

Rosewood Movers FY2011: Two-Year Follow-up Interviews



Prepared for the
Maryland Developmental Disabilities Administration

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Judy Volkman served as the Ask Me! Survey Project Manager at the Arc Maryland in FY2009 in charge of all the field work activities, and was assisted by Edith Sodowsky who coordinated the Rosewood interviews. In FY2011, Ms Volkman returned to coordinating only the central region for the Ask Me! Survey and coordinated the interviewers on the Rosewood followup.

Fifteen committed and skilled interviewers, who themselves receive support funded by the DDA, make this Ask Me! project possible. Four conducted surveys in both years. Five conducted surveys in only FY2009 and six conducted surveys in only FY2011. The nine interviewers in FY2009 averaged 7 years of experience and conducted an average of 12.4 interviews with Rosewood residents, generally as part of a two-person team. The ten interviewers in FY2011 averaged 10 years of experience and conducted an average of 8.2 interviews:

April Carr (2011)	James Devore (2009, 2011)	Peggy Nazelrod (2009)
Christy Scott (2009, 2011)	Lori Powell (2009, 2011)	Scott Heim (2009, 2011)
Crystal Stephens (2009)	Marianne McNally (2011)	Valerie Smith (2011)
Diana Warther (2009)	Michael Raidt (2011)	Vernon DeHaven (2011)
Emerald Coleman (2009)	Patty Worff (2011)	Vicki Mills (2009)

Ask Me! has a training manual available for organizations interested in conducting the project in other states. The manual provides all necessary materials and information to conduct the survey. It is available at cost and includes the survey, interview protocol and interviewer training information. All documents are also in Word. To protect the integrity of the project, The Arc Maryland has developed a licensing agreement for entities that wish to become certified to use the survey. For additional information, contact The Arc Maryland, 49 Old Solomons Island Rd., Suite 205, Annapolis, MD 21401, 888-272-3449, www.thearcmd.org.

This report is available on the website of the Maryland Developmental Disability Administration, <http://www.dhmd.state.md.us/dda>, and it and other publications listed at the end of this report, can be accessed through the website of Bonham Research, <http://www.bonhamresearch.com/Level%201/AskMe.htm>.

Rosewood Movers FY 2011

Executive Summary

“My home is better than Rosewood. I have my own room, clothes, furniture. I help pay for my food. I am looking for a job.”—self respondent after two years

The Maryland Developmental Disabilities Administration (DDA) began moving people from its institutions many years before, but decided at the beginning of FY2009 to completely close the Rosewood Center, the largest of the four, by the end of the fiscal year. DDA contracted with The Arc Maryland to interview the remaining Rosewood residents prior to their moves to community agencies and again two years later. The Arc Maryland used a slightly modified *Ask Me! Surveysm* to conduct baseline interviews for 61 people in FY2009 and follow-up interviews in FY2011 for 39 of them. The interviewers, who themselves receive support in the community, determined that one-third of the individuals could respond for themselves on the baseline survey and one-third could respond for themselves on the follow-up survey. Eight individuals responded for themselves in both surveys, and proxies responded for 27 people in both surveys. All baseline proxies were Rosewood residential staff; most community proxies were family members or day staff.

The *Ask Me! Surveysm* measures quality of life in eight domains. Four hypotheses guided the study and this analysis.

Hypothesis 1—Self respondents report different levels of quality of life than proxies report for people unable to respond for themselves.

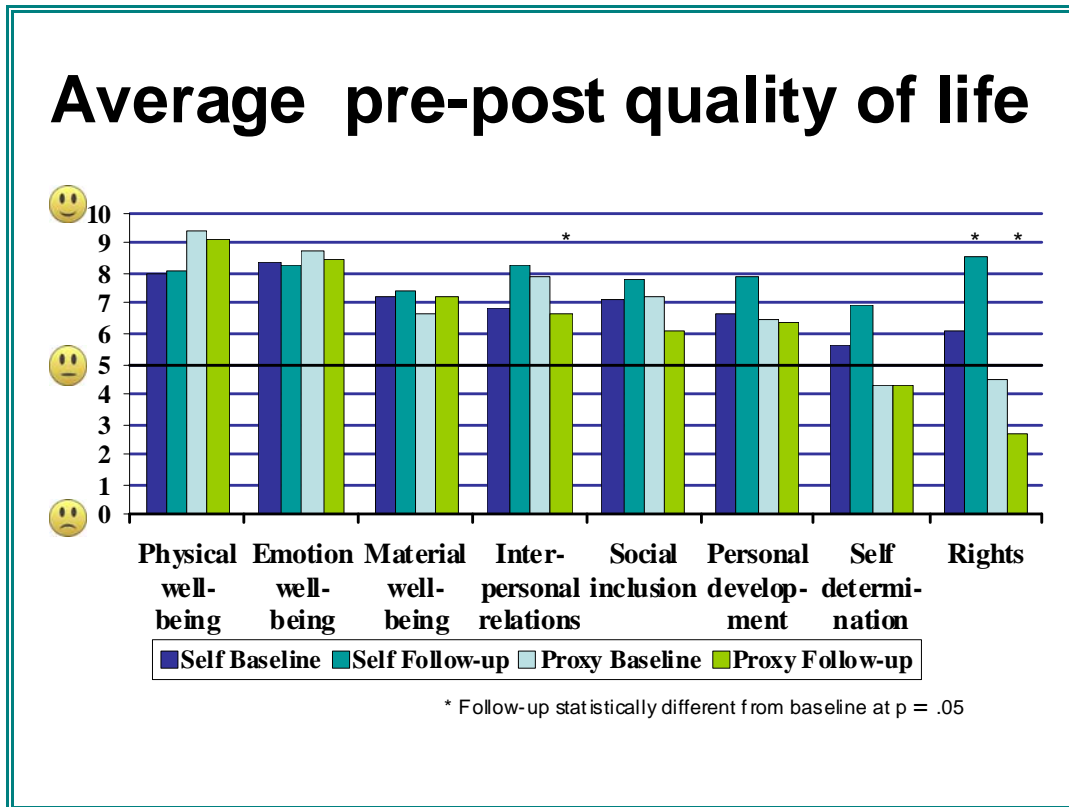
- Self respondents at Rosewood reported significantly lower Physical Well-being than proxies for people at Rosewood, the same as found for people already living in the community;
- Self respondents at Rosewood reported significantly higher Self Determination and Rights than proxies at Rosewood, the same as for those already in the community;
- Smaller percentages of self than proxy respondents at Rosewood reported getting all the services they needed, receiving the right concern about their health, and being helped to learn to do things themselves.

Hypothesis 2—The quality of life in Rosewood is lower than that in the community, whether reported by individuals for themselves or by proxies for them.

- Self respondents living in Rosewood report significantly lower Self Determination and Rights than self respondents already living in the community;
- Proxies for people living in Rosewood also report significantly lower Self Determination than proxies for people living in the community, along with lower Physical Well-being, Emotional Well-being, and Material Well-being.

Hypothesis 3–Self-reported quality of life will show consistency over the two years and be higher after the move to the community than before in the institution.

- The Rights, Social Inclusion and Physical Well-being self respondents report after moving to the community are significantly related to what they reported in Rosewood;
- Self respondents report significantly higher Rights after moving into the community, and slightly higher Self Determination, Personal Development, Social Inclusion and Interpersonal Relations (see chart);
- Self respondents expressed that they liked living in the community better than living in Rosewood.



Hypothesis 4–Proxy-reported quality of life after the move has no relationship to that reported before the move, but will be lower overall due to less proxy bias.

- Community proxies report low Material Well-being for people Rosewood proxies reported as high and high when Rosewood proxies reported low, but otherwise there is no relationship between their reports;
- Community proxies report significantly lower Rights, Social Inclusion, and Interpersonal Relations than Rosewood proxies report;
- Almost all community proxies express that the people they support are better off in the community than Rosewood, mentioning better behavior, going out more, and liking their own home or room.

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Background

The *Ask Me! Survey*sm has been used annually in Maryland since FY2002 to collect information from a probability sample of people receiving support in the community through funds from the Maryland Developmental Disabilities Administration (DDA). The survey has not been used prior to this study to measure the quality of life of people who only receive support in one of the four Maryland institutions for people with developmental disabilities. Findings from the FY2009 survey can be found in Bonham, Volkman and Sorensen (2009).

DDA selected the *Ask Me! Survey* to gather information for individuals who were moving from an institutional setting into the community. The move was prompted by the closure of Rosewood, the largest of the four facilities operated by the state of Maryland. The DDA used funds from its Money Follows the Person Grant (MFP) to support the moves.

Maryland began moving people from institutions many years before. Those left in Rosewood were those whom staff and guardians believed could not thrive in the community. Therefore it was expected that their quality of life in the institution would be lower than the quality of life of those already in the community. The strong push by self advocates for closing Rosewood, particularly by those who had once lived in Rosewood, indicated that they had experienced increased quality of life after moving to the community. It is therefore expected that people who can respond for themselves will express increased quality of life between the baseline survey and the two-year follow-up survey. It is not clear how the quality of life would change for those unable to respond for themselves. The Ask Me! Survey has shown that proxies respond differently than self respondents, and that different types of proxies for the same person respond differently. Ideally, the same proxies would respond to the baseline and follow-up surveys. This proved impossible from a practical standpoint. Families of Rosewood residents had organized opposition to its closing, including taking legal action. The jobs of Rosewood staff were ending, and those with opportunities to provide support at community providers had already left. Further, Cummings (2002) summarizes studies that show caregivers tend to rate peoples' quality of life higher than self respondents due because want to believe that the people in their care are positively benefitting from the process. Since caregivers in institutions have total responsibility for individuals' well-being, it was expected that Rosewood proxies would rate quality of life higher than would community proxies who are likely to have responsibilities for only a part of a person's well-being.

Project Description

Sample

The project was designed to conduct Ask Me! Interviews with all individuals leaving Rosewood and moving to the community under the Money Follows the Person grant. Rosewood staff provided a list of 135 people residing in Rosewood in August 2008 that became the baseline sample frame. The DDA files of July 1, 2008, identified 45 people receiving services at

Rosewood who were not on the Rosewood staff list and this study assumed they had previously left Rosewood. The DDA files had records for 17 people identified as receiving services from community agencies rather than Rosewood. The DDA files had no records for 21 people on the Rosewood staff list, so age and disability characteristics for these are missing. (See **Figure 1.**) The initial plans were for interviews to be conducted with all the people at Rosewood prior to their leaving the facility. However, over half (71) of those on the Rosewood list had already left Rosewood before interviews began in October 2008. Two individuals refused and one was incarcerated. Regular Ask Me! interviewers (who have disabilities themselves) conducted interviews with the remaining 61 individuals or their proxies. Follow-up interviews began two years later in August 2010. By this time, ten individuals with baseline interviews had died, two were too ill during the fieldwork period, five refused or their guardians refused, and three could not be located, one had a non-responsive agency, and a follow-up interview could not be scheduled with one who was working. Regular Ask Me! interviewers conducted follow-up interviews with or for 39 individuals. All of the follow-up refusals were from or for people who had responded for themselves on the baseline survey. All twelve of the people who had died or were hospitalized by the time of the follow-up had proxy responses on the baseline survey. They were significantly more likely to have disabilities other than intellectual, and had significantly higher Social Inclusion reported by their Rosewood proxies than those who remained healthy.

Rosewood list and DDA file as Rosewood services	97	
Rosewood list and DDA file as other providers	17	
Rosewood list and not on DDA file	<u>21</u>	
Rosewood baseline sample frame		135
Moved prior to interview	71	
Refused, not available	<u>3</u>	
Baseline interviews completed		61
Died before follow-up	10	
Ill during fieldwork	2	
Refused follow-up	5	
Could not find or schedule	<u>5</u>	
Follow-up interviews completed		39

Figure 1. Number of People on Lists and with Surveys

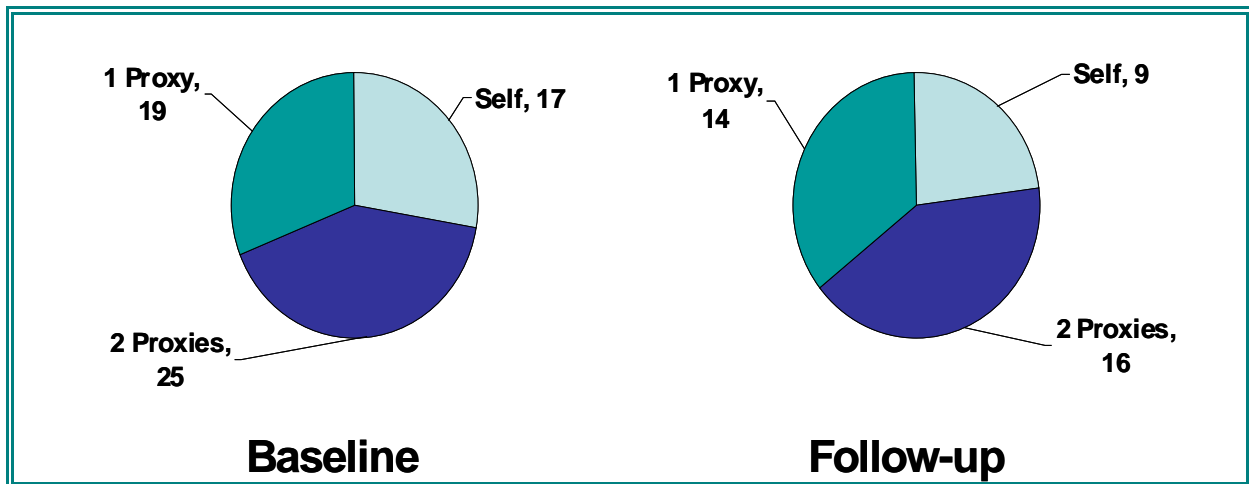


Figure 2. Number of Respondents by Type on the Baseline and Follow-up Interviews

Of the 61 individuals with baseline survey data, 17 (28%) responded for themselves, 25 (41%) had two proxies respond for them (both residential staff), and 19 (31%) had only one residential staff knowledgeable enough to respond as a proxy for them. (See **Figure 2.**) On the follow-up survey, 9 individuals (23%) responded for themselves, with eight of them also having responded for themselves on the baseline interview. Sixteen (41%) had two proxies respond for them, six with a family and a day member staff, nine with a residential and a day staff member, and one with two residential staff members. Fourteen (36%) had one proxy respond for them, with thirteen being day staff and one being a residential staff member.

Survey Procedures

The DDA files identified gender, birth dates, and up to 21 disability classifications. Age was calculated for this report by subtracting the date of birth from July 1, 2008, and truncating to a whole number. Gender could generally be determined by name for those on the staff-provided list and not on the DDA files. Dates of birth and types of disabilities were not available for them.

The project utilized the FY2002-09 *Ask Me! Survey*, but omitted the transportation questions. Due to the unique situation that presented itself with individuals moving to the community, the project replaced the transportation availability questions with additional questions on social networks (Q50-Q53), personal development (Q54, Q55, Q58), and community participation (Q56, Q57). (See **Appendix C.**) The *Ask Me!* coordinator asked one additional question after the peer interviewers had completed the follow-up survey: “Do you have comments about life in Rosewood compared to life in the community?” She recorded the answers as close to verbatim as possible. Except for this last question on the follow-up, the questions followed the same format as the rest of the *Ask Me! Survey*. The *Ask Me! Survey* measures eight quality of life domains, using six indicator questions for each. Respondents can give one of three answers to each question. The first listed answer is favorable (“yes,” “a lot,” “very happy,” “most times,” etc.), and is keyed as 1. The second listed answer is neutral (“sometimes,” “a little,” “OK,” etc.), and is keyed as 2. The third listed answer is unfavorable (“no,” “none,” “not happy,” “no times,” etc.), and is keyed as 3. When a person answers four or more of the six indicator questions for a quality of life domain, a scale score is calculated as $15 - (5 * \text{average keyed value})$. Thus the scale score would be 0 if the person gave unfavorable responses (3) to all the questions in the scale, 10 if the person gave favorable responses (1) to all questions, and 5 if the person gave neutral responses (2) to all questions, or an equal number of favorable and unfavorable responses. The scales in the FY2008 *Ask Me! Survey* had Cronbach Alphas that ranged from 0.57 to 0.69, a range that is considered reasonably reliable.

The additional questions for the Rosewood Movers followed the 48 indicator questions so they would not influence answers to the standard questions. The new questions could be combined into a single scale with a fairly good fit (Cronbach alpha = 0.67). However, no scale was constructed as factor analysis suggested there were three underlying components related to outside interest (Q50, Q51, Q54, Q55), control (Q51, Q52, Q56 and Q58) and trust (Q53 and

Q57). One question loaded on both the first two factors, and two questions had inverse loadings on the third factor.

Ask Me! interviewers have a standard protocol of six questions to obtain informed consent from people to be interviewed. When the two-person interviewing team determines that a person does not understand enough to give informed consent, they interview proxies instead of continuing the interview. The first proxy interviewed is generally the staff who brought the person to the interview location and knows the person well. The usual process is to interview a second proxy who knows the person well, but in a different setting. Rosewood residents often had only residential staff that knew them well enough to try to answer the questions for them. Residents in the community had a wider range of staff and family who could respond for them. When a second proxy could be interviewed, Ask Me! procedures average the responses of the two proxies to provide the best estimate of what the person would have said if she or he could have responded. Otherwise, the responses of the single proxy were used no better information was available.

The study originally planned to conduct follow-up interviews one and two years after the people moved out of Rosewood and into the community. DDA did not fund the follow-up study until the second year.

Demographic Characteristics

The Rosewood movers interviewed in FY2011 two years after they left Rosewood had similar characteristics to the Rosewood residents interviewed in FY2009, and the residents interviewed during FY2009 fairly well represented all the people who remained at Rosewood at the beginning of FY2009. Rosewood residents in FY2009 differed in many ways from the people with intellectual and developmental disabilities already in the community who were interviewed in the FY2009 Maryland *Ask Me! Survey*. (See **Figure 3**.)

About one-fourth (28%) of the people living in Rosewood at the start of the study had guardians, but only 6% of the people that were interviewed for the baseline survey and 3% of those interviewed in the two-year follow-up survey had guardians. The Ask Me! procedures require agencies to obtain permission from guardians before people are interviewed, although it does not record in the datafile who had guardians. This discrepancy suggests that guardians were generally unwilling to let people participated in the study, or Rosewood staff did not want to ask guardians to give permission since many guardians had organized to prevent Rosewood from closing. The findings of this study, therefore, may not represent what happened to people with guardians after they left Rosewood.

Peer interviewers determined that about the same percent of the people could respond for themselves in both the baseline interviews (28%) and follow-up interviews (23%). This was substantially lower than among those already living in the community where 76% in FY2009 responded for themselves.

Rosewood Movers had different characteristics from people who were already supported in the community. While 54% of those supported in the community and interviewed as part of the FY2009 *Ask Me! Survey* were men, 71% of the people living in Rosewood at the start of FY2009 were men. Men participated less in the study than women, so the gender distribution of people interviewed in two years after they moved more closely resembles the gender distribution of those already living in the community in FY2009 than those living in Rosewood at the start of FY2009.

Two-fifths (41%) of those already in the community in FY2009 were less than 35 years of age, compared with 9% of those living in Rosewood, and 5% of those interviewed two years after leaving Rosewood. At the other end of the age distribution, only 4% of the people living in the community in FY2009 were 65 years and older, compared to 14% or Rosewood residents at that time, and 26% of the people interviewed two years after leaving Rosewood. Therefore, the findings from this follow-up study may represent older movers from institutional more than middle age movers.

The DDA file identifies categories of disabilities. Some Rosewood residents at the beginning of FY2009 had no recorded disabilities while others had six listed. Most had 1-3 disability categories indicated. Rosewood residents were substantially less likely than those living in the community to have intellectual disabilities(50% vs. 83%), speech and language impairments (5%

<i>FY2009 Characteristic</i>	<i>Rosewood</i>			<i>Community Survey</i>
	<i>Followup</i>	<i>Baseline</i>	<i>All</i>	
Total number	(39)	(61)	(135)	(1292)
Total percent	100%	100%	100%	100%
<i>Guardian</i>				
Yes	3%	6%	46%	--
No	97%	94%	54%	--
<i>Respondent</i>				
Self	23%	28%	--	76%
Proxy	77%	72%	--	24%
<i>Gender</i>				
Male	59%	62%	71%	54%
Female	41%	38%	29%	46%
<i>Age</i>				
<35 years	5%	3%	9%	41%
35-44 years	8%	9%	10%	25%
45-54 years	24%	37%	33%	21%
55-64	37%	34%	34%	9%
65+ years	26%	17%	14%	4%
<i>Disabilities (multiple)</i>				
Intellectual disability	61%	51%	50%	83%
Deaf, hearing	47%	55%	55%	6%
Epilepsy, seizures	34%	29%	27%	20%
Orthopedic	16%	20%	16%	13%
Cerebral Palsy	8%	6%	4%	11%
Mental disorder	8%	4%	7%	7%
Chemical Depend	5%	16%	16%	--
Blind, vision	5%	11%	5%	7%
Speech, language	5%	4%	5%	28%
Specific learning	5%	2%	2%	16%
Behavior problems	3%	2%	4%	15%
Autism	3%	2%	1%	5%

Figure 3. Characteristics of People with Interviews

vs. 28%), specific learning disabilities (2% vs. 16%) and behavior problems (4% vs 15%). Rosewood residents were more likely than those already in the community to have hearing disabilities (55% vs. 6%) and chemical dependencies (20% vs. so few in the community that this disability is not tracked for the community survey). The disability characteristics of the people interviewed two years after leaving Rosewood are fairly similar to the characteristics of all the Rosewood residents at the beginning of FY2009. The greatest difference related to intellectual disabilities. Only 3% of Rosewood residents with DDA records showing intellectual disabilities died or were hospitalized within two years after leaving Rosewood compared to 35% of those with no indication of intellectual disability in the DDA record. Although the people responding to the baseline survey reflected almost the same percentages with hearing impairments, epilepsy/seizures, and chemical dependency as all Rosewood residents, those with hearing impairments and chemical dependence were more likely to die or be hospitalized during the following two years than those without these disabilities, while those with epilepsy and seizures were less likely than others to die or be hospitalized. Thus Rosewood residents with these disabilities were also more or less represented among those with two-year follow-up interviews than Rosewood residents without them.

The DDA files in July 2011, prior to the start of the follow-up survey, identified residential placements for 34 of the 39 people interviewed in the follow-up. Chimes provided residential services to nine movers and Lifeline provided residential services to five. (See **Figure 4.**) Three agencies provided residential services to three individuals interviewed in the follow-up survey and two agencies provided them two individuals. Emerge provided services to two additional individuals who did not receive residential services. Ten agencies had one person interviewed. The DDA files listed Chimes as providing residential services for three people about whom Chimes reported no knowledge. ACCFX Gallagher, The Arc Baltimore, Emerge and Quantum Leap provided services for people who refused follow-up interviews. Interviews could not be scheduled with people supported by The Arc Baltimore or Rock Creek Foundation. The DDA closed Lifeline before second proxies could be interviewed.

<i>Agency</i>	<i># Interviewed</i>
Total	39
Chimes Inc	9
Lifeline LLC	5
Arc Baltimore	3
Arc Central Chesapeake	3
Progress Unlimited	3
ACCFX Gallagher	2
Emerge	2+2*
Arc Howard Co	1
Bello Machre	1
JAPEC Residential Programs	1
Life	1
Mid Atlantic Human Ser Corp	1
Quantum Leap	1
NCIA CBAI	1
Arc of Southern Maryland	1*
Fidelity Resources	1*
Medsource	1*
* Other than residential services	

Figure 4. Number of Follow-up Interviews by Residential Agency

Timing of Interviews

Baseline interviews were conducted during a seven-month period between October 2008 through April 2009. Follow-up interviews were conducted August 2010 through May 2011. Interviewers conducted follow-up interviews an average of 24.8 months after the baseline interview. The

interval between interviews was as short as 19 months and as long as 30 months. (See **Figure 5**.) Although baseline interviews were scheduled as soon as individuals were identified for transfer, the actual move date may have been sometime later. Close to half (44%) of the plans for services in the community were prepared a month or more after the baseline interview. Assuming the date of these plans reflected the earliest date that the person could have moved into the community, one person had lived in the community less than 16 months before the follow-up interview.

Total	39
19-20 months	3
21-22 months	6
23-24 months	13
25-26 months	12
27-30 months	5

Figure 5. Months Between Baseline and Follow-up Interviews

Statistical Difference

Analysis used SPSS (Statistical Package for the Social Sciences). Statistical differences between self respondents and proxies tested two independent samples with a probability of error of 0.05 of the hypothesis that they were different without specifying the direction (two-tail). Tests between FY2009 Rosewood (baseline) respondents and FY2009 Ask Me! respondents already in the community, tested two independent samples with a probability of error of 0.05 of the hypothesis that they had a lower quality of life (one-tail). Statistical differences between baseline and follow-up responses for self respondents at both times tested the hypothesis that quality increased using paired samples with a probability of error of 0.05 (one-tail). Statistical differences between baseline and follow-up proxy responses tested the hypothesis that Rosewood proxies reported higher quality of life than community proxies using paired samples with a probability of error of 0.05 (one-tail).

Quality of Life in Rosewood

The *Ask Me! Survey* measures quality of life in eight domains that research has shown to be important nationally and internationally in fields of intellectual and developmental disabilities, health, mental health, aging, and education. Each domain is measured by six indicator questions that comprise a scale that can vary from zero (0, negative) through five (5, neutral) to ten (10, positive). Findings from the FY2009 *Ask Me! Survey* of the quality of life of people living in the community provides a comparison with the quality of life of people at Rosewood prior to moving into the community. The FY2009 *Ask Me! Survey* found that self respondents and proxy respondents report differently. It was expected that interviews at Rosewood prior to moving would show similar differences between self and proxy respondents and would need to be controlled in comparison with people already in the community.

Self and Proxy Differences

Hypothesis 1—Self respondents report different levels of quality of life than proxies report for people unable to respond for themselves.

Rosewood residential staff proxies reported significantly higher levels of Physical Well-being than self respondents reported (9.1 vs. 8.1, $t[19]=2.07$, $p=.05$) and significantly lower levels of

Self Determination (4.6 vs. 6.7, $t[35]=3.68, p=.01$) and Rights (4.9 vs. 6.3, $t[23]=2.22, p=.04$). (See **Figure 6**.) Proxies also reported higher levels of Emotional Well-being, Interpersonal Relations and Social Inclusion than self-respondents reported, and lower levels of Material Well-being and Personal Development,

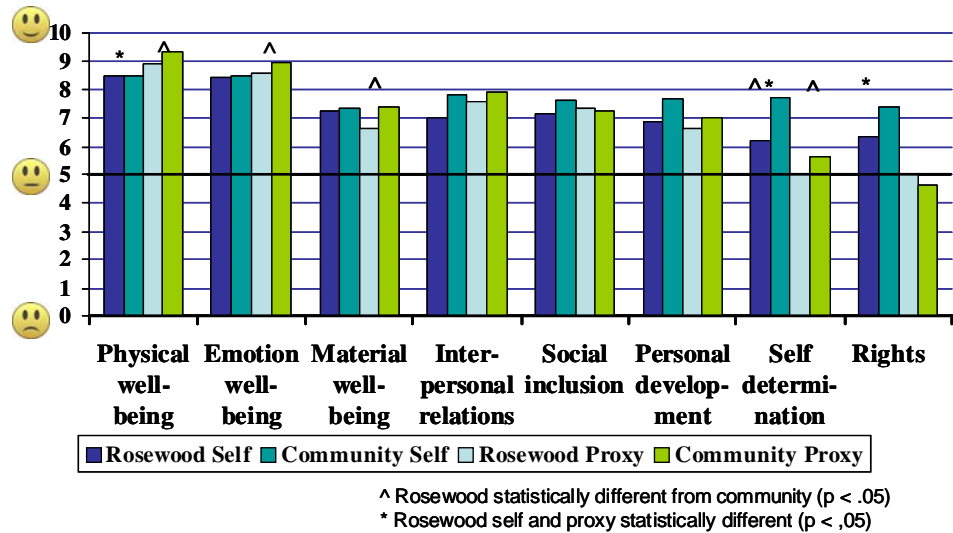


Figure 6. Quality of Life in Rosewood and Community by Respondent

although these differences were not statistically significant. It is hard to understand why people who cannot understand and respond to questions should have higher Physical Well-being than people who can understand and respond to questions for themselves. It is more reasonable to suggest that Rosewood staff believed, and therefore reported, that the individuals they supported were physically well off, since that was one of their primary responsibilities, and probably the most visible. It is reasonable to suppose that people who can understand and respond to questions can be given more choices and afforded more rights than those who do not have the ability to understand and respond. However, proxy perceptions and expectations may still be involved in these domains.

Rosewood self respondent gave significantly more favorable responses than proxies on 10 of the 48 quality of life questions. Almost all (93%) of self respondents said that their work, or what they do each day, made them feel important, while proxies for only half (50%) gave this favorable response. (See **Figure 7**.) Perhaps closely related, 82% of self respondents said they had the opportunity of earning good money, compared with

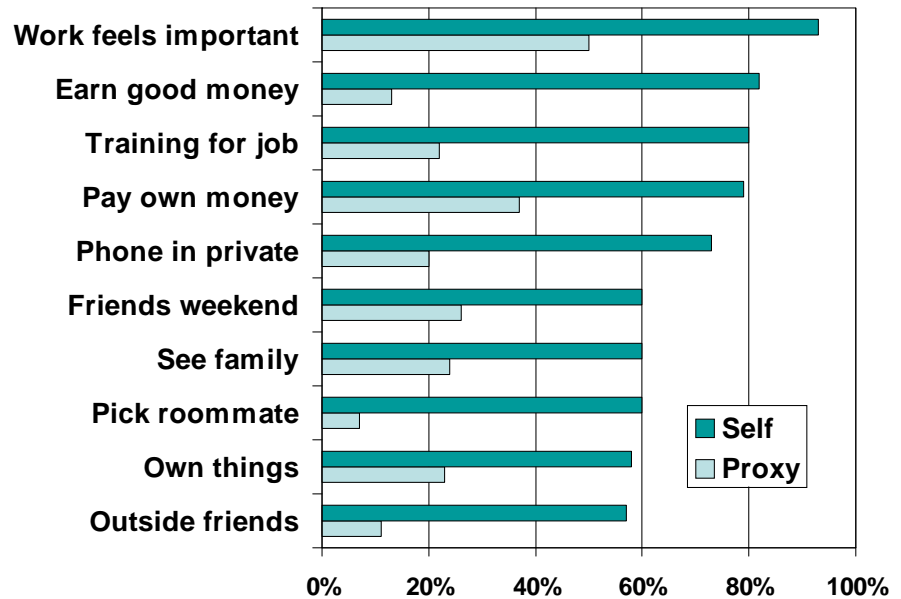


Figure 7. Questions with Baseline Self More Favorable than Proxies

only 13% of the people for whom proxies responded. Most of these questions are affected by intellectual ability and the ability to communicate, so it is expected that self-respondents would answer more favorably. (Favorable responses to all the questions are shown in **Appendix A.**)

Rosewood self respondents gave less favorable responses than proxies gave on 4 of the 48 questions. (See **Figure 8.**) Almost all the proxies (98%) said the person received all the services they needed, while only 64% of self-respondents said they did. Most of the proxies (93%) said that they and others had the right

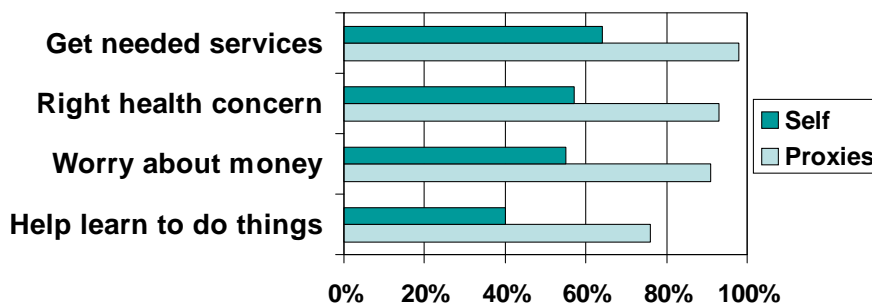


Figure 8. Questions with Baseline Self Less Favorable than Proxies

amount of concern for the person’s health. Only 57% of self-respondents gave this favorable response, with 14% feeling people were too concerned, and 29% feeling that others did not care about their health. Residential staff proxies were also more likely than self-respondents to say that people were not worried about money and that people help them learn to do things for themselves. It is unlikely that intellectual and communication ability should interfere with such things as getting the services they need, and with other people helping them learn to do things for themselves. It therefore seems reasonable to assume that staff proxies do not know how the people with difficulty understanding and communicating truly feel, and/or their perspective differs from the perspective of the people they are supporting.

The survey for Rosewood movers included nine questions not included in the Maryland Ask Me! Survey. Self respondents answered more favorably than proxies to the question about visiting their families as much as they liked (64% vs. 20%). Self respondents answered less favorably than proxies to the question about trusting the people around them (46% vs. 98%). Self and proxy responses to the other seven questions did differ statistically.

Rosewood and Community Differences

Hypothesis 2—The quality of life in Rosewood is lower than that in the community, whether reported by individuals for themselves or by proxies for them.

Self-respondents living in Rosewood reported significantly lower Self Determination than did self-respondents living in the community (6.20 vs. 7.75, $t[952]=2.142$, $p=.02$, equal variances). (Refer back to **Figure 6.**) They reported somewhat lower quality of life in all the other domains, although the small number of Rosewood self respondents kept these differences from being statistically significant.

Proxies for people scheduled to move from Rosewood reported significantly lower quality of life than proxies for people already in the community in four of the eight domains: Physical Well-

being (8.92 vs. 9.34, $t[59]=2.31$, $p=.01$), Emotional Well-being (8.57 vs. 8.99, $t[60]=1.86$, $p=.03$), Material Well-being (6.61 vs. 7.38, $t[60]=2.23$, $p=.01$) and Self-Determination (5.00 vs. 5.64, $t[272]=1.76$, $p=.04$, equal variances). Rosewood staff reported about the same quality of life as community proxies reported in the other four domains.

Self respondents living in Rosewood gave significantly less favorable responses on the baseline survey than self respondents already living in the community to 8 of the 48 questions, three of them in the domain of Self Determination. They gave significantly more favorable responses to two questions. Rosewood proxies gave significantly less favorable responses than community proxies to 13 questions, and significantly more favorable responses to 7 questions.

Change in Quality of Life

The Ask Me! interviewers generally made the same determination at follow-up interviews of who can respond for themselves as they made at the baseline interviews. Eight people responded for themselves in both interviews and 27 needed proxies to respond for them on both interviews. Three people responded for themselves in the baseline interviews and had proxies respond for them in the follow-up interviews. One person had proxy responses at baseline and self response at the follow-up. Self and proxy response for the same individuals might provide useful insight if the data were complete, but much of the data were missing for one of the interviews.

Self Respondents

Hypothesis 3—Self-reported quality of life will show consistency over the two years and be higher after the move to the community than before in the institution.

Eight individuals responded to the survey for themselves while living in Rosewood and about two years after moving into the community. These eight reported statistically significant increases in the quality of life in the domain of Rights from 6.1 to 8.6 ($t[6]=2.12$, $p=.04$). (See **Figure 9**.) Their quality of life also appeared to increase in Self Determination,

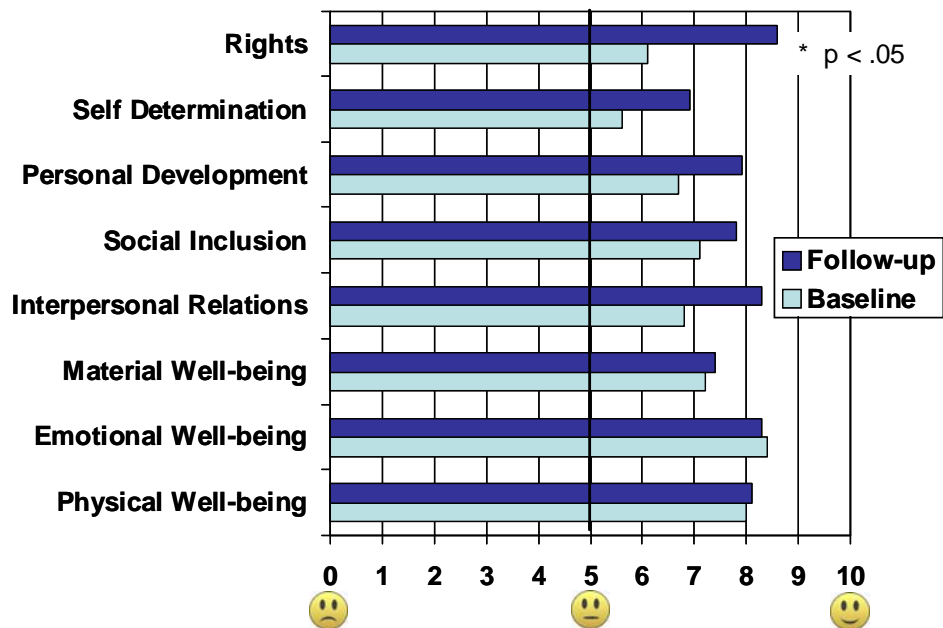


Figure 9. Self Reported Pre- and Post-Move Quality of Life

Personal Development, Social Inclusion, and Interpersonal Relations, although the increases did not meet statistical significance due to the small number of self-respondents. Very little change appeared to occur in the domains of Material Well-being, Emotional Well-being and Physical Well-being. Self respondents were relatively consistent in their reporting of quality of life before and after moving from Rosewood, i.e., those who reported higher quality of life before moving also reported higher quality of life after moving. The correlations were positive and statistically significant for Rights (0.80, $p=.03$), Social Inclusion (0.77, $p=.04$), and Physical Well-being (0.94, $p<.01$). They were also positive, although not statistically significant for Interpersonal Relations (0.43), Material Well-being (0.53), and Emotional Well-being (0.40). Only in Self Determination (-0.12) and Personal Development (-0.14) were the correlations negative.

Proxy Responses

Hypothesis 4—Proxy-reported quality of life after the move has no relationship to that reported before the move, but will be lower overall due to less proxy bias.

Community proxies reported significantly lower quality of life in Rights (2.7 vs. 4.5, $t[21]=2.75$, $p=.01$), Social Inclusion (6.1 vs.7.2, $t[23]=1.95$, $p=.03$), and Interpersonal Relations (6.7 vs. 7.9, $t[24]=2.58$, $p=.01$) for former Rosewood residents than did Rosewood staff proxies at the time of the baseline survey. (See **Figure 10**.)

They reported about the same average

quality of life in the other five domains. Community proxies reported higher Material Well-being for individuals who Rosewood proxies had earlier reported with lower Material Well-being, and lower Material Well-being when Rosewood proxies had earlier reported high Material Well-being (correlation = -.41, $p=.05$). A negative correlation between community and Rosewood proxies on Social Inclusion approached statistical significance (correlation = .32, $p=.07$). Otherwise, the reports of community proxies had no relationship with the reports of Rosewood proxies (-0.15 to 0.14).

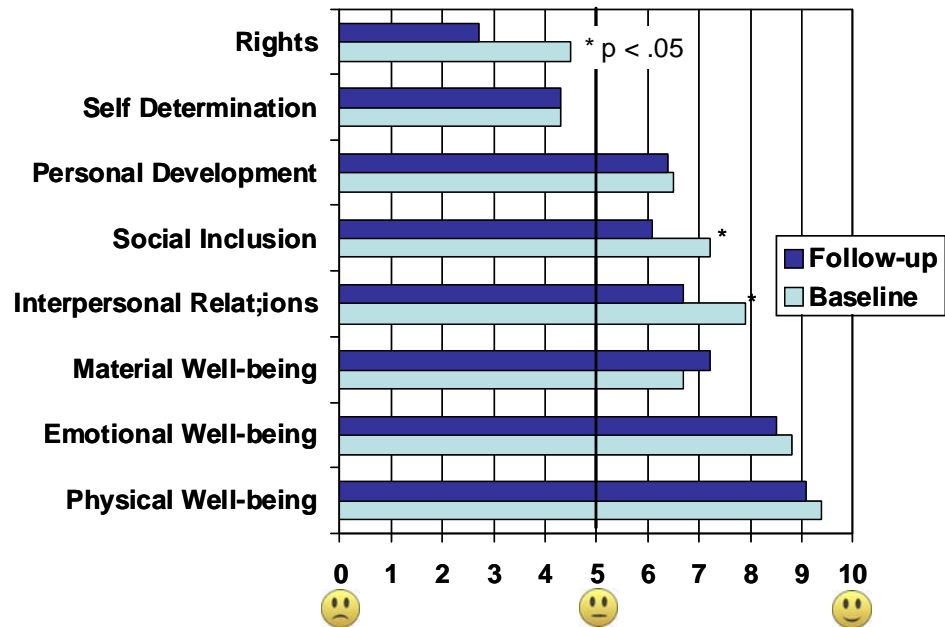


Figure 10. Proxy Reported Pre- and Post-Move Quality of Life

Expressed Change

After the interviewers had completed all the questions that were in the baseline survey, the interviewer coordinator on the follow-up survey asked the respondents for comments about life in Rosewood compared to life in the community. The coordinator recorded verbatim the comments from 6 of the 9 self respondents and from the proxies for 22 of 30 people who could not respond for themselves. Most of the proxies that did not provide a response said they did not know the person prior to leaving Rosewood. The proxies who provided comments may not have known the individual prior to leaving Rosewood, but felt they could report how the individuals had changed since they first came to the agency from Rosewood, or merely described the individuals' present situation, assuming it was better than at Rosewood.

All six of the self respondents expressed that they liked living in the community better than in Rosewood:

- “He says he loves to go to the YMCA and go swim. He says he is happy.”
- “Better in community; gets out everyday/weekend. Sleeps in own bed. Girlfriend can stay over on weekend.”
- “I like to help people out and stay out of trouble. Everyone should be brothers and sisters.”
- “I love being in the community. It's quiet and no one bothers me.”
- “It's better out here. I get to do more stuff and get to go to work. I like being out in the community.”
- “My home is better than Rosewood. I have my own room, clothes, furniture. I help pay for my food. I am looking for a job.”

Proxies for 20 of the 22 individuals who could not respond for themselves said that the person was better off in the community than in Rosewood, although two of them said the person either had a difficult time in the initial adjustment or was currently having physical problems. Proxies for the other two said they saw no change.

Specific comments said that the physical or psychological behavior of nine of the Rosewood movers had improved in the community setting (e.g., hygiene, eating,

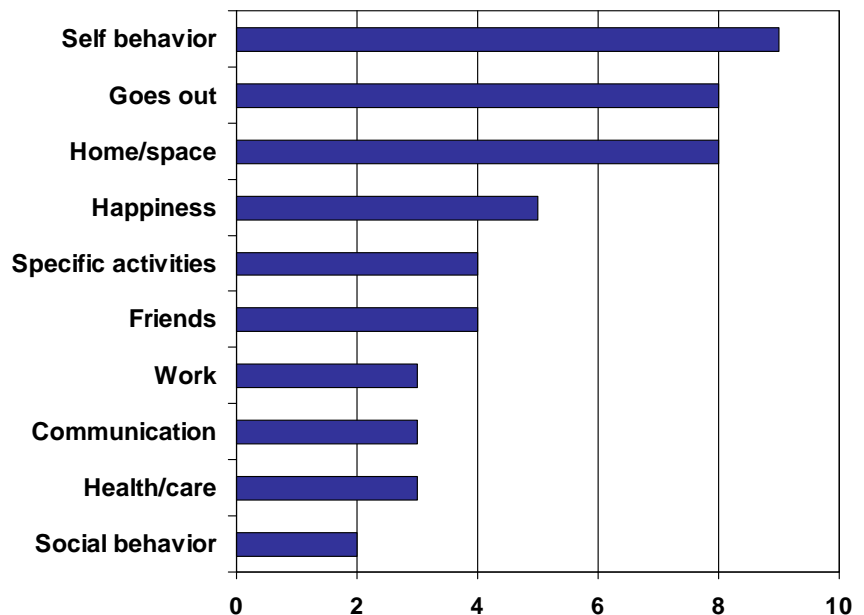


Figure 11. Number of People by How Community Life is Better than Rosewood Life

patience and crying). (See **Figure 11.**) Eight comments specifically mentioned going out into the community and eight mentioned liking their home, room or own space. Seven comments specifically included the words “happy” or “happier.” Four comments included specific activities like swimming or working puzzles, and four mentioned friends. Three mentioned being able to work, going to work more regularly, or planning to work. Three comments indicate improved communication ability and three indicated improved health and health care. Two comments mentioned improved social behavior. (See **Appendix B** for verbatim comments.)

Discussion

The State of Maryland operated four institutions in July 2008 for people with intellectual and other developmental disabilities. Advocates, particularly self advocates who had once been lived there, mounted an aggressive campaign to have Rosewood, the largest of the four, closed. The governor made the decision to permanently close the facility by June 30, 2009. Family members of residents, Rosewood staff, and the surrounding community uncertain about future use of the property opposed the closure, arguing that the residents were too medically fragile or had criminal backgrounds that prevented community placement. Half of the people remaining at Rosewood for its final year had guardians, half were above 55 years of age, half had hearing impairments and one-fifth had chemical dependency compared to one-eighth or less of those already living in the community. The Maryland Developmental Disabilities Administration (DDA) authorized the current study to evaluate the effect the move would have on the quality of life of the individuals.

The actual closing of Rosewood occurred rapidly, and only half of the residents could be interviewed, or have proxy interviews conducted for them, with the slightly modified *Ask Me! Survey* before they left. Staff was busy with the transition, the Ask Me! interviews were not a priority for them, and the first interview could not be arranged until October 2008. Many of the staff were not aware that interviews were taking place, nor the purpose of the interviews. It is also not clear how well the staff helping with the transition knew the people for whom they provided proxy information, as only one proxy could be interviewed for two-fifths of those who could not respond for themselves. However, pre-move quality of life information was collected for 61 individuals scheduled to leave Rosewood Center during FY2009. One-third of the individuals responded for themselves in the baseline survey and two-thirds had Rosewood residential staff responded for them. Those with baseline data had about the same characteristics as those who had already been transferred by the time interviews began. The study then conducted interviews with two-thirds (39) of the individuals or their proxies two years after they moved into the community. Half of the remainder had died or were in the hospital, one-quarter refused, and the other one-quarter could not be found or contacted. The characteristics of those with follow-up interviews reflected the characteristics of all those with baseline interviews.

This study of Rosewood movers used the same Ask Me! Survey instrument and procedures that had been used to measure the quality of life of all adults with intellectual and other developmental disabilities supported in the community through funds from DDA. This allows

initial comparisons between the quality of life of the surveyed residents of the institution and those already in the community as well as before and after comparison of those moving. The arguments against closing Rosewood suggest that the last residents of the institution have more severe disabilities than those in the community, and might suggest that they would have poorer quality of life. However, quality of life involves subjective as well as objective aspects, and it is unclear how people within institutions think about their lives. In addition, people who respond for themselves report differently than proxies report for them. Proxies cannot know for sure another person's subjective feelings, especially when the person is unable to understand and respond to questions. Proxies therefore provide their subjective views that tend to be biased in the areas for which they have responsibilities. As expected, the baseline Rosewood survey found substantial differences between self respondents and proxy respondents, similar to the differences found in the community. Therefore, this report analyzed self response and proxy response independently.

Self respondents to the Rosewood baseline interviews reported significantly lower Physical Well-being and higher Self Determination and Rights than proxies reported, the same as found in the regular Ask Me! interviews the same year. On the extra questions asked only for Rosewood interviews, self respondents gave significantly less favorable answers than Rosewood staff proxies to questions about getting needed services, the amount of attention given to their health, and help in learning to do things for themselves. Physical well-being, health, services and help in learning are all areas in which Rosewood residential staff has substantial responsibility, and thus would be expected to have a favorable bias, whether conscious or unconscious. People who can understand and respond for themselves can be expected to have more Self Determination and be afforded more Rights than those without this ability, so it is not clear the direction or magnitude of bias that accompanies proxy reporting in these domains.

The hypothesis that Rosewood residents had lower quality of life than those in the community is supported by both self respondents and proxies. Self respondents in the Rosewood baseline survey reported significantly lower Self Determination than self respondents already living in the community, and reported slightly lower quality of life in the other seven domains that were not statistically significant. Proxies in the Rosewood baseline survey also reported significantly lower Self Determination, Physical Well-being, Emotional Well-being, and Material Well-being than proxies in the community reported. They reported slightly lower qualities of life in two additional domains, but slightly higher qualities of life in two domains.

The best understanding of the effect of moving from Rosewood to the community came from the eight people able to respond for themselves in both before and after interviews. It was hypothesized that they would report higher quality of life two years after the move than they had at Rosewood. However, with such a small number, changes had to be large in order to have confidence that they could not have occurred by chance. Self respondents reported significantly greater Rights in the community than in Rosewood and slightly higher quality of life in six other domains. Only the domain of Emotional Well-being gave even a hint of decreased quality of life. All of their comments recorded at the end of the interview indicated that they liked living in the community better than in Rosewood.

Proxies provided baseline and follow-up information on what they thought 24 people would say if they were able to respond for themselves. All the proxies for the baseline survey were Rosewood residential staff, and often knew very little about the individuals since staff and residents were being reassigned as cottages closed and vacancies in open cottages occurred. Only two residential staff provided proxy information for the follow-up survey, and these worked for the community agencies responsible for some of the services required by the individual. It was hypothesized that follow-up proxy responses would have little relationship to baseline proxy responses since they were both different people and had different relationships to the people for whom they were reporting. It was further hypothesized that follow-up proxies would report lower quality of life than baseline proxies, not because the quality of life had actually decreased but because they would insert less favorable bias because they knew the person better and had more limited responsibility for the person's quality of life. The significant negative correlation between baseline and follow-up for proxy reporting of Material Well-being, and the almost significant negative correlation for Social Inclusion, support the hypothesis. The ones Rosewood residential staff reported as having the greatest Material Well-being and Social Inclusion were the ones families and community day staff reported as having the least Material Well-being and Social Inclusion. All of the other correlations were small, centered around zero, or no relationship. The rest of the hypothesis is also supported. Community proxies reported significantly lower levels of Rights and Interpersonal Relations than Rosewood proxies reported, and slightly lower quality of life in five of the other six domains. The slightly higher Material Well-being reported by community proxies than Rosewood proxies may have been related to Money Follows the Person funds supporting the people in the community. The finding that self respondents reported significant improvement in their Rights after moving into the community, while community proxies reported significantly lower Rights than Rosewood proxies reported, suggests that Rights of the people they supported was the domain in which Rosewood staff most viewed through rose-colored glasses. Almost all community proxies commented at the end of the interviews that the person was better off in the community than in the institution.

This study supports the position of closure advocates that living in the community supports higher quality of life than living in an institution, even an institution with fewer than 150 residents. It also supports an argument that opponents of closure have overly optimistic views of the quality of life available to the residents of institutions. However, the closure of the community agency which took the second greatest number of Rosewood movers in the study, suggests that not all community agencies may be able to provide the services needed by the individuals leaving institutions.

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Appendix

Appendix A. Response to Individual Questions

Appendix Table A1. Percent Giving the Favorable Response by Question and Respondent								
Question	All Rosewood Baseline		With 2-Year Follow-up				FY2009 Ask Me!	
	Self	Proxy	Self both		Proxy both		Self	Proxy
			Base	Follow	Base	Follow		
(Number of people surveyed)	(17)	(52)	(8)	(8)	(24)	(24)	(1043)	(245)
<i>Emotional Well-Being (Average QOL)</i>	<i>(8.0)</i>	<i>(8.6[^])</i>	<i>(8.4)</i>	<i>(8.3)</i>	<i>(8.8)</i>	<i>(8.5)</i>	<i>(8.5)</i>	<i>(9.0)</i>
Q1 Would you say that you are a happy person?	69	62	75	44	63	44	83	72
Q2 How do you feel about your home where you live?	56	59 [^]	75	50	54	64	73	73
Q4 How safe do you feel in your neighborhood?	81	91	100	75	96	96	77	92
Q5 Do you like yourself?	81	84	75	88	85	54 ⁺	82	85
Q6 Feel others treat you the same as any other person?	44 [^]	73	50	83	70	68	67	65
Q7 In general, how happy are you with your life?	80	55	75	100 [*]	58	54	77	67
<i>Social Inclusion (Average QOL)</i>	<i>(7.1)</i>	<i>(7.3)</i>	<i>(7.1)</i>	<i>(7.8)</i>	<i>(7.2)</i>	<i>(6.1⁺)</i>	<i>(7.7)</i>	<i>(7.3)</i>
Q8 Do people help you to be part of your community?	60	82 [^]	75	83	77	60	75	71
Q9 Do you go to fun things in your community?	53	76 [^]	50	71	78	52 ⁺	70	63
Q10 When you do to fun things, are you active?	67	49	75	100 [*]	41	24	75	42
Q11 Do you think your neighbors like you?	57	47	63	83 [*]	44	0	75	56
Q12 Friends from places other than work or home?	57 [*]	11 [^]	50	50	7	13	56	23
Q13 How often do you see these friends on weekends?	60 [*]	26	50	29	28	0	39	20
<i>Interpersonal Relations (Average QOL)</i>	<i>(6.8)</i>	<i>(7.6)</i>	<i>(6.8)</i>	<i>(8.3)</i>	<i>(7.9)</i>	<i>(6.7⁺)</i>	<i>(7.9)</i>	<i>(7.9)</i>
Q14 People help you learn to do things for yourself?	40 ^{*^}	76 [^]	38	29	74	46 ⁺	62	58
Q15 When you make a mistake, do people help you?	73	96	88	100 [*]	96	75 ⁺	78	91
Q16 Do people help you reach your goals?	73	51 [^]	88	86	81	80	77	80
Q17 How often do you see or talk with your family?	60 [*]	24 [^]	50	86 [*]	22	14	67	48
Q18 How many close friends do you have?	40	21	50	60 [*]	19	18	51	18
Q19 Does what you do let you look good to others?	53	56	50	67	59	35	73	59

Appendix Table A1. Percent Giving the Favorable Response by Question and Respondent

Question	All Rosewood Baseline		With 2-Year Follow-up				FY2009 Ask Me!	
	Self	Proxy	Self both		Proxy both		Self	Proxy
			Base	Follow	Base	Follow		
<i>Personal Development (Average QOL)</i>	(7.3)	(6.7)	(6.7)	(7.9)	(6.5)	(6.4)	(7.8)	(7.0)
Q20 Does what you make you feel important?	93*^	50	88*	57	46	50	78	58
Q21 Are you getting training to help you get a job?	80*	22	88*	57*	15	10	66	24
Q22 Others give you a chance to be what you want?	64	57	63	67	58	43	70	61
Q23 Learning things to make you a better person?	64	61	50	57	56	75	80	69
Q24 Get the information you need about sexuality?	29	10	38	61*	8	11	49	13
Q25 Do you get the services you need?	64*	98^	63	71	100	96	77	89
<i>Self-Determination (Average QOL)</i>	(6.6*)	(5.0^)	(5.6)	(6.9)	(4.3)	(4.3)	(7.7)	(5.6)
Q26 Did you pick who you live with?	60*	7^	63*	57	4	21	70	25
Q27 Can you be alone when you want to?	73	60^	50	17	56	26+	72	28
Q28 How much choice do you have in your food?	40^	16^	50	33	15	2	62	28
Q29 Do you get a chance to say what you think?	43^	29^	38	83*+	21	19	65	49
Q30 Do you pay for things with your own money?	79*	37	88*	83*	39	33	81	49
Q31 Choose your job or what you do most days?	43^	17^	57	71*	12	9	70	37
<i>Physical Well-Being (Average QOL)</i>	(8.1*)	(8.9^)	(8.0)	(8.1)	(9.4)	(9.4)	(8.6)	(9.3)
Q32 On your health are people concerned?	57*^	93	57	27	92	92	83	90
Q33 Is your health good?	86	58^	86	67	68	62	76	78
Q34 Would you say your eating habits are good?	87^	58	75	100*	62	60	71	74
Q35 Do you have regular check ups with a dentist?	80	77	88	86	85	83	73	86
Q36 Get the sleep you need without being disturbed?	64	89	63	57	96	92	74	88
Q37 Do staff or people you live with hit or hurt you?	86	100^	100	86	100	92	96	96
<i>Material Well-Being (Average QOL)</i>	(7.1)	(6.6^)	(7.2)	(7.4)	(6.7)	(7.2)	(7.4)	(7.4)
Q38 How many things do you own?	58*	23^	43	17	15	38	62	51
Q39 How often do you worry about money?	55*	91	71	50*	86	96	55	94

Appendix Table A1. Percent Giving the Favorable Response by Question and Respondent

Question	All Rosewood Baseline		With 2-Year Follow-up				FY2009 Ask Me!	
	Self	Proxy	Self both		Proxy both		Self	Proxy
			Base	Follow	Base	Follow		
Q40 On money, do you feel that you are well off?	46	78	43	57	83	94	59	83
Q41 Do you have money each week to spend?	64	57	57	71	64	52	71	67
Q42 Do you save money?	27 [^]	14 [^]	29	71	14	41	57	41
Q43 Do you have the chance to earn good money?	82 [*]	13 [^]	100 [*]	71 [*]	8	6	69	24
<i>Rights (Average QOL)</i>	<i>(6.6[*])</i>	<i>(5.0)</i>	<i>(6.1)</i>	<i>(8.6⁺)</i>	<i>(4.5)</i>	<i>(2.7⁺)</i>	<i>(7.4)</i>	<i>(4.6)</i>
Q44 Staff ask permission before entering your home?	64	68	71	71	62	36 ⁺	69	59
Q45 Can you lock the bathroom door if you want to?	36 [^]	16	43	71 [*]	15	12	68	25
Q46 Can you talk on the telephone in private?	73 [*]	20	71 [*]	86 [*]	19	0 ^a	80	26
Q47 Can you spend time by yourself if you want?	91	67 [^]	86	100 [*]	63	24 ⁺	81	37
Q48 When problem with staff, easy to say something?	55	34 [^]	43	100 ^{*+}	26	5 ⁺	70	57
Q49 How often do you vote in government elections?	27	0 [^]	29	40	0	5 ⁺	43	2
<i>Rosewood Movers Questions (Average)</i>	<i>(7.0)</i>	<i>(7.3)</i>	<i>(6.8)</i>	<i>(8.1)</i>	<i>(7.4)</i>	<i>(6.9)</i>	--	--
Q50 Visit with your family as much as you would like?	64 [*]	20	86 [*]	83 [*]	24	10	--	--
Q51 How many friends who are not paid staff?	55	30	71 [*]	50	22	30	--	--
Q52 Are there people in your life you can depend on?	82	86	86	83	85	78	--	--
Q53 Can you trust the people around you?	46 [*]	98	57	83	100	96	--	--
Q54 Are there things you really enjoy doing?	83	73	86	83	82	75	--	--
Q55 Do you look forward to things?	82	61	86	83	62	50	--	--
Q56 How often do you get away from where you live?	10	16	17	33	11	23	--	--
Q57 Do you feel people in the community know you?	36	38	43	83 [*]	37	9 ⁺	--	--
Q58 At meetings about you, do people talk to you?	73	67	86	83	70	52	--	--
* Self response different from proxy response at p ≤.05 (two-tail)								
[^] Rosewood baseline different from FY2009 Ask Me! at p ≤.05 (two-tail)								
⁺ Follow-up different from baseline at p ≤.05 (one-tail)								

Appendix B. Life in Rosewood Compared to in the Community

Self Responses

- He loves to go to the YMCA and go swim. He says he is happy.
- Better in community; gets out everyday/weekend. Sleeps in own bed. Girlfriend can stay over on weekend.
- I like to help people out and stay out of trouble. Everyone should be brothers and sisters.
- I love being in the community. It's quiet and no one bothers me. (*Lives with staff, no roommates*)
- It's better out here. I get to do more stuff and get to go to work. I like being out in the community.
- My home is better than Rosewood. I have my own room, clothes, furniture. I help pay for my food. I am looking for a job. (*Had attended Day Program on Rosewood grounds*)

Proxy Responses

- A lot happier and participates more. When lived at Rosewood, was not happy to go home. Now, happy to come to program and happy to return home.
- She has indicated that she likes the community better. She is encountering more physical problems.
- At first happier and expresses himself more.
- Eats a lot more and sleeps. Exhibits less SIB.
- Gives her a better opportunity to be who she is. Have investigated more medical options, and more attention has been given to personal preferences.
- Had a rough transition. Now comes to work on a regular basis. Feels good when he makes money. Likes his staff, goes out and does things. Has friends.
- Much different environment in community. She does much of the same things in community as she did in Rosewood.
- Have been with her six months. Have seen no changes.
- Hygiene is better, clothes are better. No longer has a stuffed animal. Friendlier.
- Less tearing of items. Incontinence has gotten better. Likes to sing and play piano.
- Much calmer, likes to do puzzles/games.
- Better care, more community activities, housing is nicer, better food (pureed).
- Much better off in community. He goes places, get out more, enjoys freedom of own space.
- Better care, more activities, better food, groomed better, likes to be around people.
- He came to program in 2009 and over that time his behavior has improved tremendously. He can communicate with program manager and she knows he is happy, sad, wants things. He knows and responds to familiar faces.
- Talks more, and more outgoing. Lets you know what she wants. Loves her house.
- Used to cry all day, now not as much.

- *Proxy 1*--Incidents of Pica and shredding clothes have decreased. *Proxy 2*-- Not properly taken care of at Rosewood, i.e., poor hygiene. Now she goes to doctors' appointments, she is properly cared for and has friends.
- *Proxy 1*--Is blind. Likes it when people let him know what is going to happen and thus is more compliant. Laughs and smiles every day. *Proxy 2*-- Happy to be in community; happy with his staff.
- *Proxy 1*-- Meds have been stabilized. Likes to go out on Fridays and observe things. Likes to be outside. Much calmer, and more content person. *Proxy 2*-- Life in the community is 100% better than life at Rosewood.
- *Proxy 1*--Now has a two bedroom home, with one roommate. Out almost every weekend. *Proxy 2*--He likes his home and staff. More in community than Rosewood.
- *Proxy 1*--Trust of other people has increased. Will patiently wait for food rather than grab it. Doesn't like veggies and doesn't have to eat them. Would push people and steal items but doesn't do it any more. *Proxy 2*-- Made Huge progress in community. Goes out to eat.

Appendix C. Additional Questions for Rosewood Movers

50. Do you get a chance to visit with your family as much as you would like?
- ☺1 Yes
- ☹2 Sometimes
- ☹3 No
51. How many friends do you have that are not paid staff?
- ☺1 Lots
- ☹2 1 or 2
- ☹3 None
52. Are there people in your life you can depend on?
- ☺1 Yes
- ☹2 Maybe
- ☹3 No
53. Can you trust the people around you?
- ☺1 Yes
- ☹2 Sometimes
- ☹3 No
54. Are there things you really enjoy doing?
- ☺1 Yes
- ☹2 Sometimes
- ☹3 No
55. Do you look forward to things?
- ☺1 Yes
- ☹2 Sometimes
- ☹3 No
56. In addition to your work or day program, how often do you get away from the place where you live?
- ☺1 Every day
- ☹2 Some days
- ☹3 No days
57. Do you feel like people in the community know you?
- ☺1 Yes
- ☹2 Some
- ☹3 No
59. At meetings about you, do people . . .
- ☺1 Talk to you?
- ☹2 Talk about you?
- ☹3 You don't go to the meetings?