

Define Elder and Caregiver Assistance Needs

The Qualitative Research Plan activities were designed to identify what aspects of independent living and caregiving pose a threat to continued independence for community dwelling elders. The goal was to understand why elders cease to function independently, and why caregivers are no longer able to facilitate independent living, in order to focus technology development on the key impedances to independent living. The team used a combination of literature reviews, interviews with adult children caregivers, and discussions with geriatric/gerontological specialists to identify the most common reasons elders leave their homes for care institutions. The appendix presents sample questions that were used during the interview process. Below is a summary of the information we collected.

The summary is organized by challenges to independence, with a brief presentation of problem prevalence, where assistance is generally needed, and how technology might be applied. The challenges are presented in decreasing order of significance. Level 1 – these issues were present in most of our sources and were deemed by the specialist team to have significant impact on institutionalization. Level 2 – these issues arose in some of our source materials and were deemed to have less impact on the decision to move into an institution. Level 3 – these issues came up in 1 or 2 of our sources and were deemed to have the least significance, of all the issues presented, on institutionalization. Our sources included:

- Geriatric specialist Kathy Krichbaum
- Gerontological specialist and formal caregiver Nancy Williams,
- Honeywell Labs employees who have recently served as a caregiver to an elderly parent,
- Friends and family members of ILSA team members who have recently served as a caregiver to an elderly parent,
- A nurse and nursing home administrator with contacts to ILSA KA team members,
- Age related web sites, and
- Literature reviews of relevant papers and books.

This information will be used to identify potential system functionality.

Medication Management		Level 1
<ul style="list-style-type: none"> ▪ Elderly adults are two to seven times more likely to experience adverse drug effects than are younger adults. [Auerbach, 1999] ▪ Older adults are more likely to experience adverse drug reactions (ADRs) because they have slower absorption, less distribution, slower metabolism, and poorer excretion. [Auerbach, 1999] ▪ 40 percent of elderly community-dwelling Americans taking prescription medications experience ADRs. [Auerbach, 1999] ▪ Associated factors recognized for placing the elderly at increased risk for ADRs include physiological changes caused by aging, chronic disease conditions, drug to drug interactions, and noncompliance with drug therapy. [Auerbach, 1999] ▪ Metering is a common form of assistance provided by caregivers and includes organizing medications into individual doses for future use (e.g., filling a pill box with daily meds for a 1–2 week period). ▪ Elders often retain expired medications because they are deemed too expensive to throw out. Using expired medications may result in treatment reduction or cessation due to ineffective medication. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Recording all medications used including, prescribed, over-the-counter, herbal, vitamins, alternative medications, and sources of alcohol, caffeine, and nicotine. ▪ Communicating med list to doctor or pharmacist. ▪ Identifying hazardous interactions. ▪ Ensuring the correct medication is taken in the correct amount, at the correct time. ▪ Secure prompt medical help when and ADR has occurred. ▪ Purging of expired medications and assistance to prevent their consumption. 	<ul style="list-style-type: none"> ▪ Provide easy method that resident, caregiver or medical practitioner can update new medications ▪ Provide easy method that resident, caregiver or medical practitioner can enter medical information ▪ Provide preprogrammed database of drugs and their possible ADRs. ▪ Provide reminders of time to take drugs, their dosage, and how they should be taken (e.g., with food?) ▪ Provide an automated dispenser to track drugs taken monitor time taken. ▪ Alert resident and caregiver if new drugs and current drugs will cause ADR, if new drugs are duplicates, if new drug is necessary, if drug duration and dosage are abnormal, if there is better alternative drug (e.g. fewer side effects, less expensive) ▪ Alert caregiver and/or EMS if possible ADR has taken place 	
<p>Sources Kathy Krichbaum and Nancy Williams. Interviews with family caregivers. Auerbach, J. (1999). Polypharmacy and the elderly. Online: http://www.swmed.edu:8090/cme/endurmat/polyphar/polyphar.htm</p>		

Medical Monitoring		Level 1
<ul style="list-style-type: none"> ▪ There are two sides to the business – Acute Care and After Hours Care. Acute care has a medical emphasis and is provided by one of three types of professionals; a nurse, a physical therapist, or a speech therapist. ▪ The following things are checked on every visit: Vitals, Blood pressure, Heart rate, Temperature, Respiration, Weight. A hands-on head-to-toe exam also is conducted to check strength, reflexes, and listen to lungs/heart/belly. ▪ After Hours Care is some combination of medical and non-medical assistance. Medical services are provided by one of the three folks listed above. Non-medical assistance might include any of the things an informal caregiver would do with respect to ADLs and IADLs. Non-medical assistance is provided by an occupational therapist, a home health aide, or a social worker. For After Hours Care about 40% of assistance is medical and 60% is non-medical. ▪ In order to qualify for MediCare for non-medical services, the elder must receive services from at least one of the medical specialists (RN/PT/ST). ▪ Visits by medical and non-medical personnel are often a week or more apart, so these caregivers are concerned about accidents or incidents that may occur between visits. They often worry about what condition they will find their elder in upon the next visit. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Monitoring for dehydration, incontinence, medication use, and bowel movements. ▪ Monitoring of chronic disease conditions like glucose levels for diabetics. ▪ Reduce worry about falls. ▪ Reduce worry about eating well in terms of nutrition, amount of food, quality of food (cooked well enough), etc. ▪ Reduce worry about whether the proper meds have been taken or are even on hand. Some elders fail to refill prescriptions so when the caregiver arrives to help with meds there are none. ▪ Improve communications among multiple caregivers. Did the other individual show up as expected, what help was given, what decisions were made that may affect the care they provide, etc. ▪ Enable caregivers to maintain quality care provision while improving efficiency in providing care. 	<ul style="list-style-type: none"> ▪ Monitor bathroom use and combine with other activity information to infer conditions like dehydration, etc. ▪ Communicate with smart medical devices to share and trend medical data and make overall health inferences. ▪ Provide reminders for elder to use installed medical equipment. ▪ Provide easy method for elders to enter medical information into system for trending and analysis. ▪ Provide easy method that caregiver can enter medical and care information. ▪ Provide caregiver task tracking capability to coordinate efforts of multiple caregivers. ▪ Provide dedicated caregiver information exchange UI facility. ▪ See Eating, Medication, and Safety issues for additional relevant technology opportunities. 	
Sources		
Kathy Krichbaum and Nancy Williams.		

Eating		Level 1
<ul style="list-style-type: none"> ▪ There is a decrease in stomach acid secretion, which is a natural defense against ingested bacteria. Over time, the immune system may become less adept in ridding the body of bacteria. ▪ Seniors become more vulnerable to illness and, once ill, it can take them longer to recover. ▪ Many elders suffer from a loss of appetite and burn fewer calories (often appetite stimulants are prescribed). ▪ Some have difficulty chewing and swallowing. ▪ The sense of taste or smell declines with age, and is sometimes affected by medication or illness, thus it may not always sound an alert when food is spoiled. Reduced senses also lower enjoyment for food. ▪ Others are new widowers with little cooking experience. ▪ Many seniors rely on delivery services for their meals ▪ In one study, 53% caregivers said they used formal services to help with housework, shopping, laundry or cooking. ▪ Cooking is the second most common cause of fires among the elderly. ▪ In one study, 37% reported that they need help but do not receive it. Most help is needed with instrumental activities of daily living (IADLs), with meal prep, outdoor mobility, and money management ▪ One study suggests that help with shopping is the most common task that formal and informal caregivers provide. ▪ 73% of caregivers went grocery shopping for care recipients; 93.7% for level 5 care recipients (Appendix A). ▪ Grocery shopping involves many physical tasks that pose difficulty for elderly, reading labels, bending, reaching, carrying heavy loads, walking with heavy loads. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Monitoring food quality, identifying and purging spoiled food. ▪ Forming a grocery list. ▪ Shopping for groceries. ▪ Preparing meals. ▪ Using appliances safely. ▪ Eating nutritionally balanced meals and meal planning. 	<ul style="list-style-type: none"> ▪ Track food for expiration dates and advise resident to dispose of food if too old ▪ Store basic list of groceries and automatically order new products or add them to an automatic grocery list once the item is used ▪ Automatically generate shopping list based on meal planning/nutritional goals. ▪ Track nutritional value of meals, and alert caregiver and resident if eating inappropriately. ▪ Monitor food degradation (e.g., if meat has been defrosted in microwave and not cooked immediately, or if meat is out for longer than 2 hours at room temp). ▪ Monitor cooking progress/success (temperature and time in oven to determine whether food is cooked). ▪ Monitor storage conditions (fridge and freezer temperatures to ensure food is cold enough). ▪ Track schedule of food delivery and alert caregiver/resident/organization if food delivery does not arrive. ▪ Allow caregiver remote access to resident's shopping list ▪ Allow for shopping online by the resident or caregiver to alleviate stress or time associated with shopping ▪ Alert caregiver or resident of store events, sales on merchandise (e.g., coupons, senior specials). ▪ Monitor appliance use, alert and/or control unsafe conditions 	
<p>Sources Kathy Krichbaum and Nancy Williams. Interview with RN. Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. Online: www.caregiving.org/reports/nacanalysis.pdf</p>		

Mobility		Level 1
<ul style="list-style-type: none"> ▪ Many IADLs that cause difficulty for older adults are the result of physical difficulties in bending, carrying, and locomotion. ▪ 30% of persons over age 65 who are independent and living on their own will fall each year. This rate rises to 50% in those over 80. [Tibbitts] ▪ Most elders fall on a level surface. [Tibbitts] ▪ Inability to get up after a fall is reported by 50% of fallers, and is associated with subsequent functional decline. [Lipsitz] ▪ Falls in this age group result in bone fracture 5% of the time and hip fractures 1% of the time, accounting for 250,000 hip fractures each year. [Tibbitts] ▪ Among the elderly who fall, the risk of hospitalization is 10 times greater and the risk of dying is 8 times greater than those risks in children who fall. [Tibbitts] ▪ In a study of 115 apartment-dwellers age 62 or older, 29% reported a fall within the last year. Of those who fell 69% were injured as a result of their fall – 49% required medical attention, 36% required at least one day of limited activity, and 15% required hospitalization. [Schoenfelder & Crowell] ▪ 75% of the deaths from falls occur in the elderly, who make up only 12% of the population. [Tibbitts] ▪ Repeated falling is a strong predictor of nursing home admission. Hospitalized patients who were multiple fallers were 2.5 times more likely than a group of hospitalized single fallers to be transferred to a nursing home. [Schoenfelder & Crowell] ▪ Falls are listed as a reason for 40% of nursing home admissions. [Tibbitts] ▪ Environmental causes are felt to be responsible for 22% of falls, particularly those that occur in unfamiliar environments. Falls that happen in familiar environments such as the patient’s home, are more likely caused by intrinsic factors (e.g., disability, diseases, and age-related changes). [Tibbitts] ▪ Factors leading to a fall include the patient’s acquired disabilities, current diseases, and age-related changes. Patients with none of these factors have a 12% chance of falling each year. Those with all three factors have a risk approaching 100%. [Tibbitts] ▪ Significant risk factors for falls included; sedative use, cognitive impairment, lower-extremity disability, palmomental reflex, foot problems, and more than 5 balance and gait abnormalities. The risk of falling increased linearly with the number of risk factors. [Tinetti et al] 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Balance and gait stability ▪ Transitioning between sitting-standing-laying ▪ Preventing falls ▪ Providing prompt assistance after a fall 	<ul style="list-style-type: none"> ▪ Obstacle detection ▪ Pathway lighting ▪ Exercise facilitation (regular exercise reduces risk of falling) ▪ Increased monitoring sensitivity based on client’s medical conditions (e.g., if know client has had a recent prescription change, increase system sensitivity for fall monitoring). ▪ Increased monitoring sensitivity based on activities or environmental conditions (e.g., seemingly minor everyday stresses, such as postural change, eating a meal, or an acute illness may result in hypotension and therefore, increased risk of falling). ▪ ILSA initiated contacting of medical and/or family members upon a fall. ▪ A panic-button-type device that is worn by the resident and can be used to summon help. 	
Sources		
<p>Tibbitts. (1996). Patients who fall: How to predict and prevent injuries. <i>Geriatrics</i>, 51 (9).</p> <p>Schoenfelder & Crowell. (1999). From risk for trauma to unintentional injury risk: falls – a concept analysis. <i>Nursing Diagnosis</i>, 10 (4).</p> <p>Lipsitz. (1996). An 85-year old woman with a history of falls. <i>Journal of the American Medical Association</i>, 276 (1).</p> <p>Tinetti, Speechley, and Ginter. (1988). Risk factors for falls among elderly persons living in the community. <i>New England Journal of Medicine</i>, 319 (26).</p>		

Cognitive Disorders (Dementia) Level 1	
<p>Dementia is a syndrome of acquired cognitive disturbance (e.g., attention, language, visuospatial, memory) that may result from a variety of disease states. Alzheimer’s disease (AD) is a cortical dementia that accounts for 50–70% of all cases. Risk factors for AD include being ≥ 60 years old, having a family history of dementia, being female and having lower levels of educational attainment. Predictors for institutionalization include 2 major categories: those within the resident and those that are caregiver-related.</p> <ul style="list-style-type: none"> ▪ There are five behavior categories for patients with dementia (Kolanowski, 1995): Aggressive psychomotor, Nonaggressive psychomotor, Verbally aggressive, Passive, and Functionally impaired. ▪ 22.4% of caregivers take care of someone with Alzheimer’s, confusion, dementia, or forgetfulness ▪ 40% of recipients of Level 5 care (> 40 hours per week) have dementia ▪ 83% of caregivers of recipient with dementia reported using 1 of 3 supportive services (Appendix A) ▪ Depressive symptoms reportedly occur in up to 50 percent of AD, which is three to four times more frequent than in non-demented elderly patients. ▪ Dementia is highly associated with caregiver burden (Cohen <i>et al</i>, 1993; Gold <i>et al</i>, 1995; McFall & Miller, 1992; Molloy <i>et al</i>, 1999; Montgomery & Koslowski, 1994; Tsuji, Whalen & Finnane, 1995; Scott <i>et al</i>, 1997). Contributors to burden include: Feelings of well-being, Overall health, Status as spouse, Gender, Living distance from resident, Employment status, and Use of community services. 	
Assistance Needs	Technology Opportunities
<ul style="list-style-type: none"> ▪ Changes in cognitive status (Cohen <i>et al</i>, 1993; Severson, 1994) ▪ Disruptive behavior (Kolanowski, 1995; Severson, 1994) ▪ Marital status (Severson, 1994) ▪ Functional status (Gold <i>et al</i>, 1995; Molloy <i>et al</i>, 1996; 1999; Severson, 1994) ▪ Changes in activities of daily living (ADL) (Scott <i>et al</i>, 1997) ▪ Control over incontinence (Cohen <i>et al</i>, 1993; Hamel <i>et al</i>, 1990; Steele, 1990) and bowels (Tsuji <i>et al</i>, 1995) ▪ Memory problems (e.g., remembering routines) ▪ Depression ▪ Difficulty performing complex tasks (toast test) ▪ Difficulty learning new information ▪ Failure to recognize familiar objects ▪ Recognizing the signs of dementia onset and/or worsening ▪ Distinguish between depression, delusion, and delirium. ▪ Reduce caregiver burden associated with caring for demented elders. 	<ul style="list-style-type: none"> ▪ Task prompts or step-by-step instructions ▪ Query dialog to ease disorientation or loss of SA (C: is someone else in the house? ILSA: you are alone in the house) ▪ Monitor activities to detect signs of depression (e.g., sleep patterns, amount of overall activity, changes in appetite, changes in voice). ▪ Administration of standardized instruments for depression assessment (GDS, CDES) Or ILSA communicates with caregiver to setup a healthcare professional to administer ▪ Monitor activities to detect signs of dementia onset or worsening (e.g., forgetting to do things ILSA or others have suggested (STM), forgetting appointments (LTM), Sundowning (see wandering), Hallucinations (see hallucinations)). ▪ Administration of standardized instruments for dementia assessment (RIL, Molloy <i>et al</i>, 1999) Or ILSA communicates with caregiver to setup a healthcare professional to administer ▪ Develop abilities to assess changes in behavior such as those listed in Kolanowski, 1994 (e.g., aggressive psychomotor - hitting, kicking, pushing, scratching, assaultiveness) ▪ Increased monitoring sensitivity and/or increased offloading of caregiver responsibilities based on client’s level of dementia (degradation in care recipient is correlated with increased caregiver burden). (Zarit or Montgomery caregiver burden assessment tools)
<p>Sources Kathy Krichbaum. Interviews with family caregivers. Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. at www.caregiving.org/reports/nacanalysis.pdf Dementia: Management of Behavior Problems at http://www.mayo.edu/geriatrics-rst/Behav.html (Mayo Clinic Geriatric Medicine Division webiste)</p>	

Safety (Fires, Burns/Scalds, Poisoning)		Level 1
<ul style="list-style-type: none"> ▪ Although less than 0.1% of reported cases of toxin ingestion have fatal outcomes. Elderly patients account for about 17% of these fatal cases, and the risk of dying from ingesting a toxin rises with age. [Mozes, 2000] ▪ Because of physical changes associated with aging, the elderly are likely to be exposed to toxins for longer periods after ingestion than children. [Mozes, 2000] ▪ Reported cases tend to be with demented residents. [Mozes, 2000] ▪ Fires are the leading cause of death from unintentional injuries in older adults. [US Fire Administration] ▪ Older adults account for 25% of all fire deaths and 30% of fire deaths at home. [US Fire Administration] ▪ Virtually all victims have come close to the source of the fire. [US Fire Administration] ▪ Older adults are more prone to accidents because of illness and impairments, economic situation, medications and are more likely to suffer serious injury because of mobility problems and increased susceptibility to injury. [US Fire Administration] ▪ Causes of fire include; smoking, use of some heating system, cooks a great deal, electrical distribution, open Flame (torch, ember), and appliances. [US Fire Administration] ▪ Risks for injury include; age, bedridden, in wheelchair, sensory deficits, use of medications that cause drowsiness, use of alcohol, living arrangements (those that live alone tend to be more susceptible). [US Fire Administration] 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Detect airborne poisons and hazards ▪ Take measures to relieve poisons if detected ▪ Guard chemicals that are poisonous ▪ Risk assessment ▪ Prevent dangerous fire hazards ▪ Perform fire warning diagnostics ▪ Provide adequate warnings before or when fire occurs ▪ Provide escape route ▪ Fire suppression ▪ Contact emergency personnel 	<ul style="list-style-type: none"> ▪ Monitor air quality ▪ Alert air quality changes to resident and caregiver if potential for danger is detected ▪ Alert EMS and caregivers if critical air quality danger exists ▪ Automatically open windows, turn on fans and air filters (air conditioners) ▪ Automatically shut off source of problem. Furnace, stove, heater. ▪ Sensor and locks placed on cabinets storing dangerous household chemicals. ▪ Alerting system if unauthorized user opens cabinet. ▪ Detect choking sounds, vomiting or changes in vitals, that would be another possibility to provide aid. ▪ Assess risk of resident and accommodate system's sensitivity to detect fires (e.g., if person is smoker, and is doing smoking near an oxygen device, ILSA would provide a warning). ▪ Monitor heating system, space heaters, fireplaces, chimneys, and appliances (especially stove, oven, toasters, grills, microwaves) and provide alerts if unusual situation occurs ▪ Diagnostics of electrical wiring, smoke alarm battery, etc. and battery replacement reminders ▪ Provide exit path guidance with signs, lighting, auditory instructions, etc. ▪ Contact caregivers if dangerous situation detected and emergency help if critical situation occurs ▪ A panic-button-type device that is worn by the resident and can be used to summon help. 	
<p>Sources Mozes, (2000). Demented seniors at risk from house poisons. http://www.sightings.com/ufo6/hfd.htm TriData Corporation for the United States Fire Administration. Fire Risks for Older Adults.</p>		

Caregiver Burnout		Level 1
<p>Subjective caregiver burden contributes significantly to caregiver burnout; similarly as this increases so does the likelihood of admittance of care recipient. One of our domain sources hypothesized that adult daycare has become popular because it allows the employed caregivers to remain "worry-free" or burden-free throughout their workday.</p> <p>According to a 1997 national survey:</p> <ul style="list-style-type: none"> • 52% of caregivers are employed full time and 12% are employed part time. • 62% are married and 41% have children at home. • 24% live more than 20 minutes away from care recipient. • One in four caregivers experience emotional stress as a result of caregiving. 		
Assistance Needs	Technology Opportunities	
<p>Reduce emotional and time burden of the caregiver:</p> <ul style="list-style-type: none"> • Alleviate feeling they always have to be with care recipient • Eliminate unnecessary travel to and from recipients residence • Enable worry-free workday • Reduce stress of balancing their responsibilities and those of parent • Check-in on recipient for their piece of mind without disturbing them • Reduce guilt 	<p>Support remote monitoring of activities and behavior</p> <ul style="list-style-type: none"> • Monitor activity levels and environmental parameters • View video images • Show trends (activity, appliance use, visitors, phone calls) • Support remote communication that serves as an equivalent surrogate for personal visits (burden and isolation) <p>Customize information content/delivery to caregivers concerns</p> <ul style="list-style-type: none"> • Support UIN-type customization of info requests (call/page/email me if recipient does not get up by 8 am on day of some appointment) • Define information that is interesting to them (e.g. stovetop temperature, front door activity, etc.) • automatic generation of a caregiver to-do list <p>Provide flexible access:</p> <ul style="list-style-type: none"> • Leverage automated UI generation capability (IDS) to deliver content to caregiver across multiple platforms and modalities (PC browser, PDA browser, WAP phone, phone) 	
<p>Sources</p> <p>Kathy Krichbaum and Nancy Williams. Interviews with family caregivers.</p> <p>Comparative Analysis of Caregiver Data for Caregiving to the Elderly 1987 and 1997. National Alliance for Caregiving at www.caregiving.org</p> <p>Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. at www.caregiving.org/reports/nacanalysis.pdf</p>		

Transportation		Level 1
<ul style="list-style-type: none"> ▪ Outdoor mobility is one of the most common difficulties older adults face. ▪ Driving safely is a major source of worry for many family caregivers. ▪ 79.6% of elders receive support with transportation; 89.6% for level 5 care recipients (Appendix A). 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Driving safely ▪ Arranging transportation ▪ Getting information about transportation options, services, schedules, etc. 	<ul style="list-style-type: none"> ▪ Allow for easy communication with transport services ▪ Facilitate access to transport schedules ▪ Alert resident or caregiver if transportation is a problem ▪ Provide information about local transportation resources 	

	<ul style="list-style-type: none"> Consider ways in which ILSA could extend to the car.
Sources Interviews with family caregivers. Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. at www.caregiving.org/reports/nacanalysis.pdf	

Isolation Level 1	
<ul style="list-style-type: none"> Isolation and lack of social contact has implications on many different aspects of elderly life. Isolation is associated with increased vulnerability to solicitations, con artists, and other predators. Healing time and recovery success are positively impacted by social interaction. Social support at times of injury is strongly correlated with the success of recovery, and lack of support is related to increased institutionalization. [Tibbitts] Isolation can lead to depression and associated changes in behavior such as alcohol abuse, reduced appetite, reduced activity level, and increased functional decline. 	
Assistance Needs	Technology Opportunities
<ul style="list-style-type: none"> Encourage and facilitate socialization 	<ul style="list-style-type: none"> Provide regular interaction with the care recipient via means that are normally associated with guests, friends, family, etc. (e.g., phone calls and emails) Provide social interaction such as “reading” to care recipient (i.e., playing books on tape) Facilitate ways in which care recipients can continue to get social contact from external sources like video phone interaction with doctors, calling in a daily/weekly shopping list to a human, ordering supplies via phone rather than web, etc. Create an ILSA community in which all ILSA users can interact with one another via the web, video gatherings, phone.
Sources Kathy Krichbaum and Nancy Williams. Interviews with family caregivers. Tibbitts. (1996). Patients who fall: How to predict and prevent injuries. Geriatrics, 51 (9).	

Managing Money Level 1	
<ul style="list-style-type: none"> In one study, 37% reported that they need help but do not receive it. Most help is needed with instrumental activities of daily living (IADLs), with meal prep, outdoor mobility, and money management. 56.6% of caregivers managed finances; 74.4% for level 5 care recipients (Appendix A). 	
Assistance Needs	Technology Opportunities
<ul style="list-style-type: none"> Manage bills – track due dates and amounts. Update register after a transaction. Balance checkbook/account. Protection from solicitors. Protection against fraud. Getting information about financial management options, services, etc. 	<ul style="list-style-type: none"> Electronic banking with automated bill payments and account balancing. Formation of a bill to-do list to facilitate caregiver who manages finances (e.g., list might include vendors and amounts due along with funds availability information). Scan phone communications for release of personal info that may indicate response to solicitation. Monitor credit card bills and check payments for unusual expenditures. Provide information about local financial management resources Checking account interlocks to prevent payments to

	<p>unauthorized persons or organizations.</p> <ul style="list-style-type: none"> ▪ Visitor screening to deter door-to-door solicitors. ▪ Support regular social contact to reduce sense of isolation, since isolation is a key reason elders talk to solicitors.
<p>Sources Nancy Williams. Interviews with family caregivers. Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. at www.caregiving.org/reports/nacanalysis.pdf</p>	

<p>Incontinence Level 2</p> <ul style="list-style-type: none"> ▪ Caregivers of the homebound elderly report that approximately 53% are incontinent. ▪ Prevalence of urinary incontinence can be as high as 15%-35% in people over 60. Women are twice as likely as men to suffer from the condition. ▪ Incontinence is often the “straw that broke the camels back”; the last event that precipitates a move to institutional care. ▪ Incontinence is treatable with medications and/or exercises, but without treatment the condition will not improve. Many elders however, fail to seek help due to feelings of embarrassment or shame. 	
<p>Assistance Needs</p> <ul style="list-style-type: none"> ▪ Mobility assistance ▪ Remembering to use the bathroom ▪ Medication induced sense of urgency ▪ Neurological deficiencies causing reduced sensation of urgency 	<p>Technology Opportunities</p> <ul style="list-style-type: none"> ▪ Provide reminders to use the bathroom ▪ Provide path lighting and obstacle detection for nighttime movement between bedroom and bathroom ▪ Increased monitoring sensitivity based on client’s medical conditions (e.g., if know client has reduced sensation, increase system sensitivity for urination outside bathroom and/or prompts to wear/change diapers). ▪ Reminders and assistance with exercises.
<p>Sources Kathy Krichbaum and Nancy Williams. Newman, DK. What's New: the AHCPR guideline update on urinary incontinence. J Ostomy/Wound Management 1997; 42(10): 46-59.</p>	

<p>Housework and Laundry Level 3</p> <ul style="list-style-type: none"> ▪ Many IADLs that cause difficulty for older adults are the result of physical difficulties in bending, carrying, and locomotion. Thus older adults who experience these difficulties will more likely avoid these chores or neglect them ▪ 13.1% of elders have under-met IADL needs. [Stone, 2000] ▪ 73.6% of caregivers provided housework assistance; 96% for level 5 care recipients (Appendix A). ▪ In one study, 53% caregivers said they used formal services to help with housework, shopping, laundry or cooking. 	
<p>Assistance Needs</p> <ul style="list-style-type: none"> ▪ Detecting via smell or vision the need to clean ▪ Remembering to clean and launder ▪ Arranging and scheduling in-home services ▪ Getting information about housekeeping options, services, etc. ▪ Difficulty performing complex tasks 	<p>Technology Opportunities</p> <ul style="list-style-type: none"> ▪ Detect clutter to suggest clean up ▪ Detect air quality (look for molds, spores, bacteria) ▪ Remind caregiver or resident to clean ▪ Detect smells on clothes ▪ Remind resident or caregiver of washing if not performed regularly ▪ Provide a washing schedule based on usage of clothes ▪ Provide information about local housekeeping resources ▪ Task prompts or step-by-step instructions

<p>Sources</p> <p>Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons. at www.caregiving.org/reports/nacanalysis.pdf</p> <p>Robyn I. Stone (2000). Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century., Milbank Reports.</p>
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<p>Shopping Level 3</p> <ul style="list-style-type: none"> One study suggests that help with shopping is the most common task that formal and informal caregivers provide. In one study, 53% caregivers said they used formal services to help with housework, shopping, laundry or cooking. [FCA] In same study, care-receivers said that they preferred that a friend/family member be the primary caregiver to do this work. [FCA] 	
<p>Assistance Needs</p> <ul style="list-style-type: none"> Identifying needs Forming a shopping list Getting information about shopping options, services, etc. 	<p>Technology Opportunities</p> <ul style="list-style-type: none"> Allow caregiver remote access to resident’s shopping list Allow for shopping online by the resident or caregiver to alleviate stress or time associated with shopping Maintain a schedule for when to go shopping Maintain a basic shopping list and track when supplies are low Facilitate the development of a shopping list Alert caregiver or resident of store events, sales on merchandise (my thought here is that certain stores have senior’s days or specials).
<p>Sources</p> <p>Making Hard Choices: Respecting Both Voices – FCA Study on Choice and Decision Making in Everyday Care – Family Caregiver Alliance.</p>	

<p>Pressure Sores Level 3</p> <p>Result from prolonged pressure from sitting/lying down. Pressure interferes with an already compromised circulatory system resulting in localized ulceration. This is further complicated by incontinence since you introduce urine moisture accumulations that lead to sores and ulcerations. This is another common event that precipitates admission to nursing care.</p> <ul style="list-style-type: none"> Reported prevalence ranges from 5% to 9%; prevalence is more than 70% in patients over 70 years. In the U.S. approximately 25% of nursing home patients have sores, and up to 30% of patients being cared for in their own homes. 	
<p>Assistance Needs</p> <ul style="list-style-type: none"> Minimize situations that contribute to the formation of pressure sores Encourage adjustment of sitting/lying positions Detect moisture (either from urine or perspiration) and encourage changing clothes, bedding and/or going to the bathroom. Encourage more frequent urinations to reduce incontinence 	<p>Technology Opportunities</p> <ul style="list-style-type: none"> Provide reminders to use bathroom Monitor for urine moisture Provide reminders to change clothing, wash clothing and sheets if moisture detected Monitor position and movement changes Provide reminders to change position and suggestions for new positions
<p>Sources</p> <p>JB Young, S Dobrzanski. Pressure sores: epidemiological and current management concepts. Drugs & Ageing 1992 2: 42-57 (reference at http://www.jr2.ox.ac.uk/Bandolier/band6/b6-1.html).</p> <p>Oot-Giromini BA. Pressure ulcer prevalence, incidence and associated risk factors in the community. Decubitus 1993;6(5):24-32 (reference at http://www.mmhc.com/cg/articles/CG9801/Bliss.html)</p>	

Using a Remote Control		Level 3
<ul style="list-style-type: none"> ▪ Family caregivers receive numerous calls per day in which the care recipient requests assistance with simple tasks like using the TV. ▪ In most cases the care recipient is holding the remote the wrong way, not pointing it to the TV, or pressing the wrong buttons. ▪ Providing instructions over the phone is often a long and frustrating interchange. For example, one care recipient was instructed to press 5 to get the desired channel, he proceeded to press 5 on the telephone keypad rather than on the remote. ▪ Similar difficulties can be present for other common and simple household devices such as the telephone. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> • How to hold unit • Where to point unit • What buttons to press 	<ul style="list-style-type: none"> • Omni-directional signal receipt (no matter what way they have the remote facing, it will control the proper device) • One-way ergonomic design (a hardware design that makes it clear there is only one way to hold the remote) • Task prompts and cues (keys light up in order as cue for entry sequence) • Voice command controls 	
<p>Sources Interviews with family caregivers.</p>		

Alcohol Abuse		Level 3
<ul style="list-style-type: none"> ▪ The 1994 General Household Survey found that in those aged 65 and over, 17% of men and 7% of women exceeded the 'sensible limits' of regular consumption i.e. around 1 in 6 men and 1 in 14 women. [Institute on Alcohol Studies, 1997] ▪ In a study of community-dwelling persons 60 to 94 years of age, 62 percent of the subjects were found to drink alcohol, and heavy drinking was reported in 13 percent of men and 2 percent of women.(8) Overall, about 6 percent of older adults are considered heavy users of alcohol. In this study, heavy drinking is defined as having more than two drinks per day. [Institute on Alcohol Studies, 1997] ▪ Of the 10 million alcoholics, 3 million are over 60. [Standridge, 1998] ▪ The effects of alcohol on the elderly include; increased likelihood of falls, increased likelihood for delirium, interacts with medications, reduces absorption of medications, increase risk for hypertension and stroke, contributes to nutritional deficits. [Rigler, 2000; Institute on Alcohol Studies, 1997] ▪ Alcohol abuse also is associated with failure to take medications and take them appropriately. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Monitor amount of alcohol consumed ▪ Encourage safe usage ▪ Prevent negative medication interactions ▪ Provide alcohol use information to caregivers (doctors are often unaware of such use and therefore unable to know of possible negative drug interactions) 	<ul style="list-style-type: none"> ▪ Fit alcoholic drinks with usage caps that monitor how often they are opened (this is done with certain drug monitoring) and record this information ▪ Provide sensors for cabinets. Since most people store their alcohol in one area, it can give a rough estimate of how often it is used. ▪ Provide warning messages if person has recently used alcohol and is about to take medication. ▪ Provide warnings if consumption is approaching dangerous levels. ▪ Send message via phone or email to caregivers if alcohol misuse is detected (unconsciousness, falls, malnutrition). 	

	<ul style="list-style-type: none"> ▪ Alert EMS if falls or accident occurs. Immediately report problem as possible alcohol related. ▪ Monitor alcohol consumption for the information of family and professional caregivers
<p>Sources Institute on Alcohol Studies. (1997). Alcohol and the elderly. Online: http://www.ias.org.uk/factsheets/elderly.htm. Rigler, S.K. (2000). Alcoholism in the elderly. Online: American Family Physician, 61, 1710 Standridge, J. (1998). Alcohol abuse and the elderly. Online: http://www.sma.org/medbytes/gm_9.htm</p>	

Wandering		Level 3
<p>Common to the elderly clients with dementia. "Sundowning" is the propensity to wander near sundown. This behavior has serious safety implications and is a common precipitating event leading to nursing care admission. Adult children worry about this a lot.</p> <ul style="list-style-type: none"> • Approximately 50% of Alzheimer’s patients in the mid and late stages of the disease exhibit purposeless activities such as wandering, picking, pacing, or rummaging. • Research has shown that simple measures such as covering doorknobs so that they are not visible or grabable is enough to alter the wandering pattern and deter passing through a doorway. 		
Assistance Needs	Technology Opportunities	
<ul style="list-style-type: none"> ▪ Monitoring to detect wandering ▪ Prevention of wandering outside home ▪ Tracking location outside home ▪ Ensuring safety both within and outside the home. 	<ul style="list-style-type: none"> • Check their schedule before the leave the house • Interact with client before they exit to try to "snap them out of it" • Contact caregiver in the event that the client is suspected of wandering • Door mat sensor and door sensor can indicate a potential exit by client (outside door mat sensor and door bell or acoustic sensor listening for a knock can confirm/ disconfirm that they are not simply answering the door) • Check client schedule to see if exit is expected • Check behavioral pattern to see if expected or unusual (exiting at 3 am) • If unexpected ILSA should engage client in dialog to try to snap them out of their wander-fog (check literature to see if there is some semantic or sensory stimulation that can do this) • If ILSA is sure they are wandering, stall them until a caregiver can arrive. • Inform client if there is inclement weather, if client leaves anyway contact caregiver • If keys are RF-tagged confirm that client has keys (if so automatically lock the door; if not do we automatically lock the door then depend on facial or voice recognition when client returns to actuate door lock) • Wandering switch – if leaving on purpose resident flips a switch at door to indicate leaving house. If not switched, front gate locks to prevent departure and contain wandering path within home territory. Notify caregiver that resident is outside if outdoor conditions are adverse. 	

<p>Sources</p> <p>Kathy Krichbaum.</p> <p>Richard B. Birrer, M.D., M.P.H., Dharamjit N. Kumar, M.D., and Robert Caruso, M.D. Alzheimer's Disease: A Primary Care Approach at http://www.mmhc.com/cg/articles/CG9908/Birrer.html</p>

<p>Hallucinations and Delusions Level 3</p> <p>Common symptom of dementia (both Alzheimer's and age related). These are worrisome symptoms for adult children that are an indication of cognitive and psychological decline. Early indication of this are frequent calls to police by elderly client regarding a stranger wandering around their house – when there is independent corroboration that the client is alone. Visual hallucinations are most common, and often involve people or animals. Hallucinations are obviously disconcerting for the client and cause considerable psychological stress and agitation. Clients, suffering from dementia, are generally not aware they are experiencing hallucinations and delusions, either during the episode or after.</p> <ul style="list-style-type: none"> ▪ Hallucinations and illusions occur in 10 to 28% of patients with Alzheimer's type dementia. ▪ Delusions are reported to occur in 30 to 57 percent of patients with Alzheimer's. 	
<p>Assistance Needs</p> <ul style="list-style-type: none"> ▪ Provide information ▪ Encourage and facilitate relaxation ▪ Distinguish between depression, delusion, and delirium. <p><i>Goal: reduce stress from hallucinations and delusions</i> <i>Cannot imagine any feasible/legal approach to actually addressing the hallucination since that would involve the administration of psychotropic medication such as anti-psychotics or strong sedatives; moreover this class of medication should generally be administered in a controlled environment since they have powerful side-effects that effect balance and attention.</i></p>	<p>Technology Opportunities</p> <p>Help client understand that they are not in any danger then call appropriate parties</p> <ul style="list-style-type: none"> • If ILSA detects agitation then system could ask what is wrong, then system could scan house for signs or an intruder then reassure them there is noone in the house (this brings up possible complications since the system has now confirmed that the person is hallucinating) • Then ILSA could call the appropriate party who could intervene to calm the client • ISLA could then log the event <p>Application of Snoezelen technique</p> <ul style="list-style-type: none"> • Sensory stimulation technique that has been successful in calming children via multi-sensory stimulation. Indications are that this technique is effective in reducing agitation in those suffering dementia. Application includes: light therapy, essential oils, soft chair, wind chimes, lava lamps, etc. While having a Snoezelen room may not be practical, applying these techniques in part in the room of the agitated client might be helpfu in reducing their agitation until a caregiver can intervene. • See http://www.vigil-

	inc.com/news/newsletters/jan2001.htm#3
Sources Interviews with family caregivers. Dementia: Management of Behavior Problems at http://www.mayo.edu/geriatrics-rst/Behav.html (Mayo Clinic Geriatric Medicine Division website)	

Appendix

A) Sample Interview Questions

The following questions exemplify the types of queries that were used to initiate discussion and set the stage for probing of issues. Questions were phrased a little differently for each participant type.

- Describe your elder in terms of age, chronic health concerns, and functional limitations.
- What difficulties does your elder have in terms of functioning independently in his/her home?
- What types of activities to you assist with when at your elder's home?
- How often do you communicate with your elder?
- What aspects of your elder's safety do you worry about when you are not with him/her?
- What aspects of caregiving would you like help with?
- Where do you see opportunities for technology to assist with caregiving?

B) Supportive Services

Service	% Utilized
Acquiring a wheel chair, walker or other device	46.7
Personal or nursing care service	37.8
Home modification	28.1
Home-delivered meal services	15.6
Assistance with housework	15.6
Financial information service	15.5
Transportation service	14.9
Respite care	14.1
Adult day care/senior center	9.5
Support group	6.6

Source: Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons at www.caregiving.org/reports/nacanalysis.pdf

C) Level of Care

Level	Description	% of all caregivers
1	No support for personal care such as dressing or bathing; no more than 8 hours per week. Caregivers average 3.6 hours per week.	25.8
2	Caregivers average 8.2 hours per week.	13.8
3	Caregivers average 9.1 hours per week.	19
4	Caregivers average 27.3 hours per week.	23.5
5	Assist with at least 2 personal care activity for more than 40 hours per week. Caregivers average 56.5 hours per week.	12.3

Source: Family Caregiving in the U.S. 1997. Final Report. National Alliance for Caregiving and American Association of Retired Persons at www.caregiving.org/reports/nacanalysis.pdf