



Changes in Quality of Life for Group Home Residents of the Bob and Judy Charles SmartHome: An Exploratory Analysis

Student Researchers:

Dannette M. Muselman, MA Candidate

Elizabeth Woodruff, MA

Faculty Research Mentor:

Yvonne Kellar-Guenther, Ph.D.¹

Colorado WIN Partners, University of Colorado Denver

November, 2010



UNIVERSITY OF COLORADO DENVER

For questions about this paper please email: Yvonne.Kellar-Guenther@ucdenver.edu

¹ Dr. Kellar-Guenther was the faculty mentor on this project. She designed the original 5-day questionnaire used for this study and worked with the students on data collection, analysis, and write-up.

Abstract

The development of smart home technology is one of the most promising opportunities for helping individuals with developmental disabilities live independently in the community. The goal of this research project was to determine if living in a group home that utilized smart home technology increased the quality of life for eight adults with developmental disabilities. Data was collected two times directly from the residents and through use of a tool designed to assess the level of supports needed in day-to-day functioning. Overall, residents' quality of life was improved and less support was needed. Although our findings point to positive results in quality of life, we believe future research needs to be done to better understand how specific technology may affect quality of life for individuals with developmental disabilities.

Changes in Quality of Life for Group Home Residents of the Bob and Judy Charles SmartHome: An Exploratory Analysis

The development of smart home technology is one of the most promising opportunities for helping individuals with developmental disabilities live independently in the community. Smart homes are in some ways the ultimate in universal design and innovation because smart homes utilize innovative technology to allow individuals to function in their environment regardless of their needs and personal preferences. In July 2009, eight residents, aged 22 to 55, with developmental disabilities moved into a new group home, the Bob and Judy Charles SmartHome (referred to as SmartHome throughout the paper). The goal of this research project was to determine if living in a group home that utilized SmartHome technology increased the quality of life for adults with developmental disabilities.

Background

Imagine! is the Community Centered Board for Boulder county and provides services for persons with developmental disabilities. Services provided range from case management to training, to independent living, to day programs, to community involvement. The SmartHome being studied is the first group home for residents with developmental disabilities to take an integrated smartHome approach via technology to assist service recipients, frontline staff, managers with remote monitoring & admin tasks, and finally, cost savings via green technology (e.g. green building practices, solar PV, solar thermal & geothermal). This project is being closely watched by cognitive, mental health, physical disability and aging service providers across the country. The Imagine! staff hope that the technology from the SmartHome can help reach Imagine! clients, and that technology in general improves and can begin to be created by many groups in order to help individuals with disabilities in general (SW, personal communication, September 15, 2010).

SmartHome Residents Quality of Life

As stated earlier, eight residents live in the SmartHome. This project began right before the residents moved in. The eight residents chosen were hand-picked by Imagine!. To be considered, all candidates needed to receive comprehensive (24hr care) services through Imagine!'s Innovations Department, not require overnight care, not need one-on-one care, and have no high risk behaviors that would lead to problems with the other residents or destruction of technology. At the time of the selection, only Imagine! customers who were not yet successfully placed in a residential setting were considered. The key factor in making the final selections were (a) Is the SmartHome appropriate to meeting health and safety needs of this resident? (b) Is the resident interested and willing to use Assistive Technology and participate in ongoing product evaluation and research? (c) How might the individual be impacted (positively/negatively) with the SmartHome being a "show home" and open for regular public tours? and (d) Is this resident a good match with the other house mates (Imagine!, personal communication, October 14, 2010 & October 15, 2010)

In December, 2008, Colorado WIN Partners staff began meeting with Imagine! to discuss the new group home and determine what data could be collected that would allow Imagine! to inform others about the impact of the SmartHome on the lives of the residents. One of the constructs identified was an improvement in quality of life. The goal of this project was to track any change in the resident's quality of life improved after moving in the home.

Quality of Life for Persons with Developmental Disabilities

As stated earlier, the goal of this study is to determine if living in a group home that uses smarthome technology increased the quality of life for the eight residents. Sheppard-Jones, Prout, & Kleinert (2005) found that people with developmental disabilities experienced a significantly lower quality of life than their general population comparison group. This lower

SmartHome Residents Quality of Life

quality of life was due to having less choice, from the mundane day-to-day decision-making of what to do in their free time to the more important life decisions of where to live and work. This finding is re-emphasized by Kishi, Teelucksingh, Zollers, and Park-Lee (1988), whose work showed that for people with developmental disabilities in community settings, opportunities for choice-making were fewer when compared with those of the general population.

An increase in quality of life is an important outcome because in many states it is the preferred standard for evaluating residential services for persons with disabilities and the elderly (Seltzer & Krauss, 2001). Quality of life is also used to aid in policy-making or justifying policies already implemented for children with developmental disabilities (Zekovic & Renwich, 2003).

Measuring Quality of Life

There are many definitions for the construct “quality of life”, especially for persons with developmental disabilities, but the two major approaches center around good health and the interaction of the person and their environment (Zekovic & Renwich, 2003). The health promotion approach proponents argue that improved quality of life can reverse or off-set the disabling process or helps modify risk factors (Patrick, 1997). Within the construct of personal wellbeing, issues such as health status and functional independence are typically considered. This approach has been embraced by researchers studying developmental disabilities because there has been an increase in the life expectancy of adults with mental retardation and developmental disabilities (Seltzer & Luchterhand, 1994; Zigman, Seltzer, & Silverman, 1994).

The second dominant approach to quality of life, interaction of the person and their environment, usually includes the following core dimensions: (a) emotional well-being, (b) interpersonal relations, (c) material well being, (d) personal development, (e) physical well-

SmartHome Residents Quality of Life

being, (f) self-determination, (g) social inclusion and (h) individual rights (which capture the decision making mentioned above) (Schalock, 1996). In this study, we took a more holistic approach that includes health, to some extent, and social indicators.

In addition to discussion around what constructs capture quality of life, there is also discussion around collecting quality of life data. “Measuring quality of life reflects the unique blend of two meanings of quality: that which is commonly understood by human beings throughout the world and that which has become valued by individuals as they live their lives within their unique environments (Shalock et al, 2002).” These two aspects of quality of life can be referred to as “objective” and “subjective”.

Why Smarthome Technology Could Improve Quality of Life

Smart homes are now being targeted to help the elderly and people with disabilities (typically physical) become more independent in their homes (Mokhtari, Ghorbel, Kadouche, & Feki, 2007). Increasing independence is important, especially in residences designed for persons with cognitive impairment. Research has suggested that adults with mental retardation who live in more restrictive settings have lower self-determination and fewer opportunities to make choices (Stancliffe & Wehmeyer, 1995; Tossebro, 1995; Wehmeyer, Kelchner, & Richards, 1995). Yet, research also shows that the most cost-effective community services are services that provide individual self determination, high quality of life, encourage family involvement in providing support, and minimize settings with full-time staff (Stancliffe & Lakin, 2007; Stancliffe & Keane, 2000). Smart homes, by their very design, promote quality of life by increasing an individual’s independence, by allowing individuals to complete tasks without assistance (Dewsbury, 2001).

H1: The quality of life will increase for the residents after living in the SmartHome for one year.

Methods

Participants

The sample group included five females and three males between the ages of 26 and 53 years (M=41years), all of whom had been living in the SmartHome since July, 2009. The following table depicts types of disabilities amongst the eight SmartHome residents and differentiates such disabilities as primary (most prominent) or secondary (not viewed as primary, yet dually diagnosed).

Table 1. Disability Type for Residents

Disability	# Residents as Primary Disability	# Residents as Secondary Disability
Cerebral Palsy	4	0
Complex Partial Seizures	1	0
Bi-Polar Disorder	0	1
Bradycardia	0	1
Hyponatremia	0	1
Hypertension	0	3
Behavioral Aggression	0	1
Syncope	0	1
Mild/Moderate Mental Retardation	5	0
Organic Affective Disorder	1	0
Osteoporosis	1	1
Spastic Quadriparesis	1	0
Atrophy of Arm and Leg	0	1
Bilateral Congenital Hip Sysplasia	0	1
Congenital Hydrocephalus	1	0
Developmental Disability	2	0
Dysthymia	0	1
Scoliosis	0	2
Bursitis	0	1
Phlebitis and Thrombosis of Lower Extremities	0	1
Hypothyroidism	0	5
Lower Extremity Edema	0	1
Microscopic Colitis	0	1
Seizure Disorder	1	0

SmartHome Residents Quality of Life

Chronic Cough	0	1
Dysphagia	0	1
Reactive Airway Disease	0	1
Spastic Quadraplegia	1	0
Obesity	0	2
Type II Diabetes	0	1
Cognitive Developmental Disability	1	0
Depression	0	1
Extremely Limited use of Hands	0	1
Incontinent	0	2
Insomnia	0	1
Limited Range of Motion of Arms	0	1
No Peripheral Vision	0	1
NonAmbulatory	0	1
Permanently Flexed Ankle	0	1
Anxiety	0	1
Posterior SubCapsular Cataracts	0	1
Down's Syndrome	2	0
Sleep Apnea	0	1
Chronic Myningitis	0	1
Mycotic Nails	0	1
PTSD	0	1

Procedures

As mentioned earlier, there is discussion around whether quality of life is a subjective or objective phenomenon (Zekovic & Renwich, 2003). The current view in the literature approaches quality of life as an interplay between subjective and objective factors (Felce & Perry, 1996a; Cummins, 2000). As a result, the decision was made to collect data for this study directly from the residents (subjective) and use a tool designed to assess the level of supports needed in day-to-day functioning (objective) for this study. The study design was reviewed and approved by the Colorado Multiple Institutional Review Board.

Data was collected two different ways. First, residents were called once a day for five days prior to moving in July 2009 and again a little over a year later (August 2010). These 30 minute calls included closed-ended questions from the National Core Indicator (NCI) Quality of Life scale and open-ended questions designed to better know how the residents spent their day

SmartHome Residents Quality of Life

and their familiarity with technology. These calls were conducted over five days to minimize a fatigue response bias. The decision to collect data from residents is important. To date, most researchers that look at issues surrounding persons with disabilities have used administrative data or collected data through proxies to learn about the issues (Cimnecki & CyBulski, in press). There is a growing consensus among researchers and policy makers looking at quality of life for persons with intellectual disabilities on the value of considering multiple perspectives: the perspective of the person with intellectual delay, others who know the person well (i.e., usually parents), and involved professionals (Zekovic & Renwich, 2003).

The first round of calls was facilitated by a staff member of the SmartHome who interviewed residents prior to moving into the home in July, 2009 (referred to as “Time 1”). The second round of data collection was facilitated by the first author a year after residents had moved into the SmartHome in August, 2010 (referred to as “Time 2”). Interviewers recorded resident’s responses; however some data was unable to be obtained due to variations in research methods of the interviewers and resident’s communication abilities.

In addition to these calls, Imagine! collected their standard data using the Support Intensity Scale (SIS), which is typically submitted to Medicaid for funding purposes. SIS data was also collected twice. As an administrative data collection tool, SIS data is collected at varying time periods for residents, and as such, the Time 1 SIS data utilized in this study was collected between 2.5 years to 14 months prior to moving into the SmartHome. The SIS Time 2 data for all eight residents was collected in August 2010. SIS data was gathered by Imagine! staff as part of their standard assessment. A single staff member collected seven out of eight Time 1 data and all Time 2 data.

SmartHome Residents Quality of Life

SIS data collection interview requires two or more respondents who know the individual with the disability (Tassé, Schalock & Wehmeyer, 2005). Respondents may include friends of the individual, family members, direct-care staff, or the individual with the disability serving as a self-advocate. In Time 1 respondents included self-advocates/residents (n=5), program coordinator (n=1), residential counselor (n=1), director of disability services (n=1), and friends of the individual with the disability (n=1). Time 2 respondents included the SmartHome site supervisor (n=8), an assistant site supervisor (n=5) and a primary counselor (n=2). No self-advocates/residents were included in Time 2 respondents.

Measures

Quality of Life: National Core Indicators

The NCI Consumer Survey is designed to measure over half of the 60 core indicators as identified on the National Core Indicators for individuals with developmental disabilities who are consumers of services and help providers better serve people with developmental disabilities and their families (NASDDDS & HSRI, 2001). The NCI Consumer Survey contains nine subscales with a total of 46 items (NASDDDS & HSRI, 2001). Subscales includes: *community inclusion* (participation in integrated activities in the community); *safety* (feelings of safety in home and neighborhood); *choices and decision making* (making choices about lives and engagement in planning services and supports); *health* (securing regular health exams); *respect and rights* (receiving the same respects as others in the community); *relationships* (friendships and relationships with others); *satisfaction* (satisfied with services and supports received); *access* (services readily available to individuals); and *service coordination* (service providers are accessible and responsive) (NASDDDS & HSRI, 2001). Higher scores on the NCI subscales mean that the residents experienced a higher quality of life, lower scores indicate a lower quality

SmartHome Residents Quality of Life

of life. For a detailed description and items of the Consumer Survey, please refer to Appendix A.

Supports Intensity Scale (SIS)

The SIS is a tool utilized for creating individualized service plans for individuals with disabilities. Imagine! uses the SIS to establish a more standardized approach to funding (www.imaginecolorado.org/SIS.htm accessed on 10-20-2010). An important feature of the SIS is that it focuses on the various forms of support needed for an individual to complete and engage in certain activities, as opposed to being a tool to define the individual's capability for such activities. The SIS data is used to address 'What support does this person need?' 'What skill does this individual need to learn?', and 'How can the environment be modified to better accommodate this person's abilities and needs?'" (Thompson et al, 2004a). Supports, as defined for use in the SIS, refer to "an array of resources and strategies, including individuals, agencies, money or tangible assets, assistive devices, or environments that enable people with developmental disabilities live in typical community settings" (www.siswebsite.org accessed on 10-20-2010).

The SIS is organized into three sections, however, for the purposes of the current study data was analyzed from only one section, the Support Needs Scale. This scale consists of six subscales and contains a total of 49 items (Thompson et al, 2004a). In each subscale, support needs are measured through scoring the frequency, daily support time and type of support needed in order for the individual to participate in the activity. For each item, residents rated on a 0-4 scale with higher numbers indicating higher levels of support needed.

The six subscales include: *Part A: Home Living* (activities of daily living such as personal hygiene, eating, and housekeeping, range of scores 0-92); *Part B: Community Living*

SmartHome Residents Quality of Life

(access to and participation in community activities with other community members, range of scores 0-91); *Part C: Lifelong Learning* (learning in areas of self-management, social interaction, and use of technology, range of scores 0-104); *Part D: Employment* (skill acquisition, maintenance and performance in an employment setting, range of scores 0-87), *Part E: Health and Safety* (maintenance of personal health and well-being, range of scores 0-94), and *Part F: Social*, (socialization with others both within and outside the household, range of scores 0-93). Higher scores indicate a higher need for support to do daily activities. Lower scores indicate a lower need for support and, therefore, a higher level of independence. For a detailed description and items of the SIS Supports Needs Scale, please refer to Appendix B.

Qualitative Data

The qualitative tool utilized in the study was developed prior to the beginning of the research study. The questions were designed to obtain detailed information about resident's daily lives that Imagine! could use to help with the transition to the new home. During the phone interviews, each resident is asked an open ended question each day. These open-ended questions were written by the research mentor after talking with Imagine!. The questions were designed to better understand how residents were spending their time and their experience with technology. The information learned from these questions was shared with Imagine! staff so they could help the residents transition into their new home and to create trainings that fit the residents' needs.

Data from Imagine!

Finally, in addition to the data collected from the residents and the SIS process, the researchers presented what was learned to Imagine! in October 2010. As part of this presentation, the researchers asked for feedback and insight from Imagine! to make sure their

SmartHome Residents Quality of Life

interpretation was correct. In qualitative research this process is called Member Checking.

Imagine! staff were helpful in helping interpret some of the findings. We present some of this insight below in our findings.

Results

National Core Indicators Quality of Life

Our research question asked whether quality of life changes for the residents after they moved into the SmartHome. To address this, we compared changes in mean scores between Time 1 and Time 2 for each of the eight residents. The decision to analyze data by comparison of changes in mean was based upon the low sample size ($n \leq 8$) that did not allow for tests of significance. Also, because of the small sample size, missing data became an issue. Mean scores could not be substituted for missing data. The decision was made to look at changes in mean scores within the subscale. For those residents who had missing data, no mean change score was computed for that category. The sample sizes for the NCI subscale mean score changes are as follows: *community inclusion*, $n=6$; *safety*, $n=8$; *choices and decision making*, $n=6$; *health*, $n=6$; *respect and rights*, $n=6$; *relationships*, $n=6$; *satisfaction*, $n=8$; *access*, $n=5$; and *service coordination*, $n=7$.

Table 2. Frequency of Change in Mean Scores for National Core Indicators: Consumer Survey (see appendix for actual score changes).

Frequency for changes in NCI mean scores			
NCI Subscale	Decrease	Stayed the Same	Increased
Community Inclusion (n=6)	2	3	1
Safety (n=8)	2	3	3
Choices & Decision Making (n=6)	1	0	5

SmartHome Residents Quality of Life

Receive Regular Health Care (n=6)	4	1	1
Respect and Rights (n=6)	2	1	3
Relationships (n=6)	3	0	3
Satisfaction (n=8)	0	7	1
Access (n=5)	0	1	4
Service Coordination (n=7)	4	3	0

Most interesting to note where that five of the six residents who gave both pre and post data reported feeling more in control of their own lives, four out of five residents reported that they had better access to resources (e.g. transportation, people to help them) than they did before, three out of six felt safer in their new home and neighborhood, two residents felt they were more respected by those around them, three residents reporting having more personal relationships and/or having more contact with friends, family, and romantic partners. One reason for the change in some of these NCI mean scores may be due to the public nature of the SmartHome. As mentioned earlier, preliminary results were presented to Imagine! and discussed for their insight. One theme that came out in the discussion is the belief that the public nature of the SmartHome has been very helpful for residents. Meeting people who are touring the home and the ability to discuss their experiences has been believed to help several residents increase their communication and interaction skills.

Two NCI subscales had a majority of residents stay the same or decrease in mean scores from Time 1 to Time 2. In the *health* subscale, the majority of the changes in means scores stayed the same (n=1), or decreased (n=4). Of interest is the change in *health* by a decrease of six

SmartHome Residents Quality of Life

points for one of the residents. This indicates out of the total respondents for *health* (n=6), five residents perceived themselves as having less availability in receiving regular health care's service from Time 1 to Time 2. However, when this information was presented to Imagine!, it was pointed out that it is required for residents to see health care providers regularly and that Imagine!'s records showed they had seen doctors within the last year. It is possible the overall decrease in the changes of mean scores for *health* may be attributed to the wording of some items in the subscale that ask about health history within a set time frame (i.e. six months), in which clients may have not seen the specific health care provider of interest in that time period, but does not mean that they had not seen such health care providers in the past year.

Last, in the service *coordination subscale* all changes in mean scores stayed the same (n=3) or decreased (n=4). Of interest is the change in *service coordination* by a decrease of five points for one of the residents. This indicates out of the total respondents for *service coordination* (n=7), four residents perceived themselves as having service providers that are as less accessible, responsive, and supportive of their needs than form the time before they moved into the Charles Smarhome. When presented to Imagine!, the group felt that this was accurate, even desired. They felt residents would get their needs met by house staff versus service providers.

Despite the decrease in residents means scores of their perceptions of *health* and *service coordination*, the overall results indicate residents perceive themselves to be the same or have an increase in the quality of life content areas as measured by the NCI.

Supports Intensity Scale

Similar to NCI data analyses, SIS data was analyzed by comparing the changes in raw scores for the six subscales and the percentile of support needs from Time 1 to Time 2. The need

SmartHome Residents Quality of Life

for less supports was viewed by the researchers as showing higher independence and, as a result, a higher quality of life.

Table 3. Frequency of Change in Mean Scores for Support Intensity Scores

Frequency for changes in SIS mean scores			
SIS Subscale	Decrease in scores	No change	Increase in scores
Home Living (n=8)	5	1	2
Community Living (n=8)	6	1	1
Lifelong Learning (n=8)	5	0	3
Employment (n=8)	7	0	1
Health and Safety (n=8)	4	0	4
Social (n=8)	3	1	4
Overall SIS Scores (n=8)	5	2	1

Overall, results indicate residents' supports needs decreased from Time 1 to Time 2. Specifically, the change in percentile of support needs decreased for five of the eight residents, remained the same for two residents and increased for one resident. This fits with what was expected. Three of the residents have physical limitations and medical conditions resulting from their disabilities that will always require a higher level of support.

To better understand the impact of living in the SmartHome had on quality of life for the residents, the decision was made to look at changes for specific activities in the SIS interview – focus on specific questions in each subsection that could be tied with technology in the home. While no data was collected that would link specific technology with a change in support intensity, one author had informal talks with some Imagine! staff. Below are the specific activities she choose to look at, the subsequent changes in scores from Time 1 to Time 2 and the technology available in the SmartHome that could explain these changes.

SmartHome Residents Quality of Life

In *Part A: Home Living Activities*, activity 3 is eating food. Half of the residents support needs increased while the other half decreased. Of interest is the change in two residents scores which increased from 0 (no supports needed) to 7 and 5 (scale is 0 to 11). When this was presented to Imagine!, one potential explanation given by Imagine! is that these residents may have been previously heating a precooked and frozen meal in a microwave and were now interested in making more involved meals. This was not measured directly for our study, however. One resident also showed a dramatic decrease in needs support (total score went from 8 to 0). Another explanation for the changes may be the technology that is available. Again, no data was collected that would link specific technology with a change in support intensity. Two pieces of technology that could make it easier to cook include the AbleLink Computer Prompting System and induction stovetop found in the SmartHome.

In *Part B: Community Living Activities*, activity 1 is getting from place to place throughout the community. Seven of the residents support needs decreased while one residents support needs stayed the same. For this item there were three residents whose scores went from high needs (scores of 11, 8, and 7) to 0 support needs in Time 2. It is possible that the dramatic drop in support needs for these three respondents is due to the Handheld GPS device that was used briefly and the AbleLink Computer Prompting System.

In *Part C: Lifelong Learning Activities*, activity 4 is using technology for learning. Five resident's support needs decreased, two resident's support needs stayed the same and one resident's support needs increased. Of interest is the change in a resident from 9 support points (maximum of 12 points) to 6 support points. This resident is an individual who is in a wheelchair with limited hand mobility who expressed to the one of the researchers that she has made positive advances with speech recognition software and use of the computer prompting

SmartHome Residents Quality of Life

systems in the SmartHome and at her day program (MK, personal communication, September 15, 2010).

Also of interest is the change in a resident who increased from 6 to 7 for support on learning activities. This resident has been creating monthly diary entries on the computer which are posted on the Imagine! website and expressed to the first author in the 5-day phone calls that she is currently learning how to use many writing features of the computer that she had never used before moving into the SmartHome (DF, personal communication, August 6, 2010 & October 4, 2010). It is possible that the increase in supports are due to the amount of new computer technologies she is learning and therefore the increased supports that may be needed in order to keep learning how to use these items.

In *Part E: Health and Safety Activities*, activity 4 is ambulating and moving about. Half of the residents supports needs decreased, three residents support needs stayed the same at 0 and one of the residents supports needs increased. Of interest is the change in three residents who decreased from 11 to 8, 12 to 9 and 10 to 8, respectively with a maximum of 12 points. These three residents all use power wheelchairs for mobility. It is possible that the decrease in support needs for these three residents can be attributed to the layout designs of the SmartHome which includes large hallways and doors.

Correlation of NCI and SIS

As explained in the methods section, a more subjective measure (NCI) and a more objective measure (SIS data) were both collected to address the research question. Based on a question from Imagine!, the decision was made to look at the correlation of the mean changes for each measure. Results indicate significant correlations in seven areas in the changes of means scores in NCI and SIS data (See Table 3).

Table 3. NCI and SIS Correlations:

Changes in NCI	Changes in SIS scores					
	Home Living Activities	Community Living Activities	Lifelong Learning Activities	Employment	Health and Safety	Social
Community Inclusion	-0.22	-0.19	-0.15	-0.75*	-0.17	- 0.79*
Safety	-0.09	0.07	0.18	-0.02	-0.06	-0.23
Choices and Decision Making	0.64	-0.25	-0.47	-0.33	0.02	-0.54
Receive regular Health Care	-0.09	-0.15	-0.16	-0.47	-0.44	-0.49
Respect and Rights	0.49	0.26	0.45	0.26	0.58	-0.44
Relationships	0.44	-0.60	-0.77 *	-0.67	0.18	-0.89 **
Satisfaction with life and home	-0.11	-0.14	-0.63*	-0.21	-0.13	-0.11
Access	-0.067	0.34	0.56	0.85*	0.35	0.99***
Service Coordination	-0.37	-0.53	-0.48	-0.55	-0.462	-0.05

Significance level:

p< .10*

p< .05**

p< .01***

For several variables—Home Living Activities (SIS), Community Living Activities (SIS), Health and Safety (SIS), Safety (NCI), Choices and Decision Making (NCI), Receiving Regular Healthcare (NCI), Respect and Rights (NCI), and Service Coordination (NCI)—there was no significant correlation between the two scales. For many of these, a correlation was not expected. For example, nothing on the NCI measured quality of life in terms of Home Life Activities. However, for others a correlation was expected, such as a possible negative correlation between NCI *Respect and Rights* and SIS *Employment* in that those who are viewed as needing less support in their work setting would also perceive themselves as having more respect from others in their environment. An additional negative correlation that was expected and not found was between NCI *Relationships* with life and home with SIS *Community Living* in

SmartHome Residents Quality of Life

that those who perceive themselves as more relationships may not be viewed as needing as much support in activities within their community as those individuals who are the friends and family members of the resident may be able to engage the residents in the community without much support from SmartHome staff. Although some of the predicted correlations were not found, several interesting correlations between the NIC and SIS do exist.

There were two strong positive correlations – NCI access and SIS employment ($r=0.85$, $p=0.06$) and NCI access and SIS social ($r=0.99$, $p=.002$). Residents who felt they had better access to supports like transportation and people to help them also had increases in the support needed for employment and social activities. Alternatively, those who felt they had less access to these supports were viewed as needing less supports around employment and social activities. One possible explanation is that this increase in intensity of supports is being noticed and reported by residents. Another possible explanation is that residents who feel like they do not have this access are being viewed as not needing it. It is possible the residents disagree with this but that data was not collected. Perhaps the most interesting finding is that the SIS social subscale and the NCI access subscale are almost perfectly correlated.

There were also several strong negative correlations. First, as the view that less SIS supports for *lifelong learning* were needed, those residents perceived their *relationships* (NCI) increased ($r = -0.766$, $p=0.07$) or as the need for support in lifelong learning increased, residents perceived that they had fewer personal relationships. Decreases in *lifelong learning* were also significantly correlated with increases in NCI *satisfaction* ($r = -0.627$, $p=0.096$). These results are not surprising and points to the possibility that as resident's view themselves as having more social relationships and time spent with friends and family they are less likely to need support in learning problem solving and self-management skills, and as such, the relationships may foster

SmartHome Residents Quality of Life

growth in these educational domains. Also, as residents report feeling more *satisfaction* with their living/work settings increase, they are observed as needing less support in areas of problem solving and self-management skills in such environments.

Significant negative correlation were also found between the NCI *community inclusion* and changes in SIS *employment*, ($r = -0.75$, $p=0.08$) and NCI *community inclusion* and changes in SIS *social* ($r = -0.792$, $p=0.06$). This negative correlation means as a resident's perception of *community inclusion* increases, their viewed need for support in *employment* and *social* activities decrease or vice-versa. This finding is expected given the possibility that those who are viewed as in need of less support in employment and social settings are more integrated with in community activities through their physical and social presence in the community through their job setting and day programs.

Finally, a negative correlation exists between changes in NCI *relationships* and changes in SIS *social* ($r = -0.89$, $p=0.02$). This negative correlation means that as a resident perceives their *relationships* as increasing, there are viewed as needing less support in *social activities*, or vice-versa. Such finding is expected due to the possibility that those who perceive themselves as gaining more friends and time spent with friends/family are more likely to not need as much support in social skills with those individuals because of the nature of such relationships.

Five Day Qualitative Analysis

Coding analysis of the 5-Day qualitative questions was completed by the two student researchers utilizing inter-rater reliability checks. One coder first independently coded the responses written and created a coding scheme. The second coder independently coded into that scheme. The two coders then met to compare their codes. All codes were reached through

SmartHome Residents Quality of Life

consensus of the two coders. Detailed description of the qualitative data findings can be found in Appendix C.

While the qualitative data was not designed to address quality of life, there are some findings that provide insight into the changes in quality of life. Going to work or to their day program was important for the residents. This was most frequently mentioned in Time 1 and Time 2 as the most important thing they did that day (n=4 for Time 1 and Time 2), their favorite thing they did that day (time 2 only, n=4), something new they did that day (time 2 only, n=3). However, in Time 2 residents began mentioning activities involving the “SmartHome coffee grinding business” (n=3). Also, the favorite thing the residents reported doing changed from watching television (n=3) in Time 1 to going to work/day program in Time 2.

When asked about “*Use of computers*” in Time 1 most respondents reported “no access to computer in current home” (n=4) and “use computer for personal interests” (n=5). In Time 2, the most common response to “Use of computers” was “access to computer in current home” (n=6) and “use for personal interests” (n=6). While the number of residents who reported having access to a computer and use of such technology for personal interest increased, it is interesting to note that two residents did not report having access to computer or using technology for personal interest in Time 2.

Discussion

Through the course of our research we believe there has been an improved quality of life for the eight residents of the SmartHome. Results from Time 1 to Time 2 data for NCI and SIS scores indicate that in the course of one year there was a change in factors that indicate improved quality of life. Specifically, a majority of the eight residents reported increases in access and choices and decision making on the NCI subscales within the year and were rated as needing

SmartHome Residents Quality of Life

fewer supports for home living, community living, assistance with lifelong learning, and employment during year 2. The overall SIS scores were also lower for a majority of the eight residents. There are a few possible reasons why we believe quality of life has increased. These include (a) forming new relationships and being involved in the community; (b) being asked to provide feedback on a new approach for residential housing; and (c) access to assistive technology.

Relationships and Community Involvement

First, the improvement in quality of life for the residents may be due to relationships and involvement within the community. Both of these increased for a majority of the residents on the NCI scale. This also fits with the research on quality of life. The two major approaches to understanding quality of life in persons with developmental disabilities focus on the interaction of the person and environment in addition to the interpersonal relationships one has with others (Zekovic & Renwich, 2003; Hatton, 1998; Schalock, 1996). Utilizing these approaches, the increase in quality of life of the SmartHome residents is due to their perceived increase in relationships amongst not only the other SmartHome residents, but also with community members both inside and outside of the home. Indeed, the residents now have greater social interactions with individuals who are touring the SmartHome, yet social relationships are not limited to the physical proximity of the home. Some of the residents are able to use computer technology for social networking that is an additional feature in the increase in quality of life. In addition, the residents are more able to have access to technologies that allow for greater independence in engagement in community activities. Several of the residents are able to better commute to their day and work programs, and such independence enable the residents to feel more respected by the physical and relational environment. Improvements in the interactions

SmartHome Residents Quality of Life

with the environment and personal relations are central features for quality of life that have been fostered in the lives of the SmartHome residents.

Improved Choices and Decision Making

Another area of improved quality of life is an increase in the choices and decision making. This area had the highest increase on the NCI. This is encouraging because past researchers have found that people with developmental disabilities had fewer opportunities to make choices and decisions (Kishi, Teelucksingh, Zollers, & Park-Lee, 1988; Sheppard-Jones et al., 2005) . The high increase in choices and decision making could be because the residents were all made aware before moving into the SmartHome that they are living in a test facility home. This role of testing, trialing, investigating, failing, and trying again has been bestowed upon the residents of the SmartHome and might be a factor in the improved quality of life we have seen in our research. In other words, the residents knew they would be asked for input. In a conversation with one of the researchers, one of the residents expressed how good she felt about what she is doing and learning in the SmartHome. She liked the idea of being involved in exploring others ways to help individuals with disabilities (MK, personal communication, September 15, 2010).

Utilization of Technology

Finally, the SmartHome is an environment created around Assistive Technology devices. Assistive Technology is defined as ‘any item, piece of equipment, or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities’ (Assistive Technology Act of 1998). Although we did not conduct research on the technology in the home, other researchers looking at smarthome technology have stated that the technology allows people to do complete

SmartHome Residents Quality of Life

tasks without assistance, thereby increasing independence and quality of life (Dewsbury, 2001).

This was supported by the decreases reported in the SIS data. In all but 2 subscales, the supported needed by residents decreased in time 2, showing that residents were better able to complete tasks more independently.

Some specific instances of the technology of the SmartHome improving the quality of life of the residents were expressed during a conversation with an Imagine! Project Manager and the Site Coordinator of the SmartHome (SW & TW, personal communication, September 15, 2010). One example involves a resident who uses his power wheelchair for mobility and utilizes an Alternative Augmentative Communication device in order to communicate. This is an individual who has been dependent on care staff in his life. While living in the SmartHome, the staff has been working towards allowing this individual to have alone time by utilizing the infrared capabilities of his Dynavox to control his environment. Due to the factors of his condition he has rarely ever had alone time. The staff also sees improvements in the residents through the AbleLink prompting system's ability to check the weather. The residents are able to see what the temperature will be like for the day in their bedrooms and can dress appropriately. This ability to self-advocate is an important factor in the quality of life of individuals with disabilities.

It should be noted, however, that not all the residents were tapping into the technological aspects of the house. Two of the residents reported they did not have access to computers in the new home. There are a few possible explanations for this. First, Sherer (1996) found in a survey of 227 adults with disabilities the overall rate of non-use (also known as "abandonment") to be 29.3%. The two non-users in the SmartHome account for 25% of the residents living there. This fits with what Sherer found. Such variability in assistive technology device used may be due to 3

SmartHome Residents Quality of Life

areas known as “Matching Person and Technology: (1) The characteristics of the milieu (environmental and psychosocial setting) in which the device is used, (2) Pertinent features of the individual’s personality and temperament, and (3) The salient characteristics of the assistive technology device itself” (Sherer, 1996 pg. 440). Literature on adapting technology in the general population can also provide some insight. According to Venkatesh, et. al. (2003), four variables effect user acceptance of technology: performance expectancy (degree to which technology is believed to help the user in their job), effort expectancy (how easy the technology is to use), social influence (perception that others think the individual should be using this technology), and facilitating conditions (perception that there is support the individual can tap into to use the technology), and predicted user acceptance of technology and usage behavior.

These previous research findings are helpful in making sense of the current studies results in regards to the use of technology. First, two of the residents did not report use of technology in the SmartHome during Time 2. This may be the result of abandonment and/or a lack of understanding and support in using the technology. It is possible that these residents do not view the technology as beneficial, and further, they may have rendered themselves unable to use the technology if adequate support for the technology was not provided. In addition, the six residents who reported use of technology may have attributed their responses to other’s expectations to use the technology. When the research study began as residents moved into the SmartHome in July of 2009, some of the technology was not working properly. Because the technology was not fully up and running, some residents may have had difficulty in using the technology for pleasure (such as downloading video games onto a computer). Thus, resident’s willingness to use the technology may have been influenced by the support received and match of technology with personality. Although our research did not measure the non-use of

SmartHome Residents Quality of Life

technology, perhaps one area to consider is the possibility that relationship with others and fit with technology may be better indicators of SmartHome technology adaptation. Indeed, several extraneous variables, such as personality and goodness of fit with technology, must be considered in understanding the non-use of technology reported by some of the SmartHome residents.

Limitations and Future Directions

There were a few limitations to this study. First, the 5-day call data was collected by two different people – someone who worked for Imagine! and was not a researcher, and then by a researcher on this project. For Time 1, there is a lot of missing or incomplete data. The missing data made tracking changes in scores difficult because there was not an overall score for some of the Time 1 scales to compare to Time 2. Thus, measuring the difference in change yielded smaller sample sizes than hoped for. An additional limitation to the study was a lack of comparison to a control group. This limitation made comparing changes due to the nature of the SmartHome (e.g. specific technologies and environment) and other extraneous variables unknown. Thus, the increase in quality of life for the residents may be due to the nature of the SmartHome; however there was not another comparison group of developmentally disabled residents living in a group home to measure.

Another major limitation was data was not systematically collected to match changes in SIS scores to specific pieces of technology. The goal of this research project was to determine if living in a group home that uses smarthome technology increased the quality of life for the eight residents. While using data collected and analyzing the changes between support needs between Time 1 and Time 2 indicated that there was a decrease in support needs, and adhering to the reasoning that less supports means more independence which we view as an improvement in

SmartHome Residents Quality of Life

quality of life, there was no specific indications as to what caused the increases and decreases in supports. In conversations with Imagine! and our understandings of the use of technology expressed by the residents we were able to create possible links between support needs and specific technology. In order to accurately pinpoint changes in quality of life due to smarthome technology future research should attempt to understand the direct correlation of specific technology to changes in support needs. An additional limitation to the study was difference of respondents to SIS data from Time 1 to Time 2. An important feature of the SIS interview process is that respondents should be individuals who are the most involved in the life of the individual with the disability for whom data is being collected. This aspect being considered, it can be argued that the best possible respondent for the SIS data be the individual with the disability as it would serve a self-advocacy forum. In Time 1 the SIS interview involved many self-advocates as respondents while in Time 2 there were no self-advocate respondents.

A final limitation to the study is that of maturation. Maturation is a threat to the internal validity of research findings as it refers to the possibility that changes in subjects scores may be due to natural growth and development between data collection periods, rather than changes due to the research design. Not having a control group, it is hard to argue that the increase in quality of life for these residents was higher than for other residents living in group homes.

Summary

The development of smart home technology is one of the most promising opportunities for helping individuals with developmental disabilities live independently in the community. The goal of this research project was to determine if living in a group home that utilized smart home technology increased the quality of life for adults with developmental disabilities. Results from the data collected indicate improved quality of life for the eight individuals living in the

SmartHome Residents Quality of Life

SmartHome. Results showed the residents having more and better relationships, increased independence and greater interaction with their environment. Although our findings point to positive results in quality of life these improvements, this was a small study with eight residents over a relatively short period of time. We believe future research needs to be done to better understand how specific technology may affect quality of life for individuals with developmental disabilities.

References

- Cheek, P., Nikpour, L., Now, H. (2005). Aging Well with Smart Technology. *Nursing Administration Quarterly*, 29(4), 329-338.
- Costanza, R., Fisher, B., Ali, S., Beer, C., Bond, L, Boumans, R. Danigelis, N.L., Dickinson, J., Elliott, C., et al. (21 authors total). (2007). Quality of life: An approach integrating opportunities, human needs, and subjective well-being. *Ecological Economics*, 61, 267-276.
- Dewsbury G, Clarke K, Rouncefield M, SommervilleI, Taylor B, Edge M. (2003) Designing acceptable "smart" home technology to support people in the home. *Technology & Disability*.15, 191-199.
- Hatton C. (1998). Whose quality of life is it anyway? Some problems with the emerging quality of life consensus. *Ment Retard* 36:104 –115.
- Kishi, G., Teelucksingh, B., Zollers, N., Park-Lee, S., & Meyer, L. (1988). Daily decision-making in community residences: A social comparison of adults with and without mental retardation. *American Journal on Mental Retardation*, 92,430-435.
- Mokhtari, M., Ghorbel, M., Kadouche, R., & Feki, M.A. (2007). From smart home to smart space in independent living: A framework for multiple contexts management. Third IEEE International Conference on Wireless and Mobile Computing, Networking and Communications.
- National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute (2001). National Core Indicators: Consumer Outcomes, Phase IV Final Report.
- Pape, T. L.-B., J. Kim & B. Weiner (2002). The shaping of individual meanings assigned to assistive technology: a review of personal factors. *Disability and Rehabilitation* 24(1/2/3), 5-20.
- Patrick, D. L. (1997). Rethinking prevention for people with disabilities, Part I: A conceptual model for promoting health. *American Journal of Health Promotion*, 11, 257–260.
- Seltzer, M.M. & Krauss, M.W. (2001). Quality of life on adults with mental retardation/developmental disabilities who live with family. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 105-114.
- Seltzer GB, Luchterhand C. (1994). Health and wellbeing of older persons with developmental disabilities: a clinical review. In: Seltzer MM, Krauss MW, Janicki MP, editors. *Life course perspectives on adulthood and old age*. Washington, DC: American Association on Mental Retardation. 109–142.

SmartHome Residents Quality of Life

- Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock, & G. N. Siperstein (Eds.), *Quality of life volume I: Conceptualization and measurement* (pp. 123–139). Washington, DC: American Association on Mental Retardation.
- Shalock, R.L., I. Brown, R. Brown, R.A. Cummins, D. Felce, L. Matikka, K.D. Keith, & T. Parmenter (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6), 457-470.
- Sherer, M.J., (1996). Outcomes of assistive technology use on quality of life. *Disability and Rehabilitation*, 18(9), 439-448.
- Sheppard-Jones, K., Prout, H.T., & Kleinert, H. (2005). Quality of life dimensions for adults with developmental disabilities: A comparative study. *Mental Retardation*, 43(4), 281-291.
- Stancliffe, R. & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual & Developmental Disability*, 25(4), 281 – 305.
- Stancliffe, R. & Lakin, C. (eds) (2007). *Cost and Outcomes of Community Services for People with Intellectual Disabilities*. Brookes Publishing. Baltimore MD.
- Tassé, M.J., Schalock, R., Thompson, J.R., & Wehmeyer, M. (2005). *Guidelines for interviewing people with disabilities: Supports Intensity Scale*. American Association on Intellectual and Developmental Disabilities: Washington, DC.
- Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D., Schalock, R. L., Silverman, W., Tasse', M. J., & Wehmeyer, M. L. (2004a). *Supports Intensity Scale*. Washington, DC: American Association on Mental Retardation.
- Venkatesh, V., Morris, M.G., Davis, G.B., & Davis, F.D., (2003). User acceptance of information technology: Toward a unified view. *MIS Quarterly*, 27(3), 425-478.
- Wehmeyer, M. & M. Schwartz, (1998). The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33(1), 3-12.
- Zekovic, B. & Renwich, R. (2003). Quality of life for children and adolescents with developmental disabilities: Review of conceptual and methodological issues relevant to public policy. *Disability & Society*, 18(1), 19-34.
- Zigman WB, Seltzer GB, & Silverman WP. (1994). Behavioral and mental health changes associated with aging in adults with mental retardation. In: Seltzer MM, Krauss MW, Janicki MP, editors. *Life course perspectives on adulthood and old age*. Washington, DC: American Association on Mental Retardation. p 67–92.

Appendices

Appendix A – NCI

Appendix B – SIS

Appendix C – Qualitative Data

Appendix D – Changes in Time 1 and Time 2 Scores

Appendix A

National Core Indicators, Consumer Outcomes. Phase IV Final Report. Fiscal Year 2001-2002 Data. National Core Indicators, Human Services Research Institute (HSRI).

Community Inclusion:

Indicated as “Consumer outcomes: Community Inclusion”. Concern statement: “People use integrated community services and participate in everyday community activities”(pg. 42). One indicator listed: “The proportion of people who participate in everyday integrated activities in their communities” (pg.42). Cronbach’s alpha= 0.89.

Subscale questions (pgs. 92-95):

1. Do you go shopping? Yes/No
2. Do you go out on errands or appointments? Yes/No
3. Do you go out for entertainment? Yes/No
4. Do you always eat at home, or do you sometimes go out to eat? Yes/No
5. Do you go to religious services? Yes/No
6. Do you go to clubs or other community meetings? Yes/No
7. Do you exercise or play sports? Yes/No

Safety:

Indicated as “Health, welfare, and rights: Safety”. Concern statement: “People are safe from abuse, neglect, and injury” (pg72). One indicator listed: “The proportion of people who report that they feel safe in their home and neighborhood” (pg. 72).

Subscale questions (pg. 110):

1. Are you ever afraid or scared when you are at home?
Rarely
Sometimes
Most Of the time
2. Are you ever afraid or scared when you are out in your neighborhood?
Rarely
Sometimes
Most Of the time

Choices and Decision Making:

Indicated as “Consumer outcomes: Choices and Decision making”. Concern statement: “People make choices about their lives and are actively engaged in planning their services and supports” (pg. 49). Two indicators listed: 1. The proportion of people who make choices about their everyday lives, 2. The proportion of people who report having been provided options about where to live and work (pg. 49). Two scales: support and related choices, Cronbachs= 0.92, and personal choices, Cronbachs=0.95 (pg.49).

Subscale questions (pgs. 96-101).

1. Who chose the place where you live?
Someone Else Chose

SmartHome Residents Quality of Life

- Person Had Some Input
- Person Chose Without Help
- 2. Do you choose who helps you at home?
 - No, Someone Else Chooses
 - Person Can Request A Change
 - Yes, Person Chooses
- 3. Who chose the place where you work (or go during the day)?
 - Someone Else Chose
 - Person Had Some Input
 - Person Chose
- 4. Do you choose who helps you at work?
 - No, Someone Else Chooses
 - Person Can Request A Change
 - Yes, Person Chooses
- 5. Did you choose your case manager/service coordinator?
 - Someone Else Chose
 - Person Had Some Input
 - Person Chose
- 6. Did you choose the people you live with (or to live by yourself)?
 - No, Someone Else Chooses
 - Person Can Request A Change
 - Yes, Person Chooses
- 7. Who decides your daily schedule?
 - Someone Else Decides
 - Person Has Help Deciding
 - Person Decides
- 8. Who decides how you spend your free time?
 - Someone Else Decides
 - Person Has Help Deciding
 - Person Decides
- 9. Do you choose what you buy with your spending money?
 - No, Someone Else Chooses
 - Person Has Help Choosing
 - Yes, Person Chooses
- 10. How many places did you visit before moving here?
 - State
 - Did Not Visit Before Moving In
 - One Place Only
 - Looked At More Than One
- 11. How many places did you visit before working [at your job or day activity]?
 - Did Not Visit Before Moving In
 - One Place Only
 - Looked At More Than One

SmartHome Residents Quality of Life

Health:

Indicated as “Health, Welfare, & Rights; Health”. Concern statement: “people secure needed health services”. Three indicators: 1. The proportion of people who have had a physical exam in the past year; 2. The proportion of women who have had a GYN exam in the past year; 3. The proportion of people who have had a routine dental exam in the past six months.

Subscale questions (pgs. 111-112).

1. When was his/her last physical exam?
Within Past Year
Over a year ago
Don't know
2. If female, when was her last OB/GYN exam?
Within Past Year
Over A Year Ago
Never Had An Exam
Don't Know
3. When was his/her last dentist visit?
Within Last Six Months
Over Six Months Ago
Don't Know

Respect and Rights:

Indicated as “Health, Welfare, & Rights: Respect and Rights”. Concern statement: “ people receive the same respect and protections as others in the community”. Five indicators: 1. The proportion of people who have an advocate or someone who speaks on their behalf; 2. The proportion of people whose basic rights are respected by others; 3. The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights; 4. The proportion of people who report satisfaction with the amount of privacy they have; 5. The proportion of people indicating that most support staff treat them with respect.

Subscale questions (pgs. 114-119).

1. Do you know who your advocate or guardian is?
No
Maybe, Not Sure
Yes
2. Do people read your mail without your permission?
No
Some Mail
Yes
3. Can you be alone with [guests], or does someone have to be with you?
No, Someone Always Present
Some Restrictions
Yes, Can Be Alone With Guests
4. Are you allowed to use the phone when you want to?
Not Allowed
Some Restrictions

SmartHome Residents Quality of Life

Can Use Anytime Total

5. Do people (including staff) let you know before they come into your home?
No
Sometimes
Yes
6. Do people (including staff) ask permission before coming into your bedroom?
No
Sometimes
Yes
7. Have you ever participated in a self-advocacy group, meeting, conference, or event?
No
Had Opportunity But Chose Not To
Yes
8. Can you be alone if you want to?
No/yes
9. Is [staff who helps you at job/day activity] nice and polite to you?
No
Sometimes
Yes
10. Is [staff who helps you at home] nice and polite to you?
No
Sometimes
Yes

Relationships:

Indicated as “Consumer Outcomes; Relationships”. Concern statement: “People have friends and relationships” (pg. 60). Four indicators: 1. The proportion of people who have friends and caring relationships with people other than support staff and family members; 2. The proportion of people who have a close friend, someone they can talk to about personal things; 3. The proportion of people who are able to see their families and friends when they want; 4. The proportion of people who feel lonely (pg.60).

Subscale questions (pgs. 102-104).

1. Do you have friends you like to talk to or do things with?
No
Yes – Staff Or Family
Yes – Not Staff Or Family
2. Do you have a best friend, or someone you are really close to?
No
Yes
3. Can you see your friends when you want to see them?
No
Sometimes
Yes
4. Can you see your family when you want to?
No

SmartHome Residents Quality of Life

Sometimes

Yes

5. Do you ever feel lonely?

Always Or Often

Sometimes

Never

Satisfaction:

Indicated as “Consumer Outcomes: Satisfaction”. Concern statement: “people are satisfied with the services and supports received” (pg. 63). Two indicators: 1. The proportion of people satisfied with where they live; 2. The proportion of people who are satisfied with their job or day program.

Subscale questions (pg. 105).

1. Do you like working at [your job or day activity]?

No

In-between

Yes

2. Do you like your home or where you live?

No

In-between

Yes

Access:

Indicated as “System performance: Access”. Concern statement: “Publicly-funded services are readily available to individuals who need and qualify for them”. Three indicators: 1. The proportion of people reporting that they received support to learn or do something new in the past year; 2. The proportion of people who report having adequate transportation when they want to go somewhere; 3. The rate at which people report that “needed” services were not available.

Subscale questions (pgs. 108-109).

1. Do people help you do new things you want to do?

No

Sometimes

Yes

2. When you want to go somewhere, do you always have a way to get there?

Almost never

Sometimes

Almost always

3. Do you get the services you need?

No

Sometimes

Yes

Service Coordination:

Indicated as “System performance: Service coordination”. Concern statement: “Service Coordinators are accessible, responsive, and support the person’s participation in service planning”. Three indicators: 1. The proportion of people reporting that service coordinators help them get what they need; 2. The proportion of people who know their service coordinators; 3. The proportion of people who report that their service coordinators asked about their preferences

Subscale questions (pgs. 106-107).

1. If you ask for something, does [your case manager/service coordinator] help you get what you need?
No
Sometimes
Yes
2. Do you know your case manager/service coordinator?
No
Maybe
Yes
3. Does [your case manager/service coordinator] ask you what you want?
No
Sometimes
Yes

Appendix B

Supports Intensity Scale (SIS)

Section 1. Support Needs Scale

Instructions: Identify the Frequency, Daily Support Time, and Type of Support that is reported necessary for the person to be successful in the six activity domains (Parts A-F). Circle the appropriate number (0-4) for each measurement (i.e., Frequency, Daily Support Time, Type of Support). (See rating key below.) Add across each line item to obtain Raw Scores. Sum the Raw Scores down to obtain the Total Raw Score for each Part.

1. This scale should be completed without regard to the services or supports currently provided or available.
2. Scores should reflect the supports that would be necessary for this person to be successful in each activity.
3. If an individual uses assistive technology, the person should be rated with said technology in place.
4. Complete ALL items, even if the person is not currently performing a listed activity.

Rating Key:

FREQUENCY: How frequently is support needed for this activity?

- 0 = none or less than monthly
- 1 = at least once a month, but not once a week
- 2 = at least once a week, but not once a day
- 3 = at least once a day, but not once an hour
- 4 = hourly or more frequently

DAILY SUPPORT TIME: On a typical day when support in this area is needed, how much time should be devoted?

- 0 = none
- 1 = less than 30 minutes
- 2 = 30 minutes to less than 2 hours
- 3 = 2 hours to less than 4 hours
- 4 = 4 hours or more

TYPE OF SUPPORT: What kind of support should be provided?

- 0 = none
- 1 = monitoring
- 2 = verbal/gestural prompting
- 3 = partial physical assistance
- 4 = full physical assistance

Part A: Home Living Activities	Frequency	Daily Support Time	Type of Support	Raw Scores
---	-----------	-----------------------	--------------------	---------------

SmartHome Residents Quality of Life

1. Using the toilet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Taking care of clothes (includes laundering)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Preparing food	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Eating food	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Housekeeping and cleaning	0	1	2	3	4	0	1	2	X	X	0	1	2	3	4	
6. Dressing	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Bathing and taking care of personal hygiene and grooming needs	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
8. Operating home appliances	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Home Living Activities (max. 92)																

Part B: Community Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Getting from place to place throughout the community (transportation)	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participation in recreation/leisure activities in the community settings	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Using public services in the community	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Going to visit friends and family	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Participating in preferred community activities (church, volunteer, etc.)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Shopping and purchasing goods and services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Interacting with community members	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Accessing public buildings and settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Community Living Activities (max. 91)																

Part C: Lifelong Learning Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
---	-----------	--	--	--	--	--------------------	--	--	--	--	-----------------	--	--	--	--	------------

SmartHome Residents Quality of Life

1. Interacting with others in learning activities	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in training/educational decisions	0	1	2	3	X	0	1	2	3	X	0	1	2	3	4	
3. Learning and using problem-solving strategies	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Using technology for learning	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Accessing training/educational settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Learning functional academics (reading signs, counting change, etc.)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Learning health and physical education skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Learning self-determination skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Learning self-management strategies	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Lifelong Learning Activities (max. 104)																

Part D: Employment Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Accessing/receiving job/task accommodations	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Learning and using specific job skills	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Interacting with co-workers	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Interacting with supervisors/coaches	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Completing work-related tasks with acceptable quality	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
6. Completing work-related tasks with acceptable quality	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
7. Changing job assignments	0	1	2	X	X	0	1	2	3	4	0	1	2	3	4	
8. Seeking information and assistance from an employer	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Employment Activities (max. 87)																

SmartHome Residents Quality of Life

Part E: Health and Safety Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
1. Taking medications	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Avoiding health and safety hazards	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Obtaining health care services	0	1	2	3	4	0	1	2	X	X	0	1	2	3	4	
4. Ambulating and moving about	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Learning how to access emergency services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Maintaining a nutritious diet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Maintaining a physical health and fitness	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Maintaining emotional well-being	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Health and Safety Activities (max. 94)																

Part E: Social Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
1. Socializing within the household	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in recreation/leisure activities with others	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Socializing outside the household	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Making and keeping friends	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Communicating with others about personal needs	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Using appropriate social skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Engaging in loving and intimate relationships	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Engaging in volunteer work	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Social Activities (max. 93)																

Appendix C

Qualitative Questions for Quality of Life

First round questions:

1. What was the most interesting thing that happened to you today? Why did you like that?
2. Did you do anything new today? If yes, what? If no, what is one thing you want to make sure you get done tomorrow?
3. What was your favorite thing you did today?
4. How do you feel about moving into the Smarthome? What is the one thing you are excited about? What is the one thing you are nervous about?
5. Do you use computers? If yes, tell me what you like to do on the computer. If no, why don't you use a computer?

Second round questions:

1. What was the most interesting thing you did today? Why did you like that?
2. Did you do anything new today? If yes, what was it? If no, what is one thing you want to make sure you get to do tomorrow?
3. What was your favorite thing you did today?
4. How do you feel about living in the SmartHome? Are there things you are still excited about? Are there things you are still nervous about?
5. Do you use a computer? If yes, tell me what you like to do on the computer. If no, why don't you use a computer?

Findings

The most common responses for *"The most interesting thing you did today"* in Time 1 were "" (n=4). In Time 2 the most common response remained "going to work and/or day program" (n=4), but more specifically activities involving the "Smarthome coffee grinding business" (n=3). The most common response for *"Something new you did today"* in Time 1 was "going shopping" (n=3), and in Time 2 "work and/or day program" (n=3). The most common response for *"Favorite thing you did today"* in Time 1 was "watching television" (n=3), and in Time 2 "work and/or day program" (n=4). In Time 1 the most common response for *"How do you feel about moving into the Smarthome? What are you excited about? What is one thing you are nervous about"* was "feel excited" (n=8), and "do not feel nervous" (n=4). In Time 2 the most common response for *"How do you feel about living in the Smarthome? Are there things you are still excited about? Are there things you are still nervous about?"* remained "feel excited" (n=7) and "do not feel nervous" (n=5). When asked about *"Use of computers"* in Time 1 most respondents reported "no access to computer in current home" (n=4) and "use computer for personal interests" (n=5). In Time 2, the most common response to "Use of computers" was "access to computer in current home" (n=6) and "use for personal interests" (n=6). While the number of residents who reported having access to a computer and use of such technology for personal interest increased, it is interesting to note that 2 residents did not report having access to computer or using technology for personal interest in Time 2.

Appendix D

Changes in T1 and T2 scores

Frequency of Change in Mean Scores for National Core Indicators: Consumer Survey.

Frequency (N) for changes in NCI mean scores

NCI Subscale	-6	-5	-4	-3	-2	-1	0	1	2	3	4
Community Inclusion (n=6)	0	0	0	0	0	2	3	0	1	0	0
Safety (n=8)	0	0	0	0	2	0	3	1	2	0	0
Choices & Decision Making (n=6)	0	0	0	1	0	0	0	2	1	0	2
Receive Regular Health Care (n=6)	1	0	0	1	0	2	1	1	0	0	0
Respect and Rights (n=6)	0	0	0	0	1	1	1	0	2	0	1
Relationships (n=6)	0	0	0	0	0	3	0	2	1	0	0
Satisfaction (n=8)	0	0	0	0	0	0	7	1	0	0	0
Access (n=5)	0	0	0	0	0	0	1	3	1	0	0
Service Coordination (n=7)	0	1	0	1	0	2	3	0	0	0	0

Change in Percentile of Support Needs Index Totals for SIS

SmartHome Resident	Round 1	Round 2	Change
1	47	50	+2
2	18	3	-15
3	82	82	0
4	7	4	-3
5	13	13	0
6	55	14	-41
7	37	35	-2
8	14	2	-12