

# **Report of Strathmont Centre Redevelopment and Community Living Project**

**(Phase 4: October 2013- March 2014)**

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## **Acknowledgment**

The authors wish to acknowledge and thank the staff, supervisors and residents who allowed us to spend time with them, and gain insight into their lives, their achievements, their expectations and the challenges they face.

## EXECUTIVE SUMMARY

This report provides a final evaluation of the quality of life of residents from Strathmont Centre placed into purpose built community-based houses. This evaluation completes a sequence of longitudinal evaluations starting in 2006, six months before the residents moved from Strathmont Centre. This Phase 1 evaluation was followed by a Phase 2 evaluation in 2007 and what was to be a final Phase 3 evaluation in 2009. The Phase 4 evaluation in 2013 was made possible because of limited finances remaining from the 2009 review and was restricted to re-interviewing staff about residents' quality of life, an audit of health and life style plans, a repetition of time sampled observations of resident day activities and interactions in the houses, and a limited evaluation of the effects of a Person Centred Active Support (PCAS) training program introduced for staff after Phase 3. This Phase 4 evaluation involved 20 residents owing to six of the 27 residents involved in the Phase 3 evaluation having died and one having moved to a different location.

The results of the Phase 4 evaluation indicated some improvements in many of the quality of life assessments, including more positive ratings by staff of the perceived impact of community living on the residents' behaviour, and their emotional and material well-being, and an increase in the variety and frequency of activities available to them, with more activities being specifically organised for individuals.

Staff reported that residents were mostly in good or excellent health with their health needs being met appropriately. All residents had received an annual medical review. Most health measures had remained relatively stable since 2009, but doctors' visits, behavioural issues and seizures had all reduced markedly.

According to staff, activities had been organised for all residents and all had achieved their lifestyle activity goals in 2013. However, while staff believed there had been an increase since 2009 in the variety and frequency of activities offered, a review of resident activity logs indicated that many activities perceived by staff in 2009 to be unsuitable and unenjoyable were still being offered in 2013. It was also reported that residents did not make independent decisions on four of seven common daily living activities.

It was unclear whether residents were actively engaged with nondisabled community members associated with activities, and only 20% were reported to have a friend who was not a staff member or family member, suggesting that after seven years in the community residents continue to live in an apparently distinct social space made up primarily of staff, family and other people with disabilities.

All residents had a lifestyle plan, but fewer individual goals were recorded in 2013, with more having only one goal, and there was a marked increase in goals where achievement was unclear or unknown. None of the goals focused on adaptive behaviours related to personal care, domestic activity, or social interaction. Goals also lacked descriptive information regarding the procedures employed to achieve the goals and limited information regarding assessment and decision making processes; when and where training or activities would occur; timelines for achievement and progress review, and there was no information regarding resident, family and/or advocate participation.

Observations of residents revealed significant but slight increases in positive and neutral interactions between staff and residents since the 2009 evaluation but resident engagement in constructive activities remained very low. As in 2009, many residents had little or no active engagement in activities and most still spent most of their time doing relatively little during their waking hours in the houses.

From 2009 to 2013 there was little difference in resident involvement and participation in the running of their own homes as evidenced by engagement in domestic activities. Residents were barely encouraged or assisted to participate in constructive activities or to socialise with other individuals and there was no evidence of the use of assistive devices to encourage more independent actions. Improvements in interactions and engagement in domestic and community activities, even with active support, remain very limited. However, residents' basic care needs appeared to be well considered and most staff seemed caring and genuinely concerned with the welfare of the residents.

### **Recommendations:**

Recommendations are similar to those in 2009 and focus on support strategies at an organisational level, and support strategies that may be used by house managers and direct care staff.

1. **Training (General):** To improve the quality of life of residents, training is required to address a wide range of changing needs for both staff (e.g., coping strategies, team-building, community engagement) and residents (e.g., activities, health, skills development, community participation). Training for staff should include mentoring and be designed within a career development format that offers incentives for participation and demonstrated competency.

2. **Training (PCAS):** Implementation of Person Centred Active Support was variable and had not become embedded into everyday routines and practices. Recommendations from staff and trainers include more examples in the training of how it could be applied to residents and follow-up mentoring in houses to show staff how to apply the training. Given the apparent lack of use of adaptive devices, it is also recommended that their use be included in the training program. Since PCAS training had not, at the time of this review, been fully implemented, its long term effectiveness, efficiency and sustainability needs to be considered together with assessment of the extent to which it enhances lifestyle outcomes for residents. Consideration also needs to be given to retraining staff, e.g., every two years, to ensure their active support skills remain up to date.

Volunteers play an important role in assisting residents to access and participate in community activities, and accordingly it is recommended that volunteers also have regular access to Person Centred Active Support training and mentoring from trainers.

3. **Job Descriptions:** The sense of confusion expressed by many staff, particularly with respect to the relative importance of household maintenance duties and/or the provision of individualised support for residents, requires a clearer delineation of their roles and responsibilities and linking them with performance appraisal in terms of client outcomes. A revised job description for selection purposes should also specify the need to engage positively with, and provide active support for, residents.

4. **Community Relations:** Attention needs to be given to implementing strategies and programs to maximise opportunities for residents to develop social connections in the community, and to exercise choice in meaningful activities. Successful examples of such strategies need to be identified to act as models for staff working with other residents and in other houses.

5. **Lifestyle Plans:** Lifestyle plans need to provide more detail (e.g., behaviourally referenced time-framed goals and objectives, implementation and evaluation strategies) and focus on adaptive behaviours across a range of lifestyle domains, including the development of friendships and decision making. Staff should receive lifestyle plan training and periodic retraining in ways to involve residents and their advocates in Person Centred approaches to planning.

6. **Communication:** Open communication within and across houses should be encouraged and supported so staff can share effective strategies, (e.g., for balancing domestic and resident duties, community engagement and meaningful activities, skill development, working as a team). Team building exercises are needed to establish and maintain effective teams that reduce the need for replacement staff and new staff which can disrupt ongoing programs and disturb residents.

7. **New Residents:** It was noted during the 2013 evaluation that many new individuals moving into the houses were performing at a higher level than the original residents, which provides greater opportunities for staff (and volunteers) to engage in Person Centred Active Support. It is recommended that the present or a similar evaluation be carried out with these residents to determine the extent to which PCAS can improve their quality of life.

## INTRODUCTION

This report presents the final Phase 4 evaluation of the placement of residents from Strathmont Centre into purpose built community-based houses. Phase 4 completes a sequence of longitudinal evaluations that had occurred first in 2006, six months before the residents moved from Strathmont Centre to the community houses. This Phase 1 evaluation was followed by a Phase 2 evaluation in 2007, one year later, and that in turn was followed by what was to be a final Phase 3 evaluation in 2009. The 2013 evaluation was not originally planned as part of the longitudinal evaluation of the residents' placement into community houses but was made possible because of limited finances remaining from the 2009 review. Accordingly, the Phase 4 evaluation could not be as comprehensive as the previous assessments and instead was restricted to re-interviewing staff about the quality of life of residents, an audit of health and life style plans, a repetition of time sampled observations of resident day activities and interactions in the houses, and a limited evaluation of the effects of a Person Centred Active Support (PCAS) training program that had been introduced for staff after Phase 3.

Findings from the Phase 3 evaluation indicated that the move from Strathmont to the community houses had been associated with many positive and important lifestyle benefits for the residents. However, concerns were raised in that review, as in the previous reviews, about the extent to which residents had remained largely unoccupied since moving from Strathmont Centre in terms of their day activities. Observations of the residents revealed that they engaged in few social interactions with staff or others and had relatively little to do during their waking hours in the houses. While staff appeared to be diligent and responsive in attending to the basic care needs of the residents, there was little evidence that residents were encouraged or assisted to participate in constructive activities or social interactions with the social world around them. A major recommendation of the 2009 review was for staff training in what was termed Person Centred Active Support; that is, assisting residents to be actively engaged in house activities, such as preparing meals and snacks, hanging up washing etc. Staff were subsequently scheduled to undertake training in Person Centred Active Support training.

The purpose of the Phase 4 evaluation was to determine whether the quality of the residents' lives has changed since the Phase 3 evaluation that was conducted in 2009.

The follow up evaluation involved assessments of the following three aspects of residents' quality of life:

1. Observations of resident related activities and social interactions in each of the three houses. The aim of this aspect of the evaluation was to determine the number, extent and nature of resident activities and social interactions with other residents and visitors, and between residents and staff.
2. A review of lifestyle plans, medical and other resident records in each of the three houses. This review was intended to evaluate the extent to which lifestyle plans contained individual goals, appropriate strategies to achieve those goals and recorded outcomes with respect to each resident's activities in the houses and in the community. It also involved a review of the health of residents as indicated in their medical records and a review of any other relevant issues with respect to the quality of life of individual residents.
3. Interviews with relevant staff regarding each resident's activities; relationships; health; community participation; and general well-being. Some of the questions concerning each of these topics were taken from the previous evaluations to allow an assessment of any changes in residents' perceived quality of life since the Phase 3 evaluation.



## METHOD

### *Staff Interviews and Review of Records*

All of the residents who moved from Strathmont to the community had significant cognitive and physical limitations and were highly dependent on others to meet their basic needs. It is difficult to use subjective evaluations from people with limited cognitive and behavioural repertoires, and little or no communication skills. Thus, subjective evaluations regarding the residents were obtained by interviewing the staff member (proxy respondent) who was most familiar with each resident. House supervisors identified staff they felt were the most knowledgeable about individual residents. These staff members were asked to respond on behalf of the target resident and comment on the resident's community living environment; activities; relationships; choice making; health; and general quality of life. Where possible, a staff member who had known and worked with the resident in 2009 was again interviewed in 2013.

The selected staff members were asked to undertake an interview that consisted of 40 questions concerning the lives of individual residents in the community. The 40 items of the resident interview focused on: the Community Living Environment; Activities; Relationships; Choice Making; Health; and overall Quality of Life. Each interview took approximately 45 minutes to complete. All interviews were conducted in the community houses.

In addition to surveying staff, information from each resident's Health Care Plan and Accommodation File was also documented (e.g., health and medical reviews, lifestyle plans).

### *Social Interactions and Activities*

The social interactions and activities engaged in by the residents were observed during 15 minute sessions over a three month period. Observational data were recorded using a partial interval recording procedure whereby a resident's activities and social interactions were observed during a 10 second interval and the results recorded during the subsequent 20 second interval. This type of recording procedure has a relatively small measurement error. Observe-record intervals were cued to the observers by use of earphones and an audio-tape machine. Four 15 minute observation sessions were conducted for each resident for a total of 29 hours of observational data. Observations were conducted Mondays to Fridays across four different time periods (9:00am – 11:00am; 11:00am – 1:00pm; 1:00pm – 3:00pm; 3:00pm – 5:00pm). Residents were not observed when engaged in any private activities such as getting dressed, bathing, or using the toilet or when they were participating in community activities. Observation sessions were randomly scheduled across time periods, days of the week, and houses and residents.

Seven main categories of activity were recorded:

- (1) *Domestic*: getting ready for or doing housework (e.g., washing clothes, cooking, gardening, setting or clearing the table, decorating)
- (2) *Personal*: getting ready for or doing a self-care activity (e.g., body positioning, drinking, eating)
- (3) *Leisure*: getting ready for or doing a recreational activity (e.g., looking at magazines, playing games, listening to music)
- (4) *Challenging Behaviour*: (e.g., aggression to others, property damage, self-injury, stereotyped movements, inappropriate vocalizations)
- (5) *Watching Television*: (e.g., sitting in front of the television with eyes directed at the screen)
- (6) *None*: (e.g., sitting doing nothing, waiting, pacing, no apparent purposeful activity)
- (7) *Other*: any other activity or behaviour that did not fit into one of the other categories

Five main categories of interaction were recorded:

- (1) *Positive*: receipt of praise, encouragement, or a sign of affection either physically or verbally
- (2) *Negative*: receipt of disapproval, restraint, enforced movement or refusal/denial, verbally or physically
- (3) *Training/Assistance*: verbal or physical prompts, demonstration or guidance to help a resident perform an activity
- (4) *Neutral*: any interaction that is neither positive nor negative or giving assistance (e.g., having a conversation)
- (5) *No Interaction*: no one interacting with a resident either verbally or physically

Reliability of observational data was checked by a second observer observing simultaneously with the first observer for 10% of the sessions. Percentage occurrence agreement for each category was calculated by dividing the number of agreements of occurrence by the total agreements plus disagreements and multiplying by 100. Overall agreement measured 94.5%.

### ***Person Centred Active Support Training***

Staff members who had completed, or who had almost completed, the Person Centred Active Support Training program were asked to participate in a group interview that sought to solicit their perspectives on the training. The four items of the interview focused on: the content of the training; staff attitudes toward the training; the perceived effectiveness of the training, including examples; and recommendations for improving the content and delivery of training.

The trainers providing the Person Centred Active Support training program were also interviewed as a group and asked for their opinions concerning the content of the training program, the motivation of the staff involved in the training, and any improvements that they thought could be made to the training program.

## **RESULTS AND DISCUSSION**

### ***Staff and client numbers in 2009 and 2013***

Twenty-seven residents were assessed in the Phase 3 evaluation in 2009 (12 males and 15 females). These residents were aged between 35 and 58 years (mean: 48 years). Twelve staff responded on behalf of the 27 residents. These 12 staff members had worked with the residents from 8 months up to 8 years.

In the final Phase 4 evaluation in 2013, six of the 27 residents who were involved in the Phase 3 evaluation had died and one had moved to a different location. Thus, only 20 of the 27 residents from the Phase 3 evaluation were assessed in 2013 (10 males and 10 females). These residents were aged between 43 and 65 (mean: 55 years). Six staff provided responses on behalf of these 20 residents. These staff had worked with the residents from 18 months up to 13 years. Due to staff turnover, rostering and rotation between houses it was difficult to match up residents with the same staff members who were involved in Phase 3 of the project. Three of the six staff interviewed in the Phase 4 evaluation in 2013 were involved in 2009 interviews but assessed different residents to those they assessed in 2009. Only three residents had the same staff member assessing them across 2009 and 2013.

### ***Person centred active support training in 2013***

At the time of the Phase 4 interviews in 2013, three of the six staff had completed the Person Centred Active Support (PCAS) training that had been introduced after the Phase 3 evaluation in 2009 and three staff had almost completed their training. Hence, evidence of the application of PCAS was varied across the houses.

In commenting on the training, the three staff who had completed the training rated it as very useful and the remaining three who had almost completed the training rated it as partly useful. Comments from those rating it as very useful included; “We were reminded to involve residents in activities rather than doing the task for them.”, “Puts everyone on the same page with respect to how to engage clients in activities of daily living.”, and “I try to encourage independence of clients and promote their quality of life through community access and activities.”. Two of the comments from those rating the training as partly useful concerned the training being tailored to more independent people, that is, people who are mobile and can communicate, with more examples being needed for people with more significant disabilities. One of these comments, however, indicated that there were opportunities to ask about specific clients and how to apply active support, and that the trainers were very helpful. The third “partly useful” rating comment indicated that the training “Got staff thinking about how to apply strategies to people with severe disabilities”.

When asked to give examples of how the Active Support training had been used with the people they support, only general comments were given including “communicating while doing tasks, even if the person can’t communicate”, “providing physical guidance”, “engaging residents in ADLs”, and “encouraging their independence and quality of life through community access and activities”.

The trainers providing the active support training were interviewed as a group and asked about their views of the training program, the trainees and the outcomes of the program. Overall, the trainers were satisfied with the content of the program and what was provided to the trainees. The trainers indicated that they had renamed the originally titled Active Support training to Person Centred Active Support (PCAS) training in order to indicate that it applied to all aspects of interactions between staff and clients and not just formal skill training opportunities.

As far as the trainees were concerned, there were comments on the variability in their motivation to accept the training and that paternalistic attitudes that involved working for, rather than with, clients were difficult to change in some staff. Moreover, a number of staff were of the opinion that many of the clients were incapable of benefiting from efforts to improve their functioning and engagement in their material and social world. Overall, however, the trainers believed that staff were able to profit from the training and it was felt that most did acquire skills and attitudes that would enable them to work in a more supportive way with clients in their daily activities.

In terms of their suggestions for improving the training, there was a consensus that more practical, hands-on, follow up assistance in the work place would be beneficial if this could be arranged, but there were considered to be practical constraints on the extent to which this might be possible. A recommendation from this evaluation would be that such follow up assistance should be provided in the workplace where trainers could mentor the trainees in identifying opportunities for implementing what they had learnt in training and in providing guidance and support in how to most effectively implement that learning to maximise its positive impact on the quality of life of the residents.

### *Individual Resident Questionnaire Results (Staff perspectives)*

#### **COMMUNITY LIVING ENVIRONMENT**

Table 1 shows the rated impact of community living on the residents' behaviour, and their emotional and material well-being in 2009 and 2013. It can be seen that while there were no negative or very negative ratings in either 2009 or 2013, there were marked increases in the positive or very positive responses for all three community living criteria with corresponding decreases in no effect ratings. In particular, positive or very positive ratings of behaviour increased significantly from 41% in 2009 to 90% in 2013 ( $X^2 = 8.73$ ,  $df = 2$ ,  $p < .012$ ). Similarly, positive or very positive ratings increased for emotional well-being from 66% to 95% and for material well-being they increased from 70% to 100% over the same time period. While there were insufficient data to test for significant differences between 2009 and 2013 with respect to emotional and material well-being, these ratings represent approximately a 40% increase over the 2009 ratings.

**Table 1. Impact of community living on residents in 2009 and 2013**

Overall impact of community living on residents'...	Very Negative		Negative		No Effect		Positive		Very Positive		Not Known	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>Behaviours</b>	0%	0%	0%	0%	41%	10%	19%	50%	22%	40%	19%	0%
<b>Emotional well-being/sense of dignity</b>	0%	0%	0%	0%	26%	0%	44%	45%	22%	50%	7%	5%
<b>Material well-being</b>	0%	0%	0%	0%	22%	0%	44%	5%	26%	95%	7%	0%

#### **HEALTH, SAFETY AND ENVIRONMENTAL ISSUES**

Table 2 presents the staff responses to questions concerning health and safety and the physical environment in the community houses in 2009 and 2013.

**Table 2. Issues in the community houses in 2009 and 2013**

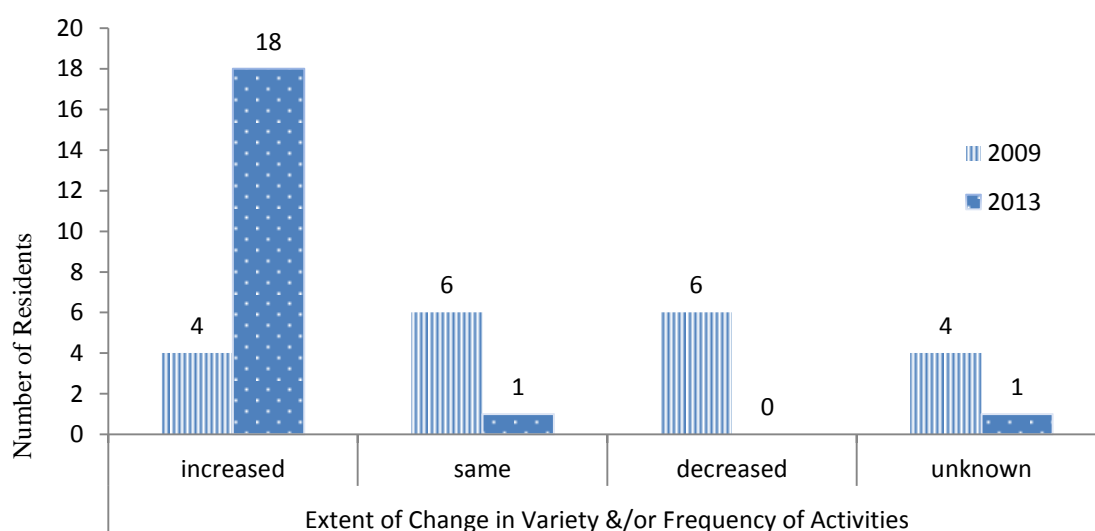
Have there been issues concerning...	Yes		No		Some		Unsure	
	2009	2013	2009	2013	2009	2013	2009	2013
<b>Health and safety</b>	15%	0%	81%	100%	4%	0%	0%	0%
<b>Physical environment</b>	15%	0%	63%	100%	22%	0%	0%	0%

As shown in Table 2, all respondents in 2013 indicated that there were no major issues concerning the health and safety of the residents or their physical environment. These ratings show a positive reported decrease of 24% in health and safety issues and a 59% decrease in physical environment issues from the relatively low percentages of such issues reported in 2009.

### RESIDENT ACTIVITIES

Figure 1 shows the extent of perceived change in the variety and/or frequency of resident activities between 2009 and 2013. It can be seen that in 2013, 90% of residents were considered to have experienced an increase in the variety and/or frequency of activities compared with only 25% in 2009. This difference was statistically significant ( $X^2 = 18.36$ ,  $df = 2$ ,  $p < .0001$ ).

In commenting on these activities, staff reported that the House Bus was primarily used to transport residents to and from community activities. However, external agencies providing activities (e.g. SCOSA) provided their own transport. Staff indicated that there were no major issues with transporting residents, with the system in 2013 generally remaining the same as in 2009.



**Figure 1. The extent to which staff perceived that the variety &/or frequency of resident activities had changed since being in the community environment (N=20).**

In 2009, thirty-five percent of the residents' were reported to have largely or fully achieved their life style activity goals. In 2013, respondents indicated that all of the 20 targeted residents had largely achieved or fully achieved their activity goals. This positive difference was statistically significant ( $X^2 = 12.12$ ,  $df = 2$ ,  $p < .002$ ).

Table 3 presents responses to questions regarding the nature of the activities organised for the residents. In 2009, a majority of the staff respondents (81%) reported that community facilities had been accessed as part of the residents' activities. Fifty-six percent of the respondents indicated that activities were organised specifically for the residents and nearly two thirds (63%) said that residents had no choice in activities, with only 26% indicating that residents were partly involved in choice of activities. In 2013, a positive change was identified in the respondents' perceptions regarding the nature of activities organised for the residents. Community facilities were reported to have been accessed for all of the residents. Respondents also indicated that activities were specifically organised for all of the residents in 2013 which was significantly more than the 56% in 2009 ( $X^2 = 11.61$ ,  $df = 2$ ,  $p < .003$ ), and that significantly more residents (30%) were perceived to have had a choice in 2013 than in 2009 (7%) about the activities they participated in ( $X^2 = 9.86$ ,  $df = 2$ ,  $p < .007$ ).

**Table 3. Information about resident access to, and choice of, activities in 2009 and 2013**

	Yes		No		Partly		Unsure	
	2009	2013	2009	2013	2009	2013	2009	2013
<b>Have community facilities been accessed as part of residents' activities?</b>	81%	100%	19%	0%	0%	0%	0%	0%
<b>Are there any activities organised specifically for the resident?</b>	56%	100%	37%	0%	0%	0%	7%	0%
<b>Does the resident have a choice about which activities they participate in?</b>	7%	30%	63%	15%	26%	55%	4%	0%

Table 4 shows that there were reported increases in total resident participation in all but one of nine listed community activities from 2009 to 2013. Approximately half of the residents showed increases in six of the activities. These increases were statistically significant for going to a club/group ( $Z = -2.42$ ,  $p < .05$ ), to a hotel/bar/pub ( $Z = -2.77$ ,  $p < .05$ ), and interacting with community members ( $Z = -3.07$ ,  $p < .05$ ). Relatively few of the residents had decreased their participation in these activities.

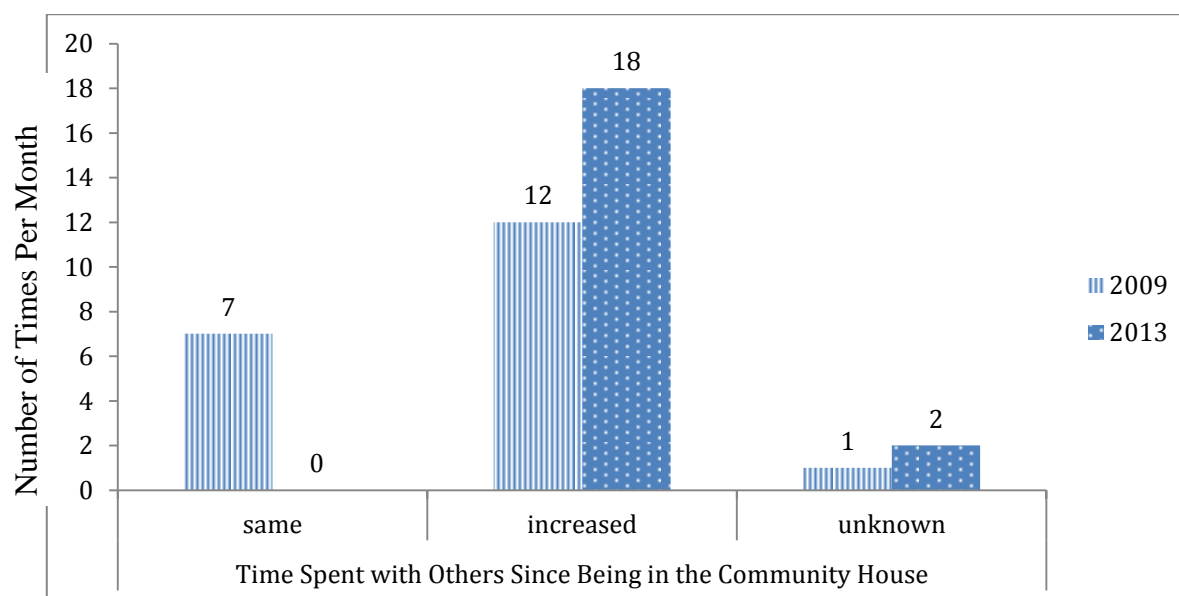
**Table 4. Resident participation in activities in 2009 and 2013**

N = 20	Total times per month 2009	Total times per month 2013	Residents with increased participation	Residents with the same participation	Residents with decreased participation
Club/Group/Society	31	58	8	9	3
Hotel/Bar/Pub	1	18*	10	9	1
Live sport event	1	.3	0	19	1
Go to place of worship	0	4	1	19	0
Interact with community members	17	62*	12	7	1
Eat out	9	50	13	7	0
Go to movies	5	18	11	8	1
Visit family / friends	12	40	10	7	3
Play sport/gym	0	8	2	18	0

\* p < .05

## RELATIONSHIPS

Figure 2 shows that from 2009 to 2013 there was a 50% increase in the staff respondents' belief that living in the community had provided residents with increased opportunities to spend time with other people such as carers, residents, and family.



**Figure 2. Time spent by residents with others since being in the community houses in 2009 and 2013**

There was a slight increase from 2009 to 2013 in the number of residents reported to have a friend who was not a staff member or family member. In 2009, only one of 27 residents was reported to have had such a friend, whereas in 2013, 4 of the 20 targeted residents were reported to have had

such a relationship. Only one of these residents, however, was reported as spending time with people of a similar age who were not staff and who did not have a disability. Friendships are recognised as an important dimension of quality of life, and one that has often been under emphasised or ignored by traditional providers of human services. Given that only 20% of the residents were reported to have a friend it will be important area for future goal setting and monitoring.

## CHOICE MAKING

It can be seen in Table 5 that in 2013, as in 2009, no resident was reported as making independent decisions about four of the seven listed activities and there was a slight decrease in the very few who did make such decisions about which residents they spent time with and the time to go to bed. However, in 2013, while there was little change in the perception of residents making decisions for themselves, there were consistent increases in the numbers of residents reported to be making these decisions with others, with approximately 76% of residents believed to be making decisions with others for some activities. There was also a marked decrease in 2013 in those considered incapable of making a choice and slight decreases in the relatively few considered to have no choice in 2009.

Caution is warranted when considering these findings as the respondents may be interpreting resident decision making in various ways (e.g., initiating a decision as distinct from giving assent to a staff question or request). Moreover, observation of staff indicated that established routines in the houses and staff knowledge of the residents often resulted in staff anticipating or predicting need and/or choice rather than waiting for or encouraging the residents to actively engage in activities and choice making. The response variation to resident decision making suggests that this area should be examined further to determine the resident, staff and contextual factors associated with resident decision making.

**Table 5. Number of residents and level of decision making in activities for 2009 and 2013**

	Decides by him/herself		Decide with others		Has no choice		Not capable of making a choice	
	2009	2013	2009	2013	2009	2013	2009	2013
<b>Clothes to wear</b>	0	0	1	11	0	0	20	10
<b>Time to go to bed</b>	3	1	10	17	2	2	6	1
<b>Food to eat</b>	0	1	14	16	4	3	3	1
<b>*TV programs to watch</b>			3	12			15	8
<b>*Residents to spend time with</b>	5	2	5	16			11	3
<b>*Group outings to go on</b>			4	18	5	1	11	2
<b>*Activity programs to attend</b>			5	17	5	1	10	3

\*missing data

## HEALTH

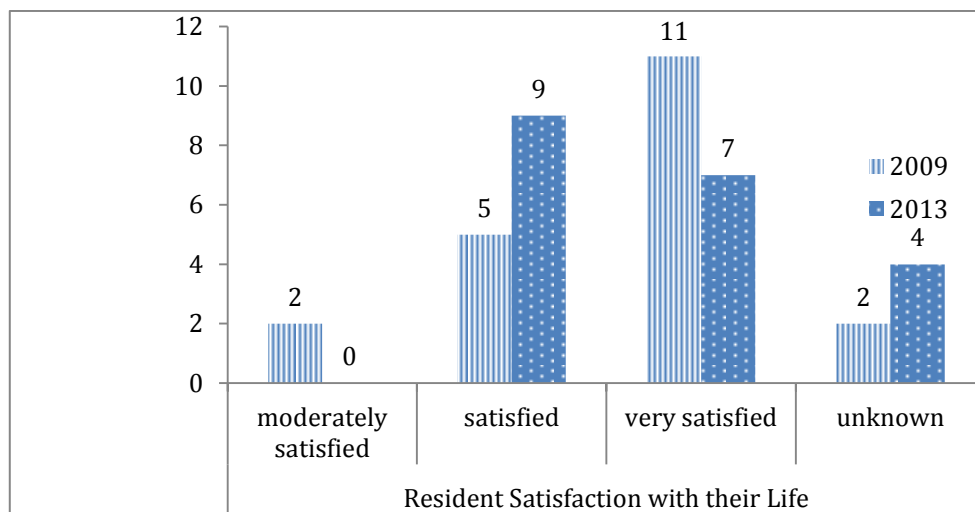
In 2013 there was a slight decrease in the health status of residents but with most residents (71%) still considered to be in good or excellent health compared with 86% of these residents in 2009. Fourteen percent of residents were considered to be in moderate health compared with 5% in 2009 and slightly more (14%) were considered in poor or very poor health compared with 10% in 2009. However, there was a slight increase in residents whose health status was considered to be better or much better with 33% in this category in 2013 compared with an equivalent 24% in 2009. There was also a decrease in those showing no change from 62% in 2009 to 33% in 2013 with only one



resident considered to be worse since being in the community in both 2009 and 2013. The slight overall decrease in health status is perhaps to be expected given the aging of the residents. In 2013 all but one resident was considered to have their health needs met with this one resident's health needs being partly met. These results were very similar to 2009.

## QUALITY OF LIFE

Figure 3 shows that while in 2013 there was a 36% decrease from 2009 levels in the number of residents considered to be very satisfied with their quality of life there was a corresponding 80% increase in those considered satisfied. Overall, 80% of the targeted residents were considered either satisfied or very satisfied in both years. It is heartening to report that in 2009 and again in 2013 none of the residents was viewed as being dissatisfied or very dissatisfied with their quality of life.



**Figure 3. Resident satisfaction with their life in 2009 and 2013.**

Staff respondents were asked to identify factors that they believed contributed to the residents' quality of life. Factors listed in 2013 were similar to those listed in 2009: staff interaction and attention (5); family involvement (e.g. resident's mum visits the house) (4); community activities (3); the home environment (2); being physically comfortable (2); time spent with other residents (3); and music (1).

Respondents also identified a number of factors that they believed contributed to the residents' dissatisfaction with their quality of life. There were generally less factors identified in 2013 as contributing to the residents' dissatisfaction than in 2009. The non-individual factors identified in 2013 included: experiencing stress as a result of a change in routine and coping with new staff.

The results for 2013 are consistent with the wide range of individual differences identified amongst residents in 2009 in what is perceived to contribute to residents' satisfaction and dissatisfaction, again supporting the recommendation in 2009 that proposed activities need to be carefully assessed in terms of which residents appear to find them enjoyable and which they would prefer not to be involved in.

Suggestions for improving the residents' quality of life were similar in 2013 to those suggested in 2009, with more activities or outings being the most frequent response (6); followed by increased staff interaction and one on one attention (2). Other individual suggestions in 2013 included more staff (3) and better (more respectful and empathic) staff (2).

In 2013 respondents believed that quality of life had increased for all but one of the residents since being in the community. This represented a marked increase from the 11 of these residents in 2009

who were believed to have experienced an increased quality of life since being in the community. In 2009, the quality of life of four residents was reported as having remained the same since being in the community and for the remaining five residents this was reported as unknown. In neither year was any resident considered to have had a decrease in their quality of life since moving into the community.

In 2013 most respondents (86%) reported being confident that their answers reflected the residents' opinions, (although none reported being very confident), and only three respondents were partly confident and none were not very confident. In 2009, the responses for being very confident and confident were different with 9 of the 20 being very confident, nine being confident and the remaining two being not very confident.

### ***Findings from the Resident Records- Health Care Plan***

#### **RESIDENT CHARACTERISTICS**

While the majority of resident folders did not provide any information indicating the residents' level of disability, it was obvious from observations and reviewing their records that they all had significant and multiple disabilities which impacted upon their daily living. In addition to their cognitive disabilities, other impairments that were noted in their records included: Spastic Quadriplegia, Cerebral Palsy; Down Syndrome; Rhett Syndrome; Maternal Rubella Syndrome; Perinatal Anoxia; Silverman's Syndrome; other chromosomal disorder; and cerebral genesis. Records also indicated that many of the residents experienced: epilepsy; anaemia; communication problems; sensory difficulties (vision/ hearing impairment); vitamin D deficiency; osteoporosis; scoliosis; difficulties with mobility; and hypothyroidism.

#### **MEDICAL REVIEW**

Medical reviews are required to be done yearly. Inspection of records indicated that all residents had an Annual Medical Review in 2013.

#### **HEALTH INFORMATION**

Table 6 summarises data for 2009 and 2013 relating to eight measures of resident health. Comparisons are made difficult by the large differences in ranges indicating marked individual differences. For example, it can be seen that the number of seizures was less in 2013 but that the large number of seizures in 2009 was partly due to one individual who had 112 seizures whereas the highest individual number in 2013 was 25. However, while it can be seen that there was little overall change between the average number of illnesses, dental visits, hospital admissions, medications used or injuries, there were noticeable decreases in numbers of doctor visits and the number of behavioural issues. There also seemed to be a marked decrease in the number of seizures even after omitting the individual in 2009 with 112 seizures.

**Table 6: Comparison of Health details for 2009 and 2013**

	Community Houses in 2009 (Approximately 2 years after the move to the community)	Community Houses in 2013 (Approximately 7 years after the move to the community)
Number of illnesses	Total for 21 residents: 58 Average: 2 Range: 0 – 11	Total for 13 residents: 31 Average: 2 Range: 0- 4
Number of dentist visits	Total for 22 residents: 26 Average: 1 Range: 0 – 2	Total for 21 residents: 20 Average: 1 Range: 0-2
Number of doctor visits	Total for 27 residents: 316 Average: 12 Range: 4 – 28	Total for 21 residents: 101 Average: 5 Range: 0-13
Number of hospital admissions	Total for 7 residents: 15 Average: <1 Range: 0 – 6	Total for 8 residents: 21 Average: 2 Range: 0-6
Number of medications used	Total for 25 residents: 247 Average: 10 Range: 2 – 21	Total for 19 residents: 165 Average: 9 Range: 3-13
Number of injuries	Total for 12 residents: 32 Average: 1 Range: 0 – 9	Total for 3 residents: 4 Average: <1 Range: 0-2
Number of seizures	Total for 12 residents: 258 Average: 10 Range: 0 – 112 (NB: one resident had 112 seizures in this timeframe)	Total for 8 residents: 44 Average: 5 Range: 0-25
Number of behavioural issues	Total for 6 residents: 56 Average: 2 Range: 0 – 21	Total for 1 resident: 2 Average: 2 Range: 0-2

*\* NB: Averages are presented in Tables, but must not be interpreted in isolation, due to the effects of extreme values (outliers) as indicated in the very large increases in some of the ranges.*

## *Findings from the Resident Records - Accommodation File*

### **LIFESTYLE PLANS**

Table 7 summarises information obtained from reviewing the residents' Accommodation Files in 2009 and 2013. Except for resident participation, little difference was noted between 2009 and 2013 in who attended the lifestyle planning meetings. Records of planning meetings indicated that 95% of the residents were in attendance at their own planning meetings in 2009 compared with 71% in 2013. Recording of resident attendance, however, was not always clearly presented (i.e., residents may have attended but their attendance may not have been recorded), hence this finding should be interpreted with caution.

With respect to goals, there were relatively fewer goals recorded in 2013 for each individual than in 2009 (with relatively more having only one goal and relatively less having two or three goals in 2013), but there was also some evidence that more residents had all or most of their goals achieved in 2013 (23%) than 2009 (16%) and with less residents in 2013 having only some of their goals achieved (19%) than in 2009 (63%). However, it can also be seen that there was a marked increase in goals where their achievement was unclear or unknown from 2009 (16%) to 2013 with more than half of the goals in 2013 (57%) having an achievement status that was unclear or unknown. Fewer of the goals in 2013 recorded a timeframe of when the goals should be achieved (62%) compared to 2009 (70%).

While 5% of goals were listed as not having been achieved in 2009, none were listed as unachieved in 2013. The difference in these results may be partly due to changes in the ways in which goals were stated and outcomes reported, with some plans providing more detail than others. The percentage of goals that were unclear or unknown is of concern in 2013 as it suggests a need for staff training or retraining and supervision in the writing and evaluation of goals.

Most of the goals in the individual lifestyle plans were focused on individual leisure activities. None of the documented goals were focused on the development of adaptive behaviours, nor did they address important lifestyle domains such as personal care, domestic activity or social interaction, including making friends. Moreover, all of the goals were written in a passive voice with no reference to active engagement or participation from the residents. The goal plans also lacked descriptive information regarding the procedures that would be employed to operationalise the goals (i.e., training methods and/or the use of adaptive equipment) and limited indication of when and where training or activities would occur.

**Table 7. Lifestyle Plans in 2009 and 2013**

	Community Houses in 2009 (Approximately 2 years after the move to the community)	Community Houses in 2013 (Approximately 7 years after the move to the community)
<b>PLANNING PARTICIPANTS</b>		
<b>Number of paid participants at lifestyle planning meeting</b>	Range: 2 - 5 Average: 4	Range: 1-5 Average: 3
<b>Number of relatives at lifestyle planning meeting</b>	Range: 0 - 3 Average: <1	Range: 0-2 Average: 1
<b>Percentage of residents who had family members attend lifestyle planning meeting</b>	60% (12 residents)	52% ( 11 residents) (23% - 5 residents were not indicated/ unclear)
<b>Percentage of residents who attended lifestyle planning meeting</b>	95% (19 residents) (5% - 1 resident was not indicated/ unclear)	71% ( 15 residents) (28% - 6 residents were not indicated/ unclear)
<b>GOALS</b>		
<b>Percentage of residents with written goals in plan</b>	100%	95% (20 residents) (5% - 1 resident not indicated/unclear)
<b>Number of written goals in plan</b>	1 Goal = 1 resident 2 Goals = 7 residents 3 Goals = 8 residents 4 goals = 3 residents 5 goals = 1 resident	1 Goal = 5 residents 2 Goals = 4 residents 3 Goals = 4 residents 4 goals = 2 residents 5+ goals = 4 residents
<b>Percentage of plans with goals specific to resident</b>	95% (19 residents)	90% ( 19 residents)
<b>Percentage of goals with timeframes indicated</b>	70% (14 residents)	62% ( 13 residents)
<b>Percentage of plans with goals achieved</b>	<b>16% (3 residents)</b> <b>(63% - 12 residents had some goals achieved and some not; 16% were unclear of unknown and 5% were not achieved)</b>	23% ( 5 residents) (19% - residents had some goals achieved and some not (4 residents); 57% were unclear or unknown (12 residents) and 0% were not achieved)

\* Averages are presented in Tables, but must not be interpreted in isolation, due to extreme values.

## CONTACTS/VISITS

Contact and visits in 2009 and 2013 are shown in Table 8. It can be seen that for the 18 residents who had family, while the average family visits to residents was similar across both years, the range was much greater in 2013 (0 to 24 visits per person) than in 2009 (0 to 8 visits per resident). Thus, while some residents were receiving many more visits in 2013 than in 2009, there were still some residents who were receiving very few or no visits. With respect to resident visits to their family homes, the average number of visits was much greater in 2013 than in 2009, as was range in the number of visits for individuals. Again, it is apparent that while some residents in 2013 were visiting their family homes much more regularly in 2013 than in 2009, there were some who were still making very few or no visits of this kind. It can also be seen in Table 8 that across both years there were no documented visits by neighbours or by other people. These results indicate that contact with people in the community other than staff remains confined for residents to their family members.

**Table 8. Contact and Visits for Residents Who Had Family/ Next of Kin in 2009 and 2013**

	Community Houses 2009 (Approximately 2 years after the move to the community)	Community Houses 2013 (Approximately 7 years after the move to the community)
<b>Number of family visits to residents</b>	Total for 17 residents: 59 Range: 0 - 8 Average: 2.8	Total for 14 residents: 41 Range: 0-24 Average: 3
<b>Number of residents visits to family homes</b>	Total for 8 residents: 36 Range: 0 – 9 Average: 3.3	Total for 7 residents: 70 Range: 0-24 Average: 10
<b>Number of visits by neighbours to residents homes</b>	0	0
<b>Number of residents who had visits by other people</b>	0	0

## OBSERVATIONAL DATA ON SOCIAL INTERACTIONS AND ACTIVITIES

Table 9 shows the percentage of time residents spent engaged in constructive activities in their homes in 2009 and 2013. Engagement in activities was similar across the two time periods. In 2009, residents were engaged in activities for an average of 7% of the total observational period (range: 3 – 9%) and in 2013 they were observed to have spent an average of 6% of their time engaged in constructive activities (range: 1 – 12%). Slightly higher levels of resident activity were observed in the Northfield houses compared to the Sturt houses and the Greenacres houses across the two time periods. On average more time was spent engaged in domestic and personal activities in 2013 (8% and 12% respectively) than in 2009 (3% and 9%). The average time that residents spent in front of the television was less in 2013 (1%) than in 2009 (9%), and less time was spent engaged in leisure activities in 2013 (3%) than in 2009 (7%). In 2013, activities that occupied most of residents' time were those of a self-help or personal nature (e.g., eating, drinking, positioning).

**Table 9. Percentage of time residents were engaged in activities in 2009 and 2013**

House	Domestic		Personal		Leisure		Television		Challenging Behaviour		Other		None	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
Greenacres	1%	9%	4.5%	12%	0%	4%	16.5%	1.5%	0%	0%	0%	1.5%	78%	72%
Northfield	2.5%	8.5	16%	18.5%	15.5%	3.5%	3.5%	0%	0%	0%	0%	0%	63.5%	69%
Sturt	5%	6.5	6.5%	6%	5.5%	3.5%	6.5%	0%	0%	0%	0%	0%	77%	84%
Average	3%	8%	9%	12%	7%	3%	9%	1%	0%	0%	0%	1%	73%	75%

Participation in the running of their own homes as evidenced by engagement in domestic activities was virtually non-existent across the two times periods, with staff observed to be conducting household maintenance tasks largely independent of resident involvement. The residents were observed to have spent the majority of their time during both observational periods (approx. 45 minutes of every hour) without being engaged in any constructive activities.

The only statistically significant difference in activities from 2009 to 2013 was an increase in the average time engaged in domestic activities in 2013 ( $Z = -2.342, p = .019$ ). There were no significant differences between the houses for time spent doing activities in 2013. Finally, there were no observed incidences of challenging behaviour in either 2009 or 2013.

**Table 10. Percentage of time residents spent in different environments in 2009 and 2013**

House	Living Area %		Resident's Room %		Front Room %		Backyard %		Front Yard %		Other %	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>Greenacres</b>	88%	75%	0%	2%	7.5%	3%	2.5%	11.5%	0%	0%	2%	8%
<b>Northfield</b>	87%	78%	3%	0.5%	8%	6%	0%	13.5%	0%	0%	1.5%	2.5%
<b>Sturt</b>	80%	96%	2%	0%	9.5%	0%	8.5%	0%	0%	0%	0.5%	4%
<b>Average</b>	85%	83%	2 %	1%	8 %	3%	4%	8%	0%	0%	1%	5%

Table 10 shows the percentage of time residents spent in different environments within their home in 2009 and again in 2013. As can be seen, in both 2009 and 2013, residents spent most of their time (avg. 84%) (approx. 51 minutes of every hour) in the living area of their own homes. Ninety-two percent of the residents' time in the living area was spent in a group situation with other residents (55 minutes of every hour).

The only statistically significant difference between 2009 and 2013 was an increase in time spent in 'other' areas of the house in 2013 (e.g., bathroom, passageway, laundry) ( $Z = -2.346, p = .019$ ). In terms of differences between the houses in 2013 the only statistically significant difference was that more time was spent in the living room at the Sturt house than in the other two houses (Chi-Square = 6.406,  $p = .041$ ). Table 11 shows the percentage of time residents interacted with other people within their houses in 2009 and again in 2013. As can be seen, residents received attention from staff at a higher level in 2013 (22%) than in 2009 (11%). While this increase was statistically

significant ( $Z = -3.287, p = .001$ ), it is important to note that seventy-eight percent of the residents' time in the houses in 2013 passed (47 minutes of every hour) with no constructive interaction with the social world of their houses. No other findings regarding the residents' interactions with others within or between the houses were significant.

**Table 11. Percentage of time residents were interacting with different people over two hours of observation in 2009 and 2013**

House	House Staff %		Family %		Medical Staff %		Volunteer %		Other Resident %		Other %		No One %	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>Greenacres</b>	8%	26.5%	0%	0%	0%	0%	0%	3%	0%	0%	0%	0%	92%	70.5%
<b>Northfield</b>	13.5%	27%	3%	0%	0%	0%	0.5%	0%	0%	0%	0%	0%	83.5%	73%
<b>Sturt</b>	10.5%	13.5%	0%	0%	0%	0%	0%	0%	0%	0.5%	0%	0%	90%	86%
<b>Average</b>	11%	22%	1%	0%	0%	0%	1%	1%	0%	1%	0%	0%	89%	78%

Table 12 shows the percentage of time that residents received different types of interactions from support staff in 2009 and again in 2013. While residents were more likely to receive attention from staff than other individuals (e.g. other residents, volunteers) in their homes, only a small percentage of this attention in 2013 was in the form of training and assistance (avg. 10 % or approximately 6 minutes of every hour). This finding indicates a 3 minute per hour average increase in training and assistance provided to the residents over a four-year period.

A significant increase over 2009 levels was evident for time engaged in positive ( $Z = -2.969, p = .003$ ) and neutral interactions ( $Z = -3.650, p = .001$ ) with staff in 2013. In clinical terms, however, the level of these types of interactions represent approximately 4 minutes of every hour of social engagement between residents and staff.

While no other findings were significant, it is encouraging that few negative comments were observed to have been directed at the residents (avg. 1%) across the two time periods. Conversely, it is disheartening to report that in 2009 and again in 2013 it was observed that residents were barely encouraged or assisted to participate in constructive activities or to socialise with other individuals. Moreover, the use of accommodations or assistive devices (e.g., hand or head activated micro-switches, sandwich holders, utensil grips, communication boards, switch activated page-turners) which might be presumed to enable and/or encourage the residents to be more independent in their actions were not in evidence during the observational sessions in either 2009 or 2013.



**Table 12. Percentage of time residents were engaged in different types of interactions over two hours of observation in 2009 and 2013**

House	Positive %		Negative %		Training Assistance %		Neutral %		No Interaction %	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>Greenacres</b>	1%	8.5%	0.5%	1%	5.5%	12.5%	1.5%	8%	92%	70%
<b>Northfield</b>	2.5%	7%	0.5%	1.5%	10%	13.5%	3.5%	6.5%	83.5%	72%
<b>Sturt</b>	3%	2.5%	0%	0.5%	6.5%	5.5%	0.5%	5.5%	90.5%	51%
<b>Average</b>	2%	6%	1%	1%	7%	10%	2%	6%	89%	76%

### Individual Differences in Activities

While averages can indicate overall changes from 2009 to 2013, it is also important to consider individual differences given that an increase in average time spent in an activity in a house can be due to a minority of individuals with no change in the majority of individuals.

Table 13 shows the percentage of time that individual residents were engaged in different activities during a total of 60 minutes of random observation time in 2009 and again in 2013. From 2009 to 2013, 50% of the individuals showed an increase in the time they were observed engaged in domestic activities. In 2013 the percentages of time spent engaged in domestic activities ranged from 0 (for eight individuals) to 31% with nine ranging between 5% and 25% and four between 25% and 31%.

There were similar results for personal activities with just over 50% (12 of the 20 individuals) showing increases from 2009 to 2013 in observed time in personal activities. In 2013 the percentages ranged from 0 (for six individuals) to 52% with eight ranging from 10% to 25% and three ranging from 25% to 52%.

Only six of the 20 individuals showed increases in leisure activities in 2013. While three were observed to spend 25% of their time in this activity in 2013, 14 were observed to spend no time on leisure and the remaining three spent less than 5% of their time on this activity. Only one individual showed an increase in the percentage of observed time (from 0 to 13%) watching TV from 2009 to 2013 with the remaining 19 in 2013 spending no time watching TV.

Overall just over half (12 of the 20) showed a decrease in time observed doing nothing in 2013. However, in 2013, 15 of the 20 individuals were observed to spend more than half their time doing nothing with nine spending more than two thirds of the observed time doing nothing, seven spending more than 75% of the time doing nothing and two individuals spending all of the observed time doing nothing.

**Table 13. Percentage of time residents engaged in different activities over 2 hours of observation in 2009 and 2013**

Resident	Domestic %		Personal %		Leisure %		Television %		Challenging Behaviour %		Other %		None %	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>LB</b>	0%	14%	0%	0%	0%	0%	25 %	0%	0%	0%	0%	0%	75%	86%
<b>AG</b>	0%	31%	25%	2%	0%	0%	8%	13%	0%	0%	0%	0%	67%	54%
<b>AL</b>	0%	13%	0%	23%	0%	0%	25%	0%	0%	0%	0%	0%	75%	39%
<b>BC</b>	0%	0%	0%	7%	0%	25%	0%	0%	0%	0%	0%	4%	100%	89%
<b>SC</b>	0%	0%	0 %	13%	0%	0%	25%	0%	0%	0%	0%	0%	75%	87%
<b>EK</b>	9%	0%	4%	0%	0%	4%	4%	0%	0%	0%	0%	0%	82%	96%
<b>SH</b>	0%	0%	2 %	31%	0%	4%	25%	0%	0%	0%	0%	7%	73%	58%
<b>AH</b>	0%	12%	13%	19%	0 %	1%	0%	0%	0%	0%	0%	0%	87%	68%
<b>GR</b>	0%	0%	36%	52%	35%	0%	0%	0%	0%	0%	0%	0%	29%	48%
<b>JP</b>	0%	25%	10%	15%	25%	0%	0%	0%	0%	0%	0%	0%	65%	60%
<b>GS</b>	0%	6%	17%	0%	0%	0%	0%	0%	0%	0%	0%	0%	83%	94%
<b>CJ</b>	8%	7%	19%	21%	0%	0%	0%	0%	0%	0%	0%	0%	72%	72%
<b>CM</b>	0%	0%	4%	0%	25%	0%	0%	0%	0%	0%	0%	0%	71%	100%
<b>JG</b>	17%	23%	25%	0%	0%	25%	0%	0%	0%	0%	0%	0%	58%	52%
<b>JF</b>	0%	0%	40%	41%	0%	0%	0%	0%	0%	0%	0%	0%	60%	59%
<b>RT</b>	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	100%
<b>MM</b>	0%	27%	27%	8%	0%	0%	0%	0%	0%	0%	0%	0%	73%	65%
<b>MD</b>	11%	0%	0%	12%	0%	0%	0%	0%	0%	0%	0%	0%	89%	88%
<b>CV</b>	0%	5%	0%	18%	0%	0%	0%	0%	0%	0%	0%	0%	100%	77%
<b>BC</b>	4%	21%	0%	12%	25%	25%	0%	0%	0%	0%	0%	0%	71%	42%

Table 14 shows the percentage of time individual residents spent with different people during a total of 60 minutes of random observation time in 2009 and again in 2013. It can be seen that most individuals (17 out of 20) were observed to spend more of their time interacting with staff in 2013 than in 2009. This difference was statistically significant ( $Z = -3.29, P < .001$ ). Seven of the 20 spent between 30% and 50% of the time with staff, 11 spent between 10 and 30% of their time with staff and the remaining two spent less than 10% of their time with staff.

No residents were observed to spend time with either family or with medical staff and only one spent time with a volunteer and only one with another resident. However, in 2013 almost all of the residents (19 of the 20) were observed to spend more than 50% of their time with no interaction with another person. Of these, eight spent between 50 and 75% of their time interacting with no other person and 11 or just over half spent more than 75% of the observed time interacting with no other person.

**Table 14. Percentage of time residents spent with different people over 2 hours of observation in 2009 and 2013**

Resident	House staff %		Family %		Medical staff %		Volunteer %		Other Resident %		Other %		No one %	
	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013	2009	2013
<b>LB</b>	0.8%	16%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	99%	84%
<b>AG</b>	25%	37.5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	75%	62.5%
<b>AL</b>	4%	27.5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	96%	47.5%
<b>BC</b>	0.8%	18%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	99%	82%
<b>SC</b>	0%	14%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	86%
<b>EK</b>	19%	22.5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	81%	77.5%
<b>SH</b>	2.5%	40%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	97.5%	60%
<b>AH</b>	26%	35%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	74%	65%
<b>GR</b>	11.6%	32.5%	12.5%	0%	0%	0%	0%	0%	0%	1.5%	0%	0%	75.8%	66%
<b>JP</b>	11.6%	49%	0%	0%	0%	0%	5%	0%	0%	0%	0%	0%	83.3%	51%
<b>GS</b>	20%	11%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	80%	89%
<b>CJ</b>	9.1%	26%	0%	0%	0%	0%	1.6%	0%	0%	0%	0%	0%	89.1%	74%
<b>CM</b>	5.8%	9%	8.3%	0%	0%	0%	0%	0%	0%	0%	0%	0%	85.8%	91%
<b>JG</b>	31.6%	17.5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	68.3%	82.5%
<b>JF</b>	15%	39%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	85%	61%
<b>RT</b>	4.1%	5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	95.9%	95%
<b>MM</b>	25%	36%	0%	0%	0%	0%	0%	6%	0%	0%	0%	0%	75%	58%
<b>MD</b>	10%	13%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	90%	87%
<b>CV</b>	0%	22%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	78%
<b>BC</b>	7.5%	14%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	92.5%	86%

## SUMMARY

The purpose of the current evaluation was to determine whether the residents' quality of life had changed since the previous evaluation conducted in 2009. The focus on aspects of life quality is an ideal way to judge the success of any social intervention given that the quality of human life is the ultimate unit of accountability for the providers of human services. An important aspect of the evaluation project is the fact that it was done at all. It is a rare but welcome innovation when public officials voluntarily hold themselves accountable for individual well-being. When that well-being is being measured by an independent third party with reliable methods, the results would seem worthy of serious policy consideration.

Findings from the 2009 Phase 3 evaluation indicated that the first 30 people who moved from Strathmont to the community had experienced an increased quality of life. Positive changes occurred in: resident-family contact, the physical quality of the residents' living environment, their perceived emotional well-being and general life satisfaction. They also experienced more personalised care and support, and their overall health remained relatively stable during their first two years in the community with notable decreases in reported illnesses and behavioural problems. There were variations in outcomes across the 30 individuals, and less progress had been made in choice making, variation and frequency of scheduled activities, and the promotion of pro-social contact with non-disabled community members. Furthermore, most of the activities the residents participated in had a "disability" focus, with much of their time being spent within their own houses. None of the residents had a close friend who was not a staff member or family member, and only one resident was reported as spending time with people of a similar age who were not staff and who did not have a disability.

At the time of the 2013 Phase 4 evaluation, 20 of the original 30 residents were still living in the houses and there had been some turnover in the staff in the houses. However, from 2009 to 2013 there had been little change in the residents' physical environments or staffing levels. The only major contextual change was the introduction of a Person Centred Active Support training program for a limited number of staff.

The Phase 4 evaluation in 2013 was limited in scope due to its being based on unspent finances remaining from the 2009 evaluation. However, the results obtained within the scope of this final evaluation indicate that there have been some improvements in many of the quality of life assessments. These improvements included more positive ratings by staff of the perceived impact of community living on the residents' behaviour, and emotional and material well-being, and an increase in the variety and frequency of activities available to residents, with more of these activities reportedly being specifically organised for individual residents. An unanswered question is "Are these outcomes good enough"?

### ***Health***

A review of resident health files indicated that all of the residents had received an annual medical review and that five of the eight measures of resident health as recorded in the files had remained relatively stable across the two time periods. For the other measures, doctors' visits and seizures had reduced by 58% and 50% respectively and residents with behavioural issues had reduced markedly. Furthermore, most of the proxy respondents considered the residents to be in good or excellent health and most were of the opinion that the residents' health needs were being met in an appropriate and timely manner. This is an important finding that suggests strongly that medical needs are being addressed and supports can be, and are being, provided to individuals with significant and complex needs to enable them to live in the community.

### ***Activities and Choice Making***

Staff reported that activities had been organised for all of the residents and that all residents had achieved their lifestyle activity goals in 2013. Staff respondents also indicated that they believed there had been an increase from 2009 levels in the variety and frequency of activities offered. However, a review of resident activity logs indicated that many of the activities that were perceived by staff in 2009 to be unsuitable and unenjoyable were still being offered to residents in 2013. It was also reported that residents did not make independent decisions on four of seven common daily living activities. Prior to the move to the community (in 2006) most of the respondents felt that the residents should be provided with more opportunities to be involved in decision making activities that reflect their interests and preferences. After more than seven years in the community, however, residents were purported to have little choice in selecting and participating in everyday activities. Observations of staff suggested that established household routines and staff knowledge of residents (or lack of) may have resulted in staff anticipating or predicting need and/or choice rather than waiting for, or encouraging and supporting the residents to more actively engage in activities and choice making. It was also observed that staff relied heavily on verbal communication when interacting with residents, possibly overestimating their receptive language abilities, which may have resulted in miscommunication or misunderstandings regarding the residents' abilities, interests and preferences.

It is not clear from the data whether these findings are associated with staff expectations and understandings regarding the capabilities of the residents or organisational and/or contextual factors that might influence staff behaviour and resident involvement in the decision making processes. These findings do suggest, however, that greater emphasis should be placed on processes, such as reflective practice and Person Centred Planning and Person Centred Active Support, which are designed to enable multiple perspectives on resident preferences and to facilitate staff practices that will facilitate and maximise the residents' potential to exercise choice or preferences and engage in meaningful activity.

While variation and frequency of community activities offered has reportedly increased over 2009 levels, it is unclear whether the residents are actively engaged in the activities and social interacting with nondisabled community members who may be associated with those activities. Moreover, little was revealed about the processes by which decisions are made about the type of community activities residents do; that is, whether residents have exercised choice in particular activities, or if the activities are meaningful to them. Furthermore, it is difficult to see how the scheduled activities enable and promote pro-social contact with non-disabled community members given that there was no evidence that the residents use public transport for community outings; and that much of the residents time is spent within their own houses with little contact with neighbours or others from the outside world. Sadly, only 20% of the residents were reported to have had a friend who was not a staff member or family member. None of the residents were reported to have even nodding acquaintanceships with their neighbours, and only one resident was reported as spending time with people of a similar age who were not staff and who did not have a disability. These findings underscore the social isolation of the residents who, after approximately seven years in the community, continue to live in an apparently distinct social space made up primarily of staff, family and other people with disabilities.

### ***Lifestyle Plans***

A review of Accommodation Files revealed that all of the residents had a lifestyle plan, although fewer goals were recorded for each resident in 2013, with relatively more residents having only one goal documented. Given the complex and multifaceted needs of the residents, it is questionable whether one lifestyle goal would be adequate in acknowledging and effectively addressing these needs. There was also a marked increase in the percentage of documented goals where achievement was unclear or unknown. Records of planning meetings indicated that approximately 71% of the

residents attended their own planning meetings in 2013. This attendance rate represents a 25% decrease from 2009 in reported resident attendance.

Documented goals in the lifestyle plans appeared to have an individualised focus, yet variation was evident in the ways in which goals were stated and outcomes reported, with some plans providing more detail than others. None of the goals, however, were focused on the development of adaptive behaviours, nor did they address important lifestyle domains such as personal care, domestic activity, or social interaction, including developing friendships. Moreover, all of the goals were written in a passive voice with no reference to the use of adaptive equipment or active engagement or participation from the residents. The goal plans also lacked descriptive information regarding the procedures that would be employed to assist the target resident to achieve the goals. There was also limited information regarding: the assessment and decision making processes used to determine individualised goals; when and where training or activities would occur; and timelines for achievement and progress review. Moreover, no information was available regarding the nature of resident, family and/or advocate participation in the planning process. If these plans are meant to serve, in part, as a road map for the residents' future, then issues regarding the development and review of individualised habilitative goal plans, and overall professional training and systems accountability will need to be examined and addressed. It will also be important to determine ways in which staff, management, families, and advocates can be assisted to provide support for enhancing resident involvement in the planning process.

### ***Social Interactions***

Observations of the residents revealed there had been significant but slight increases in positive and neutral interactions between staff and residents since the 2009 evaluation. However, resident engagement in constructive activities remained very low and this was evident in both average scores for the group and in terms of the numbers of residents actively involved. As in 2009, it was still observed to be the case in 2013 that many residents have little or no active engagement in activities and even those residents observed to be the most engaged, still spent most of their time doing relatively little during their waking hours in the houses.

From 2009 to 2013 there was little difference in resident involvement and participation in the running of their own homes as evidenced by engagement in domestic activities. In 2013, on average, 47 minutes of every hour passed without the residents being engaged in any constructive interaction with the social world around them. This represented a 6 minute average increase in engagement over a four year period. Across all the houses, residents were barely encouraged or assisted to participate in constructive activities or to socialise with other individuals. Moreover, the use of accommodations or assistive devices (e.g., hand or head activated micro-switches, sandwich holders, utensil grips, communication boards, switch activated page-turners) which might be presumed to enable and/or encourage the residents to be more independent in their actions were not in evidence in any of the houses during the observational sessions.

A typical day for the residents consisted mainly of sitting in a group situation in the living area of their house with little physical or social engagement in any constructive activities. Many staff were observed to spend the majority of their time in household maintenance and administrative duties, providing passive supervision and limited support to, and conversation with, the residents under their care. This lack of engagement may reflect an attitudinal perspective on the part of staff who may view domestic duties as their primary responsibility and not as an opportunity to assist residents in developing their domestic, community and social interaction skills. Many of the staff were of the opinion that most of the residents have very limited capabilities and that scope for improvement in their interactions and engagement in domestic and community activities, even with concerted efforts in terms of active support, remain very limited. If staff see their primary role as being focused on household maintenance tasks, and if they do not believe that the residents are capable of acquiring new skills and more independence, they are unlikely to work towards fostering

and encouraging this in the context of their relationships with the residents they serve. Given the numerous and competing demands on staff and management, it may also be necessary to establish programs using specialised staff, including developmental educators, with a more explicit focus on developing domestic and community participation for residents that can complement and support the work of staff. Such programs could also act as champions of community participation and, through demonstration of its diversity, may help to convince staff of the possibilities for all people with an intellectual disability regardless of their level of impairment.

The low level of participation in constructive activities and meaningful social interaction would seem to represent a lost opportunity given the improved environmental context of the community houses. Moreover, the lack of meaningful engagement may produce a sense of disconnection between the residents and their physical and social world, and confirm that the residents have little, if any, control over their lives. It is important to note, however, that in spite of the limited social experiences afforded to the residents, their basic care needs appeared to be well considered. Their houses were clean and well maintained. Moreover, most staff members appeared to be caring and genuinely concerned with the welfare of the residents under their charge. It will be important to continue to monitor services to determine if improvements have been made on these measures and if the gains acquired are being maintained. However, without systematic and consistent strategies by staff and management to promote resident interpersonal and lifestyle skills there may be little reason to expect improvements in residential adjustment, well-being, and quality of life.

## RECOMMENDATIONS

The following recommendations are similar to those offered in the 2009 and focus on support strategies that can be used at an organisational level, and support strategies that may be used by house managers and direct care staff.

**1. Training (General):** Staff may require specific information, mentoring, training and/or technical assistance in order to be more effective at improving the quality of life of the people they serve. In 2009 and again in 2013, many of the staff who were interviewed for this project indicated that they valued the opportunity to participate in professional development activities that enhanced their abilities to effectively support the residents they served. Importantly, many of them recognized deficits in their own knowledge and skills and were readily able to identify their own training priorities in terms of content and delivery. Building on this apparent awareness, staff should be encouraged to take a more active role in the design and delivery of training programs that are timely, flexible, convenient, and relevant to their needs. Staff bring different experiences, expectations, skills and knowledge to their positions. Hence, the training opportunities should be sensitive to, and directed at, different levels of need (e.g., induction, awareness, skill development, application, maintenance). The use of “user friendly” training experiences should also be considered (e.g., self-instruction modules, on-line applications, small groups, visits to other programs). Furthermore, it will be important to continuously shape a program of staff development experiences that address a wide range of changing needs for both staff (e.g., coping strategies, team-building, community engagement) and residents (e.g., activities, health, skills development, community participation). If possible, training opportunities should also be developed to include a mentoring component and be designed within a career development format that offers incentives for participation and demonstrated competency.

**2. Training (PCAS):** Evidence of the consistent and systematic application of Person Centred Active Support was variable across the houses and had not become embedded into everyday routines and practices. Trainers providing the PCAS training and staff from the houses who participated in the training were positive about the content and usefulness of the training course. Suggestions for improvements from staff participating in the training included more examples of

how the training could be applied to residents in the houses and training staff considered that follow up mentoring in the houses would be useful in showing staff how to apply what they had learned. It is recommended that consideration be given to providing such follow-up mentoring in order to maximise the transfer and maintenance of the acquired training expertise. It has been noted that observations in the houses did not indicate any use of adaptive devices with residents and this suggests that more consideration should be given to including training on how such devices can be used as part of the PCAS training program.

Because PCAS training had not at the time of this review been fully implemented in all the houses, further attention must be paid to ensuring its long term effectiveness, efficiency, cost-effectiveness, fidelity, and sustainability. It will also be important to assess and monitor the extent to which lifestyle outcomes for residents are affected by the nature and extent of PCAS training experienced by staff. Consideration needs to be given to how often staff should be provided with this active support training program, e.g., every year or two, to ensure that their active support skills are kept up to date.

In 2013 as in 2009 the residents were reported to have had limited interactions with neighbours or visitors and that their engagement in the community was largely restricted to that provided by volunteers. Volunteers play an important role in assisting the residents to access and participate in community activities. However, the volunteers have not, at the time of this final evaluation, had access to Person Centred Active Support training. It is recommended that such training, including refresher courses every year or two, be continued for all staff in the houses and extended to volunteers who wish to take part in it. To the extent possible trainers should not only endeavour to provide mentoring in the houses for staff but also, if possible, for the volunteers to help them to apply what they learn in the training program in order to maximise the positive effects on the quality of life of the residents. This training and, if possible, associated mentoring are needed to overcome the tendency for staff and volunteers to do things for, rather than with, residents.

**3. Job Descriptions:** Providing support services in community settings to individuals with significant and multiple disabilities is a challenging and complex task. This task can be made more difficult and confusing when staff are given a considerable degree of autonomy and responsibility in their jobs without a clear understanding of their expected roles and responsibilities. In the houses observed, this apparent role confusion may have been compounded by rostering practices and the increasing use of casual staff whereby house supervisors did not frequently work alongside all staff. This in turn may have led to an absence of opportunities for house supervisors to exercise guidance in the form of coaching, role modeling, monitoring and constructive feedback on desired performance. If staff are left to implement their own understandings of practices such as “domestic duties”, “support”, “community participation”, “social inclusion”, and “choice making” in their day-to-day interactions with residents, or selectively decide the feasibility of particular practices, then both desired and achieved outcomes for residents may be compromised.

Many staff members expressed a sense of confusion and ambiguity regarding their roles and responsibilities, particularly with respect to the relative importance of household maintenance duties and/or the provision of individualised support for the residents. If staff are expected to achieve organization goals and objectives related to supporting people with disabilities in community settings, their roles and responsibilities should be clearly delineated and this should be reflected in performance appraisals. This may require the systematic analysis of the functional requirements of their job (e.g., physical, cognitive, social, decision-making, academic) and how those requirements relate to desired client outcomes. Without such descriptions direct services staff (and other professionals) may have difficulty discerning which responsibilities are of priority and which are legally and ethically their own. If job descriptions are revised to include responsibilities for improving the quality of life outcomes (general and specific) of residents, and this aspect of their work is considered as part of their performance appraisal and career development, then staff may be



more inclined to focus their attention and energies in this area. Staff should also be supported and encouraged to adopt working methods designed to enable and facilitate desired resident outcomes that are related to organisational goals. They should also be provided with (or encouraged to develop) indicators of successful outcomes for residents that can be used to evaluate their work performance and set appropriate work goals for staff development (e.g., community participation, social inclusion, choice making, active engagement). A revised job description should also specify the need to engage positively with, and provide active support for, residents and this information should be provided to applicants for staff positions and used to select those suitable for this role. Such information could be obtained from relevant questions to referees and in recruitment interviews concerning the applicant's positive engagement with clients and co-workers in their previous work experience.

**4. Community Relations:** Facilitating and maintaining community relations should be part of an on-going plan for improving the social inclusion and community participation of the residents and staff. Resident development is only likely to be actualised if the individual participates in activities and relationships that broaden their experiences and enable them to develop new skills and interests. In isolation, the strategies for enhancing community relations may not be sufficient, but the cumulative effect of several strategies may mean the difference between residents who attain mere "physical presence" in their local communities and residents who achieve a true sense of acceptance and belonging. The establishment of a range of community relationships should be seen as an important part of staff members' roles and responsibilities (e.g., getting to know the neighbours, becoming known in local establishments). Attention must be given to the implementation of strategies and programs to ensure their day-to-day operations maximise opportunities for residents to develop their social connections in the community, as well as to exercise choice and engagement in meaningful activity. It will be important for administrators and policy makers to more clearly define what is meant by community participation, social inclusion, and active engagement, and their possible manifestations for people with significant and complex disabilities. This will support the implementation of more differentiated and targeted strategies for enhancing the opportunities for residents to actualize their potential.

Various strategies are available for facilitating and maintaining community relationships (e.g., patronising local businesses, mapping relationship networks, assisting neighbours with chores, making community presentations to local organizations, attending local community events, scheduling regular "in-house" events for members of the community). The effectiveness and appropriateness of any particular strategy is dependent on a range of factors (e.g., community location, staff competencies and motivation, prior experiences with people with disabilities, local resources) that need to be carefully considered before they are adopted for implementation. Successful examples of such strategies need to be identified by management and through research so that they can be act as models for staff working with other residents and in other houses.

**5. Lifestyle Plans:** Individual program plans should be used as a guide for the development and monitoring of programs, supports and activities. Each resident should have an individualised plan that is based on a careful assessment of the abilities, skills, talents, preferences, and needs of the individual, including prescriptive steps toward the attainment of increasingly independent levels of functioning. These plans should be developed in concert with the meaningful participation of residents and their family and/or advocates. Programming toward more complex skills and experiences can also be more easily attained and evaluated if desired tasks and behaviours are defined in measureable terms. The 2013 review revealed that the residents' written goals lacked this specificity. Moreover, there was an apparent lack of coherence across goals included in each resident's plan. That is, the goals did not appear to present a holistic or habilitative approach to service planning or delivery, nor were they focused on the development of adaptive behaviours, and they did not address important lifestyle domains such as personal care, domestic activity or social

interactions, including developing friendships and decision making. Without this perspective the entire program planning process loses much of its logic, direction and focus.

It is suggested that the plans provide more detail (e.g., behaviourally referenced time-framed goals and objectives, implementation and monitoring strategies outlined) and focus on the development of adaptive behaviours and use of assistive technologies across a range of important lifestyle domains. It is also recommended that staff receive training in designing, implementing and evaluating lifestyle plans with periodic retraining and associated support that involves residents and their advocates in meaningful participation in Person Centred approaches to planning.

Disability Services has indicated that it is planning to implement a pilot person-centred planning process that is intended to address the lifestyle planning and programmatic issues identified in the current evaluation.

**6. Communication:** Open communication within and across the community houses should be encouraged and supported. If staff are to work toward the goal of an improved lifestyle for the residents, they must have access to information that will assist them in this endeavour. Staff should be encouraged and supported to consider openly the social, domestic and community experiences of residents in other houses, to share effective strategies, to build mechanisms to deal with the most likely practical problems (e.g., balancing domestic duties and resident duties, lack of community engagement, access to meaningful activities, facilitating skill development, working as a team) and to discuss these issues regularly with other staff who face the same challenges, and share the same visions. These types of discussions also offer the opportunity to nurture an atmosphere of “team work”, where staff work together toward common goals and support and acknowledge one another. Team building exercises are needed to establish and maintain effect teams that reduce the need for replacement staff and new staff which can disrupt ongoing programs and disturb residents. It was noted in the section of quality of life that non-individual factors identified in 2013 as contributing to residents’ dissatisfaction with life included: “experiencing stress as a result of a change in routine and coping with new staff”. Exit interviews need to be conducted with staff who leave to identify any factors that might be contributing to job dissatisfaction amongst staff, particularly with respect to teamwork. Newsletters that feature articles on staff members, their team accomplishments, and their innovative ideas might serve as a motivational mechanism and as a way of acknowledging their individual and collective efforts.

Disability Services has acknowledged the importance of communication within the organisation and are implementing strategies to improve communication within and across sites. It is likely, however, that communication will present ongoing challenges given the existence of multiple sites, large work teams, fluid staffing configurations, and limited access to computers.

**7. New Residents:** It was noted during the 2013 evaluation that a number of new residents had moved into the community houses. Many of these new individuals were performing at a higher level than the original residents. These increased capacities on the part of the new residents provide greater opportunities for staff to engage in Person Centred Active Support, and this would also be the case for volunteers if they were to be trained in the use of PCAS techniques. Given the perceived limited capabilities of the original residents and the increased capabilities of new residents, it is recommended that a further evaluation of the quality of life of these new residents should be undertaken. Such an evaluation would provide an opportunity to assess the extent to which PCAS training is capable of substantially increasing the active engagement and quality of life of individuals with a variety of needs co-residing in the community houses.