The View from Here: Resident Quality of Life at Long Term Care Facilities
Inglis House, Philadelphia

Robert Wood Johnson Foundation Clinical Scholars Program
2013 Summer Community Project

Marcus Bachhuber, M.D.
Elizabeth Brown, M.D.
Brandon Maughan, M.D.
Pooja Mehta, M.D.
Loren Robinson, M.D.
Charlene Wong, M.D.

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Executive Summary

This report was executed by the Robert Wood Johnson Foundation Clinical Scholars Program in partnership with the Pennsylvania Empowered Expert Residents (PEERS) of Inglis House and the Center for Advocacy for the Rights and Interests of the Elderly (CARIE) in response to the following charge:

1) Understand the elements that impact quality of life for individuals living in long-term specialty care facilities

2) Develop strategies for individuals living in long-term specialty care facilities to actively partner with staff and administration to improve quality of life

3) Identify ways in which these findings may be disseminated locally and/or nationally

Interviews with residents, staff, and other key stakeholders were conducted. Throughout the interviews, three core principles relating to quality of life emerged. Subsequent recommendations are organized around these core principles: communication, autonomy, and accountability.

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<td>More can be done to support effective communication between residents, staff and administration</td>
<td>Residents want to maximize choice and self-determination within their individual constraints</td>
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<th><strong>RECOMMENDATIONS</strong></th>
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<td>Implement integrated communication training: utilize residents as trainers and focus on conflict resolution</td>
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<td>• Open discussion on resident-identified sensitive topics, e.g. race, sexuality, grief</td>
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<td>• Update residents regularly regarding day-to-day operations</td>
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<td>• Clarify feedback mechanisms through a visual display developed with resident, staff, and administrative collaboration; display throughout the facility</td>
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<td>• Employ novel feedback mechanisms that incorporate adaptive technology: interactive “electronic suggestion box”</td>
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Quality of life relates to choice and control, positive and meaningful interactions, and equitable, person-centered care.

This concept is being used to redefine how society thinks about many aspects of medical care, including long-term residential care for persons with chronic illnesses and disabilities. Over recent years, a “culture-change movement” has initiated a dramatic shift by using a quality of life approach to redefine norms within long-term care facilities. This movement focuses on transforming nursing homes from impersonal institutions into “person-centered homes” and includes thirty years of consumer advocacy and legislative work aimed at improving quality of life for residents (Koren 2010).

The term “quality of life” has clearly been defined in the long-term care literature as well as elsewhere. Implied in its use is the belief that even though the perception of one's personal well-being is a subjective phenomenon, a quality of life construct can be used at a micro and macro level to sensitize and individualize care (Schalock et al 2005). At the micro level, it can be used as a basis for self-advocacy, person-centered planning, and a valued person-referenced outcome from education and rehabilitation programs (Anderson & Burckhardt, 1999; Schalock et al., 2002; Schalock & Verdugo, 2002). At a more macro level, it can be used for program planning, resource allocation, participatory action research, and continuous program improvement (Schalock & Bonham, 2003). In this report, the specific elements that have been established and replicated in cross-cultural studies as key contributors to quality of life will be further explored.

How does one define “long-term care”? The phrase includes a diverse array of services provided over a sustained period of time to people of all ages with chronic conditions and functional limitations. Needs can range from minimal personal assistance with basic activities of everyday life to total care and are met in a variety of care settings such as nursing homes, assisted living facilities or people’s individual homes.

The aging of the U.S. population and the projected growth of the oldest age bracket (85 years and older) will have a major effect on the demand for and supply of long-term care, as well as the resources needed to provide those services. This makes generating innovative solutions that address the challenges of providing and financing long-term care particularly important. However, not all residents of long-term care facilities are elderly, and populations with a greater range in age who spend a larger portion of their life course in residential facilities may have a more diverse range of quality of life needs (Koren 2010).

In terms of the history of the culture change movement in long-term care, in the 1980s, a consumer advocacy group called the National Citizens Coalition for Nursing Home Reform, now known as the National Consumer Voice for Quality Long-Term Care, pioneered a Consumer Statement of
Principles for the Nursing Home Regulatory System, conducted focus groups on how nursing home residents defined “quality,” and contributed to the development of a pivotal Institute of Medicine Report (NCCNHR 1985). These efforts led to the comprehensive 1987 Nursing Home Reform Act, which outlined specific quality of life requirements for facilities to receive Medicaid reimbursement.

The Nursing Home Reform Act states that a facility should provide care so residents can, “attain or maintain the highest practical physical, mental, and psychological well being” and that there should be “no diminution in a resident's function unless it is clinically unavoidable.” Among the resident rights protected by the Act are the right to be free from restraints, the right to voice a grievance without retaliation, and the presence of an ombudsman—that is, an advocate that acts as a liaison between a resident and the facility—in every state. Resident rights must be clearly posted in every nursing home and distributed to all residents (CARIE 2011).

The law also made nursing homes the only sector of the entire health care industry to have a statutory requirement for providing what is now called “person-centered care.” Interpretation and implementation of this aspect of the law, however, still varies greatly from facility to facility.

In order to set a national standard, a key stakeholder meeting held by the Agency for Healthcare Research and Quality established that key aspects of “person-centered care” should consist of: resident direction of activities; a homelike atmosphere; close relationships between residents, family members, staff, and community; staff empowerment; collaborative decision-making; and quality-improvement processes.

Moves to universally incorporate such priorities have been limited by financial challenges, diversity between and within facilities, and lack of concrete implementation strategies that embody the values of “person-centered care” (Koren 2010).

The project outlined in this report reflects one long-term care facility’s desire to develop innovative, concrete implementation strategies in partnership with a community-engaged consulting entity and community partners. The purpose of this partnership was to elicit and address quality of life needs for residents, and generate specific strategies to optimize quality of life as the transition to truly person-centered care takes place.
Quality of Life at Long Term Care Facilities

Project Overview

About Us:

Robert Wood Johnson Foundation Clinical Scholars® Program

A group of six physicians, recently trained in different disciplines, began the Robert Wood Johnson Foundation Clinical Scholars® program at the University of Pennsylvania in July 2013.

For more than three decades, the Robert Wood Johnson Foundation Clinical Scholars program has fostered the development of physicians who are leading the transformation of health care in the United States through positions in academic medicine, public health, and other leadership roles. Through the program, future leaders learn to conduct innovative research and work with communities, organizations, practitioners and policy-makers on issues important to the health and well-being of all Americans. This program is supported in part through collaboration with the U.S. Department of Veterans Affairs.

Partners:

Inglis House is a specialty nursing care facility providing long-term, residential care for approximately 300 adults with physical disabilities, including multiple sclerosis, cerebral palsy, spinal cord injury and stroke, among others. Inglis House is funded in part through Medicaid reimbursements and in part through a private philanthropic endowment. Inglis House is remarkable among similar facilities for the diverse range in age and functional status of its residents.

Key initiatives in progress at Inglis include the prioritization of “person-centered care,” comprehensive Social Enrichment and Adaptive Technology programs, and a move to explore and incorporate the Program of All-inclusive Care for the Elderly (PACE) model, which seeks to shift long-term care from institutions to the community for adults with appropriate functional status.

Pennsylvania’s Empowered Expert Residents (PEER) Program trains a small group of residents residing in long-term care facilities in how to advocate and maintain their
rights for themselves and their fellow peers using state certified ombudsmen. Inglis House was one of the sites where this program was initially developed in the state of Pennsylvania. At Inglis House, residents with diverse abilities and backgrounds have been selected from each “neighborhood” as representatives and trained as PEERS.

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) is a non-profit organization based in Philadelphia that is dedicated to improving the quality of life for vulnerable older people through client-centered activities, community education programs, professional training and counseling, and referral.

## Project Charge
The 2013-2015 cohort of the Robert Wood Johnson Foundation Clinical Scholar Program at the University of Pennsylvania was provided with three main objectives that were generated through a process of community consultation:

1) To develop a comprehensive understanding of the elements that impact quality of life for individuals living in long-term specialty care facilities;

2) To develop strategies for individuals living in long-term specialty care facilities to actively partner with staff and administration to improve quality of life at these facilities; and

3) To identify ways in which these findings may be disseminated locally and/or nationally to a community of individuals and staff living and working at long-term specialty care centers.
Quality of Life at Long Term Care Facilities

To identify key manuscripts defining and characterizing quality of life, a literature review was conducted using PubMed. Then, utilizing a community-engaged approach, qualitative interviews of key stakeholders at Inglis House were conducted. These key stakeholders included residents, caregivers, administrators, and the Board of Trustees. Interviews were also conducted with outside stakeholders and community leaders. Site visits of two peer facilities, the Boston Home in Boston, MA and the Raker Center at Good Shepherd in Allentown, PA, were conducted. An iterative process was used to elucidate themes and recommendations.

Inglis House Interviews

Residents. Residents were initially interviewed in a group setting. A group of resident leaders were identified through the PEER program. At each of these meetings, a group of six PEERs was present to discuss with the RWJ cohort. Group interviews were conducted on four occasions.

Resident Council Meeting. Inglis House Resident Council is composed of an executive board of four residents and is open to all residents at Inglis House. The Council meets monthly with the exception of June, July, and August, when the council breaks for summer recess. On July 17th, a special Resident Council meeting was called to open the quality of life discussion to all residents of Inglis House. Thirty-three residents attended the meeting, which also included a presentation and answering of questions by the Director of Nursing, Director of Dietary Services, and Co-Executive Director, as well as the Ombudsman from CARIE.

Social Enrichment Team. The social enrichment team is led by two individuals and responsible for coordinating recreation and social activities both at Inglis House and in the community, i.e. field trips. Additionally, all volunteer services and assignments are coordinated through this office. The Social Enrichment Team occupies a unique niche between the residents and administration, particularly because of close relationships and regular interaction with the residents. Interviews were conducted with both the Director of the Social Enrichment Team and the Volunteer Coordinator, both leaders of the Social Enrichment Team.

Nursing. At least one nursing supervisor (RN community clinical leaders), Certified Nursing Assistant (CNAs) and Licensed Practical Nurse (LPNs) were interviewed from the majority of neighborhoods. These representatives were identified by the Director of Nursing.

Administration. Interviews were conducted with the Director of Nursing, who also serves as Co-Executive Director of Inglis House and with the CEO of the Inglis Foundation. Inglis House leaders identified that the transition to Person-Centered Care will improve quality of life issues. Person-centered care will help divide Inglis

Methods

• Review of the literature
• Interviews with key stakeholders
House into smaller communities/neighborhoods and address the issues of the challenge of improving quality of life at such a large scale. Administration identified that it would be helpful to identify the quality of life issues most important to residents in order to create a priority sequencing and plan of how to address specific themes and issues.

Outside Interviews

Interviews were conducted and community perspectives obtained from several external stakeholders (Appendix 2). These representatives included a physician advocate with disabilities who is living independently in the community, the Philadelphia Deputy Mayor for Health and Opportunity, representatives from CARIE, and a former administrator and expert on the Program for All-Inclusive Care for the Elderly (PACE). The PACE model suggests that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible.

Site visit: The Boston Home. The Boston Home was selected due to a shared history and demographic compared to Inglis House. It was founded in 1881 through philanthropic donation by an advocate and has a private endowment. It is non-geriatric with average resident age of 58 with approximately 100 full-time residents with a day program. Quality of life issues were discussed with the President and CEO, and the Director of Wellness as well as Director of Admissions.

Site visit: The Raker Center. The Good Shepherd Home at the Conrad Raker Center is a long-term care facility open to adults with primary diagnoses including cerebral palsy, muscular dystrophy, quadriplegia, or multiple sclerosis. While the goal of the Raker Center is long-term care, several residents are working toward a goal of living independently in the Community Transition program. Residents receive similar services (OT, PT, speech/language, social work, and recreation) as the residents of Inglis House. The Raker Center is also a non-geriatric, approximately 100 bed facility, with an average resident age of 60 years. Quality of life issues were discussed with the Interim Facility Director, Director of Nursing and Director of Social Work.

“Quality of life for me is independence, doing what I choose to do when I choose to do it.” – Inglis House Resident
Quality of Life at Long Term Care Facilities

Key Findings

The information obtained through interviews was organized into the eight widely recognized elements that comprise quality of life: emotional well-being, interpersonal relations, social inclusion, personal development, self-determination, personal development, physical well-being, material well-being, and rights (Schalock 2005). These elements have been studied and replicated across age, culture, and disability.

Emotional well-being is how people feel about themselves and their lives, including being able to manage emotions while dealing with challenges. One resident described quality of life as “a sense of wellness and balance with oneself.” It includes having a general sense of safety and satisfaction with life. All stakeholders said that feeling emotionally fulfilled is important to quality of life, but that the determinants of emotional well-being vary among individuals. Several people noted that although they have physical challenges, they do not want to allow their physical limitations to prevent them from enjoying life.

Interpersonal relations include the relationships that people maintain with family and friends but also the support and help that is available to them. Many interviewees noted that relationships with caregivers are very important to quality of life. With many people living and working together at Inglis House, interpersonal relationships can be a source of both strength and challenge. During the interviews, three types of relationships were discussed:

Resident-staff relationships can be very intense because residents are reliant on staff to meet their most basic daily needs. Many residents noted positive, treasured relationships with certain staff members. However, residents also said that at times, they do not feel like staff are listening or being sensitive to their needs. Frequently cited sources of concern were staff turnover, float nurses, and the difficulty in dealing with unfamiliar caregivers.

Resident-resident relationships are similarly varied. Although many residents have formed deep friendships, some also brought up the difficulty of being forced to live in close quarters with people with whom they do not agree.

Resident-administrator relationships were described as an area for possible improvement. Many residents felt distant from the administration and wished that the administrators were present more regularly. One resident said, “administrators here used to stop in the elevators or hallways to talk to you and that made a difference.”

In addition to some of the concerns raised by residents, staff members also commented that resident’s family members add a layer of complexity. Staff noted the difficulty in negotiating between residents and their families when they disagreed on care.

Administrators agreed that interpersonal relationships are important for quality of life of both residents and staff. They cited some staff training in this arena, including the use of a communication tool called “heart-head-heart” which encourages verbally expressing the importance of positive aspects of the relationship before and after addressing conflict.

Social inclusion refers to an individual’s community integration and participation. Residents noted that they feel like part of the Inglis House community, but that there are barriers to connecting
to the community outside of Inglis House.

The “community driver” program at Inglis House allows residents who have demonstrated the ability to maneuver their wheelchairs safely to travel freely between Inglis House and the rest of Philadelphia. Community drivers expressed frustration with the inconsistencies of the public paratransit system. Those who are not community drivers generally dislike having to hire an assistant to take them anywhere outside of Inglis House and feel that it restricts their freedom. Staff and administrators acknowledged those concerns, but said that resident safety makes the restrictions necessary.

Inglis House recognizes the importance of social inclusion and has a robust day program for community members with disabilities. Other community stakeholders identified ways in which persons with disabilities live independently in the community as well as the availability and simultaneous constraint on resources available for those doing so.

**Personal development** means being able to pursue interests and having opportunities to learn about what one finds important. Almost everyone interviewed highlighted the wealth of activities available to residents. The adaptive computer lab and education programs, including the ability to pursue higher education degrees, at Inglis House are examples of where Inglis House shines.

**Self-determination** means having the freedom to make choices about your life. The residents were determined not to let their disabilities rob them of their independence. However, as residents need assistance with personal care, routine decisions (e.g., when to get out of bed) need to be orchestrated based on staff availability.

Many residents wished that they could fully control their daily schedules. They expressed frustration, for example, when they waited for extended periods of time for a response to their call bells. They believed that hiring more staff would improve their ability to control their days. In addition, residents generally saw the rules and regulations at Inglis House as restrictive and geared toward making things easier for staff rather than improving quality of life for residents. Finally, some residents acknowledged the positive intentions of the administration in implementing person-centered care, but perceived that residents had not been involved adequately in the planning process.

Staff members agreed that self-determination is a key element of quality of life. They reported doing their best to respond to patient needs, but that they are unable to fully accommodate resident desires because of time and staffing constraints.

Administrators acknowledged that balancing staffing and patient needs is a challenge. They noted that self-determination is a key element of person-centered care, and are hopeful that residents will feel more in control of their lives as person-centered care moves forward. One widely cited effort in this arena was the made-to-order breakfast that had occurred on some units, although so far this is on a limited basis.

**Physical well-being** means physical health and access to health care. Although the residents of Inglis House all use wheelchairs, each individual deals with different disease processes and physical symptoms that can vary from day to day. A sense of not letting symptoms dictate every day was pervasive. One common concern was the boredom,

“Staff are more mechanical because they have no time. They’re good people, but they get overworked.”
– Inglis House Resident
frustration, and isolation of residents that are temporarily bed-bound, usually due to pressure ulcers. Many residents also pointed to inconsistent compliance with wheelchair cushion checks, which can help prevent pressure ulcer formation, as an example of one of the ways that they feel staff are not always sensitive to their needs.

Material well-being includes having access to material goods to meet basic needs, as well as having control of important personal possessions. Personal possessions did not come up frequently during the discussions, except in the context of a recent reduction in thefts after the initiation of a successful neighborhood watch program. This came out of a “rapid action team” that was convened in response to resident concerns about a rash of thefts.

Rights include freedoms that are guaranteed and universal entitlements. Residents brought up many concerns that could be considered under the category of rights. A right to be treated with dignity and respect was discussed as a key component of quality of life. Residents indicated that although most of the interactions at Inglis House are respectful, it could not be taken for granted.

Staff using cell phones during resident care was an example of disrespectful behavior cited by multiple residents. Several residents also brought up a right to privacy. This included residents at times feeling unable to deal with grief or difficult situations without the intrusion of other residents or staff. Privacy to express sexuality also came up multiple times. Residents said that sexuality is an important topic that is rarely formally addressed.

Staff also commonly mentioned a right to dignity and respect as important to quality of life. Sexuality was mentioned by staff as well, with some staff members saying that they are unsure how to address this important issue with residents.

Administrators also commonly cited a right to dignity as essential. Some mentioned changes that had been made to the physical structure and to care processes to make it easier to maintain dignity, such as remodeling of the bathrooms and shower rooms.

“The best part about Inglis is all the activities!” – Inglis House Resident

“Thefts are down after we started the neighborhood watch.” – Inglis House Resident
Residents, staff, and administrators noted strengths and concerns for each of the eight elements of quality of life. When talking about potential solutions, residents, staff, and administration identified three core principles that would need to underlie any change aiming to improve quality of life at Inglis House:

**Communication, Autonomy, and Accountability.**

Under each core principle, several interventions aimed at increasing quality of life at Inglis House are proposed; some interventions address more than one core principle. Using information gathered from the interviews with Inglis House residents and staff as well as outside stakeholders, combined with a literature review, tailored recommendations aimed at improving quality of life at Inglis House were developed. The scholars facilitated the development of these ideas, but their ultimate form was determined by residents and staff, the people who would be directly affected by such changes.

**Review of the Literature**

Scholars reviewed the literature on quality of life for those in long-term care and identified numerous quality of life interventions, ranging from changes to daily activities such as bathing and feeding to sweeping culture transformations. Examples of effective culture changes include the Wellspring model, which is a network of 11 freestanding nursing homes that shared educational modules and institutional expertise and focused on team-based care and showed improvements in quality of care and reduction of staff turnover (Stone et al 2002). The Green House model emphasizes shifting care to small homelike settings with only 6-12 residents, and is currently being evaluated under a project of the Robert Wood Johnson Foundation (Appendix 3).

While most of the literature focuses on interventions for geriatric populations, curricula have been generalized to non-geriatric settings. For example, OASIS is a curriculum focused on communication and staff empowerment that was originally designed to reduce antipsychotic use in residents of long-term care facilities by teaching staff to understand the underlying cause of behaviors. The Boston Home, which primarily serves a non-geriatric population, implemented OASIS with great success. Boston Home administrators reported that the success of OASIS went far beyond reducing antipsychotic use and extended to reducing resident concerns and improving continuity of personal care.

**Communication**

Nearly all stakeholders interviewed believed that improving communication at Inglis House...
would improve quality of life for residents and staff. Within communication, stakeholders identified several specific targets for improvement: informational updates about Inglis House at an organizational level (e.g., updates about restructuring or other initiatives), resident feedback (e.g., concerns or issues related to clinical care), and general discussions about important and sensitive topics to residents. Stakeholders believed slightly different approaches were needed for each area, in addition to increased general conflict resolution skills, which would improve communication globally. Inglis House residents have a diverse array of communication styles, and so any interventions around communication should be designed to ensure applicability to all residents.

Communication: Conflict resolution skills. Residents and CNAs at Inglis House work incredibly closely together. CNA’s help residents with their most personal needs: feeding, using the bathroom, and moving around their rooms. Because of the nature of the work, stakeholders believed that conflict is inevitable and building skills to handle conflict is essential. As this is a common concern at all long-term care facilities, several organizations have developed comprehensive curricula to improve conflict resolution skills among residents, staff, and administrators.

Recommendations:

1. Evaluate existing curricula on conflict resolution skills for appropriateness to use at Inglis House (e.g., OASIS; see Appendix 3 for a listing)
2. Pilot test and modify, as necessary
3. Implement throughout Inglis House

Communication: Integrated Training, Residents as Trainers. Existing staff trainings at Inglis House around clinical care, sensitivity, and respect, may not directly involve residents. However, through the interviews it became evident that residents are the foremost experts in these topics.

Recommendation:

1. Residents to be integrated into all trainings with staff and administration around clinical care, sensitivity, and all other topics.

Communication: Sensitive Topics. Residents at Inglis House struggle with the same issues as community residents. Residents, staff, and administrators expressed unease in communicating around topics such as sexuality, race, dignity, grief and loss. Fostering an open discussion about staff and resident views and expectations around these issues could serve to improve comfort levels.

Recommendations:

1. Residents compile a list of discussion topics at Resident Council or by anonymous submission (paper or electronic)
2. Residents, staff, and administrators plan small-group discussions about these sensitive topics; create expectations, for example, around responsibilities of staff facilitation of sexual activity among residents

Communication: Updates About Inglis House. As Inglis House undergoes the transition to person-centered care, residents expressed that they wanted to...
know more about what is going on “day-to-day” as this is a major transition. PEERs expressed that they could be sources of information for other residents and could even do active outreach, sharing key updates from staff, nursing, and administration.

Recommendations:

1. **PEERs engage with administration and nursing** to convey information to all residents
2. **Residents identify areas of concern** such as measures of wounds or urinary tract infections to make sure these areas are addressed
3. **Administration and nursing update residents at regular intervals** about what is happening at Inglis House, even if there is little to report

**Communication: Outreach.**
Throughout the interviews, Inglis residents had incredible stories to share about their personal experiences. The residents expressed a desire to share these stories and experiences with the community at large, and this could foster even greater understanding and engagement between Inglis House and the community.

Recommendations:

1. **Residents form a Speakers’ Bureau** to outreach to schools, community centers, and churches

2. **Residents record their stories** either in verbal or written format, with help from volunteers and staff if needed, to be publicized via the Internet

“Being bed-bound is like being in solitary.”
– Inglis House Resident

**Autonomy**

The issue of autonomy emerged as an important theme in the interviews of residents at Inglis House. It is clear that protecting resident autonomy—or ability to negotiate their own day-to-day decisions—must be balanced against resident safety and varied functional autonomies.

**Autonomy: Create a Bed-bound Team.** One of the greatest threats to autonomy at Inglis House is medical illness. For example, residents with wounds may require prolonged periods of bed rest, severely limiting their ability for social engagement.

Recommendations:

1. **Residents compile a list of needs** when bed-bound, with facilitation by staff and administrators
2. **Create a bed-bound team** to reach residents; the composition of this team could include volunteers, physical therapists, nurses, and even

**Autonomy: Develop Resident Preference Profiles.** Resident profiles containing medical information are created and updated for residents on a continuous basis. While a record of medical information is essential, residents also wished that they could record their personal day-to-day preferences (e.g., what time they like to get up, how they like to spend their days). This could also serve to improve continuity between nursing staff and residents. By maintaining a list of resident preferences, nursing staff that are not familiar with the resident will have an easily accessible guide.

Recommendations:

1. **Residents and families determine what types of information to include in Resident Preference Profiles,** while there should be flexibility between residents, there should be some standardization of the elements to ensure readability
2. **Consider including Resident Preference Profiles in the electronic medical record** thus ensuring that this information is accessible in real time for clinical staff
Quality of Life at Long Term Care Facilities

(Continued)

**Autonomy: Resident Involvement in Program and Leadership Committees.** Inglis House has incorporated resident involvement in committees on Adaptive Technology, Food Services, and Person-Centered Care Implementation, and residents gave positive feedback on this.

**Recommendation:**

1. **Include residents on all decision-making committees** at Inglis House

**Autonomy: Improve Resident and Staff Self-Advocacy Skills.** Self-advocacy, the ability to express one’s needs and preferences, is an essential skill, especially at a long-term care facility. Residents expressed that when people came from long-term care facilities that were not as responsive to resident needs, they were less able and willing to communicate their concerns. Residents referred to this as a “nursing home mentality”. In addition, staff expressed that they wanted training on how to communicate with residents around self-advocacy. This is a commonly reported concern at long-term care facilities, and in the literature review, several examples of self-advocacy curricula were identified (see Appendix 3).

**Recommendations:**

1. **Evaluate self-advocacy curricula** for appropriateness to use at Inglis House

2. **Pilot test** and modify, as necessary

3. **Implement** throughout Inglis House

**Accountability**

Inglis House residents, staff, nursing, and administration all believed that accountability to each other, and to themselves, is critically important to quality of life.

**Accountability: Feedback.** It was clear from the interviews that residents, staff, nursing, and administration demand excellence in clinical care. It was also clear that resident feedback and concerns are taken seriously and acted upon but all stakeholders agreed that more could be done. One of the strengths of Inglis House is that multiple staff, nurses, and administrators are accessible and open to feedback. However, this can be confusing to residents, who reported that they were not always sure where to go with their concerns. For residents who had different communication styles (e.g., were non-verbal), venues to provide feedback could be expanded. In addition, residents said they often did not know what happened with the feedback they gave. Staff, nursing, and administration gave several examples of resident feedback that was acted upon, but were not sure if the results were communicated directly back to the resident who raised the concern. Finally, several residents wished for a clear way to give positive feedback about care at Inglis House.

“Sometimes residents tell me a concern, but I don’t know where to take it.”

– Inglis House CNA

**Recommendations:**

1. **Streamline and clarify the feedback process;** create an easy-to-follow chart that residents can use to determine where their concerns should go; include a mechanism to give positive feedback

2. **Display this chart on all floors** in a clearly visible location

3. **Train PEERS as guides in the feedback process** for example, to provide outreach to all residents about using the chart and to address resident concerns

4. **Create an electronic forum** in which feedback or suggestions can be collected from residents, this could be an interactive site where residents can view others’ suggestions and “like” them

5. **Ensure that the feedback loop**
is closed to the best extent possible while protecting any confidentiality (e.g., if a resident raises a concern about a nurse, the resident can be notified that the concern was addressed, but it may not be appropriate to disclose exactly what actions were taken)

Accountability: Neighborhood-based Clinical Challenge (the Inglis Challenge). Inglis House, like any other workplace, has small, yet important, tasks that may not happen with the strict consistency that is required. For example, at Inglis House, all residents use air cushions with their wheelchairs to prevent skin breakdown and wounds. These cushions require periodic checking to verify inflation; however, residents interviewed felt that checking has not always been consistent. To address this, Inglis House residents, staff, nursing, and administration could create a contest between neighborhoods, which could encourage friendly competition resulting in consistent cushion checks. This approach could be generalized to almost any other clinical activity. Systems of this type (token economies) have been used successfully in diverse industries such as health care, mining, and manufacturing to improve workplace safety, attendance, and productivity (for example, Fox, Hopkins, & Anger 1982; Newby & Robinson 1983; Pedalino & Gamboa 1974; Stephens & Burroughs 1978).

The exact structure of the contest is open to modification by Inglis House residents, staff, and administration. For example, when a staff member performs the task of interest (e.g., checks a cushion), the resident gives the staff member a ticket. The staff member then puts the ticket into a bin containing all tickets for that neighborhood. Then, at the end of the contest period (e.g. 1-2 months), the number of tickets will be counted up by neighborhood. The neighborhood with the most tickets wins the challenge, and receives a communal prize such as a made-to-order meal for the entire unit, or some other socially desirable activity.

Recommendations:

1. **Design a clinical challenge suitable for Inglis House** using existing literature and input from residents, staff, and administration
2. **Pilot test** within one or two units to determine feasibility and acceptability; modify as necessary
3. **Implement** throughout Inglis House; the challenge can be rotated to address any other clinical issue

**Prioritization**

During a meeting with residents and staff, the following recommendations were considered priorities:

- Implementing conflict resolution and self-advocacy curricula
- Discussion around sensitive topics
- Clarifying feedback processes

“The residents are Inglis’ greatest strength.”
– Inglis House Staff Member
Program Evaluation

Program evaluation describes the steps that should be taken to ensure the timely, successful implementation of the study recommendations and to measure their impact on resident and staff communities within Inglis House. Evaluations may take several forms. For the first few months, program development should be assessed by measuring achievement of specific implementation goals. While these goals do not measure the program’s impact on the Inglis House community, they serve as interim milestones for monitoring the actions being taken on each recommendation.

Once each recommendation has been implemented, the overall program impact should be assessed by measuring quality of life among residents at Inglis House. Other outcomes measures could include the number and type of complaints submitted by residents after program implementation. It is also important to assess the impact on Inglis House staff members, including their perception of resident care, resident quality of life, and their own work satisfaction. These evaluations should be performed on a quarterly basis.

Educational programs, such as the conflict resolution training, will need to be evaluated in phases as each program is developed. Early goals will include creation of a leadership team (including both residents and staff) to guide the implementation of each program at Inglis House. Once implemented, the programs will be evaluated by the number of residents and staff who have completed these programs. It must be acknowledged that there exists a cap on the number of people who could feasibly complete each program every month, so each program leadership team may develop a reasonable goal for monthly program achievement.

Evaluating the recommendation on the feedback system could be achieved by means of a survey. Integrating questions on the feedback process into the quarterly resident satisfaction survey would be one means of completing this goal. Residents could be asked about their satisfaction with the feedback system, as well as their comfort with the different feedback options available. Evaluating the process of “closing the feedback loop” could involve speaking with a few residents 2-3 weeks after they submitted a comment for feedback. These residents would be asked whether they have been informed of the status of their feedback.

Individual criteria should be made to assess the impact of each recommendation, for example:

- **The bed-bound team** could be evaluated on the number of residents who have been visited as well as the satisfaction of these residents with the team. In particular, what activities or components of the experience are regarded most highly by the bed-bound residents, and how would they
recommend improving the experience?

- **The Inglis House Speakers’ Bureau** could be evaluated on the number of residents who have reached out and spoken with community groups. Has a team of residents and staff members been created to lead this program? What has the experience of speakers been? Once the program is launched, how many residents know about it, and how many have participated?

- **Committee representation** could be evaluated on how many committees have at least one resident representative? What is the perception of the resident representatives of serving on the committee?

- **Communication from the administration to the residents** could be evaluated on whether information has been posted for residents to see, such as wound and urinary tract infection rates, as well as whether quality of life survey results have been assessed and if so, what are the results of those surveys?

- **Use of Resident Preference Profiles** could be evaluated on how many resident profiles have been updated: Do residents perceive that new caregivers have been better prepared to work with them? How do staff members feel the new profiles have changed their experience?

Staff members’ perceptions should also be assessed: Do they think resident quality of life has improved? What is their impression of the workplace environment? How is their job satisfaction? Does staff member turnover change in the months after program implementation?

With a straightforward and systematic means of evaluating the success of each program, one can ensure that recommendations are enacted in a timely fashion and that each program is reviewed to guarantee it is improving resident quality of life at Inglis House.
The final part of the project charge was to identify ways in which these findings may be disseminated locally and/or nationally to a community of individuals and staff living and working at long-term specialty care centers.

Dissemination of a Single-page Summary of this Report

A single-page summary of the main findings in this report will be produced and distributed to Inglis House residents. The RWJF Clinical Scholar Cohort will assist the Inglis House in disseminating this report to relevant partners:

• Partner facilities: Boston Home, Good Shepherd Home at the Conrad Raker Center, Holy Redeemer, and the Philadelphia Nursing Home

• Other relevant organizations (see Appendix 2 for a complete list).

The full report will be posted online at the Robert Wood Johnson Foundation Clinical Scholars Program and CARIE websites.

Present Findings at the National Consumer Voice for Quality Long-Term Care, National Conference

A summary of this project methodology, findings, and recommendations, will be presented at the National Consumer Voice for Quality Long Term Care conference by a PEER, RWJF clinical scholar, and the Ombudsman from CARIE. The Consumer Voice’s mission is to represent consumers at the national level for quality long-term care, services and supports. Consumer Voice members come from nearly all 50 states and are comprised of local citizen action groups, local and state long term care ombudsman, legal service programs, professional groups, long term care administrators and growing numbers of family and resident councils.

Enable Inglis House Residents and PEERS to Share their Experiences with Other Communities

Building on the themes of autonomy and communication identified in this project, will enable Inglis House residents and PEERS to share these findings and their experiences around this process with residents at other long-term care facilities. The residents of Inglis House could also share their personal stories with the community-at-large, using a forum such as the speakers’ bureau. Inglis House PEERs and the ombudsman can educate PEERs from other long term care facilities about this project.

Scholarly Publication

A final potential mechanism for dissemination is an editorial or viewpoint article co-authored by a RWJ scholar and project partner about this quality of life project.
Inglis House has a proud tradition of providing exceptional care to adults with physical disabilities for nearly 150 years. From the start of this project, it was clear that Inglis House was already an exceptional institution for its broad range of social enrichment activities, the widespread use of adapted technology, and its decision to adopt a person-centered care model.

The people at Inglis House were most impressive. The clinical staff was very dedicated to their work and displayed remarkable poise in dealing with complicated issues. Administrators were very open and willing to spend time educating the Clinical Scholars about daily operations at Inglis House. Most of all, the Clinical Scholar cohort was struck by the creativity, enthusiasm, and passion of the Inglis House residents. Many ideas reflected in this report were inspired by comments from residents who developed innovative solutions to improve quality of life at Inglis House.

The coming years will bring significant change to Inglis House. Implementing the person-centered care model and redesigning the neighborhoods will be major steps toward improving quality of life for residents. The hope of the Scholars is that these recommendations to enhance communication, accountability, and autonomy will improve life for everyone at Inglis House, from residents to staff members. Adopting a communication curriculum and integrating training sessions will help everyone better understand each other. Clarifying the feedback process and closing the feedback loop will ensure that residents have clear routes to submit their comments and be informed about what was done in response.

Launching the Inglis Challenge will create a cooperative neighborhood effort to improve resident concerns about cushion checks. Self-advocacy training and a new bed-bound team will help guarantee that all residents can live with the greatest amount of independence.

The issues expressed at Inglis House were issues common other long-term care facilities, and therefore, the findings and recommendations contained herein are likely applicable outside of Inglis House. It is hoped that this report will assist residents, staff, and administrators in implementing changes to improve quality of life. There is no doubt that Inglis House will continue its long history of innovation to provide an even higher quality of life for its residents in the years to come.
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Welcome to Inglis House

Inglis House is a soap opera on wheels. The reason I call Inglis House a soap opera on wheels is. We fall in love with we cheat on each other, we feel like killing each other (but we don't). Anything that goes on in the outside world goes on in here! We might look all nice and innocent, but looks can be very deceiving.
## Chart of Community Interviewees

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<tr>
<th>Outside Interviews</th>
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<tbody>
<tr>
<td>Boston Home (Boston, MA)</td>
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<td>Deputy Mayor for Health and Opportunity, City of Philadelphia</td>
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<tr>
<td>Good Shepherd/Raker Center (Allentown, PA)</td>
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<td>Mayor's Commission on People with Disabilities, City of Philadelphia</td>
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<tr>
<td>National PACE (Program for All-Inclusive Care of the Elderly) Association (Philadelphia, PA)</td>
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<tr>
<td>Philadelphia Nursing Home (Philadelphia, PA)</td>
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Resources

Educational Resources:

- **The OASIS Program**: an educational curriculum with a focus on communication, currently being used at over 70 nursing homes in Massachusetts. Website: http://www.leg.state.vt.us/jfo/healthcare/Overview%20of%20OASIS%20program%20November%202012.pdf


- **Dr. Susan Wehry**, creator of OASIS program. Website: http://www.susanwehrymd.com

- **The Pennsylvania Partnership for People with Disabilities and Families**. Website: http://www.temple.edu/thetrainingpartnership/

Local, State, and National Resources:

- **CARIE**: Center for Advocacy for the Rights and Interests of the Elderly. Website: http://www.carie.org

- **Pennsylvania Department on Aging**. Website: http://www.aging.state.pa.us/portal/server.pt/community/department_of_aging_home/18206

- **National PACE Association**: Program of All-Inclusive Care for the Elderly. Website: http://www.npaonline.org/website/article.asp?id=4

- **The Pioneer Network**: Pioneer Network was formed in 1997 by a small group of prominent professionals in long-term care to advocate for person-directed care. Website: https://www.pioneernetwork.net

- **Peer Institutions**
  - The Boston Home: http://www.thebostonhome.org/
  - The Raker Center: http://www.goodshepherdrehab.org/long-term-care