

**New York State**  
**Money Follows the Person**  
**Demonstration:**  
**Quality of Life Survey Evaluation**

**2009-2011**

## **SECTIONS**

1. Executive Summary
2. Characteristics of Target Populations
3. Key Indicators
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## I. Executive Summary

The Department of Health (DOH), in collaboration with other New York State agencies, took a broad leadership role in addressing needed services for individuals requiring community based long term care services. In 2011, Governor Cuomo embarked on an aggressive restructuring of the Medicaid system through a Medicaid Redesign Team (MRT) tasked to shape policy, reduce costs, and increase quality and efficiency in the provision of health care.<sup>1</sup>

Consistent with this effort, The Money Follows the Person Federal Rebalancing Demonstration Program (MFP) provides states with additional Medicaid reimbursement for services provided to recipients who transition from nursing homes to community based care. To measure the impact of the demonstration, the Centers for Medicare and Medicaid Services (CMS) developed the Quality of Life (QoL) Survey to monitor MFP participant satisfaction with their living situation and care. CMS requires that states conduct the survey at three different times during the participants' transition process. First, baseline interviews are conducted before the participant transitions into the community, and two follow-up interviews are conducted for two years annually following transition.

This evaluation of survey results was implemented to measure change in MFP participant satisfaction as an indication of the benefit of community based care as an alternative to institutionalization. The analysis was modeled after the Federal evaluation conducted by Mathematica Policy Research Inc. For the purposes of this study the data analyzed utilized responses only from New York State participants who completed both a baseline survey and an eleven month follow up survey between January 1, 2009 and December 31, 2011. The analysis specifically examined the evolution of participants' quality of life as they remain in the community approximately one year post-transition.

Participants' survey responses to specific domain indicators (satisfaction with care and life, unmet personal care needs, respect and dignity, satisfaction with living arrangements, community integration, mood status, and choice and control) were assessed in relation to the target populations (elderly, physically disabled, those with a traumatic brain injury, and those with a dual diagnosis) at pre and post transition points. Overall, NYS MFP participants reported higher satisfaction with their lives post-transition as measured through a variety of QoL survey questions—demonstrating that community based care augments the lives of those in need of long-term care assistance.

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<sup>1</sup> [www.health.ny.gov](http://www.health.ny.gov), Medicaid Redesign Team, Redesigning the Medicaid Program.

## II. Characteristics of Target Populations

Individuals completed the QoL surveys on a voluntary basis with their service coordinators. In exceptional cases assisted, proxy, and phone interviews were provided if a one on one/face to face interview was deemed implausible. Data collections and survey conductions provided valuable input regarding the implementation of the transition program. The findings helped to identify the magnitude of difference in the quality of life of MFP participants as they return to the community.

The sample survey respondents' include four MFP sub-populations: the elderly (24%), aged 65 or older, and the physically disabled (49%), over age seventeen, served through the Nursing Home Transition and Diversion (NHTD) Medicaid 1915(c) waiver; those with a traumatic brain injury (TBI) (22%) served through the TBI waiver; and those with a dual diagnosis (4%) served through either waiver. (Table 1) While the eleven participants representing the dual diagnosis population was a statistical challenge, including the population as a separate group was necessary to fully account for all MFP participants.

Table 1. Study Sample, By Target Population		
MFP Target Population	Number	Percentage (%)
Elderly (E)	61	24
Physically Disabled (PD)	121	49
Traumatic Brain Injury (TBI)	56	22
Dual Diagnosis (DDx)	11	4
<b>Total</b>	<b>249</b>	<b>100</b>

Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys January 2009 through December 2011.

## III. Key Indicators

### **Satisfaction with care and life:**

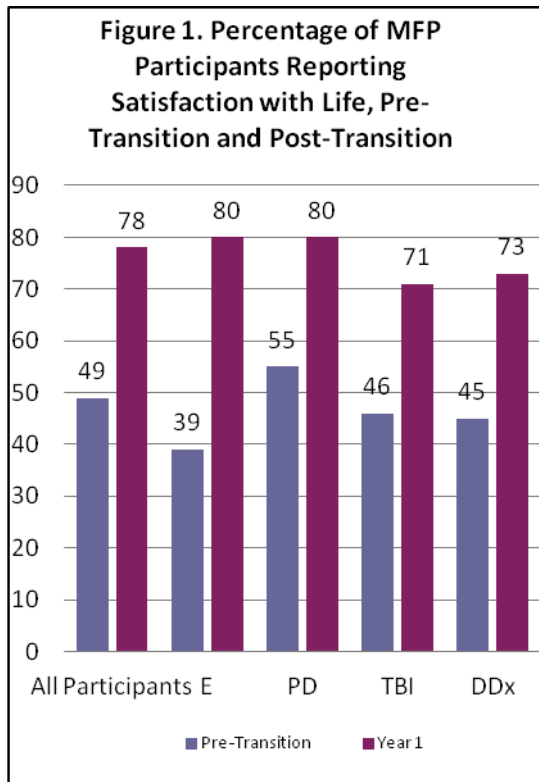
It is of interest if MFP participants report an increase in satisfaction with both care and life once transitioned into the community. Survey findings were that after transition, MFP participants across all target populations reported a significant increase in satisfaction in regard to the way they lived their lives, and equally, the care they received (Figure 1 and 2). In order to determine the change of satisfaction with care and life pre and post transition, the study evaluated the percentage of

participants reporting satisfaction with life and care.<sup>2</sup>

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<sup>2</sup> To properly gauge participant's satisfaction with their care and life both pre and post transition the study analyzes the responses to the following questions: "Taking everything into consideration, during the past week have you been happy or unhappy with the help you get with things around the house or getting around your community?" and "Taking everything into consideration, during the past week have you been happy or unhappy with the way you live your life?"

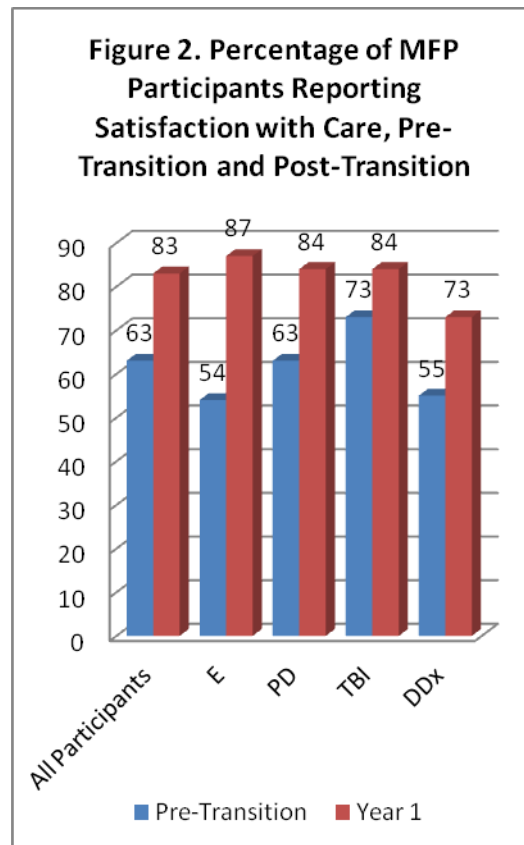
Taken as a whole 49 percent of MFP participants reported satisfaction with their life pre-transition; this percentage increased significantly to 78 percent post-transition (Figure 1).



Source: NYSDOH analysis of MFP-QoL surveys submitted January 2009 through December 2011, representing baseline and 1-year follow-up.

A similar pattern was exhibited in regard to participants' reporting satisfaction with care. As Figure 2 illustrates, satisfaction improved significantly with 63 percent of participants reporting satisfaction with care at the baseline to 83 percent reporting satisfaction with care at the 1-year follow-up.

Participants from the TBI waiver showed the least improvement with only an 11 percent increase in satisfaction with care, although, a greater percentage of TBI participants reported satisfaction with their lives at the baseline compared to the other target populations (Figure 2).



Source: NYSDOH analysis of MFP-QoL surveys submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

The elderly reported the most significant improvement; there was a 33 percent improvement in satisfaction with care reported by the elderly population (Figure 2). The findings of the study demonstrate that across all target populations participants' satisfaction with care and life were significantly improved once transitioned into the community.

**Unmet personal care needs:**

In order to decipher if participants' personal care needs went unmet pre and post transition, the study assessed the percentage

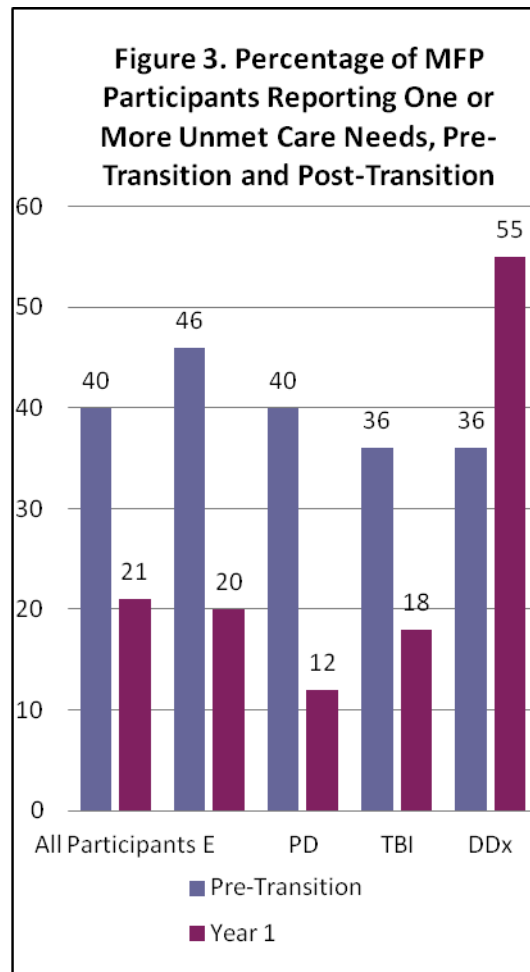
of participants reporting one or more unmet care needs across all target populations.<sup>3</sup>

As MFP participants' transition into the community, continuity in meeting their personal care must remain a priority. Fortunately, Figure 3 illustrates a significant decrease in unmet personal care needs after transition. There was a drastic improvement in the percentage of physically disabled participants reporting unmet care needs, dropping from 40 percent to only 12 percent post-transition.

However, participants representing the dual diagnosis population reported an increase of unmet personal care needs post-transition (Figure 3). There are many factors that are attributable to this increase within the dual diagnosis population, but there is more research that needs to be done in order to properly determine the reason for the increase. For example, some participants could be lacking the informal supports that other participants benefit from. Specifically, the dual diagnosis population represents participants that have significant personal care needs compared to the other target populations.

Additionally, although the dual diagnosis population reports an increase in unmet personal care needs they also report an increase in satisfaction in regard to their level of care (Figure 2). Again, this discrepancy can be accounted for by a variety of reasons. This would be a good area to research further to gain insight as to why the dual diagnosis population reports an

increase in satisfaction with their level of care while simultaneously reporting an increase in unmet personal care needs post-transition.



Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

### **Respect and Dignity:**

Respect and dignity are of vital significance in all dealings with persons in institutional care. In order to properly understand the quality of life of all participants it was necessary to determine the percentage of participants reporting treatment with respect

<sup>3</sup> The study calculates these percentages by evaluating the number of MFP participants that have answered no at least once to any of the following questions: "Do you ever go without a bath or shower when you need one?", "Do you ever go without a meal when you need one?", "Do you ever go without taking your medicine when you need it?", and "Are you ever unable to use the bathroom when you need to?"

and dignity both pre and post transition.<sup>4</sup> Respectful treatment by paid caregivers is a key component of the quality of life of MFP participants. Thus, CMS maintains a certain standard by which caregivers must abide. These safeguards may have influenced the level of satisfaction perceived by participants in regard to their treatment. As illustrated in Figure 4, the CMS safeguards may account for the high percentage of participants reporting satisfaction with their treatment at the baseline. In fact, the lowest percentage of participants reporting treatment with respect and dignity across the target populations was 73 percent. A remarkable 100 percent of the dual diagnosis population reported receiving treatment with respect and dignity post-transition. Also, the lowest reported percentage of participants reporting treatment with respect and dignity post-transition was 89 percent.

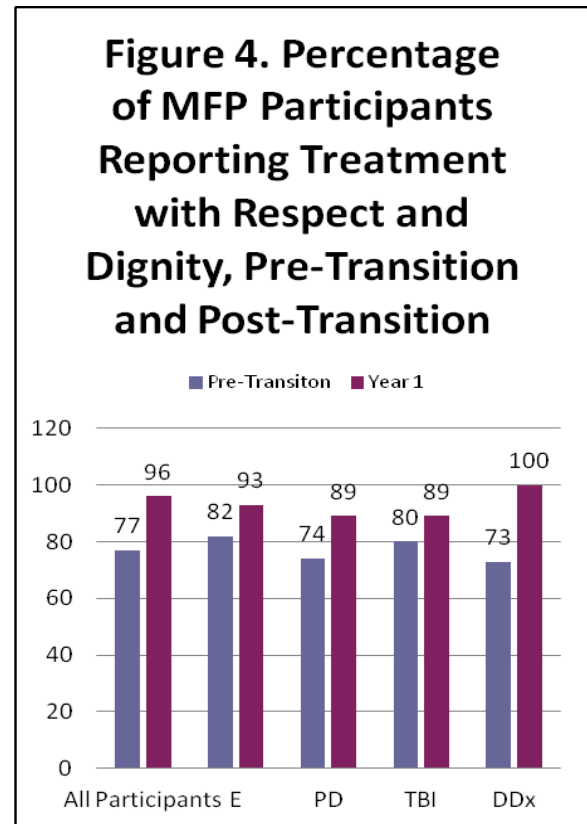
These findings emphasize the increased level of treatment received by participants' post-transition. This can be due to many factors, perhaps greater community involvement, greater autonomy, and/or greater satisfaction with living arrangements leads participants to be of the opinion that the treatment received post-transition is provided in a more respectful and dignified manner than the care received while in long-term care institutions.

**Satisfaction with living arrangements:**

The living arrangements of MFP participants are an essential area to analyze as the responses to this section epitomize

<sup>4</sup> In order to understand the change/lack of change in the level of respect and dignity received by the participants after transitioning into the community, the study analyzed participants responses to the following CMS QoL survey questions: "Do the people who help you treat you the way you want them to?" and "Do the people who help you listen carefully to what you ask them to do?"

one of the fundamental policy goals of the MFP program: to transition participants from institutional care to community based care while maintaining the same level of care.<sup>5</sup> Thus, measuring the level of satisfaction participants reported in regard to living situation is a crucial measure in distinguishing the aspects of life that have changed for the participants'.



Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

Housing has been a considerable policy concern for the MFP Demonstration. Difficulty finding suitable housing for participants continues to be an obstacle for

<sup>5</sup> In order to explore whether participants were more satisfied living in a long-term care institution or within the community, the study analyzed the responses to the following question to determine the percentage of participants reporting satisfaction with living arrangements both pre and post transition: "Do you like where you live?"

community care. Environmental modifications and other mechanisms have been increasingly utilized to combat physical accessibility barriers. All of these factors play a major role in how participants perceive their living arrangements.

Improvement across all target populations was very much evident. As Figure 5 shows, the lowest percentage of improvement among the target populations was 46 percent. In fact, looking across all of the domains analyzed in this study, satisfaction with living arrangements represented the highest level of improvement across all populations.

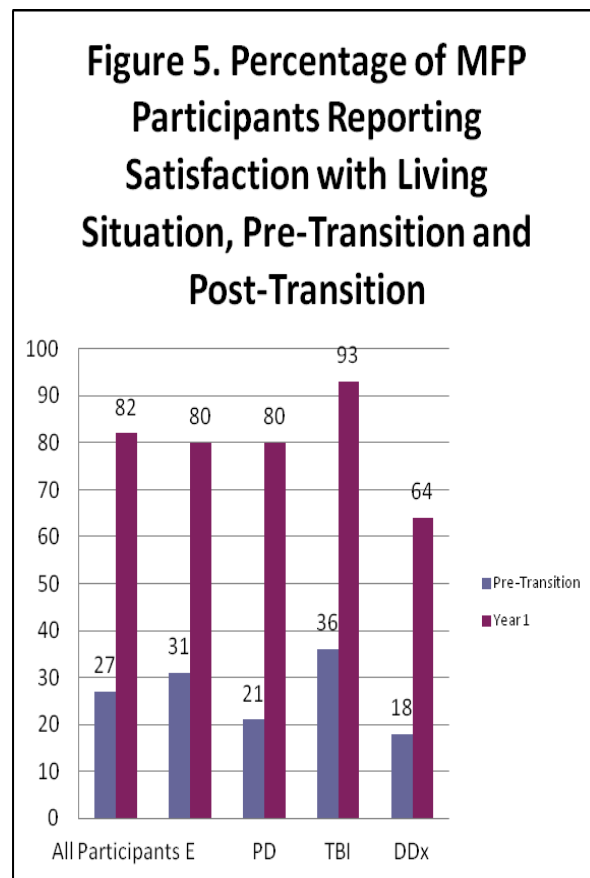
**Community integration:**

Actual involvement within the community has been a concern.<sup>6</sup> Community integration goes hand in hand with some of the other categories in measuring participant’s quality of life. For example, participants that report greater Community integration also report more favorably to other areas of the survey, such as, treatment with respect and dignity. As Figure 6 demonstrates, there was a significant improvement post-transition as to the number of participants reporting barriers to community integration.

The dual diagnosis population reported a 46 percent improvement in community integration (Figure 6). Figure 6 shows that nearly half of all participants reported barriers to community integration at the baseline, this figure decreased significantly

<sup>6</sup> In order to understand whether participants felt included within their community both pre and post transition, the study assessed the responses to the following questions in determining the percentage of participants reporting barriers to community integration both pre and post transition: “Do you go out to do fun things in your community?”

post-transition. At the baseline, 82 percent of dual diagnosis participants reported barriers to community integration, this number dwindled dramatically to 36 percent, demonstrating the significant barriers experienced by participants while in institutional care (Figure 6).



Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

**Mood Status:**

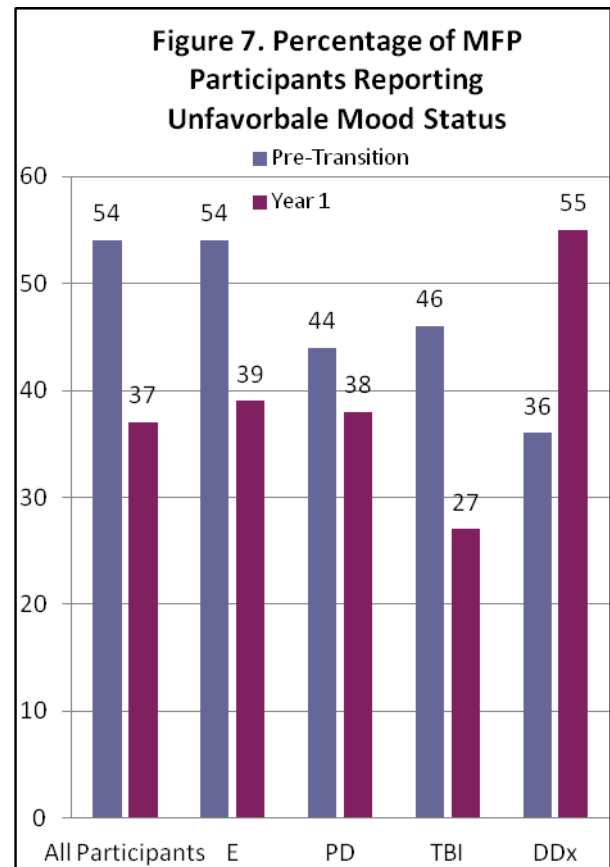
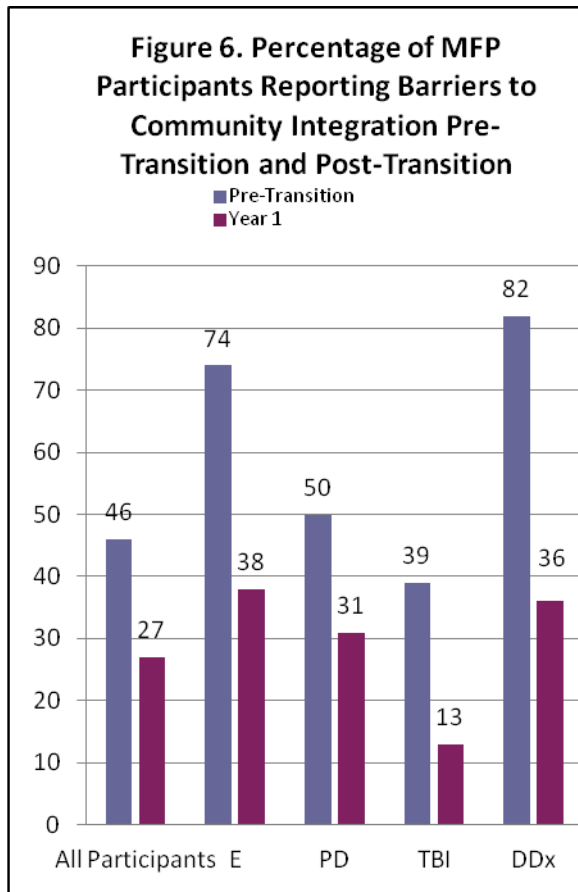
Mood status is a difficult variable to examine because of its inherent subjectivity.<sup>7</sup> This category is arguably one

<sup>7</sup> To properly determine the participant’s mood status both pre and post transition the study evaluates the responses to the following question in determining the percentage of participants reporting negative mood status: “During the past week have you felt sad or blue?”



of the more critical domains in determining participants overall quality of life. Figure 7 shows the dual diagnosis population as having a negative change in terms of participants reporting unfavorable mood status. This may be attributed to the innate subjectivity of the question “During the past week have you felt sad or blue?” Additionally, the QoL survey’s section accounting for mood status

exercised by participants across all target populations demonstrate the significant improvement participants reported in controlling their lives in the community. This increase in perceived autonomy shows the significant lack of control experienced by participants while in institutional care.



Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys. primarily relies upon this one question. The results of this particular analysis may have identified a possible shortcoming in measuring mood status on the QoL Survey that necessitates further inquiry.

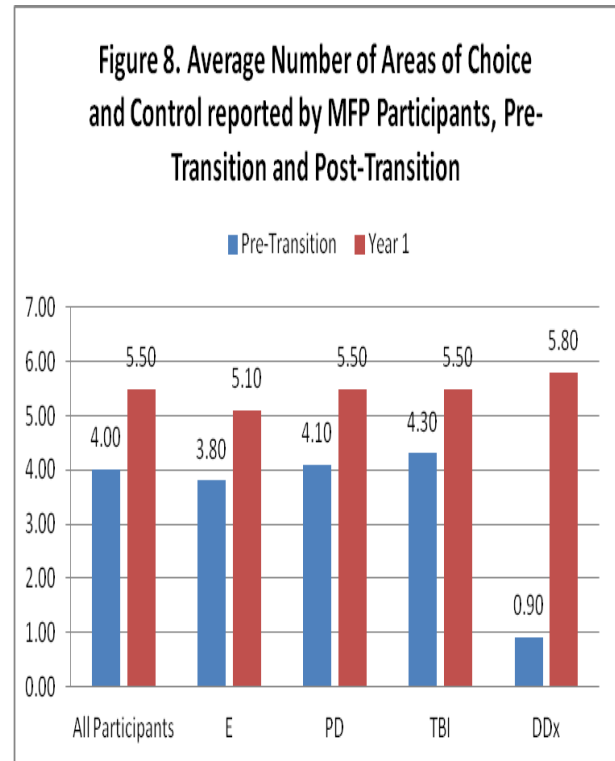
Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

The considerable increase in the average number of areas of choice and control

### **Choice & Control:**

Establishing the level of choice and control participants experienced both pre and post transition proved an arduous but necessary task in determining the overall quality of life of participants.<sup>8</sup>

Once transitioned back into the community participants expect greater autonomy. Markedly, the dual diagnosis population's average reported number of areas of choice and control was less than 1 at the baseline, however, this very low average increased significantly to 5.8 post-transition. Trends amongst the other populations were similar, although most gains were not as drastic (Figure 8).



Source: NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011 representing baseline and 1-year follow-up surveys.

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<sup>8</sup>The study assesses the average number of areas of choice and control exercised by participants by analyzing the participants' responses to the following six questions: "Can you go to bed when you want?", "Can you be by yourself when you want to?", "When you are at home, Can you eat when you want to?", "Can you choose the foods that you eat?", "Can you talk on the telephone without someone listening in?", and "Can you watch TV when you want to?"

#### IV. Summary of Findings

This evaluation of MFP participants' quality of life pre and post transition from institutional care implies that participants experienced a considerable enhancement to their overall quality of life. Respondents were asked an array of questions to determine their satisfaction with their overall quality of life. Responses to the questions revealed significantly similar rates of increase in reported quality of life among the four target populations (Table 2). The largest level of improvement reported by participants was satisfaction with living arrangements. The high ratings in the domains of community integration, respect and dignity, and satisfaction with life further helps elucidate that MFP participants' overall quality of life is indeed improved once transitioned out of institutional care (Table 2). These findings imply that the programs focused on alternatives to institutional care are not simply moving individuals from one place to another, but rather providing them with the proper facilitation in order to enhance their quality of life.

Overall, the respondents across all target populations conveyed an overwhelming increase in satisfaction eleven months after their transitions into the community (Table 2). The dual diagnosis population was the only target population to show a negative change in two domains, however, the significant improvements reported by the dual diagnosis population in all other domains creates an inconsistency that warrants further attention.

<b>Table 2. Summary of Findings: Percentage of Improvement</b>					
<b>Domain Indicator</b>	<b>Total (%)</b>	<b>E (%)</b>	<b>PD (%)</b>	<b>TBI (%)</b>	<b>DDx (%)</b>
Satisfaction with Care	20	33	21	11	18
Satisfaction with Life	29	41	25	25	28
Unmet personal care needs	19	26	28	18	-19
Respect & Dignity	19	11	15	9	27
Satisfaction w/ living arrangements	55	49	59	57	46
Community Integration	32	36	19	26	46
Mood Status	17	15	6	19	-19
<b>N</b>	<b>249</b>	<b>61</b>	<b>121</b>	<b>56</b>	<b>11</b>

*Source:* NYSDOH analysis of MFP-QoL survey submitted January 2009 through December 2011, representing baseline and 1-year follow-up surveys.

## V. Data Limitations & Methods

Many factors limited this evaluations' sample size. For the purposes of generating the best sample size allowable for this particular evaluation a good level of comparison was essential. Thus, the sample was limited to only those participants having both a baseline and first follow up survey completed between the years 2009 and 2011. In effect, the study had an overrepresentation of physically disabled participants in comparison to the number of participants representing the other target populations. Yet, this limitation was not a major cause for concern for the study because individuals under age 65 with physical disabilities actually represent the largest group overall of MFP participants.

Another very general limiting factor for this study is that some of the quality of life ratings are inherently subjective, as explained by some of the discrepancies found within the mood status domain. However, this did not seem to disadvantage the study as there was a noticeable improvement from the baseline to the follow-up despite the subjectivity of certain questions.

Additionally, there were answer choices in the QoL Survey that could not be accounted for as accurately as some of the other choices because it left significant room for interpretation. For instance, the question the study used to determine if participants were satisfied with their living arrangements provided "sometimes" as a possible answer choice. This was a tough response to account for because there were a good portion of participants that responded with sometimes, and discerning whether to count those responses as satisfaction, dissatisfaction, or simply to not count it as a measure of satisfaction nor dissatisfaction was difficult to decide because it seemed those responses would sway the data considerably.

The small dual diagnosis population was another limitation faced by the study. Some of the findings from this population were inconsistent with the overall trends. It was difficult to determine if these inconsistencies were attributable to the differences between the dual diagnosis population and the other target populations, or if the inconsistency reflects a weakness within the evaluation. Nonetheless, the paradoxical finding of the dual diagnosis population reporting increased unfavorable mood and unmet care needs post-transition warrants further inquiry. Perhaps, including an analysis of the 24-month surveys will further address some of the shortcomings of this study

## **VI. Overview**

New York's rapidly evolving Medicaid health care infrastructure must be delivered to individuals in a cost effective and efficient manner that maximizes care State's rich community base resources for service and supports. MFP-QoL Survey was developed to elicit participants' perception of change in the quality of their life and care following transition from long-term care institutions back into their community. Analysis of the responses to the QoL Survey from 2009 to 2011 is fundamentally positive, although the study identifies certain barriers, particularly within the dual diagnosis population, that remain.

This evaluation of the QoL Survey validates the intention for transition from unwanted institutionalization to improve overall quality of life. Each quality of life domain indicated a statistically significant positive change in participant satisfaction with their life circumstances and quality of medical care post transition from a nursing home. Results of the evaluation will be used to inform Nursing Home Transition and Diversion and Traumatic Brain Injury 1915(c) waiver managers, service coordination providers, other stakeholders throughout the State.