commented that the other clients in the group home held back a consumer who was higher functioning.

Perhaps predictably, some staff members also mentioned that consumers would benefit from more staff and, specifically, more one-on-one time with staff members.

When staff were queried about the reasons consumers did not undertake certain household or daily living tasks, their answers revealed an acceptance of consumers' preferences and, sometimes, a lack of emphasis on participation. The most frequent response was that the consumer preferred not to do the activity, or had “just never tried it.” “He only doesn't do what he doesn’t want to do,” a staff member reported. “He's just lazy – it’s really a behavioral thing,” another explained. “He's just not interested in self-care or personal hygiene – he does the minimum and even that’s a struggle,” one staff member commented. Sometimes the answers were somewhat surprising – for example, a consumer who didn’t use the linen closet because he didn’t use sheets on his bed, or a consumer who didn’t set the table because he ate his food directly from packages. “Things get done,” one staff member explained. “He's alive and happy. And he's learning the consequences of his behavior. You get rid of the flies once.”

In several instances, staff lamented consumers’ learned inhibitions. “It’s been drilled into her head that she'll get burned,” explained one staff member when discussing a consumer’s refusal to help with cooking. “Someone convinced him can openers are dangerous,” another commented.
Consumers, some staff reported, sometimes had no opportunity to learn to do some activities because of the established and unquestioned household routine. These activities included unlocking the door to a group home, cooking, doing the laundry, and running a bath. “We’re just so used to doing it,” one respondent commented. “It’s the staff’s job,” another explained (echoing consumers’ explanations). “It’s easier for us to do it,” said another. “It would be frustrating for her to try that,” a staff member predicted. “She would be apprehensive about doing it,” another explained. “He could get the mail,” a staff member admitted, “but he doesn’t need to.” “She’s used to relying on the staff to get things out of the refrigerator,” commented another.

Some staff also discouraged activities that they felt were “too big a risk” – most often using the stove and oven. “She could burn herself,” “his judgment is not so keen,” were among the staffs’ observations.

The final question asked the staff was to name one change that would most help the consumer achieve a greater degree of independence. While a number of staff felt consumers had reached their peaks, the insightful answers given by others mirrored the complexity of the situations they experienced regularly. A few mentioned barriers in the physical environment – the lack of a ramp, a house where things were out of reach to people of short stature, and issues surrounding clutter. Several mentioned that if the staff had more time to spend teaching consumers in a one-on-one format, they could learn to do more for themselves. One staff person thought that if a consumer were placed with housemates who were at her own functional level she would gain autonomy and independence. Another suggested that if the consumer knew how to read his
options would increase. One mentioned healthier habits: “Get him to quit smoking and lose weight.” Another felt having more financial resources would help the consumer gain more control of his life. Behavioral issues, however, permeated the discussion. “Motivate her to see the importance of keeping herself and the environment clean and orderly,” one suggested. “Address [the consumer’s] laziness,” said another. “He wants the staff to do things for him that he can do independently.” “She has to want [more independence],” said a third. “He might prefer not to do things,” another reflected. “She wants the staff to wait on her,” remarked yet another. “He has a mind of his own,” still another staff member explained wryly. “He does what he wants to do.”

SUMMARY OF CONSUMER AND STAFF PERCEPTIONS

While the quantitative data show a strong positive relationship between mobility impairment and functional ability, the qualitative data not only affirm and explicate this finding, but also extend beyond mobility to activity participation and engagement and the relationship of these pursuits to life-satisfaction. For people with physical impairments, the data reveal many factors that influence mobility, participation and individual fit with the environment. Loss of physical strength and stamina, along with other medical problems associated with aging, limited activity participation for many of the participants. Features of the physical environment that influenced activity participation included ease of use of appliances and other household fixtures and furnishings, as well as the general physical layout such as the need to use stairs. The proximity of neighborhood amenities such as shops, churches, and recreational facilities influenced activity participation and community involvement. One of the strongest,
non-physical influences on consumer activity was individual motivation and the dependency can prevail when staff members are ever-present.

The qualitative analysis also reveals several themes related to life-satisfaction. Overall the consumers were fairly satisfied with their current living arrangements. Consumers viewed a number of issues both positively and negatively such as privacy and independence, lack of ownership, accessibility, housemates, and staff support. Consumers in supported-living settings (apartments) generally viewed independence and accessibility issues more favorably that those in group homes. Consumers felt positive about ownership with regard to their possessions but not with regard to their living space. Social issues regarding housemates and group living varied according to individual needs for privacy which may be compromised by group living environments. Staff issues are also influenced by the individual personalities of consumer and staff; however, while a few consumers saw the staff as overly supportive, many of the staff saw the consumers as less than adequately challenged.

PERSON ENVIRONMENT FIT AND ITS RELATIONSHIP TO SELF-REPORT

The triangulation of the consumer perceptions expressed during the interviews, staff perceptions and researcher observations during the task assessments reveal that the complexities of designing a physical environment supportive of each resident's needs is a formidable task. Although the physical environment’s role in supporting functional ability was often not recognized proactively, the repercussions of this disregard were sometimes overt and rarely far below the surface. Regardless of what questions were asked throughout the interview, or what task consumers were
performing, the lack of well-matched person-environment fit was reflected in many of both the verbal responses and the task assessments. During quite a few of the assessments, obvious maintenance issues that had a negative impact on a person’s ability to use the home environment were readily evident. Although more easily operated door handles, light switches and other environmental controls had been readily available for some time, these potentially enabling features had often been overlooked.

One area where these environmental limitations were particularly evident was in lighting – particularly lighting in consumers’ bedrooms. Assessments revealed that many consumers had no lights near their beds, and some had only one small light in their bedrooms. Consumers’ desks, for those who had desks, often lacked task lighting or any nearby lighting. Lights were sometimes not working because they were not plugged in and some of these were not near outlets, and needed extension cords that were evidently unavailable. Bulbs were frequently burnt out and not replaced. One consumer had no working lights in his bedroom. There were also sockets without bulbs where bulbs would have been useful. Some lights were broken and had not been repaired – often exterior lights and porch lights. Sometimes there were not enough electrical outlets to plug lights into.

Permeating many of the assessments was evidence that a sizable number of consumers did not perform and were not typically expected to perform routine household tasks and activities of daily living. This fact was obvious not only in the data collected from consumers and staff members, but also in the recorded observations of
the researchers which often indicated a mismatch between consumers' abilities and the demands imposed by the physical environments of their homes. The artificial lighting in one group home’s living room consisted of two lamps that both had small switches that a consumer could not manipulate because his hands shook. When asked if they could think of any way to change their house or apartment to make it easier for them, sixteen consumers mentioned improving the lighting in some area of their house. One consumer complained throughout the assessment of a “table lamp that tips over every time you touch it;” another said she needed more light “in the bedroom and the living room” – which were the only rooms in her small efficiency apartment apart from the bathroom.

During the assessment consumers were asked to turn on lights in various rooms, as the assessment progressed through the house. Some consumers obviously had no idea which switch was the appropriate one to use, and eventually switched the light on after a number of miss-tries. One consumer explained, “I don’t much use the lights.” While light switches were at wheelchair height in one group home, in another a wheelchair user couldn’t reach any of the switches.

When one of the wheelchair users was asked if he could reach a light from his bed, he explained, “I don’t have a light by my bed. I have a pull cord. The staff comes and turns on the light. If I have to go to the bathroom in the night, the staff gives me a bottle.”

Other environmental limitations involved the kitchen. Some consumers didn’t know where dishes were stored or which knob operated which burner on the stove.
Some did not know how to regulate the water temperature at the sink and it was clear to the interviewer that this was not a task they regularly undertook. One consumer opened a cabinet only to be bombarded with its overflowing contents of pots and pans. Handles on cabinets were sometimes missing or broken. A sink was plumbed so that the hot water was on the right and the cold water was on the left. One consumer kept water glasses, cups and plates in a bedroom dresser drawer because there was no reachable storage in the kitchen.

An example of how consumers' lack of participation in household tasks impacted their perceptions and behaviors is illustrated by a consumer's comment, "I don't cook here. I used to cook on the stove. I like it. I used to cook at my mother's house. I liked to cook hot dogs and hamburgers. I don't cook here." Another consumer ruefully explained, "I did cook at my parents' house, but not here. Here we can't do anything." Yet another remarked, "I don't use the stove. Somebody cooks for me. I'd like to cook for myself – I cooked one time here. Everybody liked my cooking. I cooked when I was with my sister. I cooked potato salad." Yet another consumer confided to me that although she knew how to cook, this was a secret she kept from the staff because she preferred to have her meals cooked for her. Consumers also often relied on staff to operate electronic entertainment equipment. When asked to insert a tape in the VCR, one consumer replied, "I can't touch the VCR – it doesn't belong to me." Another refused to insert a tape, saying, "I don't want to blow the house up."

The assessment included opening windows in the bedroom and living room, and this was another task that seemed to have been often relegated to the staff. "Staff does
that;" “Staff does it for me;” “I don’t know how;” “I can’t;” “I’m not allowed to open a window;” “I’ve never tried it;” These were all remarks made when consumers were asked to demonstrate how they opened a window. In some cases, once the interviewer or a staff member demonstrated how to unlock and/or open the window, the consumer was able to do it easily themselves. Other consumers said the windows weren’t used because the air conditioning was on all the time. This was obvious when furniture or clutter were blocking access to windows.

**MAINTENANCE ISSUES**

Assessments indicated that houses and apartments often had unresolved maintenance issues that had the potential to compromise consumer safety and restrict functional ability. In many cases, windows were broken, locks on windows were broken or missing, windows were difficult or impossible to open, screens were missing, and window blinds were broken.

In the kitchen, some stove burners didn’t light properly and some microwaves were broken. Some cabinet doors didn’t close or had missing hardware. Knobs and controls on stoves were sometimes loose, missing, or in disrepair. A dishwasher door was broken and fell to the floor every time it was opened. A broken drawer fell out when it was opened.

Consumers remarked about screws that were coming out of door hardware, missing doorknobs, loose hooks and hardware, and doors that stuck. One consumer had a hook mounted upside down on the door of his bedroom closet so that anything hung
there slid off. Another consumer’s closet clothes pole had broken on one side so that everything hanging on it was falling onto the floor.

There were also maintenance issues in the bathrooms. Some bathrooms had broken towel racks or insufficient towel racks. In one instance, the towel rack had been inappropriately used as a grab bar and pulled from the wall. Some consumers mentioned a lack of hot water, rust in the water and a toilet that needed to be flushed manually from inside the tank.

Other maintenance issues included broken intercoms in apartment buildings, broken mailboxes, and a roof in need of repair. In describing his apartment, one consumer explained, “It’s not bad, but they don’t take care of the place. Maintenance is terrible. The ceiling needs to be replaced. The carpeting needs to be replaced. The front of a drawer broke off. There are all kinds of little odds and ends. They never do anything.” Another consumer remarked, “When I first moved in here the carpet wasn’t sewn right and I fell and broke my leg.”

**Issues of Consumers who Relied on Wheelchairs for All Ambulation**

The mobility issues that were found, in the quantitative analysis, to significantly effect the functional ability of full-time wheelchair users also permeated their responses throughout the assessment process. Researcher observations provide triangulation and confirm the potency of findings related to mobility limitations. Assessments indicated a number of accessibility issues in the built environments of people dependent on wheelchairs for mobility. At times, when the environment was accessible and it would have been possible for a wheelchair-user to do a task on their own, some consumers
seemed to accept the "patient" role and let others do things for them. In addition to elucidating the pervasiveness of their dependence, several other themes emerged from the comments of the full-time wheelchair users subset. One of these was the overall lack of fit between these consumers' abilities and the physical environment of their homes. Despite the fact that 10 of these 11 individuals lived in either purpose-built or heavily modified housing, the physical environment did little to enable them do everyday self-care tasks. When these consumers spoke about their homes, their conversation usually concerned features that didn't suit their needs, rather than what did. Examples include a toilet placed too close to the wall to allow for smooth transfers from a wheelchair, top-opening washers and dryers unreachable from a seated position, and front sidewalks too steep for a consumer to ascend in her manual wheelchair. The second theme, which was interwoven with the inadequacies of the physical environment, was the routine performance of everyday tasks for the consumers by the staff regardless of whether the consumers had the potential to do the tasks for themselves or not.

Two of the subjects with quadriplegia – a 32 year-old woman and a 48 year-old man—lived in the same heavily renovated one-story group home. While the man could not speak intelligibly due to physical impairments caused by cerebral palsy, the woman clearly articulated some of her functional abilities and limitations:

I can't open the [front] door on my own or close it – staff has to assist me....Staff has to assist me [sitting down in or getting up from the chairs and sofas in my house]....I can turn on the TV and change the channel with the remote....I can work my own VCR....Staff has to get [clothes from my closet]....Staff helps me do laundry – staff carries it to the laundry room – they help me sort it and tell me what color goes in. They put in the laundry detergent
and turn it on. I can’t reach the dryer – dryer is too low, so staff has to take it out for me. Staff helps me fold. Staff takes it back to my room. We both put it away.

Observational data found that some staff, seeing a person in a wheelchair, jumped to the premature conclusion that this was a person, unable to care for themselves, who needed others to provide care. Because of the inaccessibility of the physical environment, the person often did need assistance. The potential support that an appropriate physical environment could provide to consumers seemed to warrant more consideration than it usually received. As in the quantitative findings, the limited functional ability of those who used wheelchairs for all ambulation was also outstanding in the qualitative results. The limited functional ability of the subjects included in the full-time wheelchair-users subset was a topic that arose repeatedly during the assessment and was iterated and explained to the interviewer by various members of this group, and also by the staff who worked in their residential settings. It may be helpful to remember that the purpose of the original applied research study, as explained to each participant, was “to figure out how to make living in your home or apartment easier for you now and in the years to come.” Most of those who used a wheelchair all day, everyday, expressed some degree of skepticism when this goal was mentioned. One stated, “There are not many things that I can do without the staff. They get me up, shower me, dress me, they do everything for me. They put me in the chair. ...I call the staff when I need something.” Another reiterated this reality of dependency:

The staff keep me clean.... They bathe me. It takes two people to lift me and raise me up from my wheelchair and put me in the shower chair.... The staff keep my clothes clean. They keep the house clean.... If I need to go to the bathroom during the night, I have a bedpan. Staff brings it in. I urinate. I don’t want to move my bowels in the bedpan because I don’t want to smell it....I let the staff
answer the phone. When I call my sister, the staff dials the number...The staff does the laundry.

The group home manager expressed her view that some of this consumer’s dependence on others came about because the staff routinely did things for her and she had lost the limited strength she once had. The interviewer’s ethnographic notes recorded at the time of the interview detail the limitations of the consumer, the inadequacies of the physical environment of the home and their mutual misfit:

Consumer only has use of right hand/arm....Has trouble turning on the bedroom light - things seem to be in way. I turned on the light because it is so difficult for her to maneuver the wheelchair adroitly enough to perform any specific tasks. Bedroom much too small – keeps bumping into things. When Hoya lift is in room it’s a very tight squeeze – Needs a bedroom about twice this size. Can only open middle dresser drawer. Light is on pole and is in her eyes. ...In the bathroom staff has to get the toothbrush for her from the back of sink. She can’t reach the faucets because they are too far back on the sink. It’s obvious that she doesn’t usually do this on her own. She can’t get her wheelchair under the sink. When the speakerphone is put on her wheelchair tray, she can dial it independently.

When explaining the limitations and abilities of the 48 year-old male with quadriplegia (who was unable to speak for himself), the group home manager stated:

He can't use his hands at all. He controls his electric chair with his head. He could use a remote if he could operate it with his head....He can’t open any doors on his own – he would need a remote door opener operated by his head....The house is too small for his electric wheelchair, but he can't operate the manual one on his own....The only thing he can do is operate the blender using an adaptive switch that he had to pay for using his own money.

The ethnographic notes recorded at the time of this consumer’s interview note:

He has a major problem getting in [to the house]. The doorsills are too high. Only one entrance is really viable. The door on the side of the house has at least a two inch step and there is no accessible path to the side door. The ramped door at the back of the house has three 90 degree turns.
The staff at the group home where the other non-verbal member of this subset resided was asked why the consumer had problems doing various tasks. A staff member explained that many were due to his physical and cognitive limitations, but for other tasks, it was admitted that the consumer had never been asked or shown how to do the activities and was probably capable of them, at least with proper instruction. Functional independence was not, one surmised, a priority at this group home.

Another member of this subset was a woman with Down syndrome who spoke very articulately about her limitations. Unlike many of the members of the subset who used wheelchairs because of lifelong orthopedic impairments, her physical limitations were recent and stemmed from cardiovascular weakness. For most of her life, this woman had been able to do many more self-care tasks that she was able to now, and she still tried to do as much as she could. For example, she got her dirty clothes to the laundry room by pushing the laundry bag with her wheelchair. She found her inability to manage all the steps in a task such as doing the laundry or food preparation frustrating because throughout her life she had become accustomed to doing so much more. She clearly reported some of the kitchen limitations that came from living in a home not designed for a person in a wheelchair:

I'm starting to learn how to cook, but I can't reach the top of the stove. I can't reach the sink faucet in the kitchen. I can't reach the high shelves in the refrigerator. I can't reach the kitchen cabinets or the microwave or the toaster. I can't reach the garbage.

Several of the sample members in this subset also mentioned the age-related deterioration that was overlaid on the disabilities they were born with or acquired during childhood. “I used to be able to walk in between the parallel bars,” stated one.
Another said, “[It’s gotten harder for me] to walk. I used to be able to walk. I’ve been in this chair for a long time.”

**The “Don’t Do” Responses**

While full-time wheelchair use made some activities impossible for people with severe physical disabilities, personal expectations and habits also had a relationship to functional ability that was more difficult to measure. The unexpected finding that a substantial number of participants “didn’t do” common everyday activities included in the interview and functional assessment necessitated unanticipated coding categories and a redefinition of missing data. The most frequent tasks that consumers didn’t do were stove-related items, where close to half of all participants announced that they didn’t do a particular task. As detailed in Table 15, over a third of the respondents didn’t dial the phone, a significant number didn’t get the mail and many didn’t open or close windows. The number of tasks consumers didn’t do ranged from 0 to 40. Less than one fifth of the sample had no ‘don’t do’ responses. In the sample as a whole the mean number of tasks consumers didn’t do was 8.6 and the median number of tasks was 5.

**Table 15**

*Number of “Don’t Do” Responses for Functional Assessment Ability Variables*

<table>
<thead>
<tr>
<th>ROOM</th>
<th>FUNCTIONAL ABILITY TASK</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kitchen</td>
<td>Turn on the stove, adjust the flame (or electric burner) from as low as possible to as high as possible, then turn off the stove.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Stir the water in the pot with a spoon.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Move the pot from the stove.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take the pot to the sink and pour out the water.</td>
<td>54</td>
<td>41.9</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take out a saucepan and fill it with cool water and put it on the stove.</td>
<td>51</td>
<td>39.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Dry off the pot with a towel.</td>
<td>47</td>
<td>36.4</td>
</tr>
<tr>
<td>Activity</td>
<td>Description</td>
<td>Time (s)</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>Dial a specific number on the phone.</td>
<td>39</td>
<td>30.2</td>
<td></td>
</tr>
<tr>
<td>Transition</td>
<td>Go to the mailbox, get the mail and put it in the appropriate place.</td>
<td>22</td>
<td>17.1</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you open and close a bedroom window</td>
<td>16</td>
<td>12.4</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Open a living room window.</td>
<td>16</td>
<td>12.4</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Show me how you turn on the TV.</td>
<td>15</td>
<td>11.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take the dish out of the dish drainer or dish washer and put it away.</td>
<td>13</td>
<td>10.1</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Please get something out of the refrigerator and put it on the plate.</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Wash one of the dishes and put it in the dish drainer or dishwasher.</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Please get a dinner plate, silverware, and a glass from the cabinet</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Now put the food back in the refrigerator.</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Now move the dishes from the table to the sink.</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Bring the glass of water to the place you set at the table.</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Transition</td>
<td>Walk from the living room to the front door, as if responding to the doorbell.</td>
<td>7</td>
<td>5.4</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Fill the glass with water.</td>
<td>7</td>
<td>5.4</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something out of your bottom bureau and then put the item back in the drawer</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something hanging on your clothes pole out of your closet and then return it to the closet</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Sit down at the table and get back up again.</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something out of your highest bureau drawer and then put the item back in the drawer</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Transition</td>
<td>Go from the kitchen into the living room (or wherever you sit and watch TV)</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Turn on a light (in the living room).</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Entry</td>
<td>When you get to your front door, open it and go into the house or apartment</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Entry</td>
<td>Once you are inside your house, turn on a light</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Entry</td>
<td>Show me how you hang up your coat</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you take your shoes off and put them away. Thanks you can put your shoes back on</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Transition</td>
<td>Show me how you walk from driveway or parking area to your front door</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get onto your bed and lie down</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Thanks, you can get off the bed now</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Transition</td>
<td>Show me how you walk from your bedroom to the bathroom and turn on a light</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Show me how you step into the bathtub or shower</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Show me how you turn on and turn off the bathtub/shower faucet (just pretend).</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Take your towel, and pretend to dry yourself.</td>
<td>0</td>
<td>-</td>
</tr>
</tbody>
</table>
The contrast of the consumers who had the most ‘don’t do’ responses with those who had fewer ‘don’t do’ responses reveals that consumers who attempted more tasks, even while experiencing age-related declines, were in fairly good health. Almost all had experienced and adapted to at least two, and often more than two provider-supported home environments. Many displayed pride in their own abilities and identified positively with their own accomplishments. The activities that these consumers ‘didn’t do’ were usually, (1) those that the home environment made difficult or inconvenient – for example, a consumer may not operate the washer and dryer because the controls are hard for them to reach or to adjust, and (2) those tasks that the staff routinely did for other, sometimes considered lower functioning, consumers, that were then typically done for these consumers also. In both of these situations, consumers got out of the habit of doing activities that they often had once done to the point where they just ‘didn’t do’ them any longer.

It remains unclear why there were so many ‘don’t do’ responses, particularly since many of those who didn’t do the most activities also were among those who made the least number of comments. When consumers did mention a reason for not doing a task, safety was often cited, particularly when the stove was involved. Because the data

<table>
<thead>
<tr>
<th>Location</th>
<th>Task</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathroom</td>
<td>Sit down on the toilet and tear off a small piece of toilet paper.</td>
<td>0</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Get up off the toilet.</td>
<td>0</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Flush the toilet.</td>
<td>0</td>
</tr>
<tr>
<td>Transition</td>
<td>Now let’s go from the bathroom to the kitchen.</td>
<td>0</td>
</tr>
<tr>
<td>Kitchen</td>
<td>When we get to the kitchen, please turn on a light.</td>
<td>0</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Show me how you go to the sink and wash your hands.</td>
<td>0</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Dry them on a hand towel or paper towel.</td>
<td>0</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>In the living room, sit down.</td>
<td>0</td>
</tr>
</tbody>
</table>
on the subjects is sparse, examining those who didn't do the most activities may illuminate this trend.

**Participant Sketches**

**Exploring the Construct of Don’t Do Responses**

This chapter, thus far, has relied on fragments of interview and observation data, organized according to topics addressed in the research instrument and themes that emerged from the collective data. In order to provide another perspective and to give a more complete picture of the participants in this study, and their functional abilities in the context of their individual, everyday lives, some brief participant sketches follow.

The sketches are organized around two topics that were not anticipated by the researchers when data collection began, but that permeate the findings: the 'don't do' responses to everyday self-care and household activities, and the relationship between self-reported and observed functional ability.

"Don't do" was a response given by the participants in this study over two and a half times as often as "can't do" and over three and a half times as often as "refused". Correlation analyses showed that it was not synonymous with can't do, and, although it could be interpreted as a type of refusal, there was no hint of defiance surrounding this response. It was simply something the consumer "didn't do", and was seen this way by staff and consumers alike. In order to gain more perspective, participant sketches of four consumers with the most "don't do" responses are contrasted with a consumer with a moderate number of "don't do" responses and a consumer with only one "don't do" response.
THE CONSUMERS WITH THE MOST 'DON'T DO' RESPONSES

Stephen, a consumer who lived at home with his elderly father:

Stephen, the subject who had the most 'don't do' responses (a total of 40) was a 55 year-old man who had very limited verbal ability. This middle-aged man had lived at home with his frail elderly father for his entire life. With the exception of having hypertension and being overweight, the subject was in good health. Although he had been diagnosed with a seizure disorder, he had not had a seizure in years. Stephen attended a day program and spent the rest of his day at home with his father. The subject's aide, who came for two hours each day, and was present during this consumer's assessment, noted that Stephen was quite forgetful, and needed help with all activities of daily living. When the Stephen's father was asked if he thought there were things that might become a problem for his son in the future, his response was, "I don't know – we just take it one day at a time." The only activities that the interviewer was able to observe Stephen doing were taking off his coat (but not hanging it up), pouring a can of soda into a cup, and clearing off the kitchen table. Although Stephen spoke, his responses were limited to one or two words. When the aide and the father were asked if there was anything around the house that could be changed to make it easier for Stephen, the aide was quick to respond that much of the household furniture was falling apart, including Stephen’s bed and dresser, that the mattress had been ruined because he repeatedly soiled the bed, that an air conditioner was needed during the summer months, and that a handheld shower hose would facilitate bathing Stephen. The aide also thought that some exercise equipment would be helpful to
Stephen. The interviewer noted that the house and its furnishings were old and in disrepair, that the interior of the home was extremely dark and that the plastic carpet-protecting runners were a tripping hazard throughout the house. When the father and the aide were asked if Stephen had the opportunity to try to do any of the tasks listed in the functional assessment instrument, they replied that these things, including such simple tasks as switching on an overhead light, had always been done for him. Stephen was one of the few subjects in the study who had lived in his family’s home for his entire life. Complying with the requests of a non-family member who was not at the home to provide direct care was completely foreign to him.

*Carlton, a consumer who had come to the group home from an institution:*

Carlton, who had the second highest number of “don’t do” responses (34 task during the functional assessment), was a 57 year-old man who with limited verbal ability, a seizure disorder and osteoarthritis, in addition to an intellectual disability. He was living in a group home where he had moved six years earlier from a state developmental center that had closed. He had a phobia of medical settings. Out of a total of 61 tasks, Carlton didn’t do 34 of them and refused to do another 21 tasks. Although Carlton spoke only in one or two word utterances, the staff member who knew him best felt that his vocabulary had increased since moving to the group home. Carlton didn’t use one arm and had motor control problems with one hand, but it had never been determined why this was so. The staff member said that his peers at the group home looked out for him and helped him because he was so low functioning. When the staff member was asked about what Carlton could and could not do, she
replied that he could open the back door himself and that that was the only door he used, that he was “always turning off lights,” that he toileted himself and under normal circumstances he would flush the toilet with verbal prompts, and that he didn’t use the existing grab bars in the bathroom. When questioned further about this consumer’s seeming lack of either ability or compliance, the staff member explained that he had lived in institutions where he received custodial care for most of his life. Now at the group home he “balks at the idea of doing things for himself,” since nothing was ever expected of him. In order to do most of the tasks listed in the assessment instrument the staff member felt that Carlton would need training, but she felt it was probably too late, since he’d been cared for all his life. “He refuses to learn,” she explained. The only task she had successfully taught him was to flush the toilet and he still needed verbal reminders every time. Carlton didn’t do even minor tasks such as turning on water at the sink. “He just never does – I don’t know why,” remarked the staff member. She also said he refused to look in a mirror and that when he saw a mirror he immediately looked down. Carlton sometimes fed himself, but would often eat too fast and choke, so the staff would often feed him. (Carlton had no teeth.) When asked, “What one change would help Carlton to achieve a greater degree of independence?” the staff member replied that a consistent, one-on-one staff person, with whom the consumer could develop a trusting relationship would probably help most.

*Peter, a frail man with age-related physical disabilities:*

Peter, who didn’t do 31 activities, was a 50 year-old male with mental retardation, Parkinson’s disease and “a bad foot” who lived in a ‘high-supervision group
home’, and used a walker to ambulate. When asked by the interviewer if there was anyway we could fix up his house to help him, he proudly pointed out his new teeth.

The consumer was very frail and could not stand on his own. Although there were stairs in the house that other consumers used, Peter did not use the stairs. The staff explained that one of his goals was to participate in cooking, however this was not working out because he couldn’t stand if he let go of his walker. The most he had been able to do was tear up lettuce for a salad while he sat at a table. The staff showered him, shaved him, cleaned his dentures and did other grooming chores for the consumer. The staff reported that Peter fell a lot, and had broken his teeth during a fall. Peter's bedroom seemed dark to the interviewer, but the staff informed her that the regulations for group homes in this category (‘high supervision’) forbade lamps that were not built-in to the room’s structure. Peter flopped into chairs if someone did not help him to sit down and needed help to get up from a seated position. The staff laid Peter’s clothes out for him, saying that his closet was tiny and his relatively small bedroom made it hard to use the walker and do anything else. When the staff were asked if anything had gotten harder for Peter as he aged they replied, “Standing, balancing, walking, getting up from a seated position, holding and/or carrying things,” and added that Peter had recently become incontinent. The interviewer noted that Peter had “major problems getting up from the couch,” that the one step up at the front door presented an almost overwhelming challenge to him, and that he needed to be holding onto something to maintain his balance. Had it not seemed so dangerous for Peter to do almost anything,
he might have been encouraged to try more activities, and had fewer “don't dos” and more “can't dos.” As it was, this approach seemed too dangerous to test.

**Lucie, a formerly active woman who has lived in a series of group homes**

Lucie, with 30 'don't do' responses was a 65 year-old woman with moderate intellectual disabilities and hypertension, but otherwise in good health. She had some age-related problems walking but it is not clear exactly why. She listed three group homes she lived in before moving into the one she lived in currently. Lucie was proud of her abilities and told the interviewer that she once did her own laundry, ironed clothes, waxed floors with a buffer, cut grass, including chopping high grass with a sickle, and shoveled snow. At her current group home, she didn’t do the laundry because the controls are at the back of the back of the machines and were hard to reach. (Lucie, like many people with intellectual disabilities, is short in stature.) Here [at the group home], she told the interviewer, she doesn’t iron because it’s hard to get the ironing board down. She no longer shovels snow because it gets too icy. She asked the staff to get things from the kitchen cabinets for her because they were too high for her to reach. Lucie’s clothes were also hanging above her reach in her bedroom closet. She had a hard time turning on the light in her bedroom because of its tiny knob that must be rotated. The staff reported that Lucie “can do a lot” and that she was higher functioning than the other consumers living in the group home and that “they hold her back.” The staff admitted that they did a lot for Lucie that she could probably do for herself, simply because they were doing these tasks for the lower functioning consumers sharing the same house. “We’re just so used to doing it,” a staff member explained. “[Doing the
laundry is] the staff’s job." They did not encourage Lucie to bathe herself saying, it’s
"hard for her getting in and out of the bathtub," and “it’s easier for us to do it.” When
cooking is discussed the staff explained that Lucie has been “drilled in her head that
she’ll get burned.” She doesn’t use the phone because she “never did,” and because
“she doesn’t know her numbers.” When the staff were asked what one change would
most help Lucie achieve a greater degree of independence, they replied, “Being around
higher functioning people.”

These are sketches of the consumers with the most ‘don’t do’ responses. The
contrast of these consumers with consumers who had fewer ‘don’t do’ responses may
give a more complete picture of this response pattern.

_Harry, a group home resident with a moderate number of “don’t do” responses:_

Harry, who didn’t do laundry or cooking and had a total of fifteen ‘don’t dos’ was
a 53 year old male who formerly lived in New Jersey’s Greystone and Ancora
developmental centers, but had been living in a group home for the past three years. He
had seizures, a chronic leg ulcer and foot problems for which he was seen by a nurse
daily. Harry was known to be physically aggressive. He said he used to cook when he
lived with his mother but he didn’t cook here. He did help set the table and he loaded
the dishwasher. The staff described Harry as a “wonderful guy” who is “very
cooperative,” but “needs verbal prompts.” The staff attributed the activities Harry
doesn’t do to the fact that the consumer preferred not to do them.

_Jim, who lived in senior citizen housing and had only one “don’t do” response:_
Jim, aged 60, had an efficiency apartment in a senior citizen apartment complex. The researchers were told that Jim has mild intellectual disabilities, asthma, arthritis, diabetes, high cholesterol, glaucoma and kidney stones. He had recently had a bad fall and sprained his ankle. The subsequent inactivity caused more severe mobility problems and the consumer used a walker at times and a scooter to go long distances. Despite these impairments, the only task Jim ‘didn’t do’ is iron. He explained that he used a lot of fabric softener so that he could avoid ironing. The staff member who worked with Jim explained that the consumer was recently encouraged to start using a laundry service.

“Old people can be really mean and they say things in his presence that are mean, and we thought if Jim improved his appearance it might improve his quality of life here.”

**Self-Reported Compared to Observed Functional Ability**

In the quantitative analysis it was found that while consumers were fairly accurate in their self-reported assessments of functional ability, 90 percent underestimated their own abilities. A significant correlation was found between being a full-time wheelchair user and having a greater difference in scores between self-reported and observed ability. With a correlation of -.340 (significant at the .01 level), full-time wheelchair use was the only variable that had a highly significant correlation with the difference between self-reported ability and observed ability. This indicates that those who use wheelchairs for all ambulation reported, or expected, to be able to do more than they actually were observed to do. To give a more complete picture of the relationship between respondents' self-predictions of their functional abilities and their observed abilities, profiles of three consumers are provided below: 1) the
consumer whose self-reported abilities most exceeded her observed abilities, 2) the consumer whose self-reported abilities most precisely matched his observed abilities, and 3) the consumer whose observed abilities most exceeded her self-reported abilities.

*Audrey, a group home resident, whose self-reported abilities most exceeded her observed abilities:*

Audrey was a 55 year-old woman who lived in a group home together with two older other women. Two staff members were working at the home 24/7. Audrey used a wheelchair for all ambulation since undergoing brain surgery five months prior to the assessment. The group home manager who was present during both the interview and assessment reported that the before the surgery Audrey had been “extremely independent,” and used a walker but not a wheelchair for ambulatory support. The brain surgery had been performed to relieve a persistent seizure disorder. The operation had been followed by a two month hospitalization, and had left Audrey with right side weakness which made her unable to walk. However, it had been successful in that Audrey had 80% fewer seizures than before the surgery and no longer needed to wear a helmet. She had been outfitted with a low manual wheelchair so that she could use her feet to guide and steer the chair. However, at the time of the assessment she still needed assistance to maneuver the wheelchair around the house. Although the house had been retrofitted so that the first floor was somewhat wheelchair accessible, Audrey had not yet fully recovered from the surgery and was still regaining skills. There were relatively few tasks that Audrey actually did. There were eight tasks Audrey refused to try, twelve that she didn’t do, and ten that she was not asked to do. The
group home manager was present and tried to be helpful as well as somewhat protective throughout the assessment.

Ted, a supported apartment resident whose self-reported abilities most closely matched his observed abilities:

Ted was a 69 year-old man who had cerebral palsy and a mild intellectual disability. He regularly used two canes and said he used a wheelchair only in rare, very physically taxing situations, such as “when I’m really sick, like a broken leg.” For the past 12 years he had shared an apartment in Senior Citizen housing with another older man who also had intellectual disabilities. Although the apartment had an elevator, it was necessary for him to traverse three steps in the hallway to get to in and out of his apartment. Ted lived in a downtown area, within easy walk of stores, restaurants and services which he enjoyed frequenting. He said he “loved” his apartment because “everybody leaves me alone,” and compared it favorably to the apartment he had lived in previously, which he described as “a dump” inhabited by drug addicts. The notes taken during the assessment indicate that the intercom at the apartment entrance was broken, there was only one small light in the bedroom, and that Ted would benefit from additional grab bars in the bathroom. Ted noted some peeling paint in the apartment.

When asked if there were activities that had gotten harder for him as he had aged, he replied that, “I don’t want it to be too easy for me – if it’s too easy I would be like a baby and I need to challenge myself.” Later in the interview Ted observed that it was hard for him to walk without the aid of two canes, but that holding onto the canes he couldn’t use his hands. Ted mentioned several accidents that had taught him to be cautious. He
had tripped over the poorly sewn carpet in the apartment and broken his leg when he first moved into the apartment. More recently he had sprained his foot when he was trying to hurry during a fire drill. Although it was clearly not easy for Ted to perform all the tasks that the functional assessment required, he did not refuse to do any of the tasks and the only tasks he didn’t do were the three that involved ironing. “I used to iron,” he explained, “but I had somebody stand over me so I wouldn’t burn myself. I don’t have an iron in the apartment now and I threw the big ironing board out because I couldn’t stand it.” Ted articulately described his difficulties setting the dials on the washer and dryer, which he could not read, taking out the garbage, and dialing the phone. He had a shower chair that he said he used only when he was ill. He described his ideal living situation: “All the handicapped get together and buy a house and repair it. I could do the flooring – I can do tongue and groove.”

Sara, who had recently moved to an assisted living facility and whose observed abilities most exceeded her self-reported abilities:

Sara was a 46 year old woman who had Familial Dysautonia, a progressive neurogenetic disorder common to Ashkenazi Jews, causing the automatic and sensory nervous systems to malfunction. Sara's poor muscle tone was evidenced by her physical fragility and her use of a walker for all ambulation. She did not go into details about her physical or sensory condition. Sara was determined to maintain her independence and had a marked pride in her ability to both deal with the disease and with life in general. She had recently been moved from a supervised apartment that she shared with two other women, to an assisted living apartment where most of the residents were senior
citizens. The reason for the move was because of Sara's physical deterioration, however it was clearly not Sara's idea and she was not happy in her 'more supportive' setting. Sara related that her cousin, who lived in Israel, had promised that if she didn't like the assisted living apartment he “would get her out.” After her move she tried to hold him to his promise. He came to the States to assess the situation, and, according to Sara, “He loved it,” and saw no need for a change. It was felt by the interviewer that Sara was negative during the interview phase of the assessment because she clearly resented the fact that her own preferences had, during this move, been ignored and was letting me know that this 'supportive setting' was actually not supportive at all. When it came to actually demonstrating what she could and could not do, however, this setting, along with Sara’s unbridled determination, actually did enable the consumer to perform many tasks. The assessment is filled with notes that observe this: “Ramp a little steep, but she does okay;” “Door heavy but she manages;” “Shelf is high but she reaches it;” etc. In contrast, during the interview prior to the assessment, Sara’s comment include, “The stove doesn't work – they cook for me;” “the cabinets are too high;” “things are out of reach.”

**Summary**

Participants' predictions of their abilities and their observed abilities are complicated by many factors, including their medical, psychological, and attitudinal dynamics. It is interesting to note that four of the nine people who expected to perform better than they actually did, were people that used wheelchairs regularly. Although this group comprised only 8.5% of the sample, they numbered 44% of those whose self-
reports exceeded their observed abilities. This could be construed as evidence that, although many daily living skills elude them, they have not yet submitted to a life of dependency.

Triangulating the data through the use of interviews, observational assessments and the researcher’s ethnographic observations was done to provide a richer portrait of the ways in which the physical and social environment interact, and to examine the impact of impairment, or the physiological, both the barriers and supports that characterize the physical environment, and the personal perceptions of the participants on their daily lives and their ability to function as independently as possible. In the following chapter, the implications of these findings will be discussed.
CHAPTER SIX: DISCUSSION

The purpose of this study was to further an understanding of the home environmental factors that can act as barriers or facilitators to adults who are aging with developmental disabilities. This subject was approached through an examination of functional ability in self-care activities among community-dwelling adults with developmental disabilities. It provides an exploratory look at issues that surround community-based living for people aging with developmental disabilities, including the personal, social, and environmental forces that promote independence and self-reliance, as well as those that bring about dependence and behavioral limitations within this vulnerable and growing population. This study was based on person-environment fit theory and a transactional model of stress and coping (Dawis, 1992; Edwards, 1996; Germain, 1983; Loquist and Dawis, 1969). Developmental disability was approached from the viewpoint of a transactional model of disability.

The transactional model holds that many behaviors do not have a single or unique cause and emphasizes the large number of variables that interrelate and effect peoples’ interactions and individual behaviors. Transactional analysis stresses that the characteristics of a person at a given time in his or her life are a joint function of the personal and environmental characteristics acting on the person’s life up to that time.

Although this study was cross-sectional in nature -- people were assessed at a single point in time -- it is essential to remember that these individuals have lived in an era when the models and definitions of disability were constantly evolving and continue to do so. The attitudes we hold toward people with disabilities today are quite different
than the attitudes that were prevalent when most of the members of this sample were children. The attitudes toward people with developmental disabilities, the opportunities afforded to them, and expectations for them have been changing relatively rapidly over the course of their lives. When many of the members of this sample were children they were not expected to live to the age they were at the time of this study. As expanded on in Chapter One, the disability rights movement, the normalization movement, and the deinstitutionalization movement, along with the Education for the Handicapped Act, all contributed to a major shift in the way people with disabilities are considered and consider themselves.

The complexity of the snapshot that emerges from this study is a reflection of the impact of the interaction of the changes described above and of each individual's experiences. Some of these experiences are common to variously sized portions of this sample. For example, there is a large subset of consumers that have spent years in group homes, and an overlapping group that spent years in developmental centers. Some participants had strong family support. The developmental disabilities of participants range from mild to severe. Some have no physical disabilities, while others are extremely disabled. Discussing these individuals as a group has inherent limitations, but their commonalities reveal both personal and environmental factors that have the potential to enhance, as well as detract from, each individual's ability to function as independently as possible for as long as possible.

Self Report and Observed Ability
One of the primary findings of the current study was that, while consumers’ self-report of their ability to perform self-care tasks were close to accurate, over 90 percent of the participants expected to perform self-care activities slightly less well than they actually did. Their self-reports fell short of their actually abilities. This could stem from a variety of factors, particularly a lacking of self-confidence, self-knowledge, and opportunities to attempt the tasks. The implications for practice may include increased expectations of adults with developmental disabilities, increased opportunities to participate in self-care tasks, and positive attitudes toward capability. The finding is not implausible, when viewed in the context of the societal attitudes toward people with developmental disabilities throughout the course of their lives. In 1952, when many of the participants in this study were children, a report by the New Jersey Commission to Study the Problems and Needs of Mentally Deficient Persons states:

The citizens of New Jersey have many reasons to be concerned about the mentally deficient. They have the right to expect that the consequences of mental deficiency shall not impair the healthy development of the families in society or society as a whole....Some provisions must be made for the orderly control of services to these persons. This can best be done by registration of all identified mentally deficient persons and appropriate follow-up through the life of the individual....The rights of the great mass of the members [of society] shall not be jeopardized by the unequal demands of a relatively small portion of the population. (pp. 33-34)

The report cites the recent good fortune of parents of mentally handicapped infants in, "having available the [recently built] unique nursery facilities at Totowa," so that the family will not find themselves "tragically burdened with a child who needed constant attention" (p. 131-2). The report goes on to deplore the problems associated with "defective delinquents", a particularly onerous subset of the "mentally deficient."
A 1962 issue of the periodical, *Social Casework*, affirmed this perspective on children with developmental disabilities when Simon Olshansky, study director of the Children's Development Clinic in Cambridge, Massachusetts, wrote,

> The parents of a normal child...know...that ultimately the child will become a self-sufficient adult.... By contrast, the parents of a mentally defective child will have little to look forward to; they will always be burdened by the child's unrelenting demands and unabated dependency. (p. 191)

From the attitudes reflected in these statements, it may be surmised that little was probably expected from these young "mental deficients," and that they were probably told more often about what they *couldn't* do, than what they *could* do. In this light, the potential for a positive self-image seems difficult, at best, to realize. It could be considered surprising and a tribute to their resiliency that the participants in this study were able to predict their abilities as accurately as they did. The question of what these individuals could do if their expectations matched their ability remains unanswered.

The more immediate and perhaps, more urgent, question is how to change the way that these consumers think about themselves and their capabilities. How does one replace an attitude of 'can't do' with an attitude of 'can do'?

Positive experiences may prove helpful in overcoming doubts about the ability to accomplish a task. It was not clear how much experience these consumers actually had performing the tasks they were asked to do, on their own, during the task assessment process. Sometimes, as with the hit and miss attempts at flicking switches to light up a room, or turning one knob after another to ignite a particular stove burner, it was obvious that this was not a task that the consumer did regularly. The fact that some
consumers had to search for the dishes with which to set the table, only to find them completely out of reach, reveals that some group homes may not always follow a philosophy of self-determination, empowerment and self-care, at least in the practice of normal household activities. The delight and satisfaction expressed by some consumers, however, when a light in the room came on (even when it was not the expected light), or when a flame rose up from the burner, give evidence to the fact the population is not immune to the pleasures of self-reliance. This finding is similar to the findings in Felce and Perry’s study of staff/resident interactions where it was observed that residents who scored low on adaptive behavior measures were not provided opportunities to participate in domestic activities (Felce and Perry, 1995). As the authors point out, when staff undertake household tasks without consumer participation, this not only deprives the consumers of a learning opportunity, but also deprives them of the staffs’ company.

A related finding was the fact that many consumers “don’t do” a range of everyday self-care activities. Only two of the 61 activities the consumers were each asked to perform, were attempted by each individual in the sample: 1) getting from the driveway to the front door, and 2) entering the house or apartment. The number of consumers who “didn’t do” the remaining 59 activities, ranged from 1 to 94 per activity. (See Appendix E.) Admittedly the tasks that had the highest numbers of “don’t do’s” had to do with ironing – a task many non-developmentally disabled people tend to avoid. However other tasks frequently “not done” by consumers included heating water on a stove, opening and closing a window, and rinsing a dish off and putting it in the dish drainer. When, in the midst of the original applied research study, administrators at one
participating provider agency became aware that the staff undertook all food 
preparation activities at a group home, they expressed surprise and some degree of 
consternation.

The overt reasons for not doing specific activities were sometimes stated by 
consumers and included: 1) not having permission to engage in the activity from staff, 
provider agency, parental/guardian or owner (e.g., “I’m not allowed to do that,” or “It 
doesn’t belong to me”); 2) a protocol that consumers aren’t expected to do the activity 
(e.g., “I’ve never tried it,” or “staff does that”); 3) feelings of inadequacy (e.g., “I don’t 
know how” or “I don’t want to blow the house up”); 4) simply opting out (e.g., “I’d 
rather not,” or “I wouldn’t care to”). In some cases, the goal of doing things for oneself 
may have been usurped by another goal such as safety or social propriety that was 
deemed more important. Examples include a consumer who had his laundry done by 
others to maintain his kempt appearance among his sometimes cruel neighbors, and the 
group home residents who didn’t get the mail because their rural mailbox was near a 
blind curve on a 50 mph highway. Nevertheless, Saloviita and Aberg’s (2000) finding 
that it is the type of residence, rather than the characteristics of the consumer, that 
generates the level and type of care that is provided, may also hold true among this 
sample.

While other causes may influence their ability to participate in self-care tasks, 
consumers living in group homes may be needlessly restricted in activities such as 
having a key to the house and an opportunity to learn how to lock and unlock a door, 
because one or more of their peers has been deemed incapable of doing the task, or not
trustworthy enough to safeguard a key. In discussing a consumer’s reluctance to use the stove, her direct care staff commented, “It’s drilled in her head that she’ll get burned. Other clients are lower functioning. She adapts.” There is no question that living with consumers who function at a lower level could hold a consumer back, unnecessarily increasing his or her dependency. Wolfensberger (1972) points out that one of the features commonly associated with institutions is the de-individualization found in “an environment that aims at a low common denominator among its residents” (p. 80). One of the reasons for this may be that it is felt that too much is at stake to risk the security of the consumers and the property of the home to residents whose judgment is either impaired or has the potential to be easily swayed. A lack of ability to read may make it dangerous for consumers to have free access to a medicine cabinet and to dispense their own medications. However, even staff members admitted that part of the problem was habit. As the staff member commented, “We’re just so used to doing it.”

The number of tasks the consumers in this study "didn’t do", could be seen as evidence of participants' low expectation of personal success. "I don't do that," may be interpreted as giving up without trying. As Zigler et al. (1982, 1986) and others cited in the literature review contend, the main motivation in these individuals may have shifted from achieving success to avoiding failure. To these consumers, "don't do" may sound preferable to "can't do".

**Risk versus Safety**

It is easy to understand how any staff member taking on the responsibility of overseeing a group home and its consumers, all of whom have impairments and
limitations, might tend to discourage risk-taking and encourage safety. Legal liability of
provider agencies for consumers who are not considered competent to be their own
guardians is undoubtedly a factor is providing protection and limiting risk. However,
staff perceptions of people with developmental disabilities are also very likely to play a
role in risk avoidance. Perske (1972) writes,

Many who work with the handicapped, impaired, disadvantaged, and
aged tend to be overzealous in their attempts to ‘protect’, ‘comfort’, ‘keep safe’,
‘take care’, and ‘watch’. Acting on these impulses, at the right time, can be
benevolent, helpful and developmental. But, if they are acted upon exclusively
or excessively, without allowing for each client’s individuality and growth
potential, they will overprotect and potentially smother the intended
beneficiary. In fact, such overprotection endangers the client’s human dignity,
and tends to keep him from experiencing the risk taking of ordinary life which is
necessary for normal human growth and development. (p.195)

If one does a literature search using the keywords ‘developmental disabilities’ and
‘risk’ the articles that are found are about children, students, adults or families who are
“at risk” or who are “high risk” and or who have a “greater than average risk.” Among the
18 articles that a “Social Work Abstracts” search recovered, only one paper on premarital
counseling for the developmentally disabled spoke of “the right to take risks” (Walker,
1977). One of the reasons for the deinstitutionalization movement was that institutions
denied residents the experiences of living a community-based, integrated life. Wehmeyer
and Metzler (1995) point out that in order to be self-determined, that is to achieve a
degree of control over one’s life, individuals need to have opportunities to express
preferences and make decisions. One cannot develop the skills to do this without
experiences that lead to realistic self-awareness and positive self-concepts. This is likely to
involve taking risks, which will in turn contribute to the development of personal
judgment. If consumers are deprived of the opportunity to take risks, they are then also deprived of opportunities to develop judgment.

**Using the Physical Environment of the Home to Foster Feelings of Ownership**

Consumers' comments revealed that having possessions and a sense of ownership was important to them. The positive feelings surrounding ownership did not always extend to their homes. In this study, the ambivalence surrounding residential ownership and belonging may be related to some consumers' willingness to secede control of, and self-reliance in, a home where they don't feel the sense of entitlement that often accompanies ownership. Findings revealed that, while many consumers are happy in their homes, there is sometimes ambiguity about whether or not group homes are really home. The consumer who, when told that I was there to inquire about how his home was working out for him, pointedly clarified that this was “the Arc's home,” readily identified his lack of ownership. The participant who, when asked what she thought about where she lived, replied that she liked it, but wanted to “go home”, was revealing some ambivalence about her relationship to the group home where she lived. “Since I like it here the state is planning to buy me my own house,” a statement made by a consumer living in a group home, again implies that a group home is not really one's own home. The group home was considered by a sizable portion of its residents to be a type of pseudo home and a number of consumers, as evidenced by these comments, were somewhat ambivalent about their residential status. For example, one group home resident mused amicably, “It's nice to live in a house like you would if it were your own home.” One flatly declared, "I don't belong here," clearly implying a lack
of choice and dissatisfaction with this choice that had been made on his behalf. Other statements reveal that ownership, a subject rarely discussed in the literature within the context of this population, is, nevertheless, a subject of importance to them, despite the fact that it often eludes them.

In a paper promoting supported living as an alternative to congregate housing, John O’Brien (1994) writes,

Many current practices deprive individuals with severe disabilities of a sense of place. Many live in facilities where they only belong because of a service provider’s continuing patronage. A service provider is legally and commonly recognized as the householder, even if he or she does not live in the facility. Individuals’ continued residence depends on compliance with service provider’s house rules and requirements for residence set by professional teams and welfare policies; for example, residents may face eviction if they lose their place in a day program. Indeed, if a service provider fails to comply with service system regulations, individuals risk loss of their place to stay. Individuals may be moved to another facility if professionals judge that they require more or less intensive programming. They may be denied the opportunity to hold a paying job if the system pays for their place in the facility with medical funding that forbids or discourages employment. ...Frequently they depend completely on those from the facility they live in for transportation. Individuals who live together must often travel together in order to maintain proper staff-resident ratios. (pp. 2-3)

Although some residents brought bedroom furniture from their parents' homes, many of the group homes included in the current study were furnished with typical sturdy and boxy items that were deemed indestructible in this setting. They seemed to the researcher to be a fixture that identified many of the group home interiors. Some homes also had large institutional exit signs, or other vestiges of congregate and institutional living. With some notable exceptions, very few had pictures or artwork in the congregate areas of the home and those that did were rarely more personalized than the decor found in a typical hotel room. Additionally, group homes were obligated
to follow the town’s fire department and Board of Health rules, as well as comply with state regulations. Sometimes this meant panic bars on exterior doors, and institutional-type signage.

It is then no surprise that having a room of one’s own was frequently mentioned as a positive feature of a residence. “I have a big room – it’s my own room;” “I have my own room and bathroom;” “I like having my own room;” are just a few of the many times this feature was cited. Having ones' own room provided some private space for a group home resident to keep his or her belongings, and personal belongings seemed to reinforce the sense of, and possibly even the fact of, belonging. A number of consumers balked at the suggestion that they throw out personal belongings and often cited a need for more storage. A handful were collectors of one or more types of items. One woman showed me a large dresser drawer filled almost to overflowing with an assortment of used wallets. Another collected non-working watches. Another respondent had an apartment filled with multiple appliances – the interview assessment lists: 3 non-working vacuum cleaners, assorted lamps (not plugged in), hot plates, coffee makers, electric can openers, blenders, toasters, so much furniture that it had to be stored in piles, suitcases everywhere, a variety of old radios, and dried flower arrangements. “It’s of sentimental value,” he explained. “I inherited these things from my parents.” The researcher got the definite sense that this clutter of objects from his past spent in his parents’ home, grounded this person in his current apartment and indeed, in his current life. Owning a television was important to many respondents, as was ownership in general.
The feeling, expressed by a number of consumers, that a group home was something less than one's own home, may have been reinforced by another factor that was observed during data collection. This was the lack of familiarity with, and responsibility for, the home. Home ownership is typically associated with a considerable degree of familiarity and control. One knows the particular way to turn the key in the lock, the time the sun lights up a room, and the place in the yard where the grass refuses to grow and weeds are apt to take hold. Much of the data from this study, however, conveyed a lack of knowledge about the workings of the home. Less than half of the study participants could open a bedroom window without problems or use the stove without difficulty. Fewer than half had keys to their houses. Roughly, one-third knew how to put a tape in the video cassette player. No one in this study mentioned participating in yardwork, and a number of participants mentioned that they didn't use the yard. "The agency takes care of the yard," one consumer explained. "A guy comes to the mow the grass," stated another. If housekeeping was discussed, consumers living in group homes were apt to explain that the staff did the cleaning. "I don't know where to take out the garbage," another expounded. "Somebody who knows where it goes does that for me."

The surprisingly large number of consumers who "didn't do" a number of daily living activities during the assessment suggests that consumers lack the needed encouragement to look after their own needs and to develop their potential for independence and autonomy. Some of the comments made by staff during the staff interviews confirmed this perception. "It's easier for us to do it," "it would be frustrating for [the consumer] to try that," "he doesn't need to [do that]," "she's used to relying on
the staff," are indicative of an underlying staff assumption that consumers don't need to
do things for themselves, and that it's easier, even an act of kindness, for staff to do things
for consumers. This brings to mind Felce and Perry's (1995) finding that residents with
lower adaptive behaviors had no opportunity for participation in household domestic
activity. As they pointed out, the residents are deprived on two counts. They are deprived
of the opportunity to participate and work toward greater competency, and they are also
deprived of the opportunity to spend time with staff, since the staff are busy doing
housework. Underlying these attitudes may be some direct-care workers' assumptions
that people with developmental disabilities don't need to build their sense of self-esteem
and self-worth through personal accomplishment, or that helping them to understand the
value of independence is not a worthwhile endeavor. This study suggests that future
research could examine whether provider agencies might engender a greater sense of
mastery among consumers by giving staff members incentives to teach and support
consumers to participate in their own care to the extent that they are able. When staff, in
an effort to be helpful or efficient or both, do things for consumers that consumers could
do for themselves they may be denying consumers the ability to gain the sense of self-
efficacy that leads to increased independence. Switching lights on and off is an example of
a simple task that many consumers living in group homes did not seem accustomed to
performing. However, if staff, instead of consumers, routinely turn the lights on and off as
needed, this one small symbol of control would be restored to consumers, who might, in
turn feel not only more capable, but perhaps more as if their home were truly theirs: a
place that belonged to them and where they belonged. More complicated tasks such as
laundry, house cleaning, weeding, and gardening are all tasks that many consumers might take pride in, given the opportunity.

While a major emphasis is now placed on consumers' participation in competitive, or at least, supported employment settings, the findings from this study indicate that very little attention is paid to consumers' participation in home management and upkeep. Consumers may be able to learn the rewards of responsibility and gain a work ethic and accountability by helping to organize, manage and maintain their own homes and grounds.

It was not unusual for consumers, during the assessment, to mention that they used to do activities, particularly cooking, in their parents' homes but no longer do it now that they're living in a group home. The reasons for this were not clear during this study, but the findings indicated reasons why staff might opt to do tasks for consumers. First, is the reality that it initially could take at least twice the time and twice the work to teach a consumer how to do a task they are unaccustomed to doing. It is much more efficient for the staff to just do it. Secondly, consumers might very well prefer not to do the task, either because they run the risk of failure, or because they have insufficient experience of the rewards of success, or just because they are accustomed to having things done for them and it may be unsettling for them to change their normal routines and habits. As mentioned in the literature review, Zigler and Bennett-Gates have both shown that lowered motivation to achieve success is a consequence of repeatedly confronting tasks beyond ones' abilities, and observed that, for this reason, and, in order to avoid failure, many people with intellectual disabilities may give up without trying (Bennett-Gates &
Kreitler, 1999; Bennett-Gates and Zigler, 1999; Bybee & Zigler, 1998; Zigler & Balla, 1982; Zigler & Hodapp, 1986). Magill-Evans et al.'s finding that parents had lower expectations for their children with cerebral palsy, may also impact the children's low expectations of themselves (2001). Future research could examine whether direct-care staff may benefit from training to help redirect their caring instincts to reflect an awareness that consumers might be helped more by being taught more and helped less.

Finally, the decentralized nature of many community-based residential programs makes it especially important that direct care staff, who are likely to work without direct supervision, are taught to implement a philosophy that favors consumer independence, autonomy and community integration. Both the literature and the results from this study suggest that consumers benefit when staff adopt an attitudinal approach that strives to empower consumers to actively participate in their homes and to care for themselves, rather than surrendering these activities to others. Future research might focus on the extent to which provider agencies actively train and support direct care staff in empowering consumers, and the effectiveness of various training methods. This support might include insuring that there are enough direct care staff to spend quality time with consumers and that administrative activities such as maintaining records and doing other paperwork do not usurp person-to-person interaction. If the day-to-day difficulties of implementing agency missions of consumer independence and empowerment were regularly addressed and dealt with, consumers might begin to experience increased functional ability and awareness of that ability – i.e., higher self-perceptions. In a study comparing the relationship between housing facility type and activities among people
aging with developmental disabilities, researchers found that participants who received one-on-one training performed the greatest number of activities (Chornoboy & Harvey, 1988). The authors conclude that, "Human factors seem to be as important as facility type in determining activity patterns" (p. 147). In a study examining attitudes of 241 provider agency community living staff, researchers investigated staff attitudes toward the empowerment of people with intellectual disabilities. They focused on the perceived similarity of persons with intellectual disability to oneself, the extent to which the staff believe people with intellectual disabilities need protection (sheltering) and the exclusion from community life (Jones, Ouellette-Kunz, Vilela & Brown, 2008). Findings revealed that, although the majority of respondents held relatively positive attitudes toward inclusion, many respondents still endorsed sheltering, and did not value empowerment.

Demographic characteristics associated with attitudes that did not reflect inclusive principles included being male, having only a high school education, and being among the older staff members. Unlike Henry et al. (1996), theses researchers did not find a positive correlation between years of experience and more inclusive attitudes, or that supervisory staff were more likely than front-line staff to promote inclusive values. Felce, Lowe, and Jones (2002b), however, did find that more experienced staff tended to spend more time assisting consumers and less time doing "other activities."

In 1995, Felce and Perry showed that observed engagement in activity was highly correlated with assessed adaptive behavior. Felce and Emerson (2001) point out that, "Behavior reflecting adaptive functioning . . . is characterized by the extent to which the individual is constructively engaged with his or her environment" (p.77).
Many studies have shown an improvement in self-care skills among consumers who have moved from institutions to community-based living (Calapai, 1988; Close, 1977; D’Amico et al., 1978; Eastwood & Fischer, 1988; Horner et al., 1988; Rosen, 1985; Schroeder & Hanes, 1978), and improvements in adaptive behavior are a substantive part of the rationale for moving consumers from institutions to community dwellings (Kim, Larson & Lakin, 2001). Conversely, one of the hallmarks of an institution is its provision of custodial care, and the lack of emphasis on rehabilitation and personal growth (Barnett, 1986; Goffman, 1961; Mortimore & Mortimore, 1985).

In a review of intellectual disability, architecture and environmental psychology literature, Annison (2000) found the meaning of home to be, "a multi-faceted concept with many contributory sub-concepts" (p. 259). He organizes these attributes according to Maslow's (1943) hierarchy of fundamental needs, intermediate needs and meta or growth needs. Intermediate needs include both (a) belonging and knowledge, and the familiarity with the physical and social environment of the home that promotes a sense of belonging; and (b) a "sense of control of the area" (p. 260). Growth needs include, "Responsibility for the home, including homemaking tasks, home improvement tasks and home ownership or tenancy" (p.260). O’Brien (1994) also contends that one of the challenges of supporting people with developmental disabilities in residential settings is to help them to establish "effective personalized control over their homes and the assistance they require" (p.1). While it is important to maintain a clean home, an orderly yard, and to have nutritious and satisfying meals, and the efforts of some consumers may fall short of agency
standards, the lack of engagement with the physical environment by consumers may actually undermine their sense of belonging.

Henry et al. (1996) points out that the philosophy of community living and person-based supports that has emerged during the last three decades hinges on attitudes of the provider agency and its direct care staff. The authors point out that the decentralized nature of small-scale, community-based residences makes it essential for staff to be personally committed to a philosophy of consumer empowerment and independence, if they are to implement this philosophy in the context of the home.

The feelings expressed by some of the consumers in this study that the group home is more of a pseudo-home than a real home, and their ambivalence about belonging, may also be reinforced by the lack of choice about housemates and the compromised sense of privacy that living among prior strangers could engender. Feeling that the only way to make the home livable would be to “move out all the people,” as one consumer put it, and not wanting any housemates other than one’s fiancé are both sentiments that illustrate this point. “I’m not friends with the people that live here. I just know them. I’d rather live on my own,” one resident observed. Some consumers had lived in so many places – institutions, rooming houses, sponsor homes, group homes and apartments – that they justifiably saw their current residence as just one more stopover in a string of lodgings and accommodations that were in an ongoing state of flux. “I just moved here. It’s all right. I was in a Keasby apartment like this,” one consumer recalled. “I don’t get much here. I’d like to move someplace else,” remarked another respondent who
had experienced a variety of settings. Another expressed satisfaction with his current residence, saying, “I’ve been a lot of places – three houses. I like it here.”

**Physical Barriers to Functional Ability**

**Restricted Mobility and a Lack of Adaptive Technology**

The regression findings indicated that measures of impairment were stronger predictors of both measures of functional ability when they were more specifically targeted to ambulation impairments. In other words, the inclusion of impairments other than those measuring the inability to ambulate diluted the relationship between impairment and functional ability. Beta rose for the impairment variable entered into the regression, as that variable became more specific to mobility limitations. That is, the inability to ambulate without using a wheelchair was the major limiting factor in functional ability. Other impairments did not appear to appreciably influence functional ability. Note that throughout the regressions, when the dependent variable, self-reported functional ability replaced observed functional ability, the same pattern emerged.

While there are some differences between the results for control variables generated by the two types of outcome measures, the core findings about the relationships between impairment and functional ability are the same for self-reported and observed functional ability. This internal replication adds to the credibility of the overall findings. In particular, the possibility that shared method variance accounts for the relationship between predictors and outcomes becomes less plausible.
The qualitative data confirmed and elucidated this finding. Not only did this 11-member subset of people that regularly used wheelchairs have the lowest functional ability scores in the sample; they also clearly articulated their feelings of helplessness and dependency when discussing issues surrounding getting their basic care needs met. The fact that all four of the individuals in the study who did not have an intellectual developmental disability are included in this subset suggests that, for this sample, using a wheelchair for mobility has a greater impact on the ability to do normal self-care activities than having an intellectual or other physical disability. This is consistent with Cleaver et al.'s (2008) finding that individuals with mobility problems had 3.6 times the likelihood of living in a high support setting than those without mobility limitations. It is also in keeping with Connell et al.'s (1993) finding that overall difficulty and dependence in performing bathroom, kitchen and entry/egress activities was higher among power wheelchair users than those who used manual wheelchairs or assistive walking devices, and that ambulatory individuals had the least amount of difficulty. The severity of the mobility limitation seems to have a major impact on both functional ability and residential choices.

Here, too, one of the reasons for this finding may have been that wheelchair users, like some others in the sample, had a dearth of opportunities to see what they actually could do, and to engage in a trial and error process that might lead to success. However, it was often painfully obvious when one compared the person with their environment, that "fit" was limited and accompanied by extremes of person-environment "misfit." Examples of misfit include kitchens where nothing was reachable
from a wheelchair, closets whose clothes were hung out of reach, sinks where the soap
dish and or faucet controls were set too far back, complicated window locks that
required manual dexterity that the consumer lacked, and light switches painted with the
same flat white paint as the wall in a house where consumers were losing their visual
acuity.

Although the houses where full-time wheelchair users lived were often barrier-
free, purpose-built, accessible homes, the extent of their disabilities limited their ability
to manipulate even a traditionally accessible setting. For this cohort, living in an
“accessible” home, simply meant that the level floor and wide doorways enabled them
to move from one room to another so that a caregiver was able to provide all other
care. When a person has very limited ability to control his/her body movements, only a
setting that can has the flexibility to respond to computer-manipulated controls can
provide a level of accessibility that translates to control. This raises the same question
posed by Ostensjo, Carlberg and Vollestad (2005) of whether modifications provide
more support to the promotion and maintenance of independence among people with
disabilities, or support for their caregivers so they can do things for consumers. While it
is true that without fairly sophisticated robots it would be difficult under any
circumstances for people with quadriplegia to fully care for themselves, assistive
technology could give them more control than they currently had. No home had
computer controls for managing heating, cooling or ventilation. None had remote
methods of locking or unlocking doors, or controlling either natural or artificial light.
None had telephones or intercoms with interfaces that people with severe mobility and
communication impairments could use. Few consumers had access to computers and it they did have them, they were likely to be old, outdated models that had no internet access. Among people with severe physical disabilities, where computer interfaces could be used to allow them some control over their physical environment, there was no evidence or acknowledgement of the possibility of such a system by their providers. The viable computers were intended for staff use.

While many studies have found an association between having a mobility impairment and living in a high-support setting (Cleaver, Ouellette-Kuntz and Hunter, 2008; Freedman and Chassler, 2004; McGrother, Hauck, Bhaumik et al., 1996), it is interesting that the support referred to is so frequently staff support rather than environmental supports or assistive technology. The solutions to environmental problems are often highly individual for each person and can be addressed using multiple strategies that include architectural modifications, assistive technology, programmatic support and staff support. Each of these types of supports has benefits and weaknesses. While staff may prove to be flexible and companionable, they may also be unpredictable, moody, or bossy. Staff who see the ends of getting a job done (whether it be preparing a meal, turning on a light, answering a phone, or closing a window) as more important than providing consumers with the encouragement and patient instruction necessary to help them learn and become accustomed to doing the task themselves may also deprive the individual of feelings of competence and self-reliance. When it is possible to improve the person-environment fit, the benefits of doing so should be considered, particularly for people with severe disabilities. In a study
of the benefits of assistive technology for people aging with developmental disabilities, Hammel et al. (2002) found that later life interventions had potentially greater benefits for adults with more profound disabilities. Through the use of assistive technology, they were able to progress from being completely dependent in carrying out an activity to performing an activity with some assistance.

Finkels’ (1999) finding that the individual's belief that their environment does not pose barriers has a positive impact on the user's ability to navigate that environment provides further support for modification of the physical environment to support the increased autonomy of its residents. Moreover, as Cleaver et al. (2008) points out, increased environmental supports could widen the range of residential options available to this cohort.

Property Maintenance to Support Functional Ability

A lack of maintenance was an issue that came up frequently throughout the interviews and assessments. Although it could be argued that all homes have maintenance issues that develop faster than they can be addressed, they were mentioned by consumers and observed by the researcher in more than a few group homes and even more often in supported living apartments. The reasons for this are unclear, but may reflect the priorities of restricted budgets.

The reasoning behind providing highly-supportive, barrier-free housing for residents who depend on wheelchairs for all ambulation is evident as is the placement of consumers with fewer internal resources in settings with high levels of supervision. It is ironic that consumers living in supported apartments who have been assessed as
having the most internal capacity to do things for themselves are often given the fewest resources to facilitate their day-to-day functioning. Consumers in supported living settings often live in apartments located either in multi-unit complexes or in downtown areas of working-class towns. These features have advantages and disadvantages. Some apartment complexes are newer than others, but too often those occupied by consumers are older garden apartment complexes in less than optimal states of repair. For example, one building had no working lights in the hallway and when the consumer was questioned about this she explained that other apartment residents stole the bulbs. Another consumer did not use the laundry room in her apartment complex because people urinated in the washing machines. Sprawling complexes often had the disadvantage of being rather isolated from services and entertainment that consumers, very few of whom drive, might wish to access.

In-town apartments, however, were often in even shabbier buildings and rife with windows that didn’t work properly, tiles missing from the floor, limited electrical capacity, broken light fixtures, poor lighting and discolored walls. Unlike group homes, where staff often laundered clothing for consumers, people living in supported apartments rarely had laundries within easy reach. Usually, they either shared an apartment complex basement laundry room with others, or opted to go to a laundromat, often cleaner and better functioning than the apartment complex laundry room.

While maintenance problems seemed to occur most frequently in supported apartments, they were certainly not confined to this setting. Group homes also
sometimes had windows that were inoperable due to disrepair, wobbly railings, deteriorating doors that stuck, loose door sills that were a tripping hazard, towel racks that had fallen out of walls, and uneven sidewalks and driveways.

Home maintenance is likely to have a relationship to home ownership. Group homes are typically owned by the state or by a provider agency such as the Arc. Supported apartments are sometimes owned by a private provider agency, sometimes, as in the case of some senior citizen apartments, publicly owned and operated, and sometimes privately owned, market-rate, rental property. The high level of maintenance issues may be due to a number of factors such as: 1) residents’ difficulties identifying and/or communicating maintenance needs; 2) provider agencies with inadequate staffing to oversee and maintain the buildings they own; 3) Some apartment-dwelling consumers’ inability to establish good working relationships with their landlords (which may involve landlord prejudice toward people with disabilities); 4) provider agencies relegating home maintenance to a low priority; 5) property budgets inadequate to the demands of the actual property; and 6) neglect fostered by a lack of personal ownership of the property, or the fact that the owner does not live on the premises.

Particularly when a home is occupied by people with developmental disabilities, good repair may have positive outcomes with regard to functional abilities. For example, a well-maintained home might encourage activity. If the windows stick, jam, or are dressed with blinds that don’t open properly, tenants are unlikely to use them. If stair treads are worn, missing, or lifting off the stairs, or if banisters are wobbly and loose, tenants may avoid using the stairs. If stoves don’t light properly, consumers may avoid
using the stove. If closet poles are missing, or if dresser drawers stick, consumers are more likely to throw the items they would otherwise put away around the bedroom, leaving it cluttered and filled with obstacles.

When people with disabilities are living in homes that are not well maintained, negative self-images and low self-expectations may be reinforced. For consumers with developmental disabilities who have a cultural and social history of oppression and disregard and who are now being told that they are worthy of rights, entitlements and choices, it seems particularly important to convey this worth in consistent and multiple, even redundant, ways, including the maintenance and care with which their homes are kept.

**SUMMARY OF IMPLICATIONS FOR PRACTICE**

**THE PHYSICAL ENVIRONMENT OF THE HOME**

While a number of the houses and apartments in the study had the typical features one associates with barrier-free accessible design, such as roll-in showers, hand-held shower hoses, ramps, and wide doorways, these features were sometimes not adequate to enable the individuals living in the home to function even semi-independently. Many of these modifications had the effect of making it easier for staff to do things for consumers rather than allowing consumers to act on their own behalf.

The physical environment of the home can act as a potential tool, enabling the occupants to engage in and master their own self-care and daily living activities. As this study demonstrates, a thorough assessment of each individual’s person-environment fit can be improved. While some
modifications, such as adjustable height sinks or door openers on sensors, may require considerable initial costs, others are minor adjustments. Closets with shelves and poles that are within reach, cabinets with pull-out shelves, and appliances that are easy to operate, are obvious modifications.

Lighting deserves special consideration. Overhead light fixtures routinely installed in every room with switches that could be manipulated easily by the consumers who used the room would be an enormous improvement. Dimmer switches would increase flexibility for those capable of operating them. Task lighting near desks, sinks, showers and baths, seating areas, and beds would be helpful. The numerous options available to turn lights on and off should eliminate the possibility of having lights that consumers cannot operate on their own.

Consumers with quadriplegia or other major physical limitations require greater technological innovation, tailored more specifically to their capabilities. The importance of having control over one’s environment, however, should not be underestimated or overlooked. Computer interfaces can be designed for individual abilities, and for those with mild or no cognitive impairment, and many aspects of the physical environment can be controlled through a computer. This might help to move toward equalizing opportunities for people with severe mobility and motility limitations.

The proper maintenance of any dwelling housing consumers with disabilities needs to be a priority. If, as Lawton and Nehemow (1973) suggest in their ecological theory of aging, people with less competence have a narrower adaptive range in which they can achieve their peak capacity to adapt to environmental press (See Chapter One;
Figure 3), it becomes of paramount importance to make routine maintenance issues a high priority. Consumers living in group homes might have regular meetings, as the tenants of co-operative apartments do, to address maintenance and policy concerns that have to do with the running of the home. This might also provide them with a greater sense of ownership of their residence. It is important to note that the qualitative research reveals that many consumers are aware of and can articulate housing concerns.

**A SENSE OF OWNERSHIP AND BELONGING**

When the physical environment is modified to reflect the capabilities of its inhabitants, this not only enables them to manipulate their own environment and achieve increased independence, but also may reinforce a sense of ownership of their home, as it has been designed and modified specifically for their personal use.

If staff encourage consumers to do things for themselves whenever possible, instead of routinely “taking care of” consumers because it is routine, efficient or expected by consumers, consumers may begin to develop more proprietary feelings toward their homes. If staff are aware that they are respecting the fact that this is the consumer’s home when they allow consumers to perform proprietary tasks such as unlocking doors, opening windows, and turning on lights, this may increase their willingness to encourage consumer control.

**INDEPENDENCE AND EMPOWERMENT**

Provider agencies may be able to better encourage consumer independence and self-efficacy if they were to look closely at what self-care activities consumers can do,
what activities they may have the potential to do with training and encouragement, what they don’t do and what they can’t do. If reasons for not participating in activities were clearly evaluated, consumers and their direct-care staff could determine which activities individual consumers can do, which activities they are capable of learning to do, and which activities are truly beyond their grasp or a major liability. Consumers may have spent large portions of their lives in institutions and other living situations where they were given custodial care, or in family homes where a protective parent did most things for them. In these and other similar situations, consumers may have been discouraged from doing things for themselves in the interest of efficiency, safety or the attitude that passive behavior is easier to control. These individuals may need help to understand the benefits of independence, autonomy and the increased choices that accompany increased responsibility and self-sufficiency.

**RECOMMENDATIONS FOR FURTHER RESEARCH**

This research study would benefit from being re-implemented as a more rigorous, primary study, using more accurate and defined methods and levels of measurement. A larger random sample, together with more quantifiable information, would allow for some generalization of the results. Even if this were not possible, more accurate data regarding health conditions and medical issues, including data on medications that could have an impact on performance, could be taken into account, or otherwise controlled. Employing an accurate measure of both cognitive ability and physical fitness and disability, both of which impact functional ability, would improve the definitiveness of the findings. A more sensitive measure of accessibility in the
physical home environment with a more incremental scale would help to better
determine its' impact on consumer functional ability, but also the impact of the specific
features that support or degrade accessibility.

A longitudinal study examining accessibility variables would better determine
how consumers with various levels and types of developmental disabilities change over
time. A longitudinal study might also give researchers a better understanding of the
causes and impacts of moving from one location to another. Moving from the
developmental centers to the community has received a relatively high degree of
attention, but moving from one community residence to another has not.

**EXPECTATIONS AND OBSERVED FUNCTIONAL ABILITY**

This study's finding that most of the participants expected to function less well
than they actually did during the task assessment needs to be confirmed by additional
studies, particularly since the literature has very little to offer in this area. If these
findings are substantiated, ways to help consumers to more accurately perceive their
own capacity and capabilities need to be explored. Research could investigate the
impact of the experience of doing more activities and doing them more independently,
to determine if this aids consumers in the development of a more accurate perception
of their own capabilities. Research might also examine the effect, on this population, of
taking carefully calculated risks, and its impact on their expectations of success. The
impact of modifying the physical environment of the home to remove barriers and
*perceived* barriers to access and accomplishment could also be investigated. It would be
helpful to know to what extent the built environment functions as an indicator and conveyor of expectations about user-capability.

It may also be useful to look at how individual consumers' expectations differ from the expectations of their direct-care staff and how each of these compare to consumers' observed functional ability.

Finally, the relatively high number of "don't do" responses from participants warrants further investigation. Research that accurately investigates consumer and staff explanations for "don't do" responses might help to clarify both consumer and staff expectations regarding consumer capabilities.

**Mobility Impairment and Functional Ability**

The relationship between mobility limitations and low functional ability deserves further study. This sample included only a small number of full-time wheelchair users, but their functional limitations were, nevertheless, striking. Because all but one resided in group homes, and all were diagnosed with developmental disabilities, it would be useful to compare a larger sample of this cohort across housing types, and also to look at more varied categories of disability. For example, how does the functional ability of people with recent-onset disabilities, such as strokes, compare to those with lifelong, developmental disabilities? How does the overlay of cognitive disabilities on severe mobility limitations impact functional ability?

Finally more research investigating the relationship of group home residents who use wheelchairs full-time, their functional abilities and limitations, and specific characteristics of the physical environment of their homes might lead to an increased
understanding of accessibility for this cohort. Examining what accessibility features and modifications have been made to the home and whether they have the impact of aiding the wheelchair users, the wheelchair users’ caregivers, or both could spur studies that focus on enabling people with severe physical limitations. Specifically, questions might address what modifications provide greatest aid to caregivers and what modifications provide the greatest improvement to a consumer’s functional ability. Is there a difference in the way staff and other care providers react to a person using versus not using a mobility device? Does a wheelchair, independent of the users’ characteristics, signify need? These are all areas that could potentially increase independence for this relatively dependent group, as well as reduce caregiver burden and personnel costs.

A SENSE OF OWNERSHIP AND BELONGING

Findings from the current study revealed that many group home residents lacked familiarity with the physical environments of their homes. A lack of resident control over the environment was also observed (e.g., not having door keys). A number of participants indicated that they felt at the mercy of poor maintenance. Many group home residents took little responsibility, if any, for home maintenance and improvement. Research exploring whether participation in home maintenance, using a house key, and familiarity with the workings of the home increases group home residents’ sense of belonging in, and ownership of, the home. It would also be interesting to look at the relationship between ownership and belonging; is ownership associated with belonging, as the current study would imply? Controlling for impairment level, do people with disabilities who live in homes they rent or own report or
demonstrate more functional ability than peers with similar impairment levels living in group homes or other provider-owned settings? Exploring the practices group home residents associate with a sense of ownership of and belonging to the home may also help to promote an increase in participation and engagement in home-based activities. These are topics that have received little attention from researchers. Group home residents' feelings of belonging to a coherent and supportive residential social structure and a sense of ownership of their home deserve further investigation.

This study emphasized consumer-based research, and included only a small sample of staff interviews. A number of the staff interviews, however, confirmed the impression the researcher got from the consumers, that consumer independence and autonomy in daily self-care activities are sometimes not a priority in group homes. Further research is needed to verify this finding and measure its extent. As Henry et al. (1996) found, and the current study suggests, direct-care staff may need increased support and encouragement to act on a philosophy of consumer empowerment and independence. It may help provider agencies to have more information on ways to provide the education and training that would effectively foster staff empowerment of consumers in self-care and other home-based daily activities.

**COMPUTING AND OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES**

Throughout the assessment process, the researcher observed that very few consumers had access to computers and that the few computers that were in possession of participants were connected to any internet browser. The instruments used in the study originally included using a computer as a typical home-based activity,
but the item was dropped early-on due to the fact that generally only staff had access to any computers present in the home. With the current emphasis on self-determination and autonomous behavior for this population, it is striking that they had such limited access to a tool that has the potential to help acquire and process information. While the participants in this study did not grow up at a time when personal computers were available, the generation of children with developmental disabilities born during the last twenty years is likely to have had computer training and regular access. Computer literacy might be a great asset to older adult consumers, but this area needs research. The lessons learned, or potentially available, from this younger generation's computer training and use might help expedite the computer literacy of their older counterparts. Given the fact software is available for all levels of cognitive ability, and that special keyboards, screens and other interfaces exist for those with physical limitations, this may be an area ripe for research and rife with potential.

**People with Limited Communication Skills**

Much of the data collected and information gleaned from this study came from a relatively small number of consumers who had relatively good communication skills. A group particularly underrepresented by the data, are the 21 consumers who had very limited or no ability to verbally communicate. Although they were not excluded from the study, they were also less accurately represented than the consumers who were able to verbally express themselves at some level. This non-verbal group warrants special attention, and research methods designed to be responsive to their capabilities.
Otherwise researchers run the risk of repeatedly overlooking the needs and issues of this hard-to-reach, out-of-sight group.

THE IMPORTANCE OF THE PHYSICAL ENVIRONMENT TO SOCIAL WORK

Both the social and the physical environment are important to social work, however the impact of the physical environment and its potential for use as a behavioral tool is often overlooked by the profession. As disability is viewed less as an inherent characteristic of an individual (the medical model of disability), and more as a product of the transactions between the individual and his or her environment (the transactional model), the ability to assess and manipulate that environment broadens in importance. While people can often be inflexible and resistant to change, the built environment remains pliable. Whether it be a hindrance or a help will be determined, to some extent, by the social worker’s perspicacity and skill in manipulating this potential tool.

LIMITATIONS OF THE STUDY

The limitations of the study include the following. The sample is purposeful, not random, and made up of volunteers among which there may be a self-selection bias. Although the topic under study, aging, is a longitudinal phenomenon, the study is cross-sectional in nature and captures a snapshot of the aging process rather than a phenomenon that unfolds over time. The data available for analysis were originally collected for an applied research study designed to improve the physical environment of the home. This secondary analysis uses these data to search for possible correlates and predictors of functional ability. There are, however, interrelationships that undoubtedly have the puissance to impact functional ability, which this study does not address. There
are many extraneous variables – each home has its own unique design, the subjects are unique individuals with all the variation in experience, abilities, interests, talents, and genetics that the phrase implies. The subjects were chosen because they have developmental disabilities. People with developmental disabilities have a wide range of IQ’s, which undoubtedly have an impact on their ability to comprehend and carry out self-care tasks. The original applied research study gathered no data regarding degrees of intelligence. This undoubtedly would have added to the validity of the study, and more could have been inferred had it been available. The measures used in the original study are assumed to have face validity.

Similarly, other medical and diagnostic data were not available on a consistent basis. There are many reasons for this that are related to the population being studied. For this cohort, medical care is often not documented, or documentation is sketchy or variable in quality. Many members of the sample had been moved from one location to another repeatedly and good medical records do not always follow the person from one location to another. People with impairment and communication problems can be difficult to accurately diagnose. Data is sometimes dependent on self-report, which is likely to be inaccurate or incomplete. This limitation was particularly seen among the higher functioning members of this sample who lived in supported apartments and acted as their own guardians. However, it should also be noted that most of the variables in this study that had the highest correlations with Mean Functional Ability – the use of a wheelchair for all ambulation, being non-verbal, being quadriplegic – are all things that can be observed by a researcher at a point in time rather than data that
relies on medical records or self-reports. This is an interesting finding and one that may be useful for others doing research with developmental disabilities.

The fact that people may perform below their abilities is a limitation in this study, since the study makes the assumption that peoples' task performance reflects their functional ability. In reality, people can always, and often do, perform beneath their abilities. Moreover, some people with developmental disabilities, in particular, may have a vested interest in doing so. Historically, the lower the performance of members of this population, the more assistance they received. People with developmental disabilities who are now 50 years of age and older, were raised in an era when their rearing was often viewed more as custodial then educational in nature. One of the things they may have learned from this arrangement is that they could manipulate the expectations of others (who were not sure what to expect) by keeping their capabilities to themselves. Several of this study's participants confided this to the researcher, admitting to her that, while they could perform certain activities and had performed them in the past, they had no intention of demonstrating this to their caregivers, who would then be, at least, reluctant to perform the tasks on their behalf.

Studies conducted by Weisz (1979) and Gargiulo and O'Sullivan (1986) showed that when mental age is relatively high (e.g. 9 years), groups with mental retardation demonstrated higher levels of helplessness than non-retarded groups of a similar mental age. Weisz's research, along with Rholes et al. (1980), suggest that susceptibility to helplessness in this population may increase with maturity. Zigler (1999) notes that, in studies of people with intellectual disabilities, the causal importance of low ability
might be over-emphasized, while other possible causes of dysfunction, such as inadequate effort, may be overlooked.

A final limitation is also related to the population under study. People with developmental disabilities often have communication impairments. Subjects with intellectual disabilities are notoriously verbally unforthcoming and may respond according to what they perceive as the researcher's expectations rather than according to their own experience, and, in cases of severe or profound mental retardation, may be incapable of a meaningful verbal response, or, in some cases, of any verbal response. People with physical developmental disabilities, such as cerebral palsy, may have muscular impairments that make it difficult and frustrating for them to speak. This also renders their speech unintelligible to varying degrees. In these cases, the researcher is left to guess what the subject is trying to communicate, or to rely on an interpreter who is more familiar with the subject's verbal quirks and nuances, but who inevitably comes to the situation with their own preconceptions and prejudices. It is this researcher's opinion that some subjects, finding themselves in these situations, acquiesce to a meaning close to, but less than that originally intended, either in sheer frustration ("how can this researcher be so dense?"), embarrassment at what they perceive as their own inadequacies, and/or the interest of expediting what is proving to be an arduous task, or a combination of all three.

CONCLUSION

The intention of this study was to contribute to our understanding of both the facilitators of and barriers to functional ability in community-based home environments
of adults who are aging with developmental disabilities. The approach used in this research was to use interview and person-in-environment assessment data to better understand the ways that adults with developmental disabilities interact with and think about the physical and social environment of their homes. The study used both qualitative and quantitative methods to gather information about functional ability and its relationship to the home environment from both adults aging with developmental disabilities and a smaller sample of the direct-care staff who worked with them.

The results of the study indicated that there was a wide range of both level of participation and competency in consumers' performance of self-care and household activities. Consumers' participation was found to be linked to mobility status, presence of a physical disability and, to a lesser extent, overall disability level. Settings that offered a higher degree of supervision also were likely to provide facilities to support more household activities (i.e., secondary entrances, washers, dryers, etc.). A comparison of the consumer interview and observed assessment data revealed that, although the disparity was small, most participants' perceptions of their abilities fell short of their observed abilities.

In addition to these findings, the qualitative data indicated that most participants valued a sense of privacy, a safe place for themselves and their belongings, and a physically and socially supportive environment. The data also suggested a number of factors that may inhibit consumer functional ability. These included inadequacies of the physical environment, consumer and staff concerns about safety and risk, consumer's diminished perceptions of their ability and concerns about lack of
competence, a poor person-environment fit, property maintenance issues, and the
habitual caregiving behaviors of some direct-care staff.

This study also demonstrated the need for further research in the relationship
between functional ability and adults who are aging with developmental disabilities.
Research is particularly needed in the area of consumers with severe mobility
limitations, their home environments, and their ability to perform self-care and
household activities more independently. Future research could further an
understanding of remaining questions about environments that are supportive of
independence, that engender a sense of belonging, and that offer appropriate levels of
challenge and support for this growing population.

The social work profession has a history of attention to "the environmental
forces that create, contribute to, and address problems in living" (NASW, 1996). As
illustrated in this sample, the physical environment has the potential to be used as a
tool that supports the functioning of, and compensates for, many of the vulnerabilities
of people aging with developmental disabilities. A safe and well-maintained physical
environment supports calculated risk, which, in turn, promotes the opportunity to
develop judgment. When the physical environment of the home provides opportunities
for successful participation in domestic activities, this success can build self-confidence
and increase feelings of self-efficacy. The sense of place brought about by an
environment that responds to an individual's needs and preferences can foster feelings
of ownership and belonging. A degree of knowledge about the workings and mastery of
the physical environment of the home can reinforce these feelings. The physical
environment, in short, has enormous potential to enhance the capacity of people aging with developmental disabilities to address their own needs. It also has the potential to undermine this same capacity. As Germain (1983) asserts, inadequate transactions can impair individual functioning and development and lead to a downward spiral of maladaptation. For the individuals in this study with severe mobility impairments, the risk of this is evidenced by the data. These individuals' functional independence was severely compromised by the press of the home environment. As Lawton and Nehemow's (1973) ecological theory of aging illustrates, people with greater impairments have a narrower adaptive range that requires an environment more specifically tailored to their needs. As technology advances and our ability to manipulate the physical environment through technological adaptations increases, we have the potential to address the needs presented by mobility impairments.

Only through an awareness of the impact of the physical environment functioning can we harness it as a tool that can promote the core values of social work. With growing numbers of people with disabilities living longer lives, and the increased longevity of the entire population, the need to further explore any means to improve the competence of the most vulnerable, and in doing so, promote their human dignity and worth, becomes imperative.
Appendix A- CONSUMER INTERVIEW

Interview #: __________  Date: _____________________

As we mentioned when we spoke to you last month, we work at a school called New Jersey Institute of Technology and we are helping [appropriate provider agency] to figure out how to make living in your [home or apartment] easier for you now and also in the years to come. We'll start by asking you some questions. After that we'll ask you to show us how you do some normal activities. Even if you don't need any help now, we want to make sure that your [house or apartment] will keep being a convenient and safe place for you as you get older.

Do you have any questions before we start the interview?

________________________________________________________________________

Qualitative Questions:

1. How long have you lived here?

2. What do you think about it here?

3. What things do you like about it?

4. What do you dislike about it?

5. Where did you live before you moved here?

6. How was [the place you lived before you moved here] compared to this house/apartment? Why?
Probes: In what ways was it worse?

In what ways was it better?

8. If you could live anywhere you wanted to, what kind of place would you choose?

QUESTIONS SPECIFICALLY ABOUT SELF-CARE ABILITIES IN THE HOME:

1. Is there anything you have problems doing now?

1b. Is there anyway we could fix up your house/apartment to help with this problem?

2. Sometimes, even though we don't have problems doing something, there are still ways that a task or activity can be made easier. Can you thing of anything or way to change your house/apartment to make it easier for you do something?

2b. If yes, what needs to be changed or fixed and how could we change or fix it?

3. How about as you get older -- is there anything that you think might become a problem in the future?

4. Can you think of anything that could be changed to make it easier for you as you get older?
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<tr>
<th>Rating Scale Questions:</th>
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<tbody>
<tr>
<td>Code: NP = No Problem; SP = Some Problem; MP = Major Problem; FP = Future Problem</td>
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<th>NP</th>
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<tbody>
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<td>1. Do you have any difficulty walking from the street or driveway to the front door?</td>
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<td>2. At night are the outside lights bright enough that you can easily see your way from the sidewalk or driveway to your front door?</td>
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<td>3. Do you have any trouble locking or unlocking the door? At night can you see what you're doing easily?</td>
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<td>4. Do you have trouble opening or closing the front door?</td>
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<td>5. Do you have any difficulty with any other outside door (including the door to the balcony, if extent)?</td>
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<td>6. Do you have any difficulty using the stairs inside your home?</td>
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<td>7. Do you have any difficulty going from one room to another?</td>
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<td>8. Do you have any difficulty with any of the inside doors or doorways -- including the door hardware (handle, knob, etc.)?</td>
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<td>9. When you're using the kitchen, do you have any difficulty standing or sitting at the counter?</td>
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<td>10. Do you have any difficulty working at the kitchen sink or using the faucets?</td>
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<td>11. Do you have any difficulty reaching or using the kitchen cabinets (both low and high) or other storage areas?</td>
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<td>12. Do you have any difficulty using kitchen appliances (such as the microwave, toaster, etc.)?</td>
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<td>13. Do you have any difficulty getting things into and out of the refrigerator?</td>
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<td>14. Do you have any difficulty using the stove's cook-top?</td>
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<td>15. Do you have any difficulty using the stove's oven?</td>
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<td>16. Is it hard for you to open some containers in the kitchen such as cans or jars?</td>
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<td>17.</td>
<td>Do you have any problems taking out the garbage?</td>
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<td>18.</td>
<td>In your bathroom do you have any difficulty using the bathroom sink or faucets?</td>
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<td>19.</td>
<td>Do you have any difficulty reaching for or using the toiletries you store in the bathroom?</td>
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<td>20.</td>
<td>Do you have any difficulty stepping in or out of the bathtub or shower?</td>
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<td>21.</td>
<td>Do you have any difficulty using the tub faucets, shower controls or drain plugs?</td>
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<td>22.</td>
<td>Do you have any difficulty taking a bath or shower?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>23.</td>
<td>Do you have any difficulty using the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Have you ever fallen in the bathroom?</td>
<td>yes</td>
<td>no</td>
<td></td>
</tr>
</tbody>
</table>
If yes, please tell me how it happened:

Are you afraid of falling in the bathroom?

<table>
<thead>
<tr>
<th></th>
<th>NP</th>
<th>SP</th>
<th>MP</th>
<th>FP</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. Do you have any difficulty getting into or out of your bed?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>26. Can you reach a light from your bed?</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. If you need to go from your bed to the bathroom in the middle of the night, do you have enough light?</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>28. Do you have any trouble sitting down in or getting up from any of the chairs or sofas in your house?</td>
<td></td>
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</tr>
<tr>
<td>Comments:</td>
<td></td>
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</tr>
<tr>
<td>29. Do you have any problems operating the TV, VCR, or CD player?</td>
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<tr>
<td>Comments:</td>
<td></td>
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</tr>
<tr>
<td>30. Is it comfortable to sit and work at your computer?</td>
<td></td>
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</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>31. Do you have any difficulty reaching clothes, coats, shoes or other items in your closets?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>32. Do you have any difficulty doing your laundry (including carrying laundry to laundry room, putting in and taking out of washer and dryer, operating washer and dryer controls and folding your clean clothes)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Comments:</td>
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</tr>
<tr>
<td>33. Do you have any difficulty getting to the telephone on time?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Do you have any trouble dialing the telephone?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Do you have any difficulty hearing the doorbell or identifying visitors?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Do you have any difficulty getting the mail?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Do you have any difficulty due to not enough light in any areas of your house?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Do you have any difficulty opening your windows?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. Do you have any difficulty cleaning your house or apartment?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. Are you able to use your front and/or back yards without difficulty?</td>
<td>NP</td>
<td>SP</td>
<td>MP</td>
<td>FP</td>
</tr>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
41. Are any outside activities (weeding, gardening, etc.) difficult for you to do?  
Comments:

42. Have you ever fallen at in or outside your home?  
| Yes | No |

If yes, where and when did you fall:

43. Is there anything that's gotten harder for you to do as you've gotten older?  
| Yes | No |

If yes, please describe::
Appendix B: CONSUMER OBSERVATIONAL ASSESSMENT

Date: ________________  Location: ______________________________________

Age: _____  Sex: _____  Race: __________________

Describe Disability:

List Mobility Devices Used:

Note: Before interviewing/observing any consumer, the interviewer will review this interview/observation form with the staff member most familiar with the consumer's routine.

Preliminary Questions for the Staff Member:

1. Are there directives and/or questions on this interview/observation form that the consumer does not perform as part of their regular routine and would therefore be irrelevant? (Cross off all such questions/directives)

2. Are there directives and/or questions on this interview/observation form that would be dangerous for the consumer to undertake? (Cross off, but note, these directives.)
Questions and Directives for the Consumer:

Part I. Entry and Egress

1. Show me how you walk from driveway or parking area to your front door.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
</tr>
<tr>
<td>5. Consumer was unable to perform task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:

2. When you get to your front door, unlock it and go into the house or apartment.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
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<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
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<tr>
<td>5. Consumer was unable to perform task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:
3. Once you are inside your house, turn on a light.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
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</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
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</tr>
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<td>4. Consumer has great difficulty performing the task (major safety issues now)</td>
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<tr>
<td>5. Consumer was unable to perform task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:

4. Show me how you hang up your coat (or would hang up your coat if not wearing one).

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
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<tr>
<td>3. Consumer has moderate difficulty performing the task (some safety issues now)</td>
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<td>4. Consumer has great difficulty performing the task (major safety issues now)</td>
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<tr>
<td>5. Consumer was unable to perform task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:
(If no severe problems doing the above):
5. Now show me how you would do the same thing carrying a bag of groceries.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
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<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
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<tr>
<td>5. Consumer was unable to perform the task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:

(If there is more than one entrance, repeat 1 & 2 for each additional entrance.)

Second Entrance location: _________________________________________________

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:
Third Entrance location: ___________________________________________________

| 1. Consumer performs task easily and without safety problems. | |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). | |
| 3. Consumer has moderate difficulty performing the task. (some safety issues now) | |
| 4. Consumer has great difficulty performing the task. (major safety issues now) | |
| 5. Consumer was unable to perform the task. | |
| 6. Consumer was not asked to perform the task. | |

Comments:

---

Part II Inside Stairs, Corridors (if existent) and Laundry

1. Show me how you go up and down the stairs.

| 1. Consumer performs task easily and without safety problems. | |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). | |
| 3. Consumer has moderate difficulty performing the task. (some safety issues now) | |
| 4. Consumer has great difficulty performing the task. (major safety issues now) | |
| 5. Consumer was unable to perform the task. | |
| 6. Consumer was not asked to perform the task. | |

Comments:
(If laundry is on a separate floor from bedroom, ask the following question only if the consumer doesn't have major problems going up and down stairs.:

2. Show me how you carry your laundry from the bedroom to the laundry room.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:

3. Put your laundry in the washer.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

Comments:
Get the detergent and pretend you are about to pour it into the washer. Put the detergent back.

| 1. Consumer performs task easily and without safety problems. |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). |
| 3. Consumer has moderate difficulty performing the task. (Some safety issues now) |
| 4. Consumer has great difficulty performing the task. (Major safety issues now) |
| 5. Consumer was unable to perform the task. |
| 6. Consumer was not asked to perform the task. |

Comments:

Pretend you are turning the washer on (i.e., reach)

| 1. Consumer performs task easily and without safety problems. |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). |
| 3. Consumer has moderate difficulty performing the task. (Some safety issues now) |
| 4. Consumer has great difficulty performing the task. (Major safety issues now) |
| 5. Consumer was unable to perform the task. |
| 6. Consumer was not asked to perform the task. |

Comments:
4. Now take it out of the washer and put it in the dryer.

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
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</tr>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
<td></td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
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</tbody>
</table>

Comments:

Pretend you are turning the dryer on. (Or if clothing is hung on a line to dry, have the person demonstrate how they do that.)

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
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<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
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</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
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</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
</tbody>
</table>
5. Take your laundry out of the dryer. Fold one or two items of laundry.

| 1. Consumer performs task easily and without safety problems. |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). |
| 3. Consumer has moderate difficulty performing the task. (some safety issues now) |
| 4. Consumer has great difficulty performing the task. (major safety issues now) |
| 5. Consumer was unable to perform the task. |
| 6. Consumer was not asked to perform the task. |

Comments:

6. Take the laundry back to your room.

| 1. Consumer performs task easily and without safety problems. |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). |
| 3. Consumer has moderate difficulty performing the task. (some safety issues now) |
| 4. Consumer has great difficulty performing the task. (major safety issues now) |
| 5. Consumer was unable to perform the task. |
| 6. Consumer was not asked to perform the task. |
7. Get out the ironing board and the iron. Set up the ironing board.

<p>| | |</p>
<table>
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</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
<td></td>
</tr>
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<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
<td></td>
</tr>
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<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
</tbody>
</table>

Comments:

Iron one small item.

<p>| | |</p>
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
<td></td>
</tr>
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<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
</tbody>
</table>
Great, now please put the ironing board and iron away.

1. Consumer performs task easily and without safety problems.
2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
3. Consumer has moderate difficulty performing the task. (some safety issues now)
4. Consumer has great difficulty performing the task. (major safety issues now)
5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

### Comments:

---

### Part III. Bedroom

1. Show me how you get something out of your bottom bureau drawer and then put the item back in the drawer.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>
2. Show me how you get something out of your highest bureau drawer and then put the item back in the drawer.

1. Consumer performs task easily and without safety problems.
2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
3. Consumer has moderate difficulty performing the task. (some safety issues now)
4. Consumer has great difficulty performing the task. (major safety issues now)
5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

Comments:

3. Show me how you get something hanging on your clothes pole out of your closet and then return it to the closet.

1. Consumer performs task easily and without safety problems.
2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
3. Consumer has moderate difficulty performing the task. (some safety issues now)
4. Consumer has great difficulty performing the task. (major safety issues now)
5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

Comments:
4. Show me how you get something down from the shelf above your clothes pole. And then put it back on the shelf.

1. Consumer performs task easily and without safety problems.
2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
3. Consumer has moderate difficulty performing the task. (some safety issues now)
4. Consumer has great difficulty performing the task. (major safety issues now)
5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

Comments:

5. Show me how you take your shoes off and put them away. (Thanks, you can put your shoes back on).

1. Consumer performs task easily and without safety problems.
2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
3. Consumer has moderate difficulty performing the task. (some safety issues now)
4. Consumer has great difficulty performing the task. (major safety issues now)
5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

Comments:

7. Show me how you get onto your bed and lie down.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
</tr>
</tbody>
</table>

7. Show me how you sit up in the bed and turn on the light. (or, Show me how you turn the lights in your bedroom on. Note if no light can be reached from the bed.)

<table>
<thead>
<tr>
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<tbody>
<tr>
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</tr>
</tbody>
</table>
6. Consumer was not asked to perform the task.

<table>
<thead>
<tr>
<th>Comments:</th>
</tr>
</thead>
</table>

8. Thank you, that's great, you can get off the bed now.

<table>
<thead>
<tr>
<th>1. Consumer performs task easily and without safety problems.</th>
</tr>
</thead>
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9. Show me how you sit down at your desk. (Thank you, you can get up now.)

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10. Show me how you open and close one of your bedroom windows.

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Comments:

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Part IV The Bathroom

1. Show me how you walk from your bedroom to the bathroom and turn on the bathroom light.

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Comments:
### Consumer's Performance of Daily Living Tasks

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<tbody>
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<td>2. Show me how you brush your teeth. (Note if no teeth, and ask consumer to demonstrate how the bathroom sink works.)</td>
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<tr>
<td>3. Show me how you step into the bathtub or shower.</td>
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4. Show me how you would turn on the faucet. (Just pretend)
   (That’s great, you can get out of the tub or shower now..)

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5. Is the faucet easy or hard to turn?

6. Is it easy or hard to make the water the right temperature?
7. Have you ever had problems with the water being too hot?

8. Take your towel off the rack and pretend to dry yourself off. (Great. Now you can put the towel back on the rack.)

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Comments:

9. Sit down on the toilet. Tear off a small piece of toilet paper.

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</table>
6. Consumer was not asked to perform the task.

Comments:

(Great, you can get up now.)

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Comments:

Once you get up, please flush the toilet.

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6. Consumer was not asked to perform the task.

Comments:

10. Take something out of the medicine cabinet.
   (Good, put it back)

   1. Consumer performs task easily and without safety problems.
   2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).
   3. Consumer has moderate difficulty performing the task. (some safety issues now)
   4. Consumer has great difficulty performing the task. (major safety issues now)
   5. Consumer was unable to perform the task.
   6. Consumer was not asked to perform the task.

   Comments:

11. Take something out of the linen closet.
   (Good, put it back)

   1. Consumer performs task easily and without safety problems.
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5. Consumer was unable to perform the task.
6. Consumer was not asked to perform the task.

Comments:

12. Can you see your reflection easily in the bathroom mirror?

Easily _______
With Difficulty _______
No__________

13. Have you ever slipped and fallen in the bathroom? If yes, were you alone at the time?
   Were you able to get up on your own or did you need help?

---

Part V The Kitchen and Dining Room

1. Now let's go from your bathroom to the kitchen.

| 1. Consumer performs task easily and without safety problems. |
| 2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future). |
| 3. Consumer has moderate difficulty performing the task (some safety issues now) |
| 4. Consumer has great difficulty performing the task (major safety issues now) |
| 5. Consumer was unable to perform the task. |
| 6. Consumer was not asked to perform the task. |
When we get to the kitchen please turn on the light.

| 1. Consumer performs task easily and without safety problems. |
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| Comments: |  |

2. Now show me how you go to the sink and wash your hands.

| 1. Consumer performs task easily and without safety problems. |
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Comments:

Dry them on a hand towel or a paper towel.

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| 6. Consumer was not asked to perform the task. |

Comments:

3. Please get a dinner plate, a glass, silverware and a glass from the cabinet (or from where they are stored).
Fill the glass with water.

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Comments:

Bring it to the place you set at the dining room table.
4. Please get something out of the refrigerator and put it on the plate.

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Comments:
5. Sit down at the table, and get back up again.

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Comments:


6. Now put the food back in the refrigerator.

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Comments:
7. Now move the dishes from the table to the sink.

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8. Wash one of the dishes and put it in the dish drainer [OR into the dishwasher].

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9. Take dishes out of the dishwasher or dish drainer and put them away.

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10. Take out a saucepan and fill it with cool water and put it on the stove.

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11. Turn on the stove, and (if gas stove) adjust the flame from as low as possible to as high as possible. Turn off the stove. (Do not allow the water to get hot.)

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Comments:

12. Stir the water in the pot with an appropriately sized spoon.

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13. Move the pan from the stove to the counter. [If counter is not heat-resistant, ask interviewee to put something under the pot.]

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| 6. Consumer was not asked to perform the task. |

Comments:

14. Take the pot to the sink and pour out the water.

| 1. Consumer performs task easily and without safety problems. |
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| 6. Consumer was not asked to perform the task. |
15. Now please dry off the pot with a towel.

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Comments:

The Living Room (or TV Room)

1. Let's go into the living room (or whatever room people use to watch TV).

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Comments:

2. Could you turn on a light for us please.

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Comments:
3. Could you please open a window.

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Comments:

4. Let's sit down.

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Comments:
5. Please show me how you turn on the TV.

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<th>4. Consumer has great difficulty performing the task. (major safety issues now)</th>
<th>5. Consumer was unable to perform the task.</th>
<th>6. Consumer was not asked to perform the task.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Please put a tape in the VCR.

<table>
<thead>
<tr>
<th></th>
<th>1. Consumer performs task easily and without safety problems.</th>
<th>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</th>
<th>3. Consumer has moderate difficulty performing the task.(some safety issues now)</th>
<th>4. Consumer has great difficulty performing the task. (major safety issues now)</th>
<th>5. Consumer was unable to perform the task.</th>
<th>6. Consumer was not asked to perform the task.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. While TV is on, ring the doorbell or have someone ring the doorbell. Did the consumer hear the doorbell?
   Yes: ________  No: ________  Can’t tell: ________  No doorbell: ________
8. Ask consumer to walk to the door as if he or she were responding to the doorbell.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
<td></td>
</tr>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
<td></td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
</tr>
</tbody>
</table>

Other

1. Ask Consumer to call a specific number on the telephone (Could be CABSR office or a made-up partial number).

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
<td></td>
</tr>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
<td></td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
</tr>
</tbody>
</table>
2. Ask consumer to go to the mailbox, get the mail and put it in the appropriate place.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Consumer performs task easily and without safety problems.</td>
<td></td>
</tr>
<tr>
<td>2. Consumer has minimal, but some difficulty performing the task (foreseeable safety problems in the future).</td>
<td></td>
</tr>
<tr>
<td>3. Consumer has moderate difficulty performing the task. (some safety issues now)</td>
<td></td>
</tr>
<tr>
<td>4. Consumer has great difficulty performing the task. (major safety issues now)</td>
<td></td>
</tr>
<tr>
<td>5. Consumer was unable to perform the task.</td>
<td></td>
</tr>
<tr>
<td>6. Consumer was not asked to perform the task.</td>
<td></td>
</tr>
</tbody>
</table>

Comments:
### Appendix C: CAREGIVER INTERVIEW

<table>
<thead>
<tr>
<th>Caregiver Interview #:</th>
<th>Client Interview #:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date: __________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client lives in:</th>
</tr>
</thead>
<tbody>
<tr>
<td>GH: _______</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

1. How long have you worked with [client's name]?

2. Approximately how many hours a week do you spend with him/her?

3. Are there specific times of day that you always work or do the times of day that you work vary? Please describe.

4. Has [client's] physical and/or mental health changed since you began working with him/her?
   4a. If yes, please describe the changes that have taken place (declined or improved)

5. Have you observed changes in [client's] behavior and/or functional abilities over the period of time you've worked with him/her?
   5a. If yes, how has [client] changed?

6. On a scale of 1 to 5, where 1 means it doesn't work at all and 5 means it is optimal. please rate how well the physical environment of the home works for [client]?
   1-doesn't work  2  3  4  5 – works great

7. Why [this rating]?
8. What changes, if any, in the physical environment of the home do you think would make it work better for [client] and allow him/her to do more activities independently?

9. What changes, if any, in the physical environment of the home would make caring for [client] easier?

10. What changes, if any, in the social environment of the home do you think would make it work better for [client] and allow him/her to do more activities independently?

11. What changes, if any, in the social environment of the home would make caring for [client] easier?

12. Finally, on a scale of 1-10, were one is completely dependent and 10 is completely independent, how would you rate [client's] degree of independence in performing day to day activities of daily living such as those just listed?

   1  2  3  4  5  6  7  8  9  10

13. What one change, if any, do you think would best help this client achieve a greater degree of independence?

   (Do not read, but code as follows & check all that apply):
   _____ 1. Staff related (more staff, better staff, more patient staff, etc.)
   _____ 2. Physical environment related
   _____ 3. Social environment related
   _____ 4. Provider agency policy related
   _____ 5. Health/Medical related
   _____ 6. Other
### Appendix D: ACTIVITIES NOT SUPPORTED BY THE HOME IN ORDER OF FREQUENCY

<table>
<thead>
<tr>
<th>Activity</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Climb up and down the stairs.*</td>
<td>37</td>
<td>27.9</td>
</tr>
<tr>
<td>Put a tape in the VCR.*</td>
<td>23</td>
<td>17.8</td>
</tr>
<tr>
<td>Walk from driveway/parking area to a [back/side] door.*</td>
<td>20</td>
<td>15.5</td>
</tr>
<tr>
<td>Brush your teeth.*</td>
<td>14</td>
<td>10.9</td>
</tr>
<tr>
<td>Get out and set up the ironing board and iron.*</td>
<td>12</td>
<td>9.3</td>
</tr>
<tr>
<td>Put the ironing board and iron away.*</td>
<td>12</td>
<td>9.3</td>
</tr>
<tr>
<td>Take your laundry from the bedroom to the laundry room.*</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Take the wash out of the washer and put it in the dryer.*</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Pretend to turn the dryer on.*</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Pretend to turn the washer on (set the dial).*</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Take laundry out of dryer and fold 1 or 2 items.*</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Take the laundry back to your room.*</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Iron one small item.*</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Put your laundry in the washer.*</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Pretend to pour detergent into the washer.*</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Hang up your coat</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Move the pot from the stove to the counter.</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Go to the mailbox, get the mail and put it in the appropriate place.</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Open and close a bedroom window</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Dry off the pot with a towel.</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Open a living room window.</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Dial [a specific number] on the telephone.</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Stir the water in the pot with a spoon.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Get something from your bottom bureau drawer and then put it back.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Get something out of your top bureau drawer and put it back.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Get something down from a shelf in your closet and put it back.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Take your shoes off and put them away. Put your shoes back on</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Go to the bathroom turn on a light.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Step into the bathtub or shower</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Set a place setting at the table.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Bring the glass to the place you set at the table.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Get something from the refrigerator; put it on a plate.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Sit down at the table and get back up again.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Put the food back in the refrigerator.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Move the dishes from the table to the sink.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Wash/rinse a dish and put it in the dish drainer or dishwasher.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Take a dish out of the dish drainer or dishwasher and put it away.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Get a saucepan, fill it with water, put it on the stove.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Turn on the stove and adjust the heat from low to high. Turn off the stove.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Take the pot to the sink and pour out the water.</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Sit down.</td>
<td>1</td>
<td>0.8</td>
</tr>
</tbody>
</table>

*Not included in the analysis due to the large amount of missing data*
### Appendix E: NUMBER OF "DON'T DO" RESPONSES FOR FUNCTIONAL ASSESSMENT ABILITY VARIABLES

<table>
<thead>
<tr>
<th>ROOM</th>
<th>TASK</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kitchen</td>
<td>Turn on the stove, adjust the flame (or electric burner) from as low as possible to as high as possible, then turn off the stove.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Stir the water in the pot with a spoon.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Move the pot from the stove.</td>
<td>55</td>
<td>42.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take the pot to the sink and pour out the water.</td>
<td>54</td>
<td>41.9</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take out a saucepan and fill it with cool water and put it on the stove.</td>
<td>51</td>
<td>39.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Dry off the pot with a towel.</td>
<td>47</td>
<td>36.4</td>
</tr>
<tr>
<td></td>
<td>Dial a specific number on the phone.</td>
<td>39</td>
<td>30.2</td>
</tr>
<tr>
<td>Transition</td>
<td>Go to the mailbox, get the mail and put it in the appropriate place.</td>
<td>22</td>
<td>17.1</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you open and close a bedroom window</td>
<td>16</td>
<td>12.4</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Open a living room window.</td>
<td>16</td>
<td>12.4</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Show me how you turn on the TV.</td>
<td>15</td>
<td>11.6</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Take the dish out of the dish drainer or dish washer and put it away.</td>
<td>13</td>
<td>10.1</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Please get something out of the refrigerator and put it on the plate.</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Wash one of the dishes and put it in the dish drainer or dishwasher.</td>
<td>11</td>
<td>8.5</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Please get a dinner plate, silverware, and a glass from the cabinet</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Now put the food back in the refrigerator.</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Now move the dishes from the table to the sink.</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Bring the glass of water to the place you set at the table.</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Transition</td>
<td>Walk from the living room to the front door, as if responding to the doorbell.</td>
<td>7</td>
<td>5.4</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Fill the glass with water.</td>
<td>7</td>
<td>5.4</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something out of your bottom bureau and then put the item back in the drawer</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something hanging on your clothes pole out of your closet and then return it to the closet</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Sit down at the table and get back up again.</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get something out of your highest bureau drawer and then put the item back in the drawer</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Transition</td>
<td>Go from the kitchen into the living room (or wherever you sit and watch TV)</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>Turn on a light (in the living room).</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Entry</td>
<td>When you get to your front door, open it and go into the house or apartment</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Entry</td>
<td>Once you are inside your house, turn on a light</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Entry</td>
<td>Show me how you hang up your coat</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>ROOM</td>
<td>TASK</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>--------</td>
<td>----------------------------------------------------------------------</td>
<td>---</td>
<td>-----</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you take your shoes off and put them away. Thanks you can put your shoes back on</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Transition</td>
<td>Show me how you walk from driveway or parking area to your front door</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Show me how you get onto your bed and lie down</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bedroom</td>
<td>Thanks, you can get off the bed now</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Transition</td>
<td>Show me how you walk from your bedroom to the bathroom and turn on a light</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Show me how you step into the bathtub or shower</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Show me how you turn on and turn off the bathtub/shower faucet (just pretend).</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Take your towel, and pretend to dry yourself.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Sit down on the toilet and tear off a small piece of toilet paper.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Get up off the toilet.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Bathroom</td>
<td>Flush the toilet.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Transition</td>
<td>Now let's go from the bathroom to the kitchen.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Kitchen</td>
<td>When we get to the kitchen, please turn on a light.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Show me how you go to the sink and wash your hands.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Kitchen</td>
<td>Dry them on a hand towel or paper towel.</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Living Rm.</td>
<td>In the living room, sit down.</td>
<td>0</td>
<td>-</td>
</tr>
</tbody>
</table>
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Youngberg v. Romeo 1982).


B. LYNN HUTCHINGS

EDUCATION:

Ph.D. (in Social Work), Rutgers University, New Brunswick, New Jersey
M. Arch., New Jersey Institute of Technology, Newark, New Jersey
M.F.A., Rutgers University, New Brunswick, New Jersey
B.F.A., Arcadia University (formerly Beaver College), Glenside, Pennsylvania

TEACHING EXPERIENCE

Fall 2010 to present  Assistant Professor (promoted from Instructor after four months) Marywood University School of Social Work (MSW) Program.

Spring 2007 and 2009  Adjunct Instructor Rutgers University School of Social Work (MSW and BSW programs)

RESEARCH AND PROFESSIONAL EXPERIENCE:

2003-2010  Senior Research Architect

College of Architecture & Design -- Center for Building Knowledge
New Jersey Institute of Technology,

2007-2010  Research Assistant

Developmental Disabilities Planning Institute
New Jersey Institute of Technology

Current Research

Co-Principal Investigator, "The Development of Mindfulness, Self-Compassion, and Empathy in Social Work Students: A Longitudinal Study." (Marywood University School of Social Work)

Northeast Pennsylvania Regional Project Director, "Eastern Pennsylvania - Delaware Geriatric Education Center" (EPaD GEC); Working within a consortium of five regional universities/facilities to develop new evidence and innovative practice models, and translate them into practical, effective curricula and programs. Funded by The Bureau of Health Professions in the Health Resources Services Administration (HRSA) of the U.S. Department of Health and Human Services.
Principal Investigator, DD Connect: A Virtual Online Mentoring Environment for NJ families that include a family member with developmental disabilities. (New Jersey Institute of Technology)

**Developmental Disabilities Research**


2001-2002 Co-Principal Investigator and Project Manager: design intervention study to modify homes of older people with developmental disabilities to enable them to age in place. Funded by the Healthcare Foundation of New Jersey and the Grotta Foundation.


1999-2000 “Aging with a Developmental Disability.”


1994-1995  "Supported Living and Supervised Apartments: Consumers' Perspectives."

**Dementia Care Research**

2008-present  Co-investigator, "Environmental Assessments and Interventions for Dementia Care." Funded by the Grotta Foundation for Senior Care

2007-present  Co-Investigator, "Environmental Interventions for Dementia Care." Funded by U.S. Administration on Aging Grant to NJ Department of Health of Human Services

1999-2000  Co-Investigator: "Public and Private Senior Housing Design and Dementia Care." Funded by the Northern New Jersey Chapter of the Alzheimer’s Association

1997-2000  Research Associate: "Media Memory Lane" (the development and evaluation of media interventions to engage people with Alzheimer's disease in a dementia daycare center); Funded by the Alzheimer's Association.

**SELECTED PUBLICATIONS:**


