

**MUSCATATUCK STATE DEVELOPMENTAL CENTER
FAMILY FOLLOW-UP SURVEY OF INDIVIDUALS WHO HAD LEFT IN
2001 AND 2002**

Submitted to:

**Division of Disability, Aging, and Rehabilitative Services
Indiana Family and Social Services Administration**

Submitted by:

**Teresa Grossi, Ph.D., David Mank, Ph.D., Alberto Migliori, M.S., Steve
Pitts, B.S., and Larry Schaaf, M.Ed.**

**Center on Community Living and Careers
Indiana Institute On Disability and Community
Indiana University
2853 E. Tenth Street
Bloomington, IN 47408
(812) 855-6508
tgrossi@indiana.edu**

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MUSCATATUCK STATE DEVELOPMENTAL CENTER FAMILY FOLLOW-UP SURVEY

The purpose of this survey was to determine the overall satisfaction of individuals with disabilities who had moved from Muscatatuck State Developmental Center in 2001 and 2002. In the spring of 2002, the Indiana Institute On Disability and Community surveyed the caregivers of individuals who had left Muscatatuck State Developmental Center in 2001. Seventy-nine percent responded to an 18-question telephone survey based on pre- and post move information using a likert scale and open-ended questions. The total group of individuals were interviewed again in the spring of 2003 using 11 of the 18 questions, however only focusing on the post-move information.

The same 18-question survey used for the 2001 respondents was used to gather information from caregivers of individuals who had left in 2002. In the spring of 2003, a telephone interview was conducted with 64% (30) respondents for individuals who had left in 2001 and 69% (36) respondents for individuals who had left in 2002 that included individuals with disabilities, family members or guardians. The following summary includes information on satisfaction of services and supports before and after living at Muscatatuck.

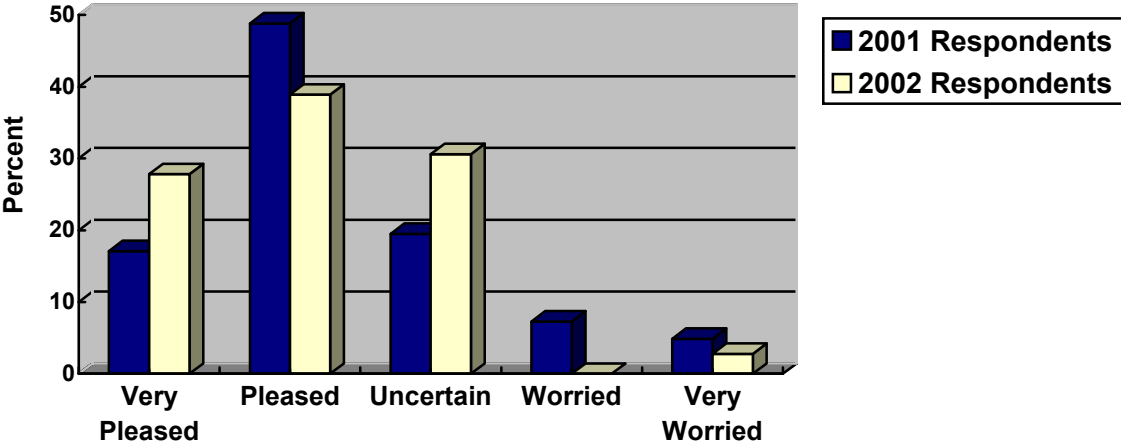
Highlights of the report include:

- As pleased as the respondents were with the overall satisfaction with Muscatatuck services for both years respectively (66%; 67%), the respondents were more pleased with their loved one's life after leaving the Center (71%; 89%). More interesting was that the 2001 respondents have a higher level satisfaction (71% vs 80%) with their loved one's life a year or more after leaving Muscatatuck.
- There seemed to be more variability in the responses on how individuals, family members or guardians felt about leaving Muscatatuck for both years. Forty-one percent (41%) were pleased or very pleased about leaving the Center during both years while over 36% and 39% respectively were either worried or very worried.
- Over half of the respondents during both years felt they were very informed during the planning and actual moving process from the Center.
- Overall the respondents for both years were pleased or very pleased (71%, 77% respectively) with the quality of their loved ones life now. More interesting was the 2001 respondents believed there was a larger difference in their loved ones life from over a year ago (71% vs 90%).
- There seem to be an improvement from individuals leaving in 2001 (27%) than with individuals leaving in 2002 (68%) about knowledge of the Bureau of Quality Improvement Services. However there was only a slight improvement (27% to 37%) of the knowledge about the Bureau of Quality Improvement Services for individuals who had left in 2001 from 2002 to 2003.

Survey Questions and Responses

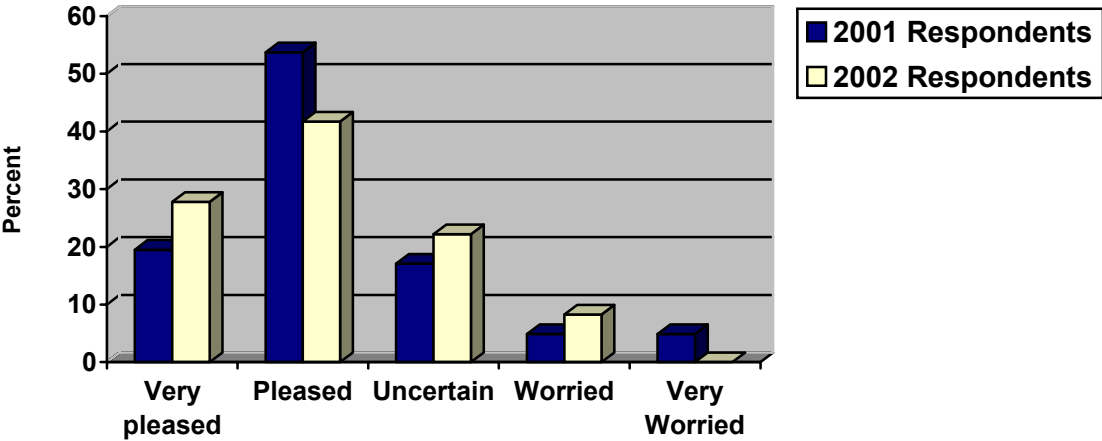
The first 7 questions elicit information on satisfaction with services while at Muscatatuck. For questions 1-7, information from individuals who had left Muscatatuck in 2001 was gathered in the spring of 2002 and for individuals who had left Muscatatuck in 2002, information was gathered in the spring of 2003.

1. How satisfied were you with services at Muscatatuck?



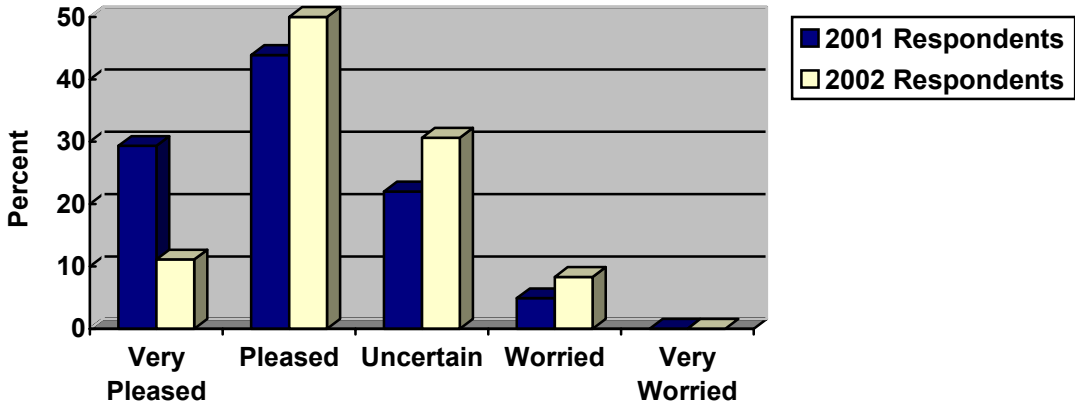
The majority of the respondents for individuals who had left during the 2 years were pleased (49%; 39%) or very pleased (17%; 27%) with the services received at Muscatatuck with isolated incidents of displeasure (e.g., hygiene, unit residing on, care given by staff, not getting enough attention).

2. How satisfied were you with the staff at Muscatatuck?



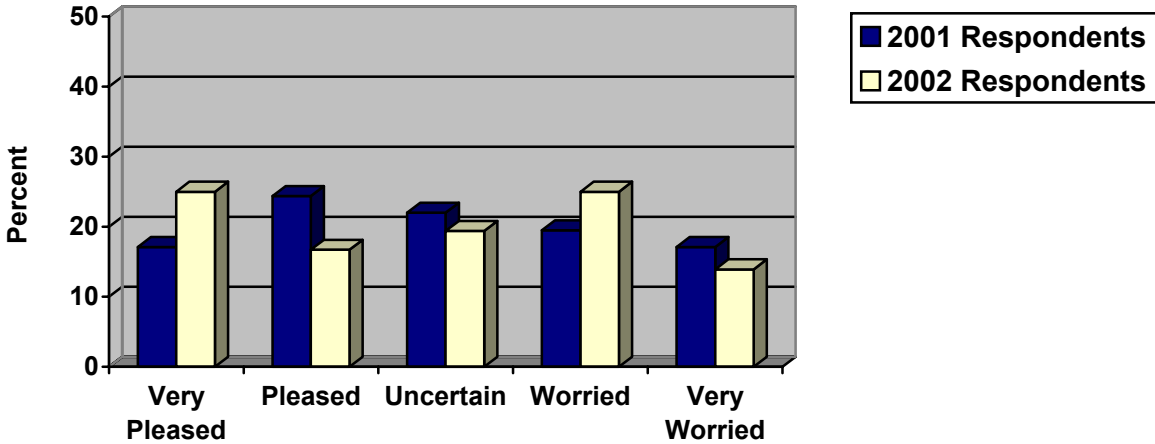
The majority of the responses were pleased (54%; 42%) or very pleased (20%; 28%) with the staff at Muscatatuck and the care they gave to their loved ones.

3. How satisfied were you with environment (e.g., building, grounds, food, etc.) at Muscatatuck?



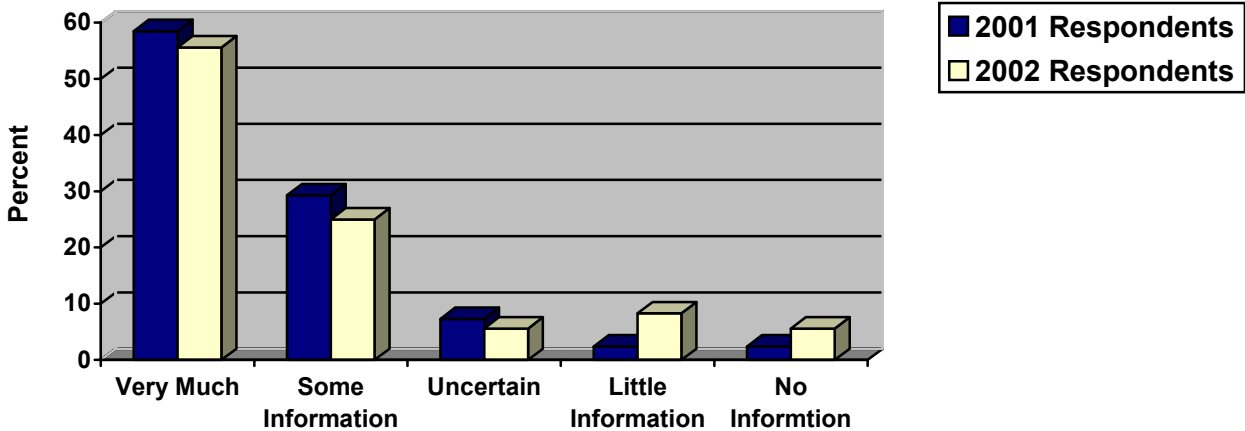
The 2001 respondents tended to be more pleased or very pleased (73%) with the overall living environment of their loved ones than the respondents in 2002 (61%).

4. How did you feel about your loved one leaving Muscatatuck?



There seemed to be more variability in the responses on how individuals, family members or guardians felt about leaving Muscatatuck for both years. Forty-one percent (41%) were pleased or very pleased about leaving the Center during both years while over 36% and 39% respectively were either worried or very worried.

5. How informed were you during the planning and moving process for your loved one?

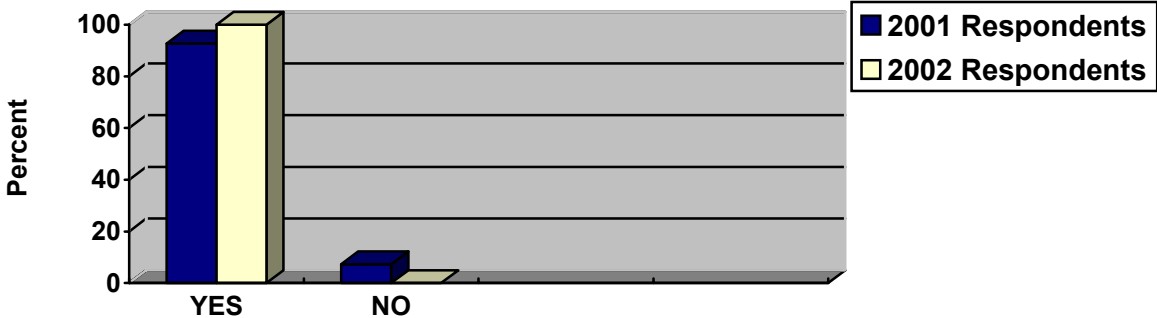


Over half of the respondents during both years felt they were very informed during the planning and actual moving process from the Center.

6. When you needed information did you have someone to call?



7. Were people responsive to your questions?

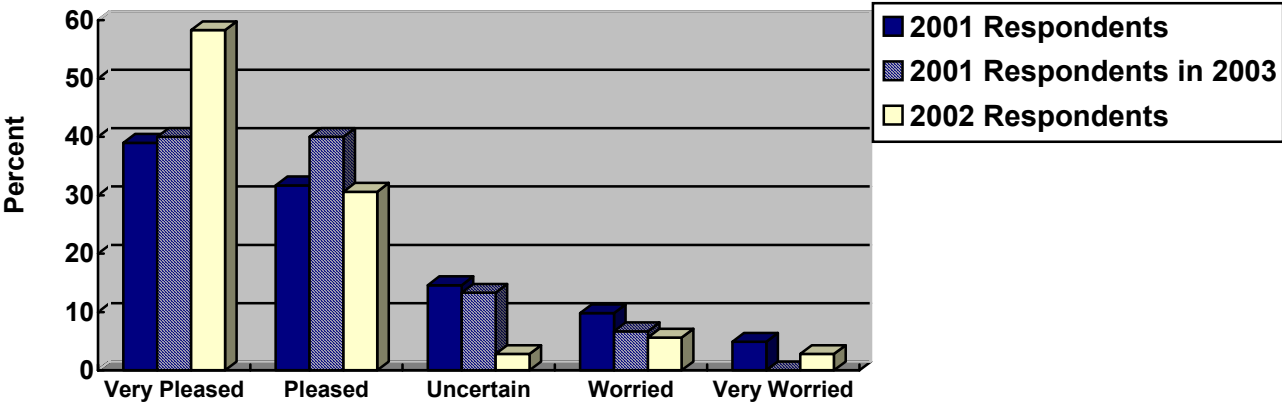


Almost all of the respondents knew the actual person to call to receive information or for questions. Additionally, the respondents felt the staff was very responsive to their questions or concerns.

POST MOVE INFORMATION

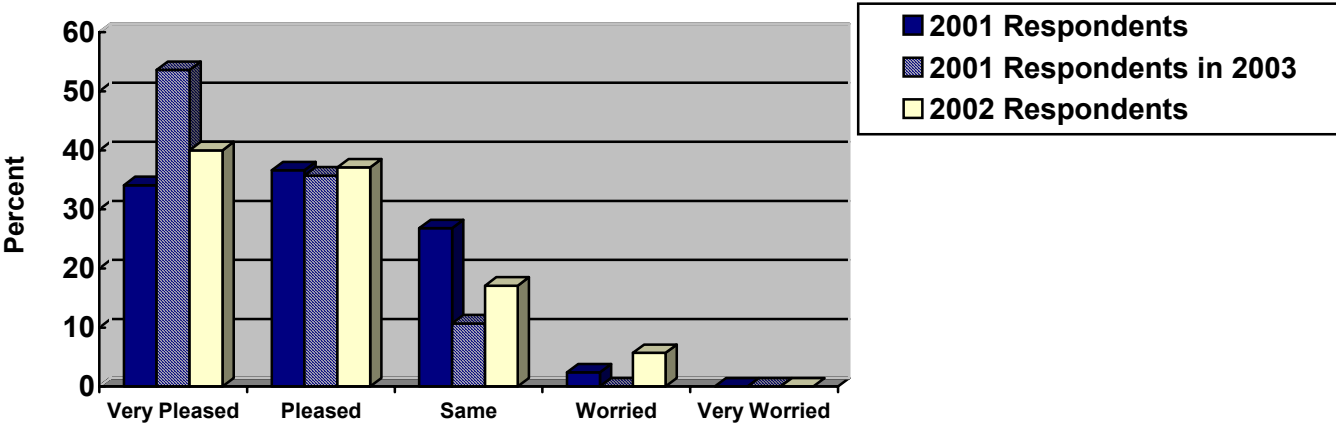
For questions 8 through 18, the individuals who had left in 2001 responded to the same questions in 2002 and 2003 (as shown by the dark solid bar and the strip bar). Responses for individuals who had left in 2002 are shown by the lighter colored bar.

8. How satisfied are you with your loved one’s life now?



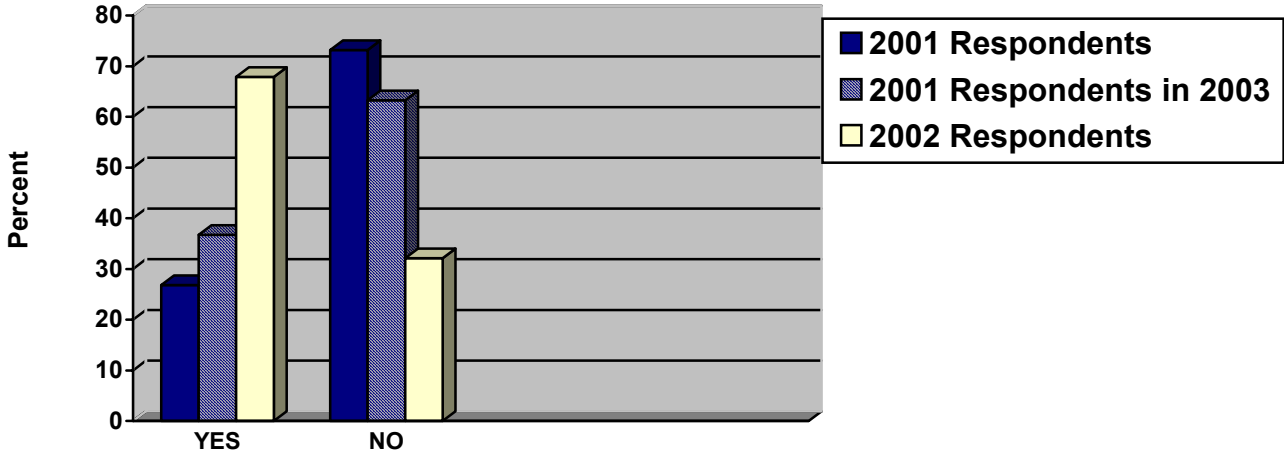
As pleased as the respondents were with the overall satisfaction with Muscatatuck services for both years respectively (66%; 67%), the respondents were more pleased with their loved one’s life after leaving the Center (71%; 89%). More interesting was that the 2001 respondents have a higher level satisfaction (71% vs 80%) with their loved one’s life a year or more after leaving.

9. Do you see a difference in the quality of your loved ones life now?



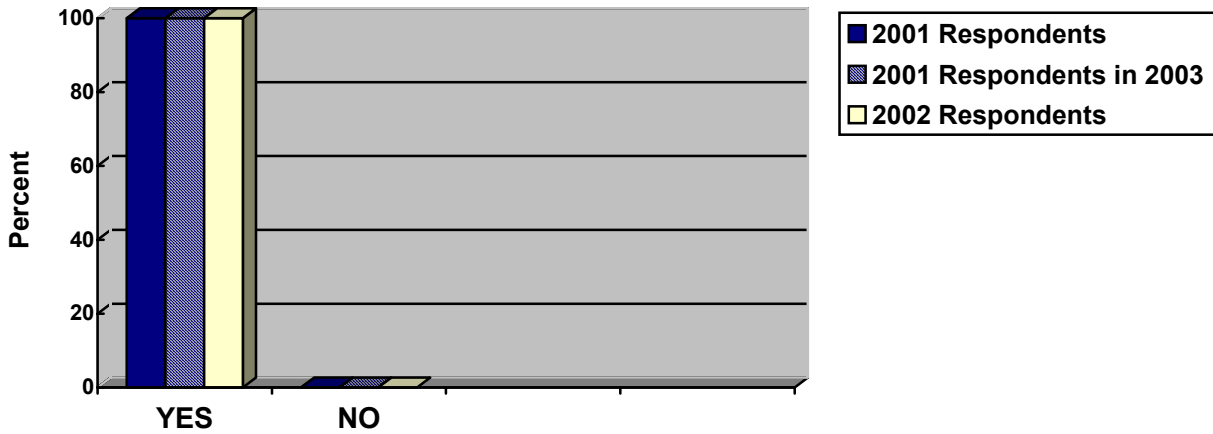
Overall the respondents from both years were pleased or very pleased (71%, 77% respectively) with the quality of their loved ones life now. More interesting was the 2001 respondents believed there was a larger difference in their loved ones life from over a year ago (71% vs 90%). Respondents believed there is a difference in the areas of more involvement in the community, ability to make own choices, living environment is more like a home, better health, better attitude, gets out to do more activities, and "more like himself".

10. Were you informed of the findings/results from the visits by the Bureau of Quality Improvement Services?



There seem to be an improvement from individuals leaving in 2001 (27%) than with individuals leaving in 2002 (68%) about the Bureau of Quality Improvement Services. However there was only a slight improvement (27% to 37%) of knowledge about the Bureau of Quality Improvement Services for individuals who had left in 2001 from 2002 to 2003.

11. If yes to Question 10, are you satisfied that any problems identified have been corrected?



All respondents who knew of the findings and results by the Bureau of Quality Improvement Services were satisfied with the outcomes.

12. What changes have happened for your loved one since moving from Muscatatuck?

Most often cited sources of satisfaction included:

- Consumer is happier
- More individualized attention
- Much more like a home environment
- More involvement in activities and community
- More independent
- Closer to family
- Receiving better care
- Having own space
- "I feel like the doors have opened up for her. She can get out and go. She can be anything she wants to be as long as she has a way to communicate. She goes shopping, to basketball games, etc."

Respondents were worried because:

- Family member does not have good access to medical care.
- Family member does not have enough structure and/or access to activities in the community.
- He is more by himself besides his staff, except when staff takes him places.
- Two isolated incidents occurred where the individuals were asked to leave their group home placement.

13. What changes or improvements would you like to see for your loved one in the next year?

Respondents would like to see:

- Many respondents indicated that they "just want (him/her) to be happy, healthy and safe.
- Other statements were made by those interviewed such as "see him in the outside world," "like to see her be more comfortable getting out in the community," and "get out of the house."
- Learn to do more for him/herself.
- Get into more activities outside the home.

Primary area of concern or worry that needs to be changed was identified:

- Several respondents indicated a fear that the potential future staff changes at the community agencies where their family members were placed would cause disruptions.

14. What do you see for your loved one's future?

A common theme in people's responses:

- Most respondents echoed the themes from the previous question, however several stated they wanted stability for their loved one that allows them to be happy, healthy, and safe.
- Several respondents indicated an interest in their family members getting a job and moving to a more independent housing arrangement.

15. What has been the biggest surprise since the move?

Surprises which are characterized by families as positive included:

- How easily and quickly their loved ones adjusted to the move and new environment. One respondent indicated their loved one lived at Muscatatuck for over 30 years and how quickly she adapted and how much more capable she really is.
- How capable their family member really is.
- How much easier their loved ones are to get along with, a better attitude, and a reduction in negative behaviors.

Surprises which are described as negative or highly negative included:

- Many respondents indicated they were more concerned about medical issues and access to medical care.

16. Do you see your loved one more often now? Less often? About the same?

- Fifty-six percent (56%) said they see their loved ones more often, 32% less often, and 12% about the same.

17. Do you have any advice for other family members as their loved ones leave Muscatatuck?

- Most common advice was for families to take a chance and that they would be surprised positively.
- Visit potential providers and really do research on the type of environment and staff at the provider facility.
- Having a good caseworker and good staff are the key to a successful transition
- Get involved.
- "Do it! Take them out! The atmosphere is so much better"

18. Additional Comments:

- Many continued to comment on how happy they are about the move and the services that their family member is receiving.
- Many commented on their continued disagreement with the decision to close Muscatatuck and discharge consumers into the community.
- “I’m still not convinced that moving people out of Muscatatuck was cost justified.”
- “I was hesitant at first to move _____ from Muscatatuck. After I felt that the move was going to have to happen and I started investigating the options, I found that it was actually a good thing. It turned out to be one of the best things I’ve ever done for her.”