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Connecticut Long-Term Care Needs Assessment

The Connecticut Long Term Care Ombudsman Program:

Part I: A National Perspective
Part II: The Experiences of Supportive Housing Residents

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Part I: The Connecticut Long Term Care Ombudsman Program – A National Perspective

I. General Overview

The Long Term Care Ombudsman Program (LTCOP) in the State of Connecticut was established by Congress in Section 307a-12 of the Federal Older Americans Act of 1965 and authorized by the Connecticut General Statutes, Section 17b-400. In 1978, the federal mandate required all states to create and develop ombudsman programs in order to address the poor quality of care found within long-term care settings and to address specific shortcomings of the nursing home regulatory system (Harris-Wehling, Feasley, & Estes, 1995).

Historically, the Connecticut LTCOP functioned as an investigative unit of Protective Services for the Elderly as well as a regulatory screening unit for the Department of Public Health (DPH). Ombudsmen held the responsibility of addressing reports of abuse and neglect on behalf of older adults, as well as making appropriate referrals to DPH for public health code violations of long-term care facilities (Office of the State LTCOP, 2007). However, the 1992 amendments to the Older Americans Act (OAA) facilitated an important shift in philosophy and focus, calling for the LTCOP to become a more resident-centered program, to provide advocacy services, and to become a community presence within long-term care settings (Cherry, 1993).

Currently under the OAA, Title VII stipulates that the LTCOP must identify, investigate, and resolve individual and systems-level grievances of those residing in long-term care facilities including residential care homes, skilled nursing and assisted living facilities. Though primary responsibilities include investigating and resolving complaints made by constituents, ombudsmen are also responsible for educating residents and families about their rights, providing information and resources regarding various long-term care services, as well as lobbying for program initiatives in state and federal government forums.

The mission of the Connecticut LTCOP is to protect the health, safety, and rights of long-term care consumers by supporting clients' rights to self-determination. This is accomplished by providing prompt and timely investigation of complaints; supporting resident and family councils in long-term care facilities; disseminating pertinent information and resources regarding options for long-term care; and representing resident interests in shaping legislative agendas (Office of the State LTCOP, 2007).

II. Funding and Program Structure

All state LTCOPs receive federal funding under Titles III and VII of the OAA (via the State Unit on Aging), and most receive additional funding at the State and local levels (Estes, Zulman, & Ogawa, 2004). At the state level, the Connecticut LTCOP receives financial support from the General Fund under the umbrella of the Department of Social Services (DSS) to meet the maintenance of effort requirements under Title III of the OAA (Office of the State LTCOP, 2005a). In the fiscal year 2005, CT Ombudsman Program expenditures totaled $1.15 million, utilizing approximately 31% of federal funds under the OAA (Department of Health and Human Services, 2005) and 69% of State General Fund monies.

In 1999, Public Act 99-176 was passed, amending Section 17(b)-400 of the general statutes and making the LTCOP an independent office in DSS, with the State Ombudsman having direct access to the Commissioner of the Department of Social Services. Because the Program is

independent within DSS, the State Ombudsman has complete responsibility over the Program's administration, operation, and budget, and oversees all employees associated with the Program. The Program is monitored and physically located at the Commissioner's level (as opposed to the State Unit on Aging) in the Central Office of DSS with Regional Ombudsmen and support staff also co-located in regional DSS operations (Office of the State LTCOP, 2005a).

The Office of the State Long Term Care Ombudsman directly employs and supervises all paid and volunteer staff. The State and Regional Ombudsmen are hired competitively according to Connecticut State employment guidelines and practices. The program is composed of one State Ombudsman, nine Regional Ombudsmen, four clerical staff, and approximately 60 Volunteer Resident Advocates (see Table I-1). Regional Ombudsmen are accessible in offices located throughout three sub-divided regions of Connecticut – Western, Northern, and Southern (Office of the State LTCOP, 2007).

One of the most successful and efficient functions of the Connecticut LTCOP is the utilization of Volunteer Resident Advocates. Historically, recruitment efforts have included publicizing volunteer opportunities via mass mailings sent to constituents of AARP as well as current and retired CT State employees, Infoline, a variety of media outlets including radio, cable and newspaper / shopper circulars, the Connecticut LTCOP website as well as word-of-mouth.[1] Volunteer Advocates come from various age, educational, and professional backgrounds. Each certified volunteer completes a comprehensive five-day training program and attends monthly in-service meetings with the Regional Ombudsman staff (Office of the State LTCOP, 2007). Under the supervision of the Regional Ombudsmen, volunteers spend approximately four hours per week in an assigned long-term care facility addressing concerns and resolving complaints of LTC residents, friends and families of residents, as well as facility staff and administrators acting on behalf of residents. Volunteer Advocates also work in collaboration with the State and Regional Ombudsmen on periodic self-assessments and quality assurance projects to strengthen all phases of the advocacy process (Office of the State LTCOP, 2007).

Table I-1. Connecticut LTC Ombudsman Program – staff members and volunteers

State Level*			**Regional or Local Level**			**Total for State**		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
1.00	1.00	60.00	9.00	3.00	N/A	10.00	4.00	60

*Number of staff members/volunteers

**Paid program staff

National Ombudsman Reporting System Data Tables, 2005

[1] Personal Communication via e-mail with Nancy Shaffer (Connecticut Long Term Care Ombudsman), on September 10, 2007.

III. Service Provision

The Connecticut LTCOP serves all residents of long-term care facilities including skilled nursing facilities and residential care homes (see Table I-2). More recently, the Program was authorized to expand services into assisted living communities within available appropriations via a pilot program in 2004 under Public Act 04-158, *An Act Concerning Services Provided by the Long Term Care Ombudsman in Managed Residential Communities and the Patients' Bill of Rights for Residents of Nursing Homes and Chronic Disease Hospitals* (Office of the State LTCOP, 2005a). The LTCOP is separate from ombudsman services provided by the Department of Developmental Services (DDS), the Department of Mental Health and Addiction Services (DMHAS), the Managed Care Ombudsman (located in the Department of Insurance), the Department of Corrections (DOC) as well as advocacy services provided by the Office of Protection and Advocacy, the Victim Advocate or the Child Advocate.

Table I-2. Connecticut licensed LTC facilities

Licensed Nursing Facilities			**Licensed Board & Care***			**Total LTC Facilities**	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
247	29,774	121	257	8,639	34	504	38,413

* Includes Assisted Living and Residential Care Homes
** Average number of beds per facility

Nancy Shaffer, Connecticut State LTC Ombudsman, 2007; National Ombudsman Reporting System Data Tables, 2005

The LTC Ombudsman Program investigates complaints that are typically received by Program Volunteers during their weekly visits or by telephone reporting from many different sources including residents, family members, and facility staff. Once a complaint is received, pertinent information is noted and reviewed by the Regional Ombudsman and/or volunteer who, in turn, verify any request for interventional services. Subsequently, such a request is investigated, resolved, and/or referred to other appropriate agencies such as DPH, DSS, DMHAS, DDS or an appropriate legal representative depending on the specifics of the case.

Currently, the Connecticut LTCOP does not provide direct legal services for consumers. However, over the years due to the nature of its work involving complaint resolution, the CT LTCOP has requested advice from, collaborated with, and referred cases to a variety of available legal resources depending on the issues/concerns. As such, the LTCOP maintains both formal and informal relationships with the: Attorney General's Office; Chief State Attorney's Office; Department Legal Counsel and Elderly Legal Services Developer; the Connecticut legal services network; Center for Medicare Advocacy; Federal and State Court Systems such as the Criminal, Probate and Bankruptcy Courts, as well as private attorneys/conservators. Additionally, periodic meetings are held with these stakeholders to consider systemic issues/concerns and provide staff trainings.

In addition, residents of nursing homes, residential care homes, as well as assisted living (dependent on income level) are often referred to the non-profit legal services network for individual legal counseling needs. These organizations offer additional resources that are available to LTC residents. From fiscal years 2004 to 2006, the LTCOP collaborated with these entities on a number of legal issues/concerns. Ombudsman activities have also included providing information/consultations regarding these services as a community resource. In addition, when the LTCOP is unable to resolve a case on behalf of a resident, an LTCOP

referral is made (in FY 2005, twelve LTCOP referrals were made).[2] Both the State Long Term Care Ombudsman and a representative from the Legal Assistance Resource Center (the association for Connecticut legal services agencies[3]) serve on the Connecticut Long-Term Care Advisory Council to continuously advocate and promote legislation related to long-term care policy in the State.

Residents are also educated about their rights and advocacy services upon admission. Ombudsman services are publicized through a number of community education efforts including media presentations, senior fairs, community forums, pamphlets/ brochures and other marketing materials; regular Volunteer Advocate visits; facility postings; social workers; Resident Councils; Family Councils; as well as the VOICES Forum – an annual statewide meeting of nursing home residents to discuss current quality of care/life concerns and best practices to promote systemic public policy and advocacy issues.

The annual VOICES Forum is sponsored by the Office of the Connecticut LTCOP, the Statewide Coalition of Resident Councils, and co-convened by the State of Connecticut DSS. This is the only such Forum of its kind in the nation. As a large bloc of voting constituents, residents of long-term care facilities invite public officials and political leaders to discuss policy and legislation affecting long-term care service provision. Each year, the Carol Rosenwald Award is presented to recognize individuals/organizations who have shown the "Spirit of Advocacy" on behalf of residents. In the past, a number of individuals/organizations including legislators, a Bankruptcy Court judge, as well as the Connecticut legal services network, have received the Carol Rosenwald Award.

In 2005, more than 200 individuals representing 75 long-term care facilities attended the VOICES Forum along with representatives from the Connecticut General Assembly, Commission on Aging, Area Agencies on Aging, AARP, DSS, and DPH (Office of the State LTCOP, 2005b). Over the years, legislative concerns have included staffing (levels, training, supervision and criminal background checks) to ensure safety and full implementation of resident care; as well as improving quality of life for residents with better access to transportation, community involvement, and weekend activities (Office of the State LTCOP, 2005b).

At this ninth annual VOICES Forum, a noteworthy concern raised by constituents was a *fear of retaliation* in long-term care facilities if residents complain about their care or other aspects of the environment in which they reside, thus limiting complaint reporting and resolution. Note, a month later, *Fear of Retaliation* was also raised at the 30th annual meeting of the National Coalition of Citizens for Nursing Home Reform by a Washington State Resident Council group as Resolution No. 4, To "Strengthen Resident Councils…without FEAR OF RETALIATION".

As a result, VOICES 2006 included a workshop specific to this concern. Most recently, in 2007, a Statewide Workgroup has been convened by the CT LTCOP to continue to address this issue. The survey of residents in long-term care settings described in Part 2 of this report included a question on Fear of Retaliation.

[2] Personal communication via e-mail with Nancy Shaffer (Connecticut Long Term Care Ombudsman), on May 14, 2007.

[3] In addition to the Legal Assistance Resource Center, the legal services system in Connecticut consists of Connecticut Legal Services, Inc., Greater Hartford Legal Aid, New Haven Legal Assistance Association, and Statewide Legal Services.

IV. 2005 Complaint Statistics and Key Issues Addressed

In fiscal year 2005, the Connecticut LTCOP investigated a total of 1,527 complaints, up from 1,461 cases handled in 2004. Since the incipience of the program, there has been a steady increase in the number of cases handled each year. Analysis of 2005 trends reveals that approximately 57% of those reporting complaints are residents themselves and 30% are relatives and/or friends of residents. A majority of complaints come from nursing homes, which account for 97% of all complaints, with complaints from Assisted Living and Resident Care communities accounting for 3% of total complaints (Office of the State LTCOP, 2005a). Major areas of concern for all facilities have been in the following areas: Residents' Rights (612 cases), Resident Care (533 cases), and Quality of Life (296 cases).

Figure I-1. Who reports complaints

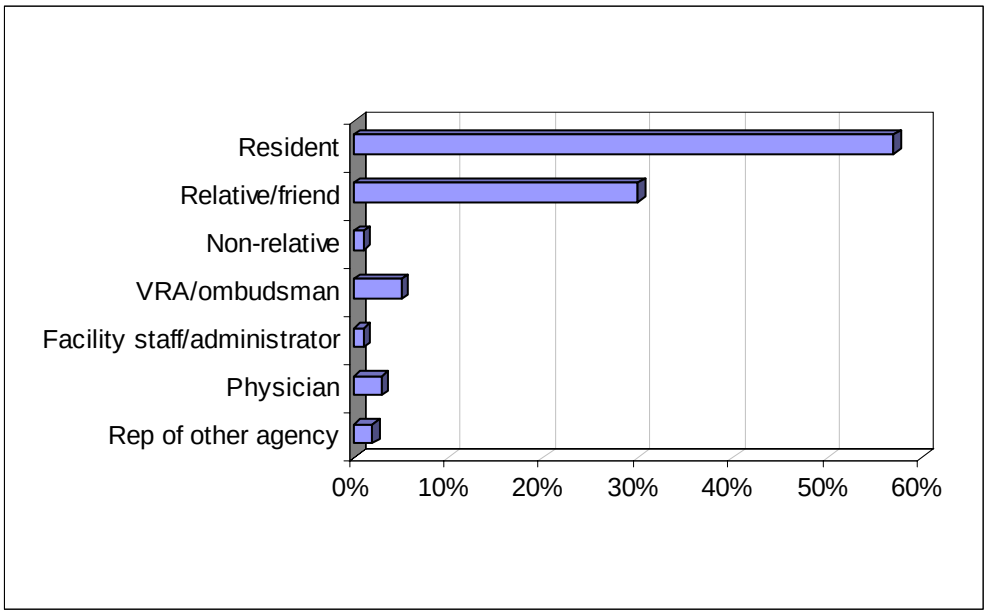


Figure I-2. Complaints by category

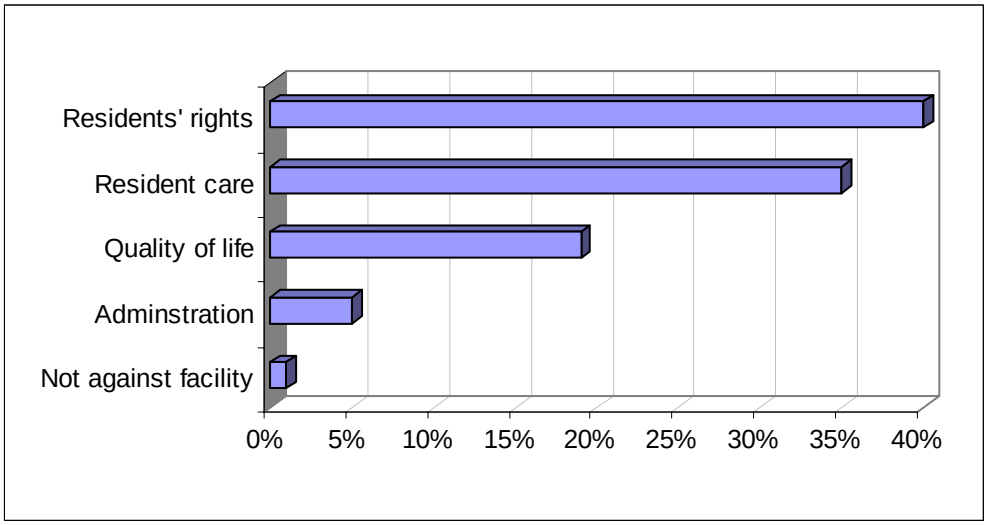

Residents' rights
Resident care
Quality of life
Adminstration
Not against facility
0%
5%
10%
15%
20%
25%
30%
35%
40%

Table I-3. Number of complaints for fiscal year 2005

	Nursing Facilities	Residential Care / Assisted Living
RESIDENTS' RIGHTS		
Abuse, Gross Neglect, Exploitation	37	5
Access to Information	58	2
Admissions, Transfer, Discharge	210	15
Autonomy, Choice, Exercise of Rights, Privacy	186	8
Financial, Property	83	8
RESIDENT CARE		
Care	403	11
Rehabilitation, Maintenance of Function	111	1
Restraints (Chemical/Physical)	7	0
QUALITY OF LIFE		
Activities and Social Services	68	1
Dietary	107	5
Environment	114	1
ADMINISTRATION		
Policies, Procedures, Attitudes, Resources	20	1
Staffing	53	3
NOT AGAINST FACILITY		
Certification/Licensing Agency	1	0
State Medical Agency	3	0
Systems/Others	5	0
TOTAL	1466	61

Office of the State Long Term Care Ombudsman (2005a).

In 2005, the Office of the Ombudsman was also involved in addressing several current policy issues including educating consumers regarding the Prescription Drug Plan (Part D) of the Medicare Modernization Act, and reviewing emergency disaster procedures for long-term care residents in the aftermath of Hurricane Katrina (Office of the State LTCOP, 2005a). The Connecticut LTCOP also had the challenge of managing an increase in the level of responsibilities with inadequate support staff brought on by the expansion of the ombudsman program into assisted living communities. The Office of the Ombudsman sponsored and planned four major events in 2005: the Statewide Volunteer Resident Advocate Training Conference, the Connecticut Workgroup on Challenging Behaviors Training Conference; the IX Annual VOICES Forum; and the Community Education Forum to educate consumers on the Medicare Modernization Act and the Prescription Drug Plan (Office of the State LTCOP, 2005a).

On a public policy level, the Connecticut LTCOP provided testimony to over thirty legislative proposals before the CT General Assembly on behalf of long-term care consumers in 2005. Testimony included public funding for nursing home residents' non-medical transportation.

At the national level, the LTCOP supported public policy initiatives including passage of an *Elder Justice Act* along with a proposal requiring nursing home sprinkler systems and participated in the CT Coalition on Aging's Carlson Forum to gather input for the upcoming White House Conference on Aging. Finally, LTCOP efforts in a joint federal-state investigation culminated in a US Department of Justice press release in May 2005 related to the most serious case of its kind in State history. Both the US Attorney as well as the CT Attorney General noted "The egregious quality of care problems found in this case were inexcusable…truly a healthcare atrocity – abusing its most vulnerable elderly patients, as well as the public trust" (Office of the State LTCOP, 2005a).

V. Organizational Placement and Conflict of Interest

The Administration on Aging (AoA) encourages variability and flexibility in organizational placement, program approach and operation, as well as utilization of human resources in implementing the ombudsman program. This results in 52 distinct and multifaceted programs across the states including District of Columbia and Puerto Rico (Netting, Paton, & Huber, 1992; Harris-Wehling et al., 1995). The variability in structures and organizations leads to difficulties in accurately depicting comparable markers for program success and in comparing data across state settings. However, research consistently suggests that successful ability to carry out program duties largely rests on the autonomy of individual ombudsmen and their state programs (Harris-Wehling et al., 1995; Estes et al., 2001; Estes, Zulman, Goldberg, & Ogawa, 2004; & National Association of State Long Term Care Ombudsman Programs [NASOP], 2003). The ensuing debate questions whether the placement of a program within a state agency is more effective when compared to a program that is fully independent from the State (Estes et al., 2001).

Currently, a large majority of state ombudsman programs continue to be a part of their State Unit on Aging (SUA) (71%). Of these, 39% are in an independent SUA, 17% are within umbrella agencies that include licensing and certification, and 16% are in agencies that do not oversee licensing and certification (Estes et al., 2004).

> "There is a potential conflict of interest simply being in state government, in the department. We are not necessarily able to speak freely on behalf of residents. If the department has a policy that the LTC ombudsman feels may be detrimental, the ombudsman might be instructed not to say anything in court."
>
> - A State Ombudsman
> (Not a CT State Ombudsman)

In the State of Connecticut, the LTCOP receives its federal funding through the State Unit on Aging housed under the auspices of the DSS, an umbrella agency that includes Medicaid reimbursement to long-term care facilities (Miller & National Association of State Units on Aging [NASUA], 2003). To prevent a conflict of interest, a Memorandum of Understanding reflects the relationship of the CT LTCOP at the public policy level with the DSS Commissioner and further establishes the independence of the Program to speak freely on behalf of residents as reflected in public testimony and in court proceedings. Further, the CT LTCOP is physically housed at the Commissioner's level of the DSS Central Office, for monitoring/accountability purposes only, and not under the State Unit on Aging nor the Medicaid Unit.[4]

A 1997 program review concluded that there was no evidence of conflict of interest in the CT LTCOP structure (Weiner Associates, 1999). Many programs located within their SUA perceive that relocation of the LTCOP outside of the SUA can diminish support. Some benefits received by these programs include financial support, administrative support, access to information and referral resources in the aging network, advocacy for the program, technical assistance, legal assistance, supervisory support, continued professional training, utilization of facilities, as well as supplies and clerical support (Huber, Netting, & Kautz, 1996; Estes et al., 2001).

[4] Personal Communication via e-mail with Nancy Shaffer (Connecticut Long Term Care Ombudsman), on February 24 and September 6, 2007.

Figure I-3. Organizational placement of Ombudsman Programs at the state level

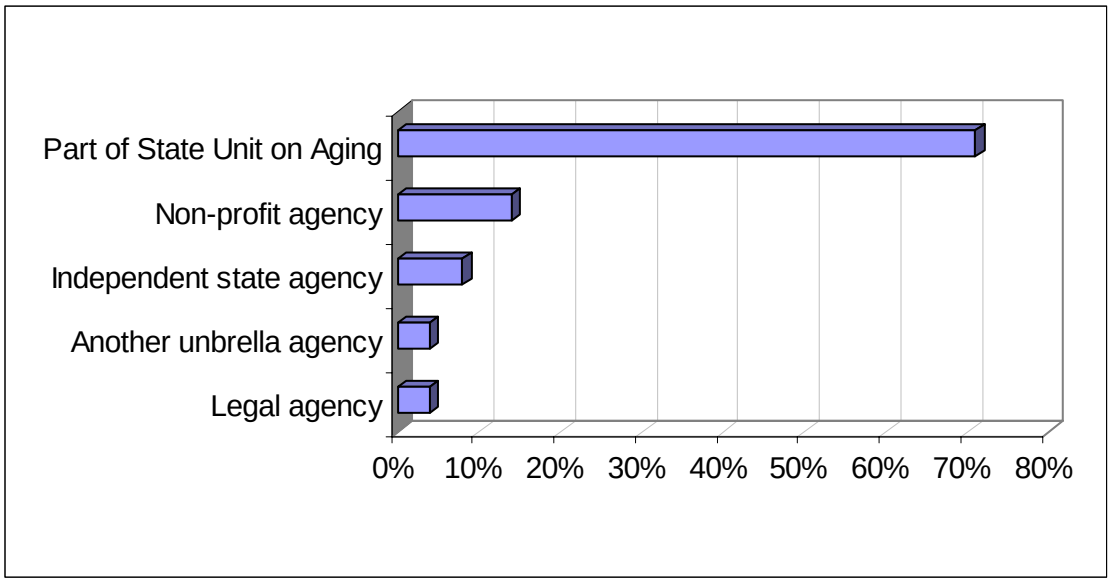


Table I-4. Location of the Ombudsman Programs at the state level

State	In state government				Outside state government			
	In State Unit on Aging (SUA)		Outside State Unit on Aging (SUA)					
	Independent SUA	SUA in umbrella agency	Outside SUA but in umbrella agency that includes SUA	Other state agency	Legal Services agency	Independent Ombudsman agency	Citizen Advocacy agency	Other
Alabama	X							
Alaska				X				
Arizona		X						
Arkansas		X						
California		X						
Colorado								X
Connecticut		X						
Delaware		X						
District of Columbia					X			
Florida	X							
Georgia			X					
Guam					X			
Hawaii		X						
Idaho	X							
Illinois	X							
Indiana		X						
Iowa		X						
Kansas						X		
Kentucky		X						
Louisiana	X							
Maine						X		
Maryland	X							
Massachusetts	X							
Michigan	X							
Minnesota		X						
Mississippi		X						
Missouri			X					

State	In state government				Outside state government			
	In the State Unit on Aging (SUA)		Outside the State Unit on Aging (SUA)					
	Independent SUA	SUA in umbrella agency	Outside SUA but in umbrella agency that includes SUA	Other state agency	Legal Services agency	Independent Ombudsman agency	Citizen advocacy agency	Other
Montana		X						
Nebraska		X						
Nevada		X						
New Hampshire	X							
New Jersey			X					
New Mexico	X							
New York		X						
North Carolina		X						
North Dakota		X						
Ohio	X							
Oklahoma		X						
Oregon						X		
Pennsylvania	X							
Puerto Rico	X							
Rhode Island							X	
South Carolina		X						
South Dakota	X							
Tennessee	X							
Texas		X						
Utah		X						
Vermont					X			
Virginia								X
Washington								X
West Virginia	X							
Wisconsin				X				
Wyoming							X	

Outside State Government – Other

Colorado: Protection & Advocacy Agency
Virginia: AAA Association
Washington: Community Action Agency

Miller and NASUA, 2003

Ombudsman programs structurally housed within their SUA can yield to organizational conflict of interest impeding the ability of LTCOPs to freely advocate for their constituents (Harris-Wehling et al., 1995; Estes et al., 2001; Estes et al., 2004). More than 54% of ombudsmen state that placement of their program under the SUA presents constraints in effectively carrying out their duties mandated by the OAA. Additionally, 62.2% of LTCOPs within an SUA and 60% of those in other state agencies reported that their placement created difficulties for service provision, compared to only 22.2% of contracted independent agencies (Estes et al., 2004). Ongoing challenges include:

- Bureaucratic restrictions placed on ombudsmen when speaking to legislators and the media
- Political implications in legislative advocacy
- Ability to conduct objective and independent investigations of complaints
- Uncooperative relationships with regulatory agencies due to lack of enforcement authority

Research suggests that programs should operate in settings where independence is maximized. This includes a location outside state government in an independent advocacy organization, in a government entity without LTC regulatory responsibilities that is directly accountable to the governor, or in an independent state commission (Harris-Wehling et al., 1995). Findings from the NASOP Retreat in 2003 further support these recommendations by suggesting that a LTCOP should not be located in an agency or entity in government whose head oversees:

- Licensure, certification, registration, or accreditation of LTC residential facilities
- Reimbursement rate setting for LTC services
- Management or ownership of a LTC facility
- Preadmission screening and decisions regarding LTC residential placements
- LTC case management
- Provision of LTC services including Medicaid waiver programs
- Medicaid eligibility determination
- Adult Protective Services
- Guardianship services

Regardless of a program's organizational placement, all LTCOPs should continue to work on improving communication and relationships with other state entities including SUA administration as well as licensing and regulatory agencies to ensure that all parties clearly understand the roles, responsibilities, and capabilities of ombudsmen (Estes et al., 2001). The Office of the LTCOP in the State of Connecticut should also continue collaborating on cases with the Connecticut legal services network and should discuss possibilities in building a more formal alliance, which may further aid in resolving issues related to conflict of interest. Though various programs function according to different philosophies and mandates, all share the same goal of assuring quality care for long-term care residents; and collaboration of LTCOP with other agencies will enhance the capacity to continue this process.

VI. Expansion of Program: Home and Community-Based Services

In addition to providing services in long-term care facilities, the Office of the Ombudsman in 13 states[5] also offer advocacy services to residents within HCBS including Medicaid service and state-funded programs, private pay services, and other specialized services such as adult day care settings (Miller & NASUA, 2003). Details of six states' programs are presented in the State Profile Pages section below. Currently, the Connecticut LTCOP does not serve residents receiving home and community-based services (HCBS). However, the expectation of the ombudsman program in advocating for quality of services across the spectrum of long-term care, including HCBS, is consistent with the program's philosophy and responsibility (Miller & NASUA, 2004).

> "There are many clients that the program comes into contact with who want to be at home. In order to advocate for them, an ombudsman must know what the HCBS sector is and be able to make those connections. This knowledge of the HCBS network is necessary whether or not the ombudsman program also covers HCBS."
>
> - Former Minnesota State Ombudsman

Ombudsmen in programs providing services to HCBS consumers state that their work and responsibilities are formed from a natural alliance between HCBS networks and LTC residents involved in nursing home transition initiatives, as well as those who desire to return to their own homes and communities (Miller & NASUA, 2004). With a core responsibility to provide resources for long-term care consumers regarding care options, ombudsmen are already equipped with a wide range of knowledge needed to provide education to HCBS consumers. Additionally, the skills utilized in investigating, mediating, and resolving consumer complaints are similar across settings (Miller & NASUA, 2004). According to the 1995 report by Harris-Wehling and colleagues, ombudsmen in HCBS focus on providing services in five general categories of rights:

1) *Informational rights*: The consumer must be aware of the extent of performed services, charge for services, admission and discharge policies, as well as the contract for services.

2) *Participation and control rights:* Consumer's choice and autonomy must be protected. The consumer should be allowed to participate in care plan decisions, selection of providers, and option to refuse treatment or care.

3) *General civil rights and protection:* These rights reaffirm treating consumers with dignity, having privacy and confidentiality in treatment and medical record keeping, as well as the right to be free from physical or chemical restraints.

4) *Remedial rights:* The consumer should be free to complain without the fear of reprisal and should be informed of the complaint process.

5) *Quality rights:* The consumer should expect safe and professional care in order to obtain the maximum state of health in his or her condition. Care providers are responsible for being punctual, trained, and professional.

Similar to publicity efforts to reach residents of LTC facilities, most expanded LTCOPs utilize posters, newsletters, public service announcements, publicized hotlines, and public speaking

[5] Alaska, California, Idaho, Maine, Maryland, Minnesota, New Jersey, Ohio, Pennsylvania, Rhode Island, Texas, Wisconsin, and Wyoming.

engagements to advertise their services to clients. Generally, most complaints have been related to access to care and quality of care within home care settings and are typically handled over the telephone (Miller & NASUA, 2004). However, some states including Maine, Minnesota, and Ohio provide professional training in home care advocacy to ombudsman program staff and perform periodic home visits (Bridges, Miller, Dize, & NASUA, 2001).

While each state differs in program scope and responsibility, having financial and professional resources specifically allocated for home care advocacy is crucial to successfully providing services in home and community-based settings. Research by Harris-Wehling et al. (1995) and Miller & NASUA (2003) reveals that many programs face budgetary constraints and have received little to no additional funding or staff to carry out their full responsibilities in HCBS settings. Thus, many programs such as Alaska, Indiana, and Virginia limit the HCBS settings in which ombudsman services are provided. The LTCOP in the State of Colorado previously handled complaints in Medicaid funded HCBS settings under an informal agreement with their SUA, but has discontinued doing so since 1999 (Bridges et al., 2001).

Furthermore, data trends of complaint records reveal that most LTCOPs with expanded ombudsman services have not been well-utilized. All expanded ombudsman programs, including the most successful such as those in Maine, Minnesota, and Rhode Island, reveal that the number of HCBS complaints received is minimal in comparison to those received from LTC facilities. Typically, less than 5% of complaints handled by expanded LTCOPs relate to home care (Bridges et al., 2001). However, Harris-Wehling et al. (1995) suggests that the small number of reported complaints is indicative of the challenges posed by limited funding and staff, which results in restricted implementation and outreach of the program.

Before implementing an expansion of the LTCOP, the program must be given full legislative authority to investigate complaints and be instructed on guidelines regarding the scope of this responsibility. It is recommended that state ombudsmen staff be actively involved in the process of developing policies, procedures, and regulations in establishing the program to ensure efficiency and best practices. Furthermore, adequate funding must be established to expand the program, as financial resources currently authorized for the LTCOP under the OAA do not allow for its utilization in home and community-based settings (NASUA, 2001). All efforts must be taken to guarantee that expansion into HCBS will not diminish the quality of existing services for residents in LTC facilities.

Tables I-5 and I-6. Checklist and considerations for Long Term Care Ombudsman Program Expansion into Home Care Settings[6]

Essential Components of a Successful Home Care Ombudsman Program

☑ **Funding:** Establish specific, sufficient additional funding to expand the program so that expansion does not dilute ombudsman services to residents of long-term care facilities and to provide ongoing support for home care advocacy.

☑ **Authority:** Enact legislation giving specific authority to the Long Term Care Ombudsman Program to investigate home care complaints and define the scope of that responsibility (e.g., all home care services or only publicly-funded home care).

☑ **Systems Advocacy**: Ensure ombudsman involvement in developing home and community-based services regulations and policies.

☑ **Consumer Information**: Require (either legislatively or through regulations) that home care consumers be given information about ombudsman program and advocacy services in home care.

Other Considerations for Expanding Ombudsman Programs into Home Care

☑ **Scope:** Determine the scope of the ombudsman's responsibilities.
Examples include:

- Advocating for individuals and/or systemic issues
- Quality assurance role
- Advisory role
- Only state/federally funded programs
- All home care agencies (licensed and unlicensed)

☑ **Staff/Training:** Determine whether there will be designated staff for home care or if all staff will be cross-trained to handle home care complaints.

☑ **Conflicts of Interest:** Consider possible conflicts of interest, especially where ombudsmen are located in agencies that also provide or administer home care services and take steps to remove any conflicts that are identified.

Prepared by the National Association of State Units on Aging, 2001

[6] Funds authorized and/or appropriated under the Older Americans Act for the Long Term Care Ombudsman Program may not be utilized for ombudsman services in settings other than those included in the program as defined by the act: nursing homes, board & care homes, and similar adult care facilities [Section 102(a) (34)]. This includes Title III funds taken "off the top" by the state under Section 304(d)(1)(B); Title VII, Chapter 2 ombudsman funds and state and other funds included in the required minimum funding levels under Sections 307(a)(21) and 306(a)(11) of the Act. (See AoA PI 94-02, issued April 5, 1994.)

VII. Conclusions and Recommendations

Providing a unique complement to the role of nursing home regulatory agencies, ombudsman programs have become a significant community presence in long-term care facilities. Over the years, amendments to the Older Americans Act have increasingly strengthened the role of the LTCOP. It is anticipated that this trend will continue, as seen in the reauthorization of the OAA in 2006 (Netting et al., 1992).

Though the variability in structure, organization, and operation of state LTCOPs results in difficulty assessing comparable markers for success and outcome measures across programs; research consistently stresses the importance of organizational autonomy (Harris-Wehling et al., 1995; Estes et al., 2001; Estes et al., 2004; National Association of State Ombudsman Programs, 2003). Due to issues related to potential conflict of interest, it is recommended that the LTCOP not be located under the SUA or in a state department with LTC regulatory responsibilities. At a minimum, however, the LTCOP must recognize and discuss the implications of program placement, as well as identify and assess areas in which the program can be strengthened, given the current placement and structure (Huber et al., 1996).

- **The Connecticut LTCOP should maintain its current structural location as an independently functioning unit within the Department of Social Services.** The existing structure of the program allows the LTCOP staff to perform their duties without conflicts of interest. Yet, the ongoing connection to the State Unit on Aging through funding and co-location within DSS facilitates collaboration and shared resources between these programs.

- **The Connecticut LTCOP should continue to enhance collaboration and coordination with the SUA; legal assistance groups; as well as other protection, licensing, and certification agencies, due to the multidisciplinary and interrelated nature of their work**. As advocates for long-term care consumers, ombudsmen have the critical roles of mediating complaints between individuals and facilities; educating consumers on LTC services including facility placement and HCBS; as well as lobbying for LTC policies in government forums. Though these various programs operate from differing perspectives, philosophies, and regulations, all share a similar agenda of ensuring safety and quality of care for LTC consumers; and collaboration among agencies is important in carrying out this agenda.

- **Empower the CT LTCOP with specific legislative authority and funding to expand into HCBS.** HCBS continues to expand to provide an increasing number of CT residents with long-term care outside of institutions. The LTCOP plays a critical role in ensuring consumer safety and rights in HCBS settings in other states. This is a critical service that should be available to CT residents using state-funded HCBS.

- **Ombudsmen should be active participants in drafting program policies, regulations, and procedures for services provided to HCBS clients**. Systems advocacy is an essential component to development of LTCOP involvement in HCBS and the LTCOP staff should be involved at every step.

- **If HCBS expansion goes forward, the LTCOP will need to define eligibility of potential clients, as well as jurisdiction and service boundaries in relation to other state agencies such as Adult Protective Services, legal services agencies, and the DDS ombudsman.**

- **Ensure that expansion into HCBS will not dilute pre-existing LTCOP services in LTC facilities.** LTCOPs in states which include HCBS in their purview, but did not receive increased financial and staffing resources with this expansion have been operating within a limited program scope due to insufficient financial resources. New and adequate funding must be attached to program expansion into HCBS.

- **Conduct an in-depth analysis of the adequacy of CT LTCOP staffing at state and regional levels to meet residents' individual needs and conduct necessary systems advocacy.** As the Program has expanded into assisted living and considers further expansion into the HCBS arena, a detailed understanding of necessary staffing levels throughout the State is needed.

VIII. State Profile Pages

The organization, program scope, and service provision differs by state. The following profiles of the LTCOPs in six states (Alaska, Maine, Minnesota, Ohio, Rhode Island, and Wisconsin) illustrate both the similarities and differences between states.

Alaska

The Office of the Long Term Care Ombudsman in the State of Alaska is located within state government outside the State Unit on Aging, under the Department of Revenue (Miller & NASUA, 2003). Previously, the LTCOP was located in the Department of Administration, which was also responsible for licensing and certification of nursing homes and assisted living facilities. Due to a conflict of interest, the LTCOP was moved to the Department of Revenue, and is no longer under the auspices of a government agency which handles licensing and certification of facilities, adult protective services, or other long-term care responsibilities (Bob Dreyer, Alaska State Ombudsman).

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
3	0.5	4	N/A	N/A	N/A	3	0.5	4

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
15	731	49	200	1,784	9	215	2,515

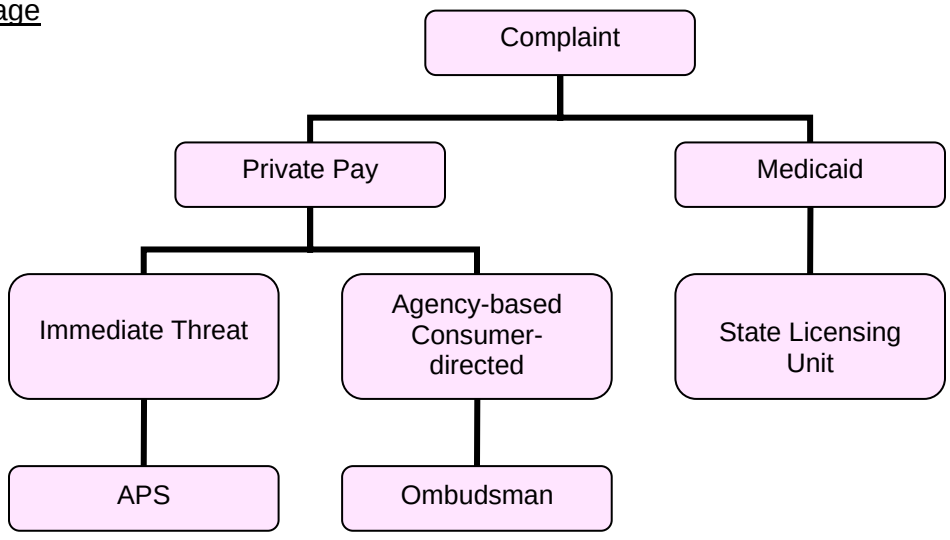
* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

National Ombudsman Reporting System Data Tables, 2005

Program Scope

The LTCOP provides services in all certified Medicare/Medicaid nursing facilities, public and private assisted living communities, state mental health facilities, HUD/public housing, acute care settings, as well as home and community-based settings (Miller & NASUA, 2003). Legislation was enacted in 1988 authorizing the ombudsman to investigate complaints related to LTC or residential circumstances of older Alaskans; however, the LTCOP is not required to do so. Due to the program's financial constraints, home care complaints are limited to those involving individual problems as opposed to systematic issues. Generally, complaints are addressed via telephone, rather than in-person (Bob Dreyer, Alaska State Ombudsman).

Complaint Triage



Bob Dreyer, Alaska State Ombudsman; Bridges et al., 2001

Maine

In the State of Maine, the Long Term Care Ombudsman Program is located outside of state government in an independent ombudsman agency. Thus, there are no conflicts of interest as a result of being structured under a state government agency which handles long-term care responsibilities or protective services (Miller & NASUA, 2003).

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
10.5	1	50	N/A	N/A	N/A	10.5	1	50

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
114	7,350	64	761	10,388	14	875	17,738

* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

National Ombudsman Reporting System Data Tables, 2005

Program Scope

The LTCOP in the State of Maine provides services in all state licensed nursing facilities including non-Medicare and Medicaid certified; private and public residential facilities (Board & Care and assisted living communities); public and private adult foster care; geriatric units in state mental health facilities; as well as HCBS including Medicaid service programs, state-funded and private pay services, as well as other specialized services including adult day health care (Miller & NASUA, 2003).

Home & Community-Based Settings

The LTCOP has had legislative authority to handle home care complaints since 1986. Maine has a higher percentage of reported home care complaints due to legislation requiring dissemination of information to consumers. Most complaints involve reduction, termination, or changes in publicly-funded home care services. The program has a high success rate in resolving home care cases.

Information & Access to Services	State requires consumers be given information about the Ombudsman Program upon entry into home care agencies and when there are any changes in service provision. The LTCOP developed a Public Service Announcement about their services in 2003 and publicizes on television stations.
Staff & Services	There are 2 Registered Nurses (trained Homecare Specialists) on staff to make home visits. Ombudsmen are also available to provide direct representation in home care appeals at administrative hearings regarding termination or reduction of service decisions, or consults with legal services.

Bridges et al., 2001

Minnesota

The Office of the Long Term Care Ombudsman in Minnesota is located under their State Unit on Aging in an umbrella agency. Though this agency is not responsible for licensing and certification of long-term care facilities, one other program responsibility includes Adult Protective Services, which may present a potential conflict of interest (Miller & NASUA, 2003).

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
4	1	N/A	12	N/A	167	16	1	167

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
400	36,366	91	1,098	47,492	43	1,498	83,858

* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

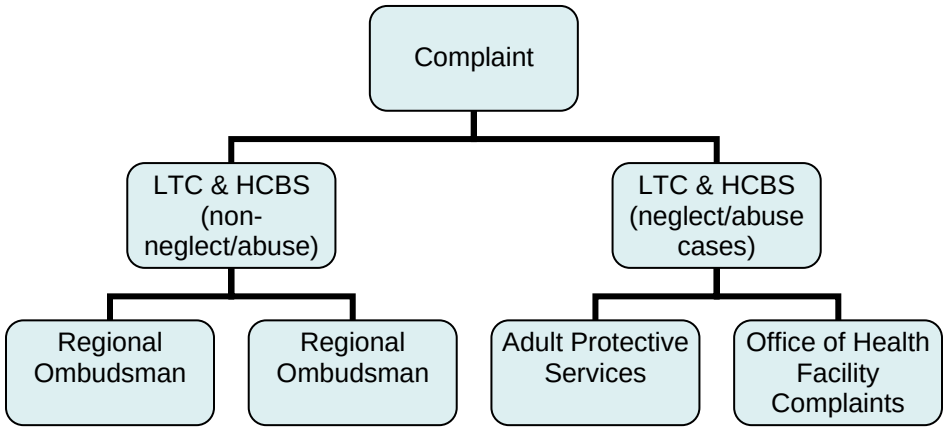
National Ombudsman Reporting System Data Tables, 2005

Program Scope

The Minnesota LTCOP provides services in all state licensed, Medicare/Medicaid certified, and VA nursing facilities; public and private residential facilities (Board & Care and assisted living communities); public and private adult foster care; acute care settings; as well as state-funded and Medicaid serviced HCBS. This includes adult day care, hospice, durable medical equipment, and home-delivered meal services (Miller & NASUA, 2003).

The Home Care Ombudsman Program was created in 1989 through legislation authorizing it as a pilot project. Since then, the program has continued to expand with support and funding. Under the home care licensing law, agencies are required to inform clients about services provided by the LTCOP, specifically when services are being terminated or when service fees are being increased (Bridges et al., 2001)

Complaint Triage



Ombudsmen can and will assist consumers in making reports to Adult Protective Services or to the Office of Health Facility Complaints. Ombudsmen will follow-up and monitor what subsequent actions are taken by the agency and are actively involved throughout the process to assist in appeals and reconsideration of decisions.

Maria Michlin, Office of the Minnesota State Ombudsman; Bridges et al., 2001

Ohio

The Long Term Care Ombudsman Program in the State of Ohio is structurally located in state government, under an independent State Unit on Aging. This agency is not responsible for licensing and certification of long-term care facilities or adult protective services (Miller & NASUA, 2003)

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
7.17	1	N/A	72.5	5.34	506	79.67	6.34	506

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
1,009	98,569	98	1,190	42,795	36	2,199	141,364

* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

National Ombudsman Reporting System Data Tables, 2005

Program Scope

The Office of the State Ombudsman in Ohio provides services in all Medicare/Medicaid certified, state licensed, and VA nursing facilities; public and private residential communities (Board & Care and assisted living facilities); public and private adult foster care; HUD/public housing; and all HCBS including Medicaid service programs, state-funded programs, private pay services, and adult day health care settings (Miller & NASUA, 2003).

Access to Services
The number of home care complaints has risen due to the 1993 *Title III and State Senior Community Services Block Grant* which required providers to inform clients about LTCOP services.
Range of Complaints in HCBS
Any health or social service provided in the home or community care settings including case management, personal care, home health, homemaker or chore services, respite care, home-delivered meals, and physical/occupational/speech therapies.
Staff Training
Ombudsmen are trained on a 100-hour curriculum which includes home care regulations. Staff members have the option of completing the 22-hour provider orientation with a home care provider instead of a LTC facility.
Funding Support
The LTCOP receives both state general revenue funds and monies collected from long-term care bed fees which support the program's advocacy in all long-term care facilities as well as home and community-based settings.

Bridges et al., 2001

Rhode Island

The Long Term Care Ombudsman Program in the State of Rhode Island is located outside of state government in a citizen advocacy agency, the Alliance for Better Long Term Care. This office is a non-profit independent group appointed by the Department of Elderly Affairs, and has housed the LTCOP since 1997. This office is also contracted with the Protective Services Unit in the Department of Elderly Affairs (Miller & NASUA, 2003).

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
10.3	2.25	25	N/A	N/A	N/A	10.3	2,25	25

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
98	9,914	101	67	3,639	54	165	13,553

* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

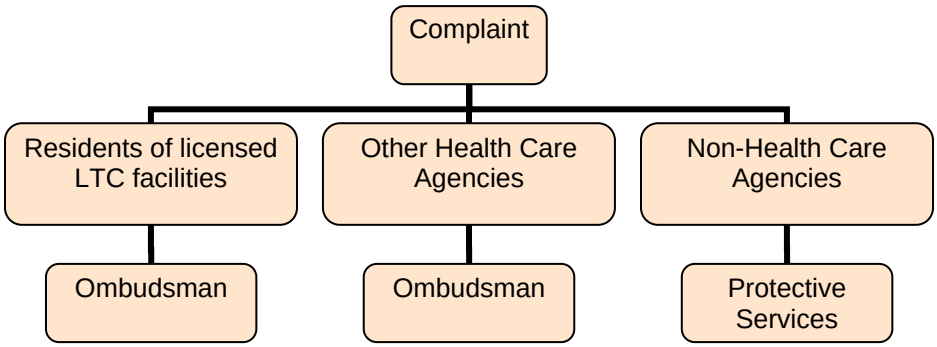
National Ombudsman Reporting System Data Tables, 2005

Program Scope

In the State of Rhode Island, the LTCOP serves residents in all Medicare/Medicaid certified, state licensed, and VA nursing facilities; both public and private residential care settings (Board & Care and assisted living); geriatric units of state mental health facilities; as well as Medicaid service programs, state-funded programs, and private pay services in home and community-based settings (Miller & NASUA, 2003). In 1999, the LTCOP received a legislative mandate to begin providing services to HCBS clients. As of July 1, 2001, the contact information for the ombudsman program has been listed on the *Client Bill of Rights* given to all home care recipients. Funding has supported the expansion into HCBS, as the State of Rhode Island allocates $50,000 per year to specifically support home care efforts (Miller & NASUA, 2001).

Complaint Triage

Complaints are triaged based on urgency. At this time, the number of reported cases from HCBS clients is much less than those from LTC facilities.



Paula Moreau, Office of the Long Term Care Ombudsman, RI

Wisconsin

In the State of Wisconsin, the Long Term Care Ombudsman Program is located in state government, but outside the State Unit on Aging in the Board on Aging and Long Term Care. The agency does not handle any licensing and certification of LTC facilities nor is it responsible for adult protective services (Miller & NASUA, 2003).

Number of Staff & LTC Beds

State Level*			Regional or Local Level			Total for State		
Program**	Clerical	Volunteer	Program	Clerical	Volunteer	Program	Clerical	Volunteer
5	1.25	N/A	16	N/A	146	21	1,25	146

*Number of staff members/volunteers; **Paid program staff

Licensed Nursing Facilities			Licensed Board & Care*			Total LTC Facilities	
Total Facilities	Total Beds	Average Beds**	Total Facilities	Total Beds	Average Beds	Total Facilities	Total Beds
404	39,322	97	2,512	34,777	14	2,916	74,099

* Includes Assisted Living and Residential Care Homes; ** Average number of beds per facility

National Ombudsman Reporting System Data Tables, 2005

Program Scope

The Long Term Care Ombudsman Program in the State of Wisconsin serves residents in nursing facilities including Medicare/Medicaid certified and state licensed; public and private residential care settings (Board & Care and assisted living communities); public and private adult foster care; and HCBS which include Medicaid service programs, state-funded programs, and specialized services such as adult day health care settings (Miller & NASUA, 2003).

In 1999, the legislature gave the LTCOP authority and funding to expand their services into HCBS under the state's managed long-term care pilot program, to managed long-term care recipients. This also included those utilizing the Medicaid waiver (Bridges et al., 2001).

Noteworthy Factors of LTCOP	Challenges of LTCOP
- Located outside the SUA in another state government agency & is independent of any health related agency in state government - Handles complaints from managed long-term care clients - Assists clients with obtaining supplemental insurance with gaps in Medicare coverage through the *Medi-Gap Helpline*	- Only 5% of program's complaints are home care issues - Most of the HCBS complainants are clients of the Medicaid waiver program. - Initial transition of restructuring posed challenges in administration such as budgeting & functioning in politically charged environments

Bill Donaldson, Office of the State Ombudsman, Wisconsin

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Part II: The Experiences of Supportive Housing Residents

I. Introduction

An important component of planning for Connecticut residents' long-term care is an understanding of the experiences and satisfaction of those currently living in different types of supportive housing. The Connecticut Long Term Care Ombudsman Program commissioned this study to better understand the needs of these residents. It will use the results and recommendations for action to enhance their operations and resources to better meet long-term care consumer needs and quality of care and life concerns.

This section of the report presents the findings of the Long Term Care Supportive Housing Resident Survey and includes results from residents of:

- Managed Residential Communities which provide for Assisted Living
- Residential Care Homes
- Skilled Nursing Facilities

A. Background: Supportive housing overview

Assisted living

Assisted living offers extended care options to older adults who may need assistance with ADLs or who have other long-term care needs (Kane & Wilson, 1993; Meyer, 1998). Extensive use of the term assisted living and substantial inconsistency among states in its definition continues to add to the debate about what assisted living is and how it should be regulated (Mollica & Johnson-Lamarche, 2005). Although the name "assisted living" is used in 41 states, a number of different terms are used for the larger residential care settings including: adult care home, assisted living, board and care homes, community-based residential housing, domiciliary care homes, homes for the aged, personal care homes, and rest homes (Hawes, Phillips, Rose, Holan, & Sherman, 2003; Mollica & Johnson-Lamarche, 2005). In addition to a substantial difference in the variety of services offered, there is also a range in the amount of privacy and level of services offered by these supportive housing types that varies from "high privacy and high services" to "low privacy and low services" (Hawes et al., 2003, p. 880).

Assisted living may take place in a licensed setting in which services and supports are delivered, or in a licensed agency that provides services in different types of settings (Mollica & Johnson-Lamarche, 2005). Only Connecticut and Minnesota view assisted living as a service, and license the provider of the service, which may be a different unit from the organization that owns and controls the residential building; other states view assisted living as a building or residence in which health and support services are available and provided (Mollica & Johnson-Lamarche, 2005). Different assisted living models that vary in state licensing and regulatory approaches include: the institutional model, housing and services model, service model, and umbrella model; these approaches occur alone or may be combined. In addition, some states require multiple levels of licensing for a single category. For example, Maryland licenses these residences based on residents' characteristics; categories for low-, moderate-, and high-need residents are based on criteria including functional status, health and wellness, medication and treatment, psychological health, and social and recreational needs (Mollica & Johnson-Lamarche, 2005).

In Connecticut, assisted living is a "managed residential community in which supportive services are provided to residents by an entity that is licensed by the Connecticut Department of Public Health as an Assisted Living Services Agency (ALSA)" (Connecticut Department of Social Services, 2000, p.7). In some cases, the managed residential community (MRC) actually holds the license as an ALSA; in other cases the MRC contracts with an ALSA (Connecticut Department of Social Services, 2000). ALSAs may provide assistance with ADLs, some nursing services and management of medications (Connecticut Department of Social Services, 2000). ALSAs in Connecticut are required to provide an on-site registered nurse 40 hours a week (on call during other times) (Fortinsky, 2006). MRCs are required to provide services such as laundry, transportation, 24-hour security, maintenance and a variety of activities; the individual resident is responsible for paying a monthly rent that includes all of these services (Connecticut Department of Social Services, 2000).

The substantial variability in MRCs stems from the fact that they are largely unregulated, by either state regulations or federal oversight (Assisted Living Quality Coalition, 1998). In Connecticut, most assisted living residences are not covered by Medicaid, making it more difficult for a majority of older adults to consider assisted living a viable alternative to nursing home placement (Bridges, 2002). Nationally, the median rate for assisted living is between $1800 and $2200 per month, however, in Connecticut, the monthly cost can be as high as $5750 (Bridges, 2002). An AARP Assisted Living Survey in Connecticut reports that about half of members are either not at all confident or not very confident that they would be able to afford to live in an MRC for even one year (Bridges, 2002).

Connecticut's affordable assisted living pilots include the moderate and low-income ALSA Demonstration Project (Public Act 98-239 and Public Act 99-279) that allowed for construction of new, stand-alone MRCs through which residents who 1) are age 65 and older, 2) are at risk of nursing home placement, and 3) meet the Connecticut Home Care Program for Elders (CHCPE) financial eligibility criteria receive ALSA services. This project is a joint partnership with the Department of Social Services (DSS), the Department of Economic and Community Development (DECD), and the Connecticut Housing Finance Authority (CHFA). In 2000, the Legislature extended the CHCPE to residents of state-funded congregate housing. This project also represents a joint partnership between DSS and DECD. Authorized by Public Act 00-2 and expanded in scope by Public Act 01-2, the State-Assisted Living Demonstration in Federally Funded Elderly Housing provides assisted living services to residents of certain designated buildings. In addition, the Private Assisted Living Pilot assists a limited number of individuals who have spent down resources while living in private MRCs with payment for assisted living services (this excludes payment for room and board). This pilot authorized 50 individuals eligible for the Medicaid waiver, and 25 individuals eligible for the state-funded levels of the CHCPE. More recently, Public Act 04-258 made it available to 75 individuals without respect to which level of care they qualify for. Currently, there is a large wait list. DSS indicates that MRC participation is very changeable and has not issued an updated list since September 2004.

Residential care homes

Residential Care Homes (RCHs), also known as Rest Homes or Homes for the Aged, are residences for adults whose limitations prevent them from living independently (State of Connecticut, 2006). Although most residents are still older adults, a large and growing percentage of those currently living in RCHs are younger people with mental illness. People living in these supportive housing types may need some assistance with daily activities, special diets and/or medication management. RCHs provide a communal living environment and offer private or semi-private rooms, with private or shared bathrooms, but no nursing services. While

services differ among RCHs, most offer services that include assistance with activities of daily living, dietary and housekeeping services, and social and recreational opportunities. In many homes, transportation is provided and in some homes it is arranged for the resident. Typically, Supplemental Security Income is the funding source for residents of RCHs.

In Connecticut, all RCHs are licensed by the Connecticut Department of Public Health and offer the following basic services: three meals a day, housekeeping services and laundry services, recreational activities, and 24-hour staff supervision (State of Connecticut, 2006). Staff are helpful in supervising medications that residents take themselves and may assist them with scheduling appointments; some homes have a nurse on site while others help residents arrange for community-based nursing services when they are needed (State of Connecticut, 2006). Age requirements vary according to the home's policy (State of Connecticut, 2006). Residents pay monthly fees that differ by community and by the room provided; in some communities, residents are able to use government assistance to help them pay for care (State of Connecticut, 2006).

Nursing homes

Nursing homes, also known as skilled nursing facilities (SNFs), are the principal providers of long-term care for individuals who have significant functional or cognitive disabilities or medical situations that necessitate more formal or 24-hour care (Pandya, 2001). Nursing homes differ from residential care and assisted living in many ways largely because nursing homes are subject to both federal and state regulations, whereas assisted living and RCHs are generally not subject to extensive state or federal mandates (Zimmerman et al., 2003).

More than 1.4 million Americans live in nursing homes (Walshe & Harrington, 2002), and estimates show that 46 percent of those 65 and older will spend some time in a nursing home (Spillman & Lubitz, 2002). In Connecticut, as of September 30, 2006, 27,689 residents were living in nursing homes; this is a 7 percent decrease from September 30, 1999 (Connecticut State Office of Policy and Management, 2007). Eighty-eight percent of residents were white, 71 percent were female, and 82 percent were widowed; this profile has been constant over time (Connecticut State Office of Policy and Management, 2007). In addition, 11 percent of residents were less than 65 years of age, 40 percent were between 65 and 84, and 48 percent were age 85 or older (Connecticut State Office of Policy and Management, 2007). There are three general sets of factors that increase the likelihood of nursing home admission: certain demographic characteristics (i.e., gender, marital status, age, race, and economic status), level of impairment (i.e., physical and/or cognitive), and access to an informal caregiving network (Lee, Kovner, Mezey, & Ko, 2001). Of all residents living in nursing homes, three-quarters require assistance with at least three activities of daily living, including bathing, dressing, eating, and using the toilet (Pandya, 2001); 20 percent had a psychiatric diagnosis or mood disorder (Harrington, Carrillo, & LaCava, 2006); and half (50%) of residents were diagnosed with dementia (Alzheimer's Association, 2006).

Nursing homes vary in the type of residents they serve. They may focus on special care, rehabilitation, clinically complex behavioral problems, or limited functioning (Fries, Schneider, Foley, Gavazzi, Burke, & Cornelius, 1994). Nationally, there are about 16,000 certified nursing homes with 1.4 million residents on any particular day (Alecxih, 2006). In 2004, approximately 65.9 percent of nursing homes were for-profit, 28 percent were non-profit, and 6.1 percent were government-owned (Harrington, Carrillo, & LaCava, 2006).

In Connecticut, as of September 30, 2006, 77 percent of 246 nursing facilities were for profit; this was a 3 percent increase from 2004 (Connecticut State Office of Policy and Management, 2007). Connecticut is one of seven states with the highest percentages of proprietary facilities in the nation (Harrington, Carrillo, & LaCava, 2006). Nursing homes are licensed at two levels of care in Connecticut: Chronic and Convalescent Nursing Homes (CCNH), known as Skilled Nursing Facilities, and Rest Homes with Nursing Supervision (RHNS), or Intermediate Care Facilities. Of the 246 nursing facilities in Connecticut, 211 (86%) are CCNH licensed, 31 (13%) have both licensures, and four (2%) nursing facilities are licensed as a RHNS only (Connecticut State Office of Policy and Management, 2007). In 2006, nearly all of Connecticut's nursing facilities (99%) accept Medicare and 96 percent accept Medicaid as a payer source (Connecticut State Office of Policy and Management, 2007).

In Connecticut, the average daily cost for nursing home care rose 8 percent in 2006 to $299 daily or almost $104,000 a year, and ranges from $200 to $350 daily for a semi-private room (Connecticut Partnership for Long-term Care, 2006). With the average length of a nursing home stay at two and a half years, the total estimated cost of care is $292,000. Medicaid continues to be the primary source of nursing home payment in Connecticut and covers 69 percent of all residents; Medicare covers 16 percent of residents, 13 percent of people pay privately out-of-pocket, and 2 percent are covered by private medical insurance or long-term care insurance (Connecticut State Office of Policy and Management, 2007).

Quality of care in nursing homes has been the focus of considerable attention among policymakers, consumers, advocates and providers for decades. Concerns regarding quality focus on care issues and conditions presenting hazards for residents and workers (Allen, Nelson, Gruman, & Cherry, 2006; Wunderlich & Kohler, 2001; Wright, 2001, 2005). Multiple studies indicate the need for improvement in quality of care in nursing homes (Wunderlich & Kohler, 2001; U. S. General Accounting Office, 2000). Accordingly, the nursing home industry is heavily regulated at the federal and state levels. State survey agencies are required to inspect nursing facilities every 9 to 15 months in categories that include resident rights, quality of care and life, resident assessment, services, dietary, pharmacy, rehabilitation, dental and physician, physical setting, and administration (U. S. Centers for Medicare and Medicaid Services, 2005; Manard, 2002). There is great variability across states in the rate of citations for deficiencies related to actual harm or jeopardy of residents, ranging from states with fewer than 5% of homes, to Connecticut, the highest in the nation, more than twice the national average at 47% (AARP, 2006). There is also variability in the approach to interpreting and enforcing the regulations during the review and inspection processes. It is not clear whether these significant variations are due to actual higher rates of substandard care, more active enforcement by certain states' surveyors, or inconsistencies in the definition of "actual harm" and "immediate jeopardy." Connecticut officials said that the growing volume of complaints, combined with limited resources, is a concern. Connecticut indicated that 90 percent of the complaints it receives allege actual harm and require investigation within 10 days, but that with fairly stagnant budget allocations from CMS, its ability to initiate investigations of so many complaints within 10 days was limited. Inadequacies indicated in a recent study included insufficient and inexperienced survey staff, uncertainty about regulations, and unsatisfactory state oversight of the review process (U. S. General Accounting Office, 2004).

Fifty percent of nursing home residents have Alzheimer's or another dementia diagnosis (Alzheimer's Association, 2006). In response to quality of care issues and in an effort to meet the growing and more complex demand for care for older persons, endeavors to improve the care and health status of people in nursing homes have been made (Kane, Kane, & Ladd, 1998; Robison & Pillemer, 2005; Robison, 2006). For example, over the past several decades,

some nursing homes have created separate units or special care units (SCUs) to care for people with dementia that include an environment favorable to the specific needs of people with dementia and the staff that care for them. Studies indicate when SCUs "meet accepted standards of environmental design, activity programming, and specialized staff training," positive resident outcomes and benefits to unit staff are realized (Robison & Pillemer, 2007, p. 15). Emphasis on a demand-oriented, integrated care delivery process and engaging residents in home-like activities within nursing homes are additional attempts to replace the traditional provider-oriented, unintegrated care delivery process (Paulus, van Raak, & Keijzer, 2005). SCUs now represent one of the fastest growing areas of the nursing home industry and are a challenge for Alzheimer advocates concerned about the quality of long-term care (Alzheimer's Association, 2006).

II. Supportive Housing Resident Survey

A. Introduction

The Supportive Housing Resident Survey gathered relevant information from Connecticut residents living in three supported living settings: skilled nursing facilities (or nursing homes), MRCs with assisted living services (assisted living), and RCHs also known as rest homes. The information includes satisfaction with services, issues of privacy, dignity and autonomy and open-ended questions regarding what it is like to live in that particular setting.

B. Methodology and analysis

The primary method of data collection was a written survey administered by phone or in person by a trained interviewer from the University of Connecticut Health Center, Center on Aging. Given the challenges in reaching this population for survey research (i.e., lack of a telephone), and the particular interest of the state in ensuring participation from a range of settings and geographic regions, the sample was developed as a purposeful convenience sample. There were a total of 150 residents from 57 supportive housing residences:

- Skilled nursing facility (n=95) from 38 facilities
- Assisted living (n=25) from 11 ALSAs
- Residential care home (n=30) from 8 RCHs

Instrument development

Survey development was informed by a comprehensive review of the long-term care and disability scientific and policy literature, as well as an examination of surveys used in other states. Staff from the Connecticut Long Term Care Ombudsman Program (LTCOP) provided significant input in this process, especially regarding areas of focus or concern. Questions were developed using information from all of these sources, along with ongoing input from the LTCOP and the literature. Emphasis was given to those issues that would help Connecticut assess the needs of its residents for long-term care services.

Supportive Housing Resident Survey

A ten page survey was developed with the following major topics: demographics, how they came to live there, what it is like living there, complaints, problems and getting help, satisfaction with quality of care, fear of retaliation, wishes and resident suggestions (See complete survey in Appendix A). The instrument comprised both quantitative and qualitative questions, with space given so the respondents could provide additional information. Below is a brief explanation of the topics covered in each section of the Supportive Housing Resident Survey:

- Demographic information (includes age, gender, race, education and marital status)
- How they came to live there (where they were prior to entering the residence and descriptive statements about their particular situation)
- What it is like living there (descriptions of a typical day)
- Complaints, problems and getting help, including whom they ask for help
- Fear of retaliation (concerns and experiences with retaliation)
- Satisfaction with quality of care (overall rating of the quality of care, and how the staff respects their privacy, dignity and choices)
- Wishes and resident suggestions (what would one change about where they live)

The convenience sample was composed of residents who came from three sources:

- The 2006 CT Long Term Care Ombudsman Program Voices Forum
- Regional Ombudsman referrals
- Outreach to supportive housing executive directors, activity directors, social workers, nursing supervisors and other key persons in the supportive housing.

Interviews were conducted either over the phone or in person depending on the person's preference. Most of the phone interviews were done with participants from the 2006 CT Long Term Care Ombudsman Program Voices Forum. These people completed a form at the forum saying that they would like to be contacted for future research. They supplied contact information and were subsequently contacted and completed the interview over the telephone or in person. The average time for any interview was approximately 30 minutes. The telephone interviews represent approximately 20 percent of the interviews.

The Regional Ombudsmen referrals identified specific supportive housing residences that would most likely be good choices. These referrals led to the initial contacts with each supportive housing residence. In addition, all member organizations of the Connecticut Association for Health Care Facilities and the Connecticut Association of Not-for-Profit Facilities for the Aged received a notification of the survey and request for facilities to identify willing residents. The research team also contacted key persons in various supportive housing residences such as activity directors, social workers, nursing supervisors or executive directors. In many cases, the executive director or other key persons were contacted and asked if they would identify residents who were willing to participate in the study. They were told that residents' participation should be voluntary and that there should be a diverse group representing differing levels of care. Most of these interviews were done in person; however, a few were done over the phone. In-person interviews were set up in such a way that the interviewer was able to meet with several people from the same residence in either one or two trips. The director of the supportive housing residence often provided a private room for the interviews. In some cases, the interviewer was conducted in the resident's room or apartment. In these instances, every effort was made in order to ensure the provision of privacy. As many as nine people and as few as one person represented each of the 57 residences. In two cases, the family member of the resident answered the survey questions on behalf of their loved one. The interviews were anonymous and the study was approved by the University of Connecticut Health Center Institutional Review Board.

Each person received a check for twenty dollars as a thank you for their time. One of the residences did not allow payment for participation in research studies which was made clear to participants before the interview.

Analysis

All data were entered into Microsoft Access tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) information. After data entry was complete, the data were converted to SPSS version 15.0, a statistical software package designed for both simple and complex analysis.

A three-step statistical strategy was employed in this study. First, a preliminary analysis determined the distribution of the sample across the independent variables (survey items) in the study. The study sample was then further examined by three different groups, using the

following dependent variables: supportive housing type, age, and length of residence. Next, data were analyzed question by question, with a series of basic tests computed: frequency, average, and percentage. The variables were then simplified by eliminating extraneous variables and by reducing the number of divisions of multi-categorical variables. A comparison of the response distribution both within and between groups was performed. Differences between groups were analyzed using chi-square and t-test for categorical and continuous data, respectively.

Content from the open-ended questions was analyzed using standard qualitative analysis techniques (McCraken, 1988). Data from each question was transcribed and analyzed line by line in order to identify and interpret each individual's response. Two researchers independently analyzed the responses for each question, reaching a consensus if interpretations were different. Major concepts or areas of interest supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each. Percentage of response was determined by dividing the number of times any particular theme was mentioned by the total number of responses.

C. Detailed results

Findings from the supportive housing resident survey are presented in order of the questions, focusing first on some descriptive information regarding how the residents came to live in their present home and what role they had in making this choice. Then questions follow regarding whom they ask for help, how often they go out into the community, transportation issues, fear of retaliation, quality of care, privacy issues, dignity issues and autonomy.

Within each area, the data are presented first as a whole, with responses from all residents analyzed together. The survey results are further analyzed and examined by supportive housing type, the age of the resident and length of stay at their current residence. When applicable, statistically significant differences or similarities in these characteristics are described. The results of these sub-analyses are included at the end of each content area.

Supportive housing type

Participants were recruited from three separate supportive housing types, nursing homes or skilled nursing facilities, residential care homes and assisted living. The majority of participants are from skilled nursing facilities (n= 95) with about an equal number of participants from assisted living (n=25) and residential care homes (n=30). Just under two-thirds of the sample reside in skilled nursing facilities. The remaining third are divided fairly evenly between assisted living and RCH residents (Table II-1).

Table II-1. Respondents by type of supportive housing

Type of supportive housing	Number of Respondents	Percent of total
Nursing home	95	63%
Assisted living	25	17%
Residential care	30	20%

Answers to all of the questions are analyzed by age. Respondents are divided into four age categories as shown in Table II-2. Differences by age are only reported when statistically significant.

Table II-2. Respondents by age

	Number of Respondents	Percent of total
Younger than 50	16	11%
Age 50 – 64	35	24%
Age 65 – 84	57	38%
Age 85 and older	39	26%

Answers to all of the questions are analyzed by length of stay at current residence in any supportive housing type (Table II-3). Differences by length of stay are only reported when significant differences exist.

Table II-3. Respondents by length of residence

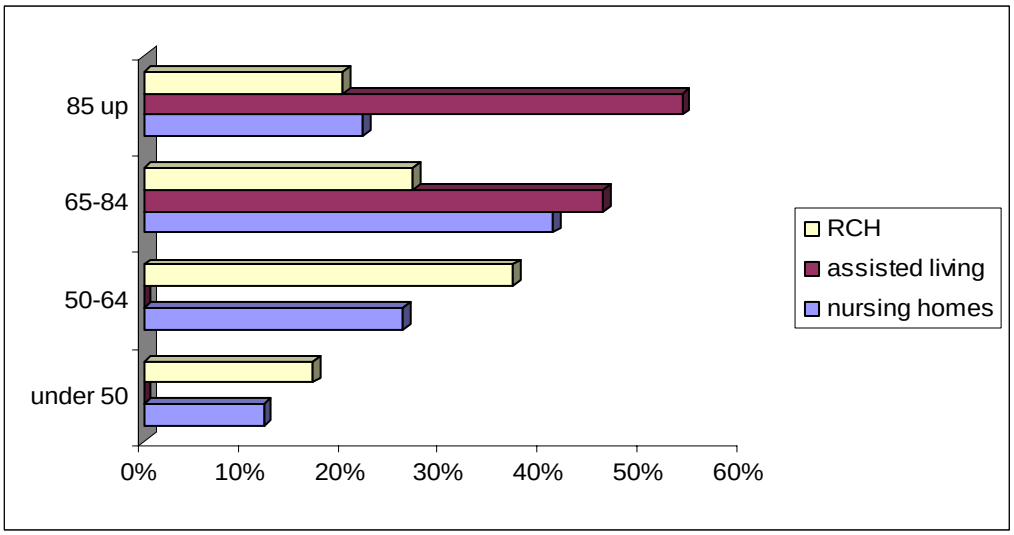
Length of stay	Number of Respondents	Percent of total
Less than 1 year	24	16%
1 to 2 years	46	31%
More than 2 years	80	53%

Differences by age

Those living in assisted living are generally older with over half of them (54%) being 85 and older and 46 percent being in the age group of 65 to 84. No one under 65 who participated in the interview is in assisted living. Only 20 percent of those in residential care homes are over

85 years old. Over half (53%) are 64 years of age or younger, and 17 percent of this group is under the age of 50. In nursing homes 12 percent of the residents are under the age of 50. The majority of residents in nursing homes (41%) are ages 65 to 84. One-fifth of those in nursing homes (22%) are 85 or older and about one-fourth (26%) of the residents are age 50 to 64.

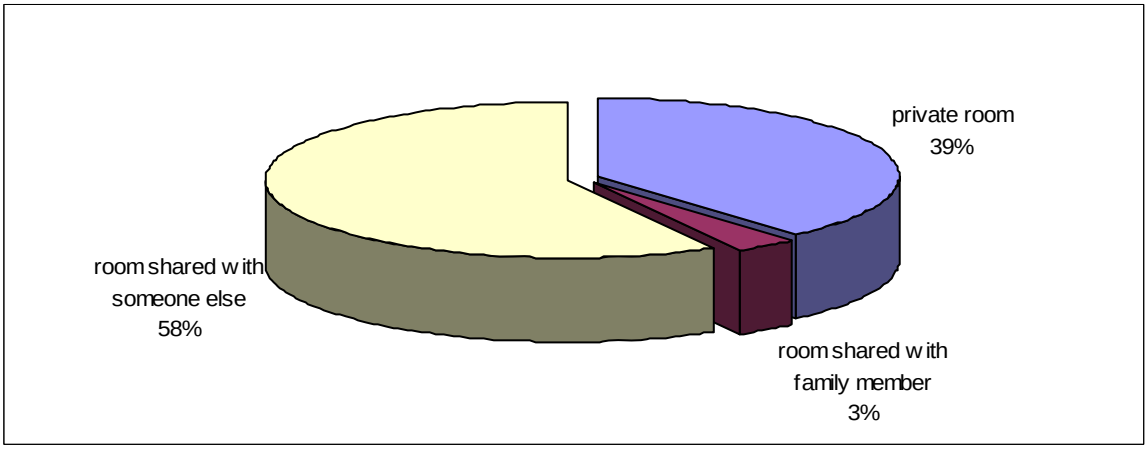
Figure II-1. Type of supportive housing by age



Type of room

Participants were asked to describe their living situation, either private room or apartment, room or apartment shared with another family member, or a room shared with someone other than a family member. Overall, the greatest percentage of participants live in a room shared with another person.

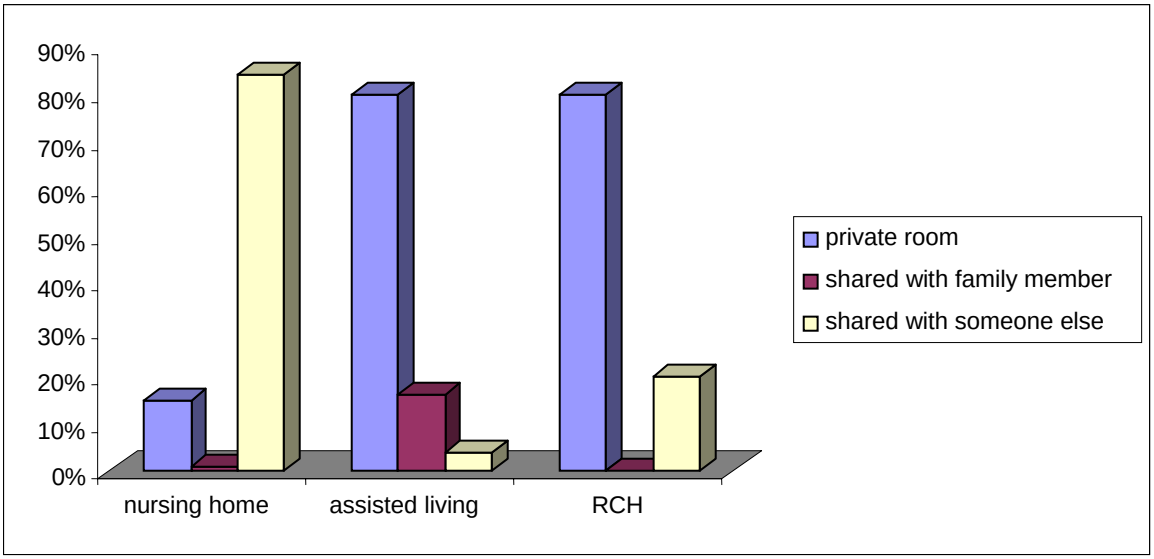
Figure II-2. Type of Room



Differences by supportive housing type

Residents of assisted living and residential care homes most commonly have a private room, while those in nursing homes typically share a semi-private room with one or more other residents. Also in assisted living situations, there is a small percent of people who continue to live with their spouses in the same apartment.

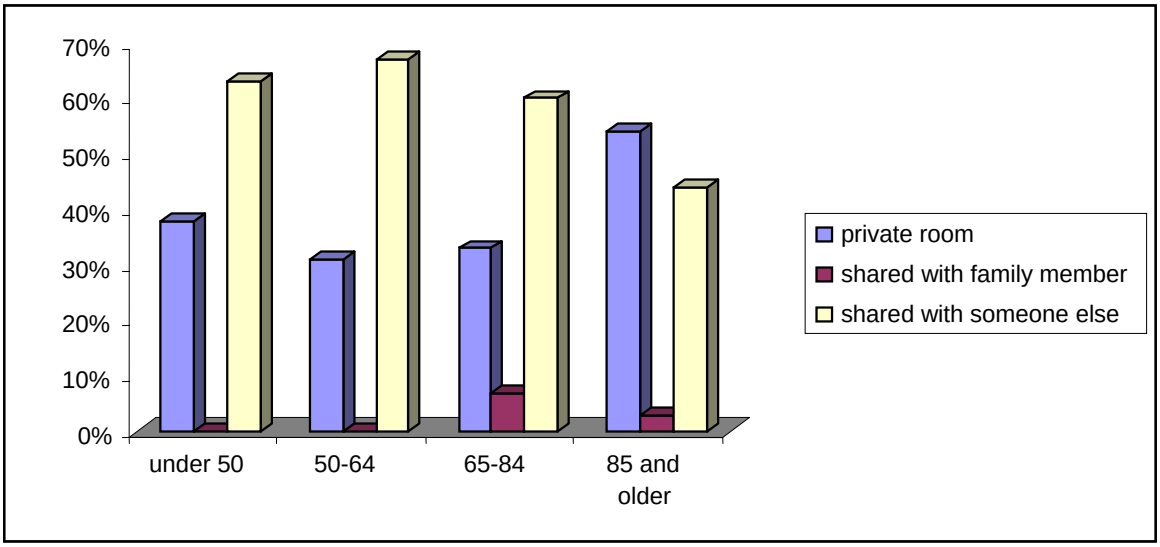
Figure II-3. Type of room by supportive housing type



Differences by age

More of the people who are 85 and older tend to have private rooms (54%) as opposed to 38 percent of those who are under 50, 31 percent of those who are 50 to 64, and 33 percent of those who are age 65 to 84 (Figure II-4).

Figure II-4. Type of room by age

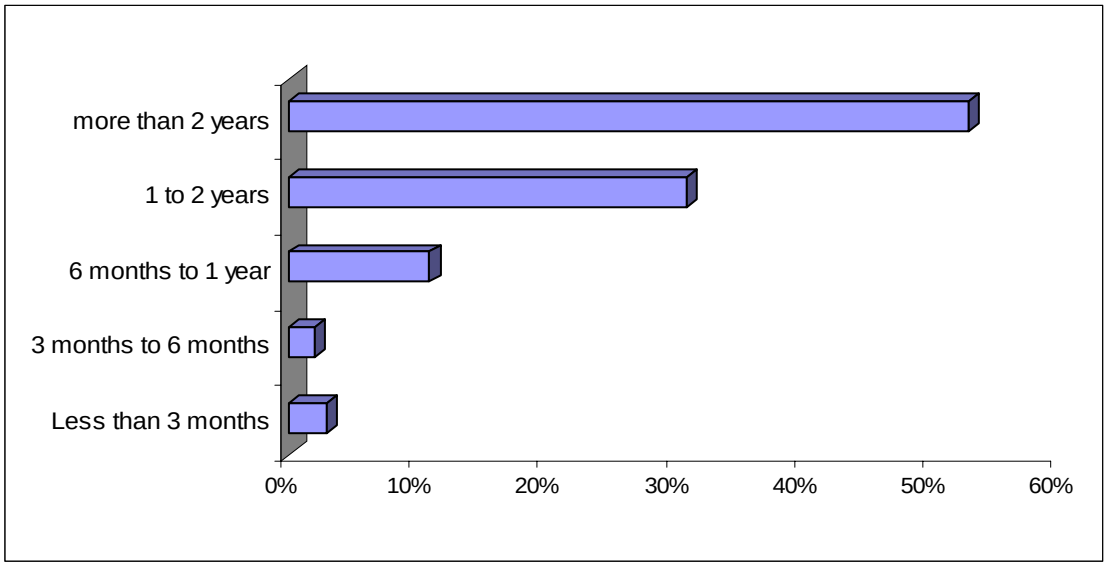


How long have you been in your current living situation?

First the residents were asked how long have they been in their current living situation. Choices for responses include less than three months, three months to six months, six months to one year, one year to two years, and more than two years.

Most of the participants have been in their current living situation for over two years (53%) with another 31 percent living in their current situation for at least one year to two years. Eleven percent have been in their residences for a period of six months to one year, and five percent have been in their present situation for up to six months.

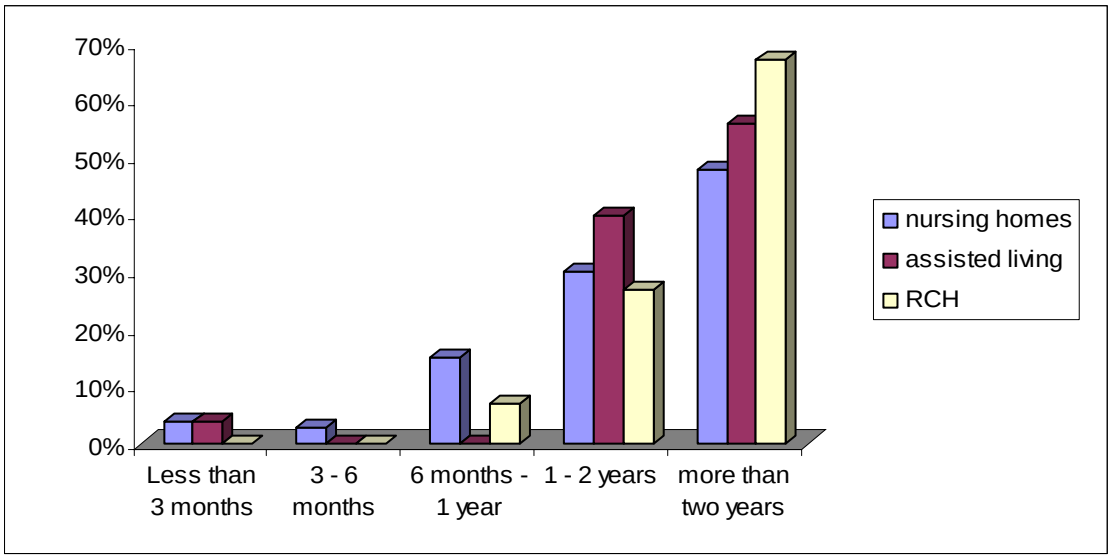
Figure II-5. Length of stay in present living situation



Differences by type of supportive housing

Over half of the respondents have been in the supportive housing environment for over two years and this proportion is highest for the RCH residents. Forty-eight percent of the nursing home residents have been there more than two years and seven percent have been there less than six months. Sixty-seven percent of the RCH respondents have been there over two years and there was no one there less than six months. Fifty-six percent of those surveyed at assisted living residences have been there over two years and only four percent have been there for less than six months.

Figure II-6. Length of stay by supportive housing type

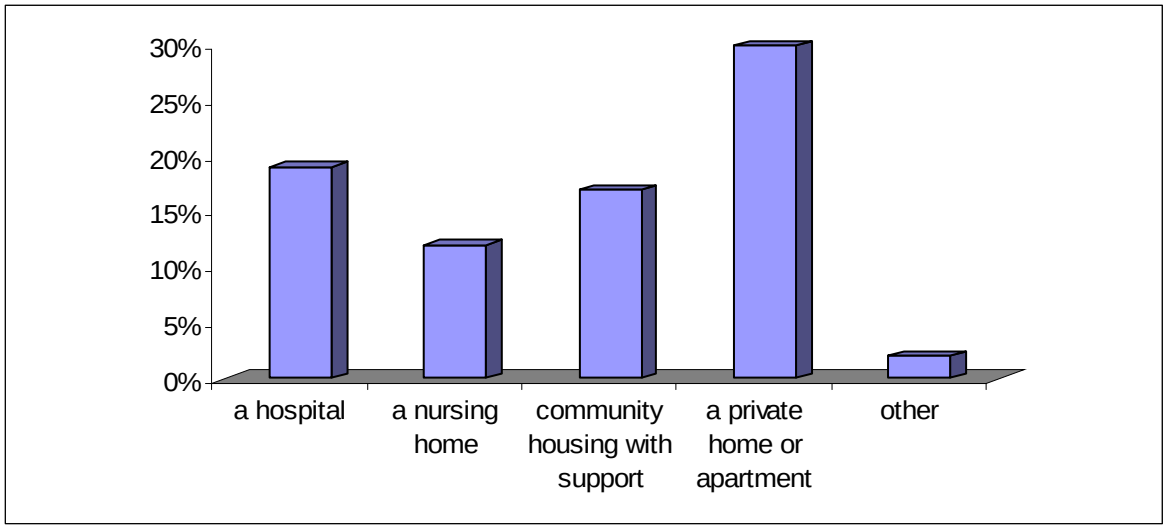


Where were you right before you came to live here?

The question regarding where they were right before coming to their present residence had several possible responses including hospital, a nursing home, any community housing arrangement with support, or a private home or apartment. Respondents were asked to indicate whether that private home or apartment was their own or someone else's.

The majority of respondents came from a private home or apartment just prior to entering their current residence (50%) and nearly one-fifth of the participants indicated that they had come from either a hospital (19%) or from some kind of community housing with support (17%). Only 12 percent said that they came directly from a nursing home and two percent (n=3) indicate something other than the above options.

Figure II-7. Previous living arrangement



Differences by supportive housing

For those residents now living in a nursing home, 26 percent of them came to that facility directly from a hospital. None of the residents of assisted living came to their current residence from a hospital and only 14 percent of those who now live in residential care homes came from a hospital. The majority of people who now live in assisted living (76%) came from either a private home or apartment. This is compared to 44 percent of those who are now living in nursing homes and 46 percent of those now living in RCHs. Twenty-five percent of those now living in residential care homes came there from some other kind of community housing with support, compared to only 15 percent of those now living in nursing homes and 16 percent of those now in assisted living.

How did you come to live here?

This open-ended question is coded for basic themes revealing several reasons why a person ended up in their current living situation. The general themes emerging from the responses include acute illness, operation or fall, going in for rehab and then staying there as a long-term resident, and the fact that the resident could no longer take care of him or herself. Other reasons include things like not wanting to be a burden on their family or loss of a caring spouse. The location of the residence was given as a reason by some, and the fact that they were referred to that particular supportive housing is an important reason for others. In some cases the person requested the move and in other cases the resident had no explanation or just didn't know how they happened to end up in that particular supportive housing. The largest number of respondents (33%) said that it was because of an acute illness or operation that they came to live in their particular living situation. Sixteen percent of all respondents indicated that they came to live in their situation because they had been referred by someone else. Eleven percent said that they could no longer take care of themselves and nine percent said that they chose their particular residence because of its location.

Differences by supportive housing type

Some individuals gave multiple reasons for how they came to live in their current residence. The following information is based on all of their responses. The majority of those now living in nursing homes said that the main reason they ended up in their current situation was because of an acute illness, operation, or fall (40%). Another 11 percent went to the nursing home for rehabilitation and ended up staying. Other prominent reasons among residents of nursing homes included that they could no longer take care of themselves (14%) and that they were referred to this particular facility by someone else (15%). For residents of RCHs, only 20 percent of responses indicated that an acute illness lead to their residing in their current residence. Twenty-nine percent of RCH respondents cited being referred by someone else as the main reason for having come to live there. Eleven percent indicated that they can no longer take care of themselves. For those in assisted living, 20 percent said that it is because of acute illness or operation or falling. For another 20 percent, it was the location of the residence, near friends and family, that precipitated the move to this particular location. Seventeen percent requested the move because they felt it was the best place for them, and 14 percent moved because they could no longer take care of their home or apartment.

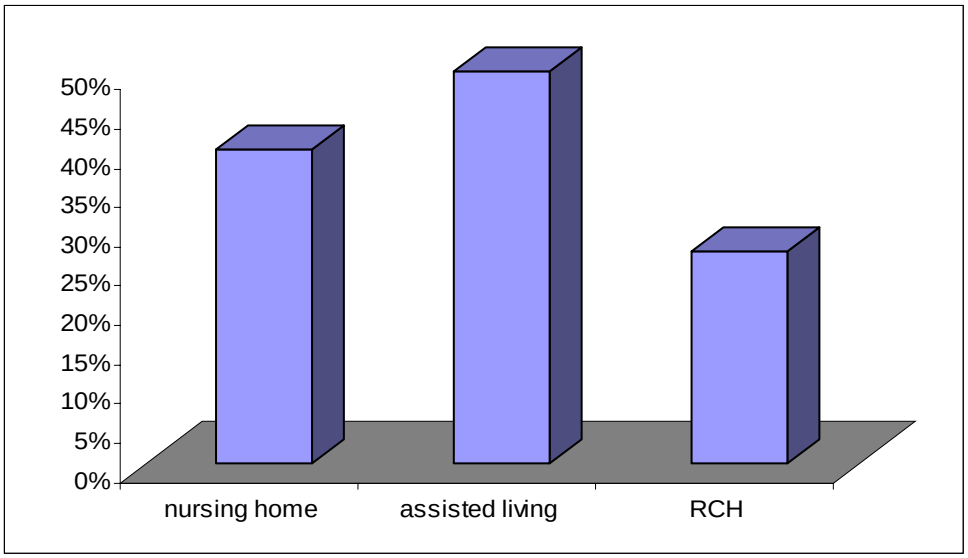
What role did you have in choosing this place?

This open-ended question yielded two basic responses, either "yes" that the resident did play some role in the choice of their current residence or "no" that they played no role in choosing their current residence. Overall, 61 percent of those who responded said that they did not have any role in the choice of their current residence and 39 percent said that they did have at least some part in deciding to be at this particular supportive housing type.

Differences by supportive housing type

There are marked differences among the three groups in terms of how much choice they had in the decision of moving to their respective residences. Forty percent of those living in nursing homes had a role in choosing their particular facility compared to 27 percent of those living in residential care homes. For those in assisted living, half (50%) indicated that they had a role in choosing their particular living situation (Figure II-8).

Figure II-8. Those having some role in choosing their supportive housing type



Only about one fourth of those in assisted living (24%) and nursing homes (23%) indicated that they were considering other types of living situations; and only about 17 percent of those who now live in residential care homes said that they considered other options.

Describe a typical day

Responses to the question, "Can you describe a typical day?" were highly varied. Most of the respondents indicated starting the day with breakfast after which the variety of answers veered off in strikingly different directions. A large majority of the respondents said that they do take part in the activities provided by each residence.

> *Every day's a new day. I'm very busy here, read a lot, on the computer a lot. I look forward to every day. Play cards, CDs and movies.* – Assisted living resident

> *I like it. I've gotten so used to it – I've been here so long. I take part in the activities as much as I can. I'm a reader so I read as much as I can and we have an excellent library on the first floor.* – Nursing home resident

> *I never lived alone before. I can't imagine any other place I would want to be. They answer your health needs. We have Bingo and bands [and] entertainment. You can be as busy or as quiet as you want.* – Assisted living resident

> *It's very busy. Some people do sit in wheel chairs, but not me. I'm up and from 7:45-8:30 we have breakfast; lots of good food; activities. We have a scenic ride almost every day; programs of interest; lunch at 11:30; other activities inside and outside.* – Assisted living resident

> *There's a schedule to follow. Every day is different. There's music, breakfast club, gourmet club, gardening. Each month has a theme. I can invite two guests*

to the dining room downstairs. This is a new version of a nursing home. I really enjoy it. – Nursing home resident

There are 200 people here. I enjoy doing some of the activities, like exercise and trips. I like to be by myself also – doing word games. Today I took the newspaper outside and read it. They have beautiful grounds here and I go for walks. – Assisted living resident

While the majority of people in the various supportive housing types are happy overall with their situation, there were a few residences where the residents were not at all happy in their current situation.

Many people here don't get along. I can't do for myself. It's terrible here. The food is bad; people are not nice. I have the visiting nurse every day to check my diabetes. – RCH Resident

[It's] the pits; depressing; just watch TV and talk on the phone. Sometimes activities, like Bingo which is my favorite. Food here is awful. – Nursing home resident

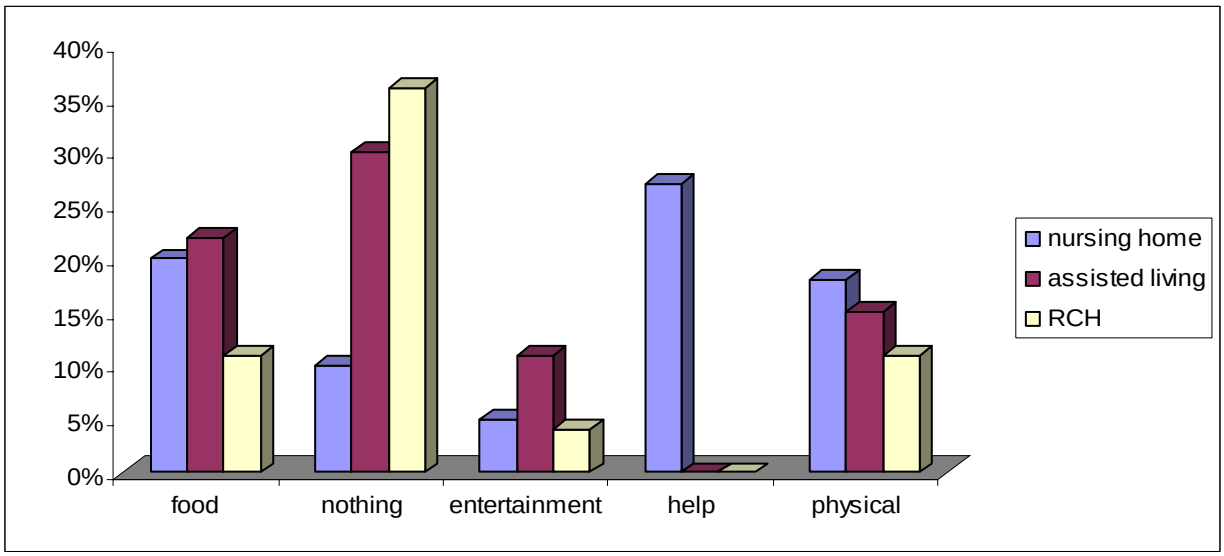
If you could change something about living here, what would it be?

Participants were asked to indicate which areas of improvement they would like to see happen. Qualitative coding of the suggestions resulted in several broad categories of areas of improvement. These categories included food (better food, hotter food, more food, less food, less sauces etc.); entertainment (more entertainment, more entertainment on more days, more trips, etc.); better help (better staff, more help, etc.); physical improvements (more space, private room, telephone, improvements to the building, etc.); the last category was "nothing" for people who were totally satisfied with their residence and believed that nothing needed to be changed.

<u>Differences by supportive housing type</u>

Individuals often gave more than one response. For nursing home residents 90 individuals responded to the question and out of those, 24 individuals had more than one suggestion. The following chart represents all responses to the question, "If you could change something about living here, what would it be?" Twenty-four of the assisted living residents responded to the same questions, with only 3 indicating a second suggestion. Twenty-six of the RCH residents responded to the question with only two individuals making another suggestion. Based on the total number of responses, only the nursing home residents indicated that they need better or more help. For assisted living and RCH residents, about one-third felt that nothing needed to be changed. Over 20 percent of the residents in nursing homes and assisted living expressed a need for improvements in the food, compared to only 11 percent of those in residential care homes.

Figure II-9. If you could change something, what would it be by supportive housing type*



*response categories are not mutually exclusive

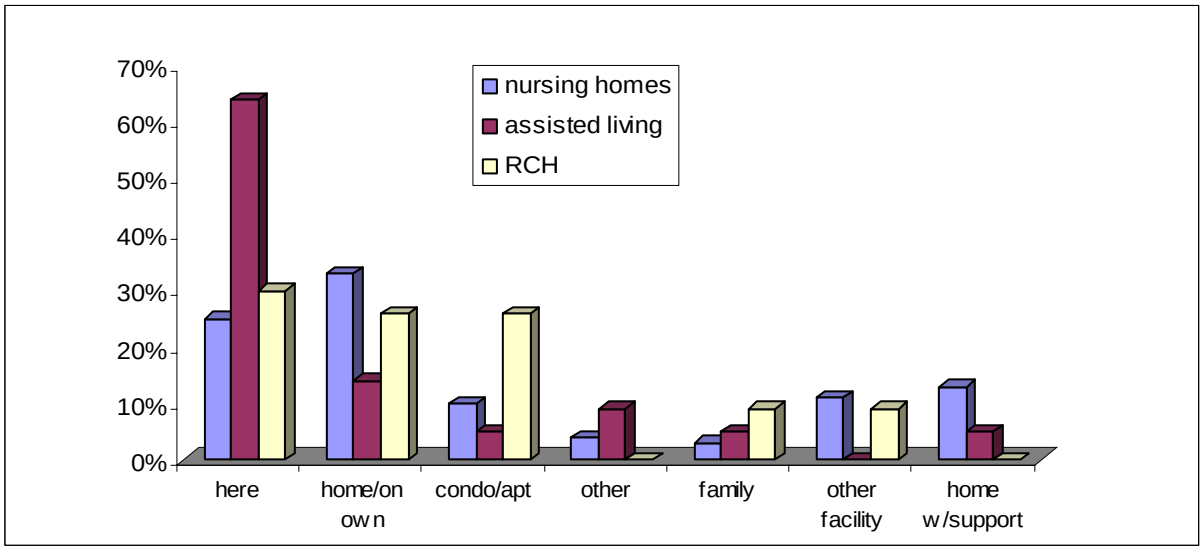
What would be your ideal living situation?

For the next open-ended question, respondents were asked to name their ideal living situation. The question is worded "Given your current condition and support needs, what would be your ideal living situation? In other words, if you had a choice, where would you like to live?" Overall, the respondents said where they are right now is the right choice (33%); 28 percent said that that they would like to be in their own home or living on their own; 12 percent indicated that they would like to be in a condo or apartment; four percent said that they would like to be with their family; nine percent would like to be in another supportive living arrangement; and nine percent would prefer to be in their own home with some support.

<u>Differences by supportive housing type</u>

Breaking this down by supportive housing type yields some differences. Only 25 percent of those in nursing homes would choose their current situation as desirable compared to 30 percent of those in RCHs and 67 percent of those in assisted living situations. Over one-fourth (26%) of those in RCHs would like to be living in their own condo or apartment compared to nine percent of those in assisted living and 10 percent of those living in nursing homes. Twenty-two percent of those living in RCHs and 32 percent of those living in nursing homes would like to live at home or on their own, compared to only 13 percent of those in assisted living.

Figure II-10. What would be your ideal living situation by supportive housing type



Most of the people from assisted living said that they were happy with the decision that they were now in this supportive housing.

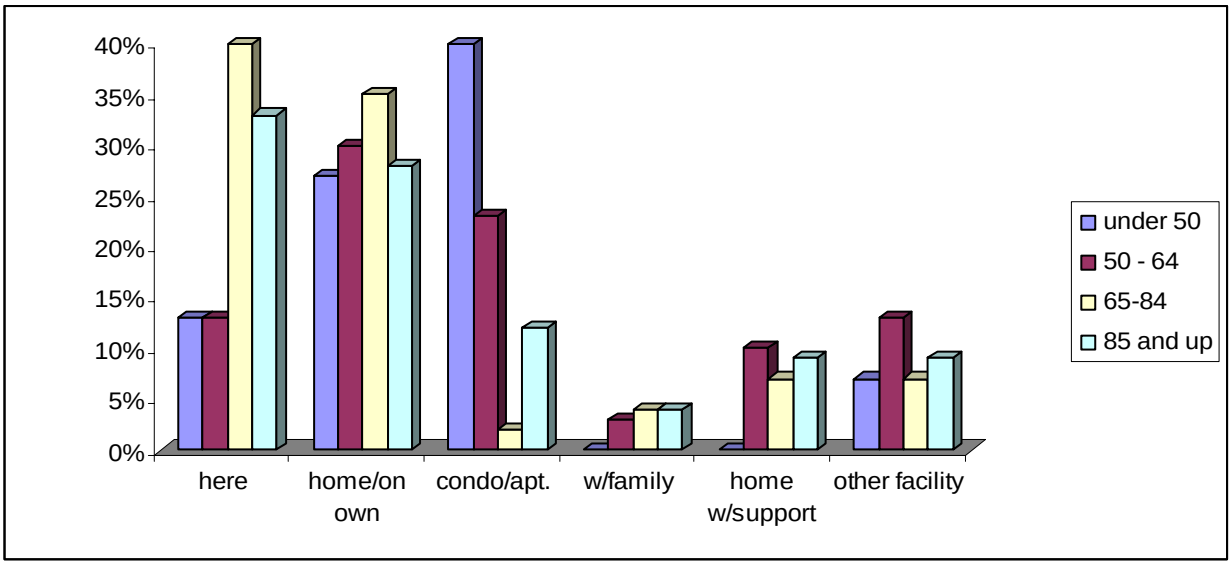
> *Right here because I'm too old to do anything else. I have two sons, but they have their own lives. I lost my husband and lived by myself for eight years before coming here.* – Nursing home resident

> *Sometimes I think it would be nice to have my own house and homemaker services come in. I know my husband would prefer that, but many times we were at home and we needed an ambulance to come and take me to the hospital. For that reason we're glad to be here.* – Assisted living resident

Differences by age

When asked "Where would you like to live?" many of the respondents who are 65 and older indicated that they would like to live right where they are. Forty percent of those age 65 to 84 and 50 percent of those age 85 and older said that they were happy where they are, compared to only 13 percent of those under the age of 50 and 13 percent of those between the ages of 50 to 64. For those younger than 50, 40 percent said that they would like to be living in their own condominium or apartment and 20 percent said that they would like to be living on their own. Among those who are age 50 to 64, 23 percent say that they would like to be living in an apartment or condo, and 20 percent said that they would like to be living on their own.

Figure II-11. What would be your idea living situation by age



Why would you like to live there?

Following this, the respondents were asked why they would like to live in that particular situation. Nearly one-half (41%) said that they would like to live there in order to be independent, and to take care of them. Comments include:

> *… being able to cook what I want; go to bed when I want; do what I want, when I want to; don't want to see people in wheel chairs all the time.* – Nursing home resident
>
> *I'd be free to come and go as I please.* – Nursing home resident
>
> *Because I can do a lot for myself. Assisted living would allow me to be a little bit more independent.* – Nursing home resident
>
> *I'd feel free and a part of society.* – Nursing home resident
>
> *I would be able to live on my own, maybe with a personal assistant for just a few things. I can do a lot on my own. Maybe I would need help getting in and out of the shower. So I wouldn't need someone there 24 hours a day. But I guess that here is OK too.* – Nursing home resident
>
> *Cook for myself, clean, be alone sometimes. I used to clean my apartment every day when I was in a CLA.* – RCH resident

Other answers to the question included a desire to be more active and be more a part of the community, to be closer to friends and family, to have more space or more privacy, or just because it's home.

Well, it's home. That's the only explanation I can give you. Everything is fine here, but I start to miss home. – Nursing home resident

For those who said that they are happy where they are, some of the reasons include:

We have security 24/7 – so it's very safe. The people here are so nice; the volunteers, the staff, the other residents. We're all like sisters. – RCH resident

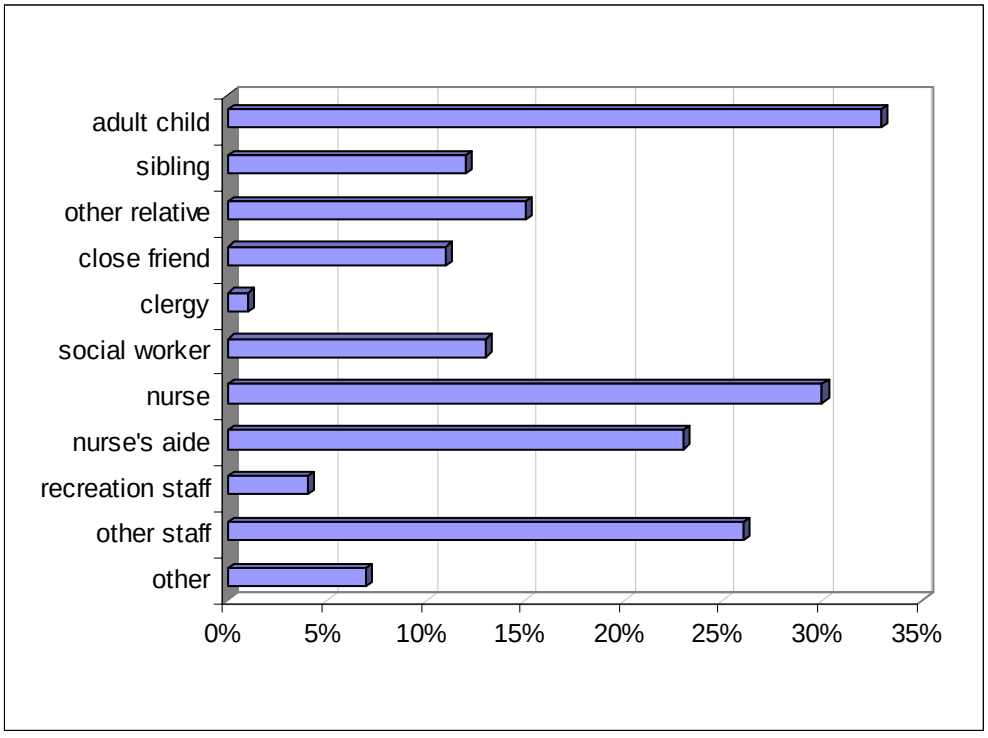
Differences by age

Being independent was most often given as a reason for their choice among those younger than 50 (63%) and those age 50 to 64 (47%). Only about one-third of those who are age 65 and older indicated a desire for such independence.

When you need help, who do you ask?

For the next question, survey participants were asked to think about all of the people they see, not only people who work here, but also family members or others who they see or talk to. The question asks "When you need help, who do you ask?" The most frequent response indicated that they would ask their adult child for assistance, however nearly as many of the participants said that they would ask either the nurse at the residence or other staff at the residence for assistance. Other staff, in many cases, included the administrator or director of that residence.

Figure II-12. When you need help, who do you ask*



*categories are not mutually exclusive

Differences by supportive housing type

More of the people who are now in assisted living (76%) indicated that they would go to their adult child for any kind of help. This is compared to only 31 percent of those now living in nursing homes and seven percent of those now living in RCHs. More of the people in nursing homes indicated that they would go to their social worker for help (20%) compared to none of the people from either assisted living or RCHs. Thirty-nine percent of those living in nursing homes said that they would go to the nurse for help, compared to only 20 percent of those in assisted living and 10 percent of those in residential care homes. Nearly half (47%) of those living in residential care homes indicated that they would go to staff, notably the administrator or supervisor, for help.

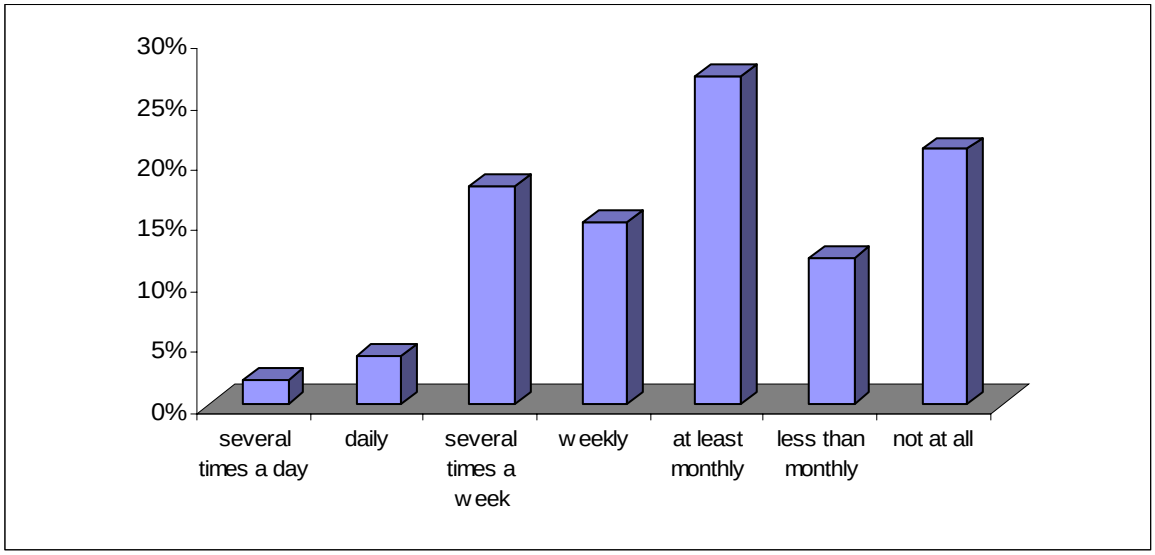
Differences by age

Breaking it down by age, those who are over 65 years of age were most likely to go to their adult child for any kind of help. Thirty-five percent of those age 65 to 84 said that they would go to their adult child, and 59 percent of those who are 85 and older would do the same. Only six percent of those younger than 50 and 14 percent of those age 50 to 64 would go to an adult child for help. Instead they were more likely to go to a sibling or other relative. Fifty-six percent of those under the age of 50 would seek out a sibling or other relative for help, and 45 percent of those who are between the ages of 50 to 64 would do the same.

How often do you go out into the community?

The following question asks how often the resident goes out into the community for recreation and enjoyment. Over one-fourth (27%) of the respondents overall said that they go out into the community at least monthly, however one-fifth (21%) do not go out at all. One-third of the respondents said that they go out either once a week or several times a week.

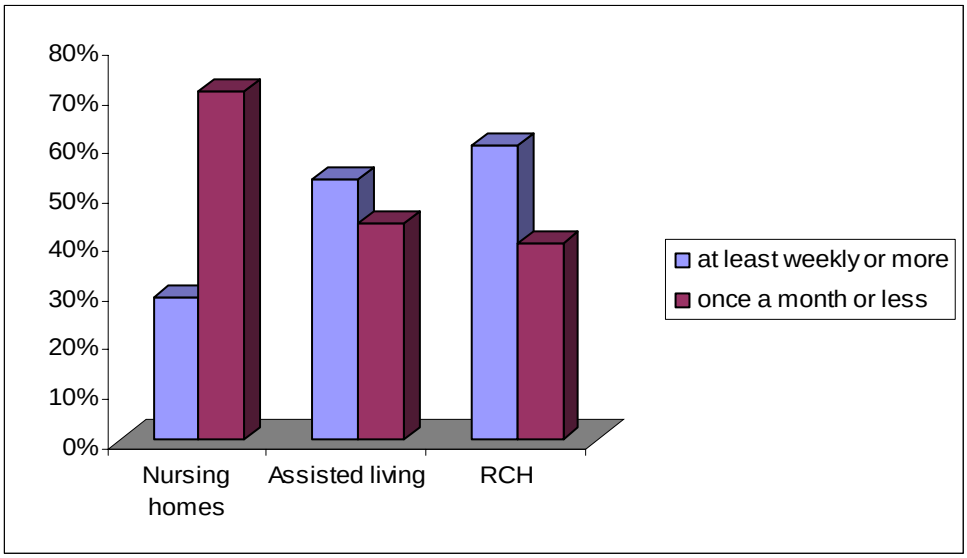
Figure II-13. How often do you go out into the community



Differences by supportive housing type

Over half of the residents in both assisted living and residential care homes said that they go out at least once a week or more. Less than one-third of the residents of nursing homes said that. On the other hand over 70 percent of those from nursing homes said that they only go out about once a month or less.

Figure II-14. How often do you go out into the community by supportive housing type



Seventy-six percent of those living in assisted living said that they do go out enough, compared to only 47 percent of those living in nursing homes and 57 percent of those living in residential care homes.

Differences by age

Breaking it down by age, more of the individuals in the two younger groups would like to go out more, with 53 percent of those younger than 50 wanting to go out more and 68 percent of those age 50 to 64 wanting to go out more. Of those age 65 and older, only about one-third expressed a desire to go out more than they already go out.

How often do you receive visits from friends or family?

Nearly two thirds (66%) of all the respondents indicated that they receive visitors at least once a week, while about one fourth (27%) receive visitors at least monthly, and seven percent were not getting any visitors at all. Over one third (38%) of the total sample said they would like to receive more visitors with sixty percent saying they received enough visits from friends and family.

Differences by supportive housing type

Twenty percent of those now living in residential care homes indicated that they receive no visits from friends or family, compared to only four percent for each of the other two groups. In addition, only 40 percent of the people who are now living in RCHs said that they receive visits

from friends or family either weekly or several times a week. This compares to 60 percent of those now living in nursing homes and 68 percent of those living in assisted living who receive visits either weekly or several times a week. There is no significant difference among supportive housing types in their satisfaction with visits from others. Sixty-eight percent of those in assisted living were satisfied with the number of visits they receive, compared to 60 percent of those living in nursing homes and 57 percent of those who are currently living in residential care homes.

Differences by age

Those who are age 65 and older seem to receive the right amount of visits with two-thirds (67%) of those age 65 to 84 and three-fourths (74%) of those age 85 and older saying that the number of visits they receive is the right amount. For those under the age of 50, nearly the opposite is true. Sixty-nine percent of those under the age of 50 said that they would like to get more visits. Fifty-six percent of those between the ages of 50 to 64 said they would like to receive more visits.

How often do you communicate with loved ones by phone or e-mail?

Eighty percent of those responding said that they communicate with loved ones by way of telephone or e-mail at least on a weekly basis, with over half of these saying that they communicate daily or several times a day.

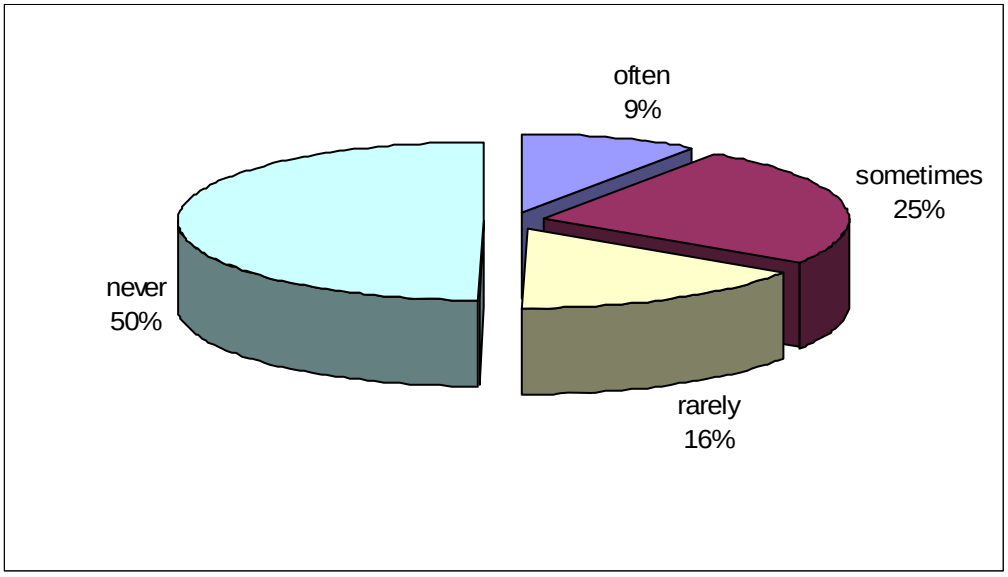
Differences by supportive housing type

One hundred percent of people who are in assisted living were satisfied with the amount of time spent communicating with friends or family via telephone or e-mail. Eighteen percent of those living in nursing homes and 20 percent of those in RCHs said that they would like to communicate more with family and friends.

Do the days here seem too long?

When asked the question “Do the days here seem too long for you?” participants were asked to indicate how often this happens: often, sometimes, rarely or never. Overall almost half (49%) of all of the respondents said that this never happens. Nearly one fourth (24%) said that it happens sometimes (see Figure II-15).

Figure II-15. Do the days seem too long



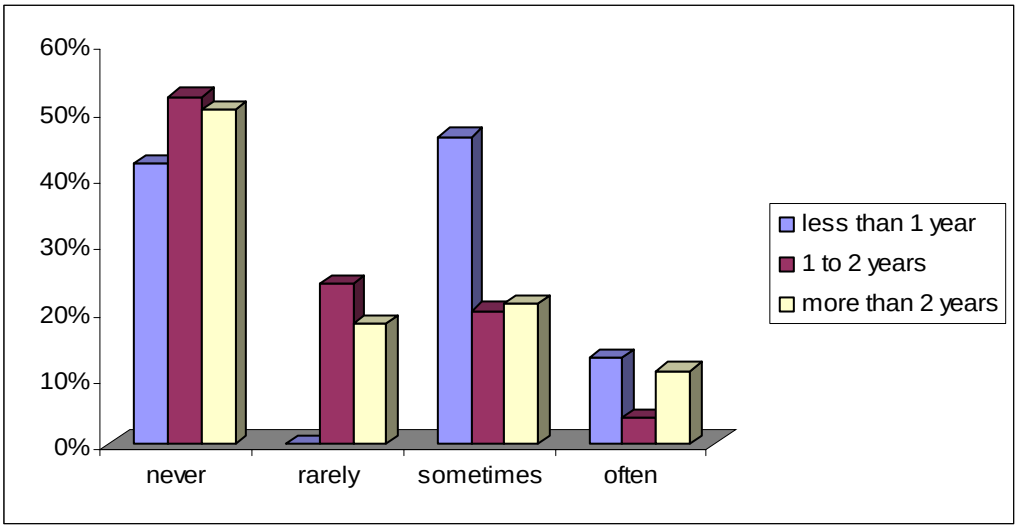
Differences by supportive housing type

For the people in assisted living, often was never chosen as an answer to this question and nearly three-fourths (72%) of assisted living residents said that they never felt that the days were too long. This is compared to only 44 percent of those living in nursing homes and 47 percent of those living in RCHs. Thirty-six percent of those living in nursing homes and 50 percent of those living in RCHs indicated that the days seem too long either sometimes or often. Only four percent of those in assisted living said that their days seem too long either sometimes or often.

Differences by length of residence

There were some notable differences based on length of stay in any given residence. For those respondents who have lived in their current situation for less than one year, over half (58%) said that the days do seem too long either often or sometimes. For those who have lived in their residence for one to two years, only 24 percent seemed to think that the days are too long either sometimes or often and 32 percent of those who have lived in their residence for more than two years said that the days seem too long either sometimes or often.

Figure II-16. Do the days here seem too long by length of residence



How often do you feel lonely?

Participants next responded to a question concerning feeling lonely. For all of the respondents, nearly two thirds (61%) indicated that they never or rarely feel lonely. Overall, twelve percent of the residents from all supportive housing types indicated that they feel lonely often.

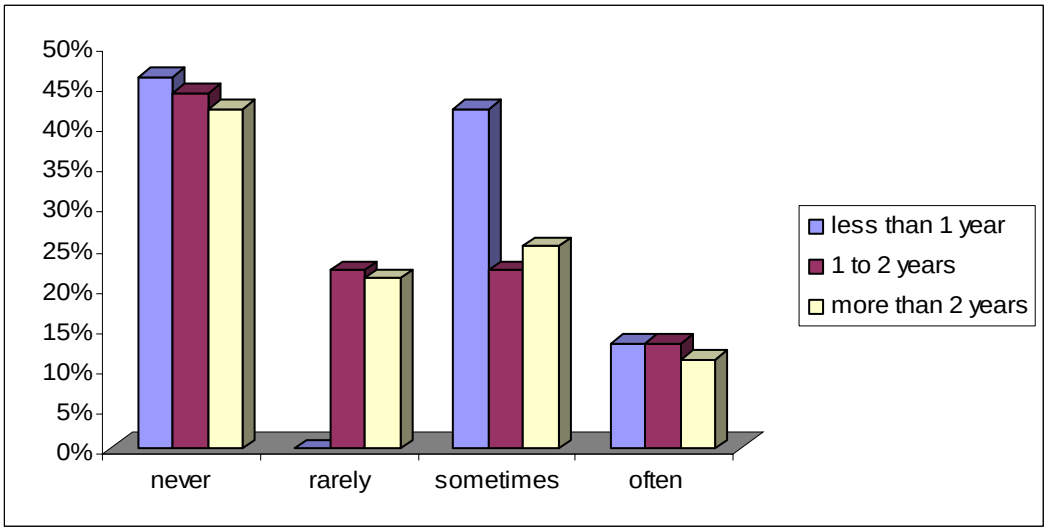
Differences by supportive housing type

Seventy-six percent of assisted living residents expressed never or rarely feeling lonely. This compares to 60 percent of residents of nursing homes and 53 percent of those living in residential care homes who said that they either never or rarely feel lonely. These differences are not statistically significant, but are interesting trends.

Differences by length of residence

While not statistically different, the people who have lived in their current residence for less than one year indicated that they felt lonely more often than those who have lived in their home for over one year. Over half (54%) of the people who have lived in their residence for less than one year said that they feel lonely sometimes or often, compared to about one-third of the other two groups (35% for those who have lived in their current residence for one to two years; and 36% for those who have lived in their home for over two years).

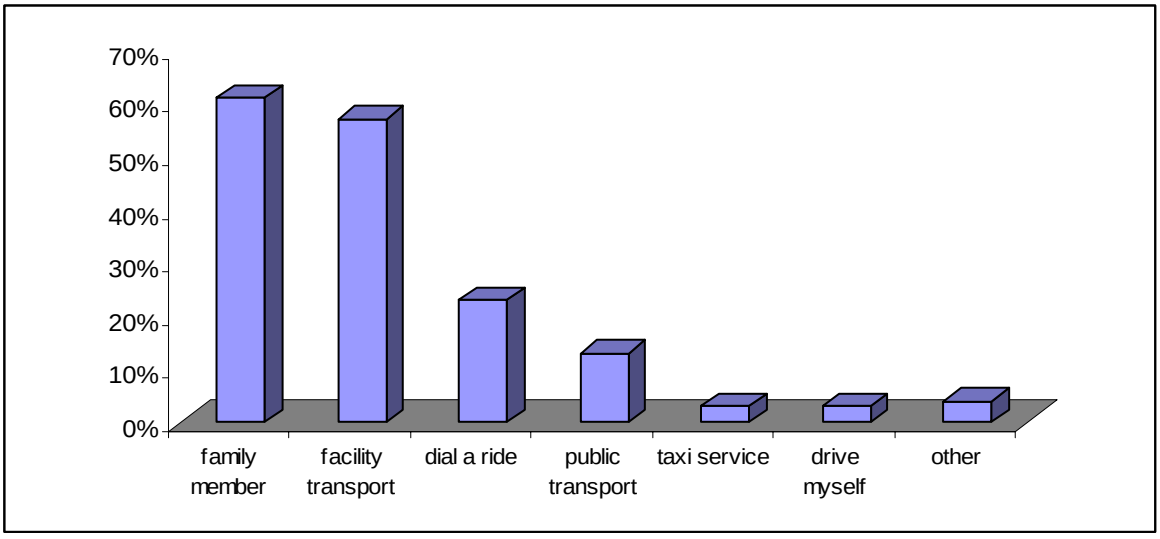
Figure II-17. Do you find yourself feeling lonely by length of residence



Transportation

Transportation is the next area of inquiry. Respondents were asked to indicate all of the types of transportation that they utilize. Overall, the majority of respondents rely on rides from family members or friends (61%). Over half of the respondents (57%) utilize transportation provided by their current residence and nearly one-fourth (23%) use dial-a-ride or other van service including volunteer drivers. Twenty-six percent of those responding indicated that they have difficulties with transportation when they do want to go somewhere. The most frequently noted obstacles to transportation were either that no family member or friend is available to give them a ride, or that dial-a-ride or van services are either inconvenient or not available where they live.

Figure II-18. How do you get to places outside of your residence*



*Categories are not mutually exclusive

Differences by supportive housing type

Seventy percent of those who are currently residing in residential care homes rely on transportation provided by that home. This compares to 56 percent of those living in nursing homes and 44 percent of people in assisted living. In addition, people who live in residential care homes were more likely to utilize public transportation. Thirty percent of people in RCHs said that they do use public transportation, compared to only 10 percent of people who are currently living in nursing homes and four percent of people who reside in assisted living. Sixteen percent of people who are currently in assisted living drive themselves, compared to none of people in nursing homes and three percent of people who are living in residential care homes.

Differences by age

More of the older individuals (age 65 and older) rely on family members for transportation. Two thirds (67%) of those who are age 64 to 84 rely on family members. Three-fourths (77%) of those older than age 85 rely on family members for transportation. This is in contrast to only 38 percent of those under the age of 50 and 51 percent of those age 50 to 64. Forty-four percent of those under the age of 50 utilize public transportation compared to only 20 percent of those who are age 50 to 64 and nine percent of those who are 65 to 84. None of those individuals who are over the age of 85 utilize public transportation.

Are there any services that are missing?

Differences by supportive housing type

The following open-ended question addresses any unmet needs or services provided by the respective residences. Once again in some cases people gave multiple responses. In the case of nursing home residents, 93 individuals responded to the question, and, of those, nine had an additional remark. For assisted living residents, 24 individuals responded to the question with only three of those offering a second remark. All of the respondents from the RCHs gave only one response to the question (n = 25). Considering all of the responses, the majority of the responses from nursing homes residents (59%) indicated that all of the services are available within their facility. This was also true for residents of assisted living, where 55 percent of the responses indicated that all services are available. Although not statistically significant, 76 percent of responses from RCH residents said that all of their needs are met within their residence.

> *No. We have two hairdressers who come here every Tuesday mornings 10 – 2. The podiatrists come every two or three months. They also have a dentist here who comes once a month. We have an ophthalmologist and audiologist. They have all their bases covered here.* – Nursing home resident

Looking at all of the responses, some of the missing services included transportation or better transportation (6%), hairdresser (6%), podiatrist (2%), dentist (2%), more shopping (4%), and more activities (2%) which was fairly consistent among all of the supportive housing types. In addition, some of the responses (6%) indicated that a family member meets these needs. Other missing services mentioned by only one or two individuals included better housekeeping, physical therapist, companions, vocational counselor, phone in room, support groups, and eyeglass store.

Medicaid

For those individuals who are on Medicaid, and for whom Medicaid pays for all or part of their care, respondents were asked if the $60 they receive each month as Personal Needs Allowance is enough for the things they need or want. Overall, 63 percent of the responses said that it is not enough, with 37 percent saying that it is enough. Thirteen percent of the responses indicated that their family or friends help them out financially, either giving them some money or perhaps buying them clothes. Overall, 13 percent of the responses said that they don't know or could not answer the question.

For those who said that $60 is not enough 44 percent say that they would be happy with up to $100 per month; 18 percent would like between $100 to $150 per month; five percent would like anywhere between $150 and $200 per month; and ten percent would like over $200 per month. Twenty-three percent of those responding said that they didn't know or were not sure about how much money would be enough.

Have any of your belongings been taken or gone missing?

Over one-third (39%) of respondents replied "yes" to the question, "Have any of your belongings been taken or gone missing since you've been living here?" The vast majority (83% or n=48) of those who experienced any kind of theft or had missing items said that they *do* report it. For all of the residents in all types of supportive housing, various and unspecified staff members were often the first ones contacted regarding the missing items. Thirty-six percent of the residents who have reported a theft or missing belongings said that they referred it to these staff members (who do not include staff in the following categories); 24 percent said that they would go directly to the administrator; 13 percent would notify the laundry staff; 13 percent would notify the nurse; and nine percent would notify the social worker of their residence. Only four percent of all residents said that they would report any items missing to the resident council. Another 10 percent of those who reported items missing went to someone other than staff.

Only thirteen percent of those who reported something missing found at least some part of what was missing. One-third (33%) of those who did report an item missing said that either the item was replaced or that they were reimbursed for at least some of what was missing. One-fourth (24%) of those who said that they reported missing items indicated that the item was replaced by whomever they reported it to. One-fourth of those who reported a lost or stolen item said that the party they contacted looked, asked, or talked about the event, but that the item could not be found and that they received neither a replacement nor reimbursement.

<u>Differences by supportive housing type</u>

For nursing home residents, half (50%) reported having items lost or stolen, whereas only twelve percent of those in assisted living reported items stolen or missing. Over one-fourth (27%) of those residents in RCHs reported having items stolen or lost.

<u>Differences by age</u>

Interestingly, 94 percent of those who are under the age of 50 reported having items lost or taken. This is compared to 37 percent of those age 50 to 64, 32 percent of those age 65 to 84 and 26 percent of those who are age 84 or older.

Do you worry about retaliation?

Two-thirds of the residents said that "no", they do not worry about retaliation if they were to report a complaint or concern. This was consistent across all supportive housing types. About a fifth (19%) of the total sample said "yes, they do worry about retaliation." Six percent of the total sample state that they do not want to complain. Other responses included items such as they "don't think about it or don't know", or "it wouldn't do any good to complain, or "I don't want to get people in trouble.

Table II-4. Fear of Retaliation

	SNF	ALSA	RCH
Yes, they worry	23%	13%	19%
No, they do not worry	70%	71%	71%
Don't want to complain	4%	8%	7%
Don't think about it/ Don't Know	2%	4%	0%
Don't want to get people in trouble	1%	4%	4%

When prompted for more details on the fear or worry about retaliation, responses varied. Among the majority of the sample who reported that they do not worry about retaliation, there were some that just do not worry and those who do not worry, but suggested any action they would take if it did occur. Example responses include:

> *Never.* – Nursing home resident
>
> *No, if I have complaints I talk to my son and he straightens it out* – Nursing home resident
>
> *No – they try to help you.* – Assisted living resident
>
> *No, people who work here know their job would be in jeopardy.* – Nursing home resident

For those who do worry about retaliation, some seem to do so because of what others have said or because they thought that retaliation might occur:

> *I think it is possible – I don't have any personality gripes. The administrator would probably be very good at listening, but maybe wouldn't do too much to remedy the situation.* – Assisted living resident
>
> *Yes, I heard a girl say that they know how to get even so I try to keep my mouth shut* – Nursing home resident

It's possible, I wouldn't allow it to happen, I'd talk to the Head Nurse. – Nursing home resident

Yes, they would send you to some place bad-for rehabilitation. – Nursing home resident

However, some responses seemed to be based upon actual occurrences of retaliation.

Oh yeah, always. That's why nobody makes the complaint. The administrator scares everyone and he's very belittling and yells at people. – Nursing home resident

Yes, there's a lot of retaliation. – Nursing home resident

Others talked about not wanting to "make trouble" or not wanting to "get people in trouble" or "tell on them". And some spoke about it "not doing any good to report it":

No – I don't want to get folks in trouble. – RCH resident

I think it is possible – I don't have any personality gripes. The administrator would probably be very good at listening, but maybe wouldn't do too much to remedy the situation. – Assisted living resident

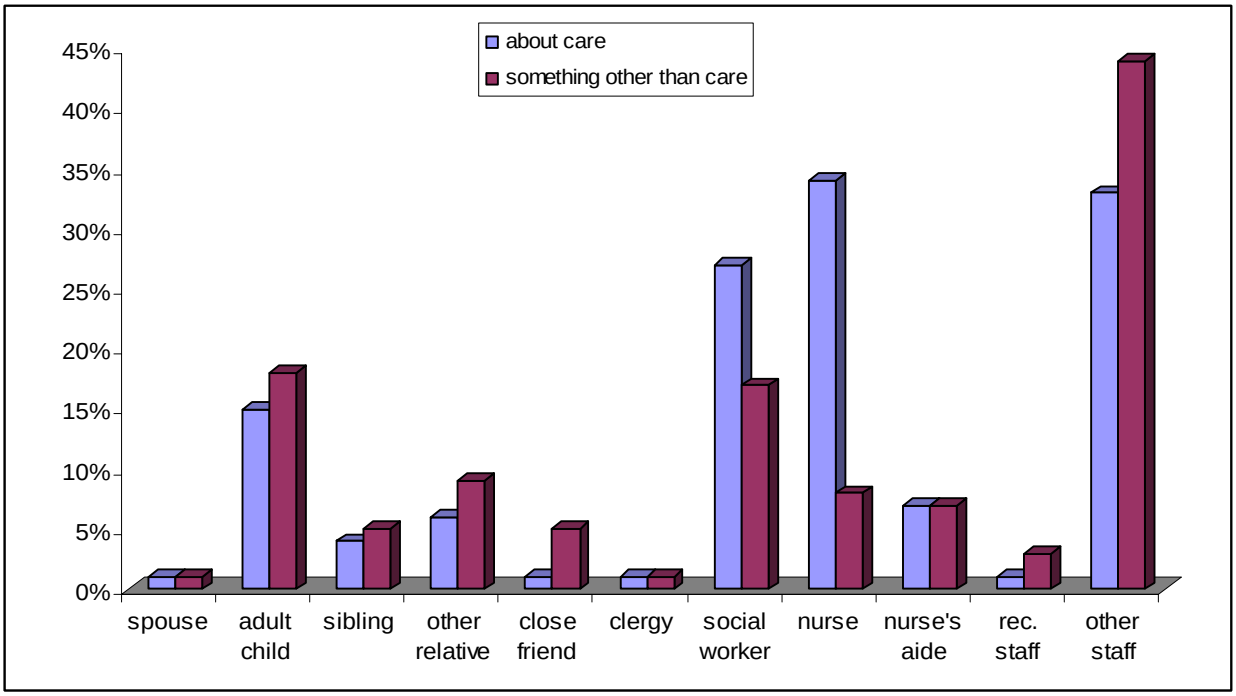
Differences by length of stay

A greater percentage (26%) of residents who have lived in their current living arrangement for over two years said that they do worry about retaliation. This compares to only 13 percent of those who have lived in their current situation for less than a year and 16 percent of those who have lived in their current situation for a period of one to two years.

Problems or complaints

The following two-part question relates to problems and complaints. For the first part of the question, the participants were asked once again to think about both the people who work at their current residence and also people that they see or talk to outside of the residence such as family. The first part of the question asked "If you have a complaint or problem with the care you receive, who do you talk to about it?" The second part of the question referred specifically to any problems or complaints that were not related to their care. If they have a complaint or problem with the care they are receiving, over one-third (34%) of the respondents said that they would go to a nurse, twenty-seven percent would go to a social worker and thirty-three percent also said that they would approach other staff, including the administrator or director. For general problems or complaints, most of the participants said that they would go to other staff, in many cases, the administrator of the supportive housing. This was consistent for all three supportive housing types.

Figure II-19. Who would you talk about problems or complaints about care vs. something other than care*

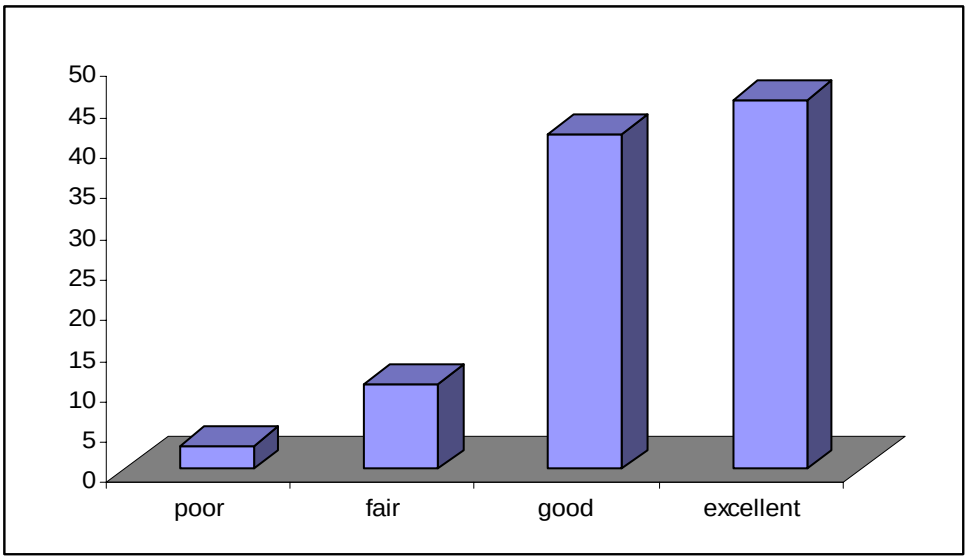


*categories are not mutually exclusive

Quality of care

When asked to report on the quality of care, most of the respondents felt that the quality of care that they receive is either excellent or good (86%). This is fairly consistent throughout all three types of supportive housing. Only three percent overall rated the quality of care as poor.

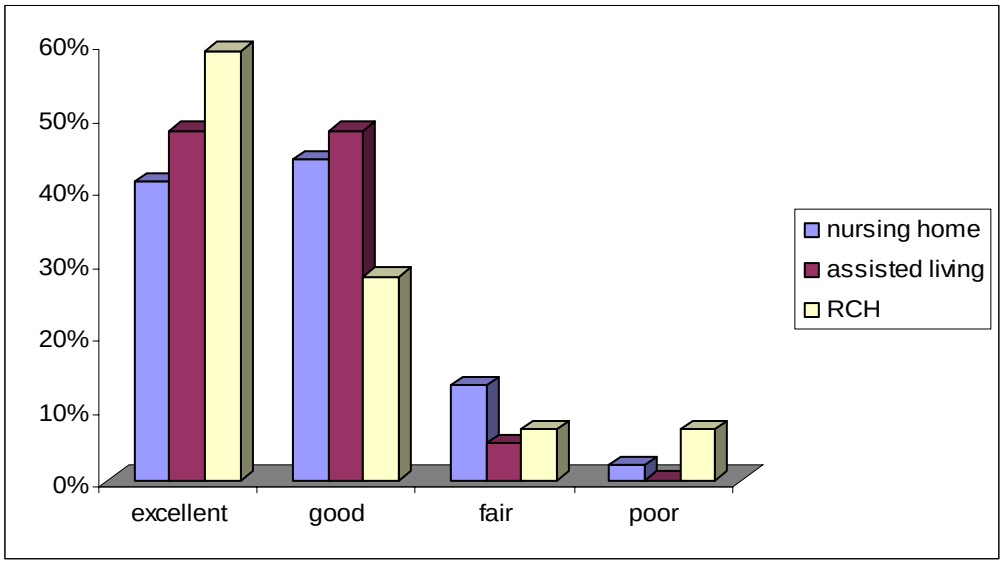
Figure II-20. Overall quality of care



Differences by supportive housing type

Rankings of good or excellent were fairly consistent among the different housing types. Ninety-four percent of those in assisted living would rank that quality of care as either excellent or good, compared to 84 percent of those in nursing homes and 85 percent of those living in RCHs. Seven percent of those living in RCHs rated the quality of care as poor, compared to only 2 percent of those living in nursing homes and none of those in assisted living. Thirteen percent of those in nursing homes would rate the quality of care that they receive as only fair, compared to only five percent of those living in assisted living and seven percent of those living in residential care homes.

Figure II-21. Quality of care by supportive housing type



Differences by age

When broken down by age, the majority of respondents in all of the age groups from age 50 up would rate the quality of care in their supportive living residence as either excellent or good. This includes 85 percent of those age 50 to 64, 96 percent of those ages 65 to 84, and 91 percent of those who are age 85 and older. Only 44 percent of those who are under the age of 50 said that the quality of care is either excellent or good. Nearly half of those under the age of 50 would rate the quality of care in their residence as only fair and 13 percent of those individuals under the age of 50 rate the quality of care as poor.

Language or cultural problems

Very few of the respondents found it difficult to talk to or understand anyone who provides care because of language differences or different cultural backgrounds. Only two percent of all respondents said that language or accents are always a problem. Eighty-one percent of all the respondents said that language or accents are either never or rarely a problem.

Privacy

Participants were asked a series of questions regarding their privacy. They were asked to respond to each of the questions with the following responses: often, sometimes, rarely, or never. The overall responses are shown in Table II-5.

Table II-5. Privacy

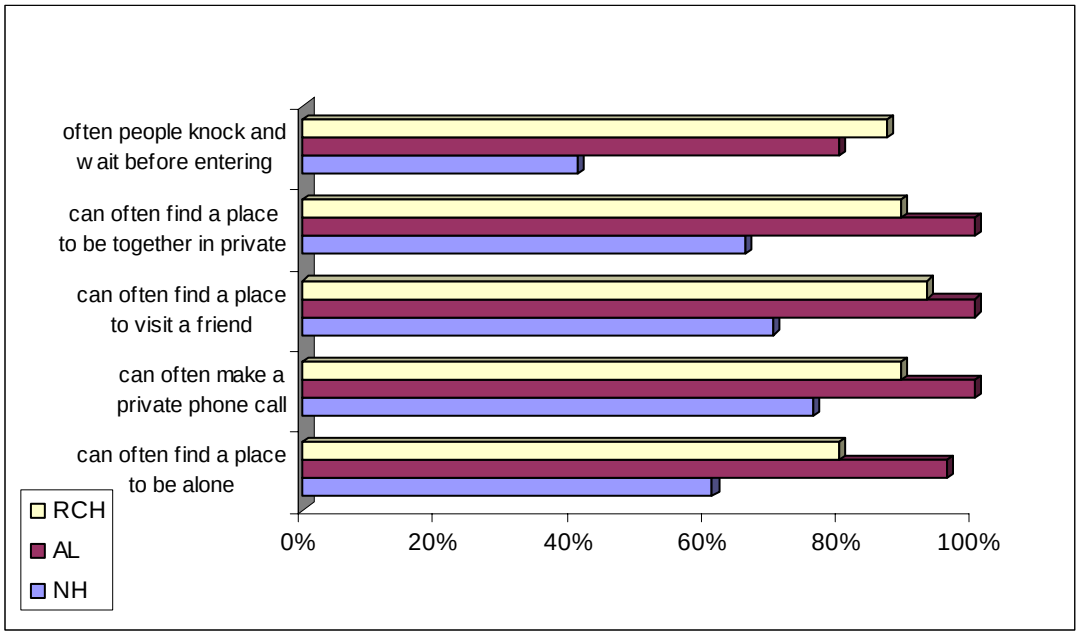
	Often	Sometimes	Rarely	Never
Can you find a place to be alone if you wish?	72%	15%	7%	6%
Can you make a private phone call?	84%	5%	7%	4%
When you have a visitor, can you find a place to visit in private?	81%	7%	3%	8%
Can you be together in private with another resident (other than your roommate)?	77%	10%	3%	9%
Do the people who work here knock and wait for a reply before entering your room?	57%	22%	11%	10%

Differences by supportive housing type

Significant differences might be expected for nursing homes residents for issues of privacy since most of the rooms are semi-private. Only 62 percent of those living in nursing homes said that they can often find a place to be alone compared to 96 percent of those in assisted living and 83 percent of those living in residential care homes. Only 41 percent of those living in nursing homes said that people often knock and wait for a reply before entering their room. This compares to 80 percent of those in assisted living and 87 percent of those in residential care homes.

The following chart shows a representation of those individuals who answered “often” for each of the questions regarding privacy. As might be expected, people in assisted living and RCHs answered “often” more frequently than those in a nursing home. This is most likely due to the type of room. Most people in assisted living and RCHs have private rooms or apartments, whereas most people in skilled nursing facilities share semi-private rooms.

Figure II-22. Privacy by type of residence



Respect for dignity

Questions regarding respect for dignity were included in all of the surveys. Once again, residents were asked a series of questions regarding the respect for their dignity, and were instructed to answer using the following responses: often, sometimes, rarely or never. However, some of the people who live in assisted living or residential care homes are not receiving care per se, only meals. Thus, the question about "staff handling you gently while giving you care" was considered not applicable for those individuals in assisted living or residents in RCHs who are not receiving hands-on care. All of the other questions were asked of all participants. Respect for dignity includes issues of staff treating residents politely and respectfully as well as gently and considerately. Responses from the three different types of living situations were not significantly different. The responses from all of the residents are shown in Table II-6.

Table II-6. Respect for dignity

	Often	Sometimes	Rarely	Never
Do staff here treat you politely? (n=150)	88%	10%	1%	1%
Do you feel that you are treated with respect here? (n=149)	83%	13%	2%	2%
Do staff here handle you gently while giving you care? (n=135)	89%	10%	0%	1%
Do staff here respect your modesty? (n=138)	81%	16%	1%	2%
Do staff take time to listen to you when you have something to say? (n=148)	74%	18%	6%	2%

Autonomy

The next set of questions addressed autonomy, defined as the choice and control that individuals have. The residents were asked to answer the series of questions on autonomy using the following responses: often, sometimes, rarely or never. These included choices and decisions about going to bed, getting up, deciding on their own clothes and making changes in things that they do not like. Often, when responding to the question "Have you been successful in making changes in things that you do not like?" the resident said something like "there's nothing I don't like." The results for all respondents are as follows.

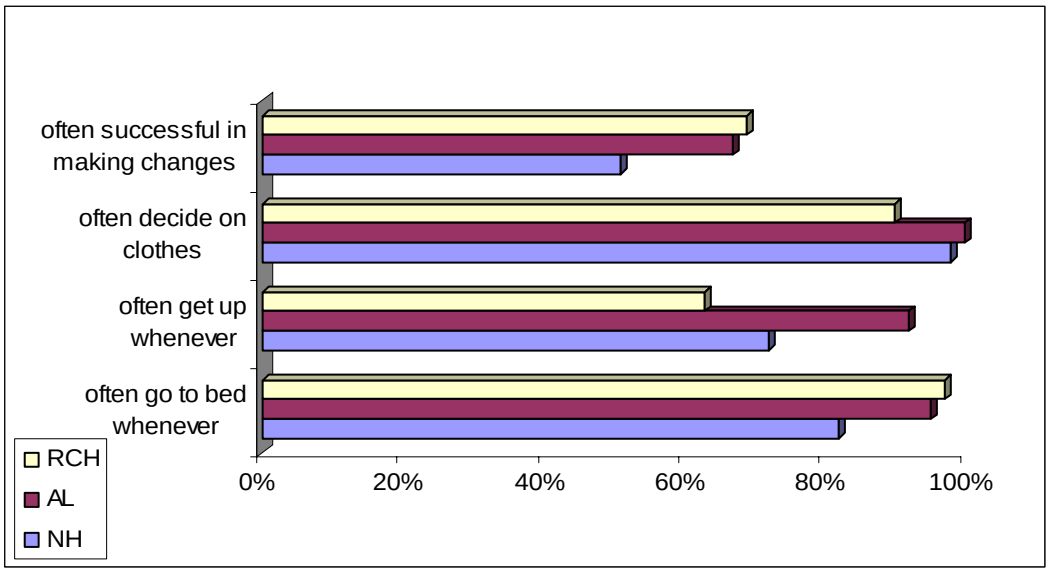
Table II-7. Autonomy scale

	Often	Sometimes	Rarely	Never
Can you go to bed at the time you want? (n=150)	87%	8%	2%	3%
Can you get up in the morning at the time you want? (n=150)	73%	7%	7%	9%
Can you decide what clothes to wear? (n=149)	97%	3%	1%	0%
Have you been successful in making changes in things that you do not like? (n=134)	57%	25%	7%	10%

Differences by supportive housing type

The results are further broken down according to the type of supportive housing. In the case of autonomy, there are slight differences among the various housing types. The following chart represents the percentage of each group who said "often" for the various autonomy questions. Nursing home residents were slightly lower in the percent of residents who answered "often" in three of the categories of autonomy.

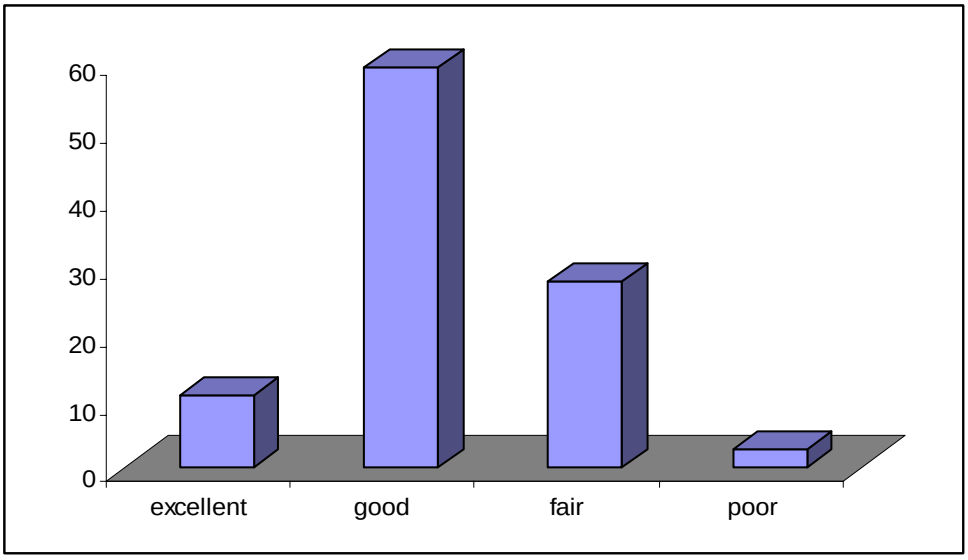
Figure II-23. Autonomy by supportive housing type



Health and depression

Each of the respondents was asked questions regarding their overall health and feelings of depression. The rating of overall health is fairly consistent from one type of supportive housing to another. Overall, the residents from all supportive housing types indicated that their health is excellent or good (70%).

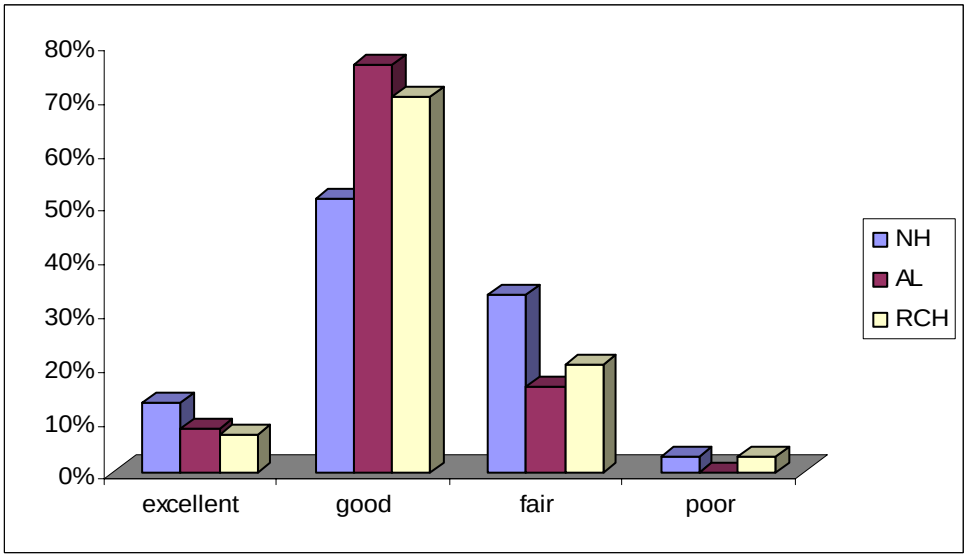
Figure II-24. Rating of overall health



Comparisons by supportive housing type

Sixty-three percent of those residing in nursing homes indicated that their health is either excellent or good, compared to 84 percent of those in assisted living and 77 percent of those in residential care homes. Over one-third of residents of nursing homes (36%) would describe their health as either fair or poor, compared to 16 percent of those in assisted living and 23% of those in residential care homes. However, these differences are not statistically significant.

Figure II-25. Rating of over health by supportive housing type

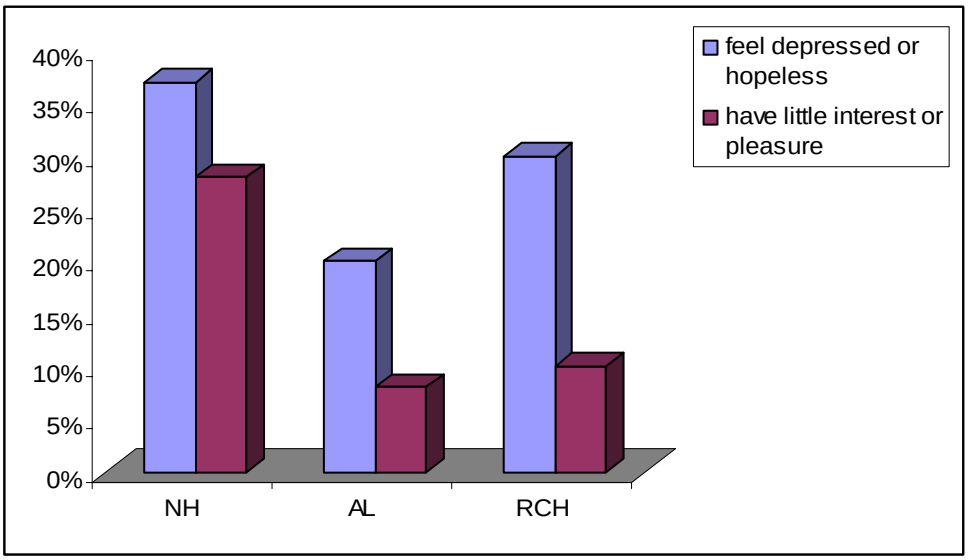


Thinking of the past month, the participants were asked about feeling down, depressed or hopeless or being bothered by having little interest or pleasure in doing things. One-third of the respondents overall indicated that they are bothered by feeling down, depressed or hopeless and 20 percent of the respondents overall said that they are bothered by having little interest or pleasure in doing things. These numbers are relatively high compared to rates of five to 10 percent in the general population.

Differences by supportive housing type

Thirty-seven percent of people who are living in nursing homes said they have been bothered by feeling down depressed or hopeless, compared to 20 percent of those living in assisted living situations and 30 percent of those living in residential care homes. Similarly, 28 percent of those living in nursing homes said that they have been bothered by having little interest or pleasure in doing things. Only eight percent of people in assisted living and only 10 percent of those who are living in RCHs said that they feel that way. The results are shown in Figure II-26.

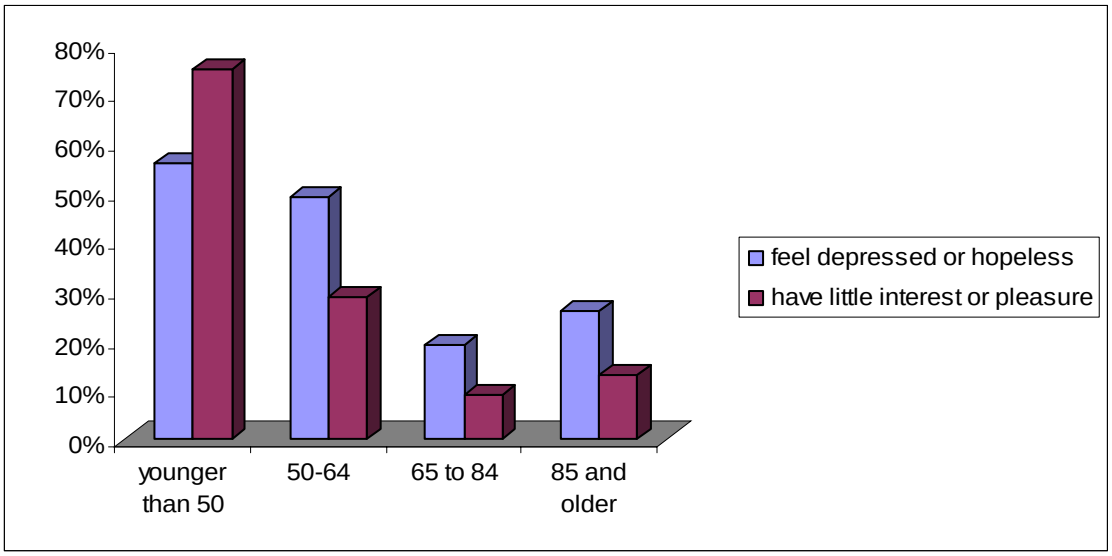
Figure II-26. Depression by supportive housing type



Differences by age

Breaking it down by age groups, more of the younger two groups felt depressed or hopeless and expressed having little interest or pleasure in doing things. Fifty-six percent of those under the age of 50 and 47 percent of those age 50 to 64 said that they do feel depressed or hopeless. This is compared to only 19 percent of those who are age 64 to 84 and 26 percent of those who are over the age of 85. Seventy-five percent of those who are under the age of 50 said that they have little interest or pleasure in doing things. This is compared to 29 percent of those age 50 to 64, nine percent of those age 65 to 84, and 13 percent of those over the age of 85.

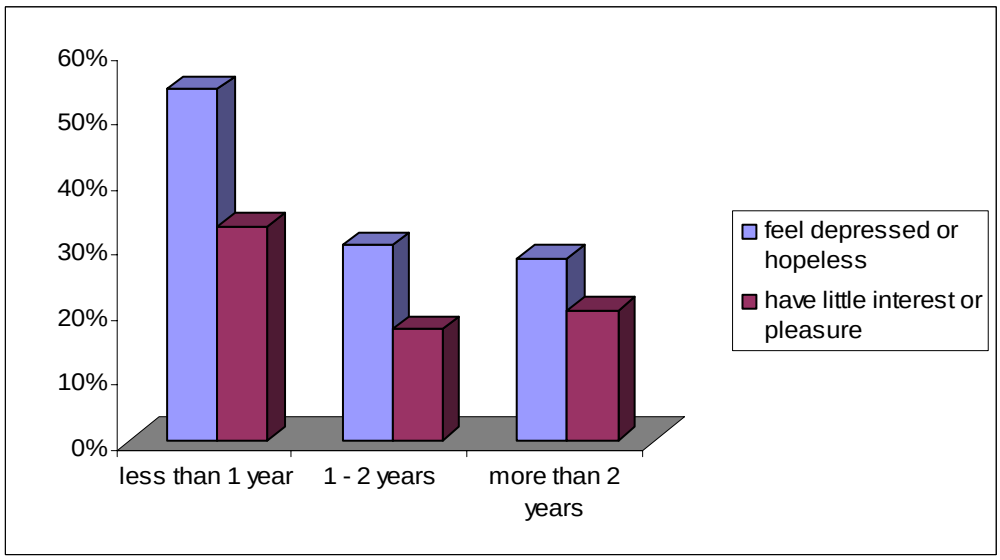
Figure II-27. Depression by age



Differences by length of residence

More than half (54%) of the people who have lived in their current home for less than one year said that they are bothered by feeling down or depressed or hopeless. This compares to 30 percent of the people who have lived in their current residence for one to two years and 28 percent of the residents who have been in their residence for over two years. In addition, one-third (33%) of those who have been in their current home for less than one year said that they are bothered by having little interest or pleasure in doing things. This is compared to only 17 percent of those who have been in their current living supportive housing residence for one to two years, and 20 percent of the residents who have been in their current residence for over two years.

Figure II-28. Depression by length of residence



Demographics

Of the residents interviewed for this study, 63 percent live in nursing homes, 17 percent are in assisted living, and 20 percent are in residential care homes. Their demographics with respect to gender, race, and ethnicity are similar to the population of residents in Connecticut long-term care supportive housing, as reported by providers in the 2007 Connecticut Long-Term Care Needs Assessment (Robison, Gruman, Shugrue, Kellett, Porter, & Reed, 2007). Their age, however, is lower on average than that of all residents of long-term care supportive housing as reported by providers (Robison et al., 2007). There are two main reasons for the lower average age of those interviewed for this study. First, many were recruited from the 2006 Ombudsman Program VOICES forum, which consists of more active residents able to travel to the meeting site. In addition, the interviews required a level of cognitive ability to understand and answer questions, which is more prevalent in younger residents.

Seventy-five percent of respondents are female and 25 percent are male. There were more males (37%) participating in the interviews from RCHs and fewer males (16%) from assisted living. White respondents account for 88 percent of the sample with 12 percent being non-white. Almost all of the non-white residents interviewed live in nursing homes. Three percent of the respondents report being from Spanish, Latino or Hispanic origin and 97 percent state that English is the language that they mainly speak with family or friends. (Note: the survey was only administered in English).

The residents interviewed range in age from 34 to 101 years old. The mean age for the total sample is 72.03 (nursing homes (m=69), RCHs (m=66), and for assisted living residents (m=85).) More people in the under-65 age group and fewer people in the 85+ age group were interviewed than would have been predicted from a random sample of people living in the three supportive housing types.

Overall, 63 percent of the sample has a high school/GED education or less. Twenty-five percent have some college or technical school and 12 percent have completed four years of college or attained a graduate degree. Assisted living residents are slightly more educated with 41 percent having completed only high school/GED, 17 percent with some college or technical school and 41 percent holding a four year college or graduate degree.

There were differences in marital status depending upon the supportive housing type. The largest percent of the nursing home sample is widowed (44%). Seventeen percent are divorced or separated, 11 percent are married and 25 percent were never married. Never married was much higher among the RCH residents (40%) and lower among ALSAs (4%). Only 30 percent of the residents of the RCHs have lost a spouse while 73 percent of the residents from assisted living are widowed.

III. Conclusions

Individuals who participated in the survey living in supportive housing types range in age from 34 to 101 years of age. Supportive housing types include skilled nursing facilities, assisted living, and residential care homes. With the exception of some of those in assisted living, most of the residents receive some form of care, whether it is help with medications, activities of daily living, instrumental activities of daily living, or transportation. The level of care required marks the differences among supportive housing types, where those in skilled nursing facilities often require a higher level of care than those living in either assisted living or residential care homes. A greater percentage of those now living nursing homes (59%) came to live in a nursing home as a result of recuperation from an acute illness, operation or fall. A greater percentage of those who now live in assisted living (76%) came directly from their home or apartment.

Half (50%) of those individuals now in assisted living had some role in the choice of residence. The percent with no input into this decision is even higher for those now in nursing homes (60%) and for those now in residential care homes (73%).

A majority of residents now in assisted living (67%) are happy with where they are right now, compared to only 25 percent of those in nursing homes and 30 percent of those in residential care homes. Overall, almost half of those interviewed (44%) said that they would like to be living somewhere else, either on their own or at home, in their own condo or apartment, or with family.

Those participants in assisted living seem to be more content in many different aspects of living, from going out into the community, having visits from relatives or friends, experiencing less depression and hopelessness. In addition a greater percentage of those in assisted living had at least some role in the decision to move to that environment.

Overall, the majority of all residents (86%) would rate the quality of care that they receive as either excellent or good. Users of long-term care services report high satisfaction with their care, and most of their needs are being met.

Significant mental health issues are reported by respondents. Using a standardized two question depression screen (see Appendix A-9), approximately one-third of all respondents reported feeling down, depressed, or hopeless, and 20 percent reported having little interest or pleasure in doing things.

IV. Recommendations

Although this report was commissioned by the Connecticut Long Term Care Ombudsman Program, many of the recommendations stemming from this survey of supportive housing residents go beyond the scope of that Program's mandate. In its advocacy role, the CT LTCOP should support the following recommendations. Three of the following recommendations (# 2, # 3, and # 5) are also included in Part II of the 2007 Connecticut Long-Term Care Needs Assessment (Robison, et al., 2007). In these three cases, the recommendation is included with supporting evidence from the supportive housing survey results. The full report of the Needs Assessment findings can be found at: http://www.cga.ct.gov/coa/incl_longtermcare.htm.

1. Increase access to assisted living models of care as appropriate. One of the most prominent themes emerging from the survey results is the fact that assisted living residents are generally happier with their living situations than are RCH and nursing home residents. Assisted living residents report more visits and contacts with friends and family, more trips into the community, less boredom, and fewer feelings of loneliness. Given the state's commitment to providing real choice and recognizing individual preferences for long-term care, programs and policies aimed at increasing opportunities to live in a community residence with assisted living services are recommended. Financial barriers to accessing assisted living should also continue to be minimized through initiatives such as the Medicaid assisted living pilot demonstration.

2. Address scope and quality of institutional care. While preferred by many residents, assisted living cannot always provide the more intensive level of care required by an individual. Institutional care may be the most appropriate choice for some individuals. In these situations, providing high quality, home-like settings and individualized care are essential for maintaining residents' quality of life.

3. Provide a broader range of community-based choices for long-term care supports. While one-third of residents reported that their current living situation is their *ideal* living situation, two-thirds would rather live somewhere else. In most cases, their choices are constrained by lack of funding, lack of support, or lack of knowledge about alternative choices.

4. Increase opportunities for consumer choice in selecting both the *type* of housing and the *specific residence* when moving to supportive housing. In most cases, across all supportive housing types, individuals expressed a desire to be as independent as possible. All of the participants were capable of expressing their opinions about their current situations and describing their ideal living situations. However, many reported having had no part at all in the decision making process regarding relocation. To the extent feasible, individuals should be given substantive opportunities to express their preferences and views on the relocation setting. Consumer input can be facilitated by those responsible for supporting individuals in housing transitions. Given the large percentage of participants who moved into the new setting from their own home or apartment, particular emphasis should be placed on ensuring that family members and community physicians have complete information about the range of housing options. Other important target groups for education include hospital and rehabilitation discharge planners, case managers, mental health clinicians, and ombudspersons. It is essential to ensure family members and health professionals responsible for these discussions have access to current, comprehensive information about the range of supportive housing options in specific towns or regions across the state.

5. Provide true consumer choice and self-direction to all long-term care users to the extent feasible. It is evident from this survey that the majority of supportive housing residents did not exercise any choice in selecting their current home. Yet many participants clearly want to direct their own long-term care on some level, either independently or with assistance from family members or professionals of their choosing.

6. Provide adequate mental health diagnosis and treatment. Residents of all three types of supportive housing reported feeling depressed at higher rates than the general population. These feelings were reported most often by younger individuals, particularly in RCHs, but also by nursing home residents. Early and ongoing attention to mental health issues is essential in these settings, beginning with comprehensive mental health assessments upon admission and continuing on a regular basis. Barriers to accessing treatment should be systematically identified and addressed as feasible in each setting through connections with community mental health professionals and in staff training. In addition, programs and practices aimed at enhancing the quality of life for these individuals should be explored and supported, potentially via linkages with the ongoing Mental Health Systems Transformation Grant.

7. Support ongoing initiatives to help people transition out of institutions and to divert people from entering institutions when that is not their preferred residence. Connecticut currently has three such initiatives, the Money Follows the Person Rebalancing Demonstration, the state-funded Nursing Facility Transition Program, and the newly-awarded Nursing Home Diversion Modernization Grant from the Administration on Aging. Information about these initiatives must be widely disseminated not only in nursing homes, but also to hospital discharge planners, community physicians and social workers, and families. The CT LTCOP should advocate for and support efficient, effective statewide dissemination of detailed information regarding these programs to these key groups and strongly advocate for state legislation necessary for their successful implementation.

8. Institute community and facility-based fall prevention programs. Many of the survey respondents reported that they moved to supportive housing due to a fall. Evidence-based fall prevention programs have been developed and tested in Connecticut by the CT Collaboration for Fall Prevention and need to be instituted state-wide. The Department of Social Services received funding to assist with these activities in the 2007 legislative session. The Ombudsman Program should offer support and guidance to the CT Collaboration for Fall Prevention in the wide-spread implementation of these programs.

9. Expand volunteer programs in supportive housing facilities. Volunteer advocates in the CT LTCOP play a key role in providing access to the Program's services. Volunteers can serve many roles in addition to this advocacy work, including providing friendly visits and participating in programs designed to bring residents into the community for a range of activities and social engagement. Many of the individuals, particularly those without any family members, are isolated in their supportive housing settings and would benefit from visits or trips into the community. Younger adults, primarily those in residential care homes, frequently reported symptoms of depression and have few contacts with supportive family members. This is in contrast to many of the older residents who do have supportive families, typically their adult children, who enhance their opportunities for involvement in community and recreation. Funding for volunteer program coordination should be expanded.

10. Develop educational materials and reporting guidelines to address fear of retaliation among supportive housing residents. About 20 percent of residents expressed a fear of staff retaliation if they report a complaint or concern. Ombudsmen need to continue to provide an

outlet for complaints of actual retaliation or fear of retaliation. Staff and residents should be educated about what retaliation is and how to deal with it, and this education should be promoted and supported by the administration. Information regarding retaliation could be effectively integrated or enhanced in current mandatory staff training on resident rights. Resident councils could present information about retaliation and procedures for reporting and dealing with complaints.

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Appendix A.

Supportive Housing Resident Survey

Supportive Housing Resident Survey

1. How long have you been living here?
   - ☐ Less than 3 months
   - ☐ 3 months to 6 months
   - ☐ 6 months to one year
   - ☐ 1 to 2 years
   - ☐ More than 2 years

2a. Where were you right before you came here?
   - ☐ A hospital
   - ☐ A nursing home
   - ☐ Community housing with support (e.g. assisted living, residential care, senior housing)
   - ☐ A private home or apartment
     - o Your own
     - o Someone else's (whose?)_____
   - ☐ Other _____

2b. How did you come to live here? [INT: Probe for narrative of what precipitated entering the NH/AL/rest home]

_____

_____

_____

_____

3a. What role did you have in choosing this [nursing home, assisted living facility, rest home]? [INT: Probe for their role in selecting, or agreeing to, their current living arrangement; who made the decisions?]

_____

_____

_____

_____

3b. Did you consider another type of living situation?

☐ No

☐ Yes → What other living situations did you consider? How many places did you look at?

_____

_____

_____

4. I'd like to hear about what it is like to live here. Can you describe a typical day for me?

_____

_____

_____

_____

5. If you could change something about living here, what would it be?

_____

_____

_____

6a. Given your current condition and support needs, what would be your ideal living situation? In other words, if you had a choice, where would you like to live?

_____

_____

_____

6b. Why would you like to live there? Or what would you like about living there?

_____

_____

7. For the next question, please think about all the people who you see, both people who work here **and** people in your family or others who you see or talk to.

When you need help, who do you ask? Anyone else? [INT: Do **Not** read categories. Check all that respondent mentions. If they only mention people who work in the facility ask "Is there anyone who does not work here?"]

- ☐ Spouse/partner
- ☐ Adult child
- ☐ Sibling
- ☐ Other relative
- ☐ Close friend
- ☐ Clergy
- ☐ Social worker at facility
- ☐ Nurse at facility
- ☐ Nursing assistant or aide at facility
- ☐ Recreational staff at facility
- ☐ Other staff at facility
- ☐ Other: _____

Ask Question 8 only for any person checked in Q#7 who come from outside the facility:

8. How often do you see _____. Would you say often (at least once a week), sometimes (at least once a month), rarely (less than once a month), or never (less than once a year)?

How often do you see …..	**Often** *(At least once a week)*	**Sometimes** *(At least once a month)*	**Rarely** *(Less than once a month)*	**Never** *(Less than once a year)*
Spouse/partner	☐	☐	☐	☐
Adult child	☐	☐	☐	☐
Sibling	☐	☐	☐	☐
Other relative	☐	☐	☐	☐
Close friend	☐	☐	☐	☐
Clergy	☐	☐	☐	☐
Other: _____	☐	☐	☐	☐

9. How often do you go out into the community for recreation and enjoyment?

- ☐ Several times a day
- ☐ Daily
- ☐ Several times a week
- ☐ Weekly
- ☐ At least monthly
- ☐ Less than monthly
- ☐ Not at all

10. Do you go out into the community as much as you want to, or would you like to go out more or less?

- ☐ Yes, I go out enough
- ☐ No, I want to go out more
- ☐ No, I want to go out less

11. How often do you receive visits from friends and family?

- ☐ Several times a day
- ☐ Daily
- ☐ Several times a week
- ☐ Weekly
- ☐ At least monthly
- ☐ Less than monthly
- ☐ Not at all

12. Do you get as many visits from friends and family as you want, or would you like more or fewer visits?

- ☐ Yes, I get the right amount of visits
- ☐ No, I would like more visits
- ☐ No, I would like fewer visits

13. How often do you communicate (telephone, e-mail, etc.) with friends and family aside from making appointments or arranging services?

- ☐ Several times a day
- ☐ Daily
- ☐ Several times a week
- ☐ Weekly
- ☐ At least monthly
- ☐ Less than monthly
- ☐ Not at all

14. Do you communicate with friends and family as much as you want, or would you want to talk to them more or less?

- ☐ Yes, I talk with them as much as I want
- ☐ No, I would like to talk to them more often
- ☐ No, I would like to talk to them less often

15. Do the days here seem too long for you? Does this happen…

- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

16. Do you find yourself feeling lonely often, sometimes, rarely or never?

- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

17. How do you usually get to places outside of _____? Check all that apply.

- ☐ Get a ride from family member or friend
- ☐ Transportation provided by the [nursing home, assisted living, rest home]
- ☐ Use dial a ride or other van service
- ☐ Public transportation, such as the bus or train
- ☐ Use taxi service
- ☐ Drive myself
- ☐ Other (describe): _____

18. Do you have any difficulties with transportation when you want to go somewhere?

- ☐ No
- ☐ Yes → **If Yes,** Please describe these difficulties:
  [Interviewer – Do not read list. Check if already on list, or write in below]

  - ☐ Friend or family member not always available
  - ☐ Dial a ride or other van service not always available or inconvenient
  - ☐ Dial a ride or other van service undependable
  - ☐ Public buses or vans unavailable or inconvenient
  - ☐ Costs too much
  - ☐ No one I can depend on or no help available
  - ☐ Physical or other impairments
  - ☐ No door to door transportation
  - ☐ Other (list below)

  _____

19. Are there any services or help that you need that you are not able to get? This could include things like seeing a podiatrist, getting your hair done, better transportation, help shopping for clothes or personal items, or any other help you need but are not getting.

_____

_____

_____

20. If Medicaid pays for some or all of your care, you are allowed to keep about $60 of your own money each month. Is this enough for the things that you need or want? **[If yes, skip to question 22.]**

_____

_____

_____

21. How much would be enough?

_____

_____

_____

22. Have any of your belongings been taken or gone missing since you've been living here?
☐ No → **If no, skip to question 26**
☐ Yes

23. Did you report that it was missing or taken?
☐ No → **If no, skip to question 26**
☐ Yes

24. Who did you tell about it? [Ask for relationship to person **Or** title of person at facility.]

_____

25. What did they do about it?

_____

_____

_____

26a. For the next 2 questions, please think again about both people who work here **and** people you see or talk to outside of this facility, like your family.

If you have a complaint or problem with the care you receive, who do you talk to about it? Anyone else? (Do not list options – just check any that person mentions. If they only mention people who work in the facility, ask "Is there anyone who does not work here who you talk to about problems with your care?")

- ☐ Spouse/partner
- ☐ Adult child
- ☐ Sibling
- ☐ Other relative
- ☐ Close friend
- ☐ Clergy
- ☐ Social worker at facility
- ☐ Nurse at facility
- ☐ Nursing assistant or aide at facility
- ☐ Recreational staff at facility
- ☐ Other staff at facility
- ☐ Other: _____

_____

_____

26b. If you have a complaint or problem <u>with something else not related to your care</u>, who do you talk to about it? Anyone else? (Do not list options – just check any that person mentions. If they only mention people who work in the facility, ask "Is there anyone who does not work here who you talk to about other problems?")

- ☐ Spouse/partner
- ☐ Adult child
- ☐ Sibling
- ☐ Other relative
- ☐ Close friend
- ☐ Clergy
- ☐ Social worker at facility
- ☐ Nurse at facility
- ☐ Nursing assistant or aide at facility
- ☐ Recreational staff at facility
- ☐ Other staff at facility
- ☐ Other: _____

_____

_____

27. Do you worry about retaliation if you were to report a complaint or concern? Can you tell me about this?

_____

_____

_____

<u>Quality of Care</u>

28. Now we would like to hear what you think about the care you are getting here. How would you rate the overall quality of care you receive here? Please rate it by telling me if it is poor, fair, good, or excellent.

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

_____

_____

29. How often is it difficult for you to talk to or understand anyone who provides care to you because they speak a different language than you, have a strong accent, or are from a different cultural background? Does this happen…

- ☐ Always
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

30. The next questions are about privacy or lack of privacy. Please tell me if this happens often, sometimes, rarely, or never.

	Often	Sometimes	Rarely	Never
Can you find a place to be alone if you wish?	☐	☐	☐	☐
Can you make a private phone call?	☐	☐	☐	☐
When you have a visitor, can you find a place to visit in private?	☐	☐	☐	☐
Can you be together in private with another resident (other than your roommate)?	☐	☐	☐	☐
Do the people who work here knock and wait for a reply before entering your room?	☐	☐	☐	☐

31. The next questions concern respect for your dignity. Please tell me if this happens often, sometimes, rarely, or never.

	Often	Sometimes	Rarely	Never
Do staff here treat you politely?	☐	☐	☐	☐
Do you feel that you are treated with respect here?	☐	☐	☐	☐
Do staff here handle you gently while giving you care?	☐	☐	☐	☐
Do staff here respect your modesty?	☐	☐	☐	☐
Do staff take time to listen to you when you have something to say?	☐	☐	☐	☐

32. Autonomy scale: The next questions are about the choice and control that you have. Please tell me if this happens often, sometimes, rarely, or never.

	Often	Sometimes	Rarely	Never
Can you go to bed at the time you want?	☐	☐	☐	☐
Can you get up in the morning at the time you want?	☐	☐	☐	☐
Can you decide what clothes to wear?	☐	☐	☐	☐
Have you been successful in making changes in things that you do not like?	☐	☐	☐	☐

General Information

33. How would you describe your overall health at this time? Would you say…
    - ☐ Excellent
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

34. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
    - ☐ Yes
    - ☐ No

35. During the past month, have you often been bothered by little interest or pleasure in doing things?
    - ☐ Yes
    - ☐ No

36. What is your age? _____

37. What is your gender?
    - ☐ Male
    - ☐ Female

38. Which category best describes your race? (Read list out loud and check only one.)
    - ☐ White or Caucasian
    - ☐ Black, African-American, or Caribbean Black
    - ☐ American Indian or Alaska Native
    - ☐ Asian, including Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other Asian
    - ☐ Native Hawaiian, Samoan and other Pacific Islander
    - ☐ Other: _____

39. Are you of Spanish, Latino, or Hispanic origin?
    - ☐ Yes
    - ☐ No

40. What language do you <u>mainly</u> speak with family or friends? (Do not list all choices - just check what respondent offers)
    - ☐ English
    - ☐ French
    - ☐ Italian
    - ☐ Polish
    - ☐ Portuguese
    - ☐ Russian
    - ☐ Spanish
    - ☐ Other _____

41. What is the highest grade or year you finished in school?
    - ☐ 8th grade or less
    - ☐ Some high school
    - ☐ High school diploma or GED
    - ☐ Technical school or community college
    - ☐ Some college
    - ☐ Two-year college degree
    - ☐ Four-year college degree
    - ☐ Post graduate degree

42. What is your marital status? (If person says single, ask whether person is if never married, widowed, or divorced.)

☐ Married
☐ Widowed
☐ Divorced
☐ Separated
☐ Never married

43. Is there anything else you would like to add?

_____

_____

_____

_____

Thank you for completing this survey with me.