

**THE NATIONAL EVALUATION OF THE
MONEY FOLLOWS THE PERSON (MFP) DEMONSTRATION GRANT PROGRAM**

R E P O R T S F R O M T H E F I E L D

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Money Follows the Person: Change in Participant Experience During the First Year of Community Living

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Introduction

The Money Follows the Person (MFP) Demonstration, established by Congress through the Deficit Reduction Act of 2005 (DRA), provides state Medicaid programs the opportunity to help transition into the community Medicaid beneficiaries living in long-term care institutions. The MFP program provides states with enhanced federal matching rates for spending on home- and community-based services (HCBS) provided to program participants and provides funding for associated administrative costs. MFP grantees, in turn, provide enhanced community services to participants during their 365-day period of program participation. In 2007, the Centers for Medicare & Medicaid Services (CMS) awarded grants to, and has since overseen the implementation of MFP programs in, 29 states and the District of Columbia.¹ CMS awarded another 13 grants in February 2011; these states are currently getting the details of their programs approved and starting program operations.

The belief that many in institutional care would prefer to live in the community forms part of the basis for the MFP demonstration program. This report presents the quality-of-life experiences of 803 MFP participants who transitioned to community living between January 2008 and December 2009 and responded to grantees' administration of pre-transition and one-year post-transition surveys. We specifically examine how reported quality of life changed after participants transitioned to community living. We find that, after one year of community living, participants reported significantly higher quality of life compared with life in institutional settings, as measured through a variety of questions. These include questions designed to assess global satisfaction with life, satisfaction with care received, and satisfaction with where participants lived. Participants reported the largest improvement in satisfaction with their living arrangements. These findings are consistent across each target population. The report concludes with a discussion of the implications of these findings for the demonstration and for other transition programs.

¹ One additional state received a grant but has not implemented its MFP program. Hereafter, we refer to the original 30 grantees, including the District of Columbia, as grantee states.

ABOUT THE MONEY FOLLOWS THE PERSON DEMONSTRATION

The MFP demonstration, first authorized by Congress as part of the 2005 DRA and then extended by the 2010 Patient Protection and Affordable Care Act, is designed to shift Medicaid's long-term care spending from institutional care to HCBS. Congress has now authorized up to \$4 billion in federal funds to support a twofold effort by state Medicaid programs to (1) transition people living in nursing homes and other long-term care institutions to homes, apartments, or group homes of four or fewer residents; and (2) change state policies so that Medicaid funds for long-term care services and supports can "follow the person" to the setting of his or her choice. MFP is administered by CMS, which initially awarded MFP grants to 30 states and the District of Columbia (although one state has yet to implement its program). The first states launched their MFP transition programs in late 2007, and Congress has authorized the demonstration through 2016. CMS contracted with Mathematica Policy Research to conduct a comprehensive evaluation of the MFP demonstration and report the outcomes to Congress.

An operating premise of the MFP program is that many Medicaid beneficiaries who live in institutions would rather live in the community and that successful transition to the community will improve the quality of their lives. Although the welfare of people who transition from institutional settings into less restrictive community-based care is a primary concern of long-term care providers, beneficiaries, and their advocates, little is known about how this transition affects the quality of their lives. This report begins to shed light on this issue and test the premise that community living enhances the quality of life of those who need long-term services and supports by examining how participants' reported quality of life changed after a year of community living.

Since 2007, 30 grantees have established MFP programs. Within specified parameters, each grantee has established a unique set of goals for transitioning target populations—such as which beneficiaries will be the focus of their program and how many of each category of beneficiaries will be transitioned—and other related objectives to measure success in program implementation. As one component of their programs, grantees survey potential transition candidates using a standardized instrument to assess participant quality of life in terms of satisfaction, access to personal care, community integration, respect and dignity, and degree of choice and control. Grantees use the MFP-Quality of Life survey instrument (MFP-QoL) to collect information directly from participants. The Data and Methods box at the end of this report describes this instrument and its administration (Sloan and Irvin 2007). Grantees survey MFP participants annually for two years following the initial transition to the community to obtain the

data needed to assess the change in their quality of life.²

This report provides preliminary results that show how participant quality of life changed over time and explores policy implications for the ongoing MFP program, its participants who have transitioned and those yet to do so, and other transition programs designed with comparable goals and objectives. This report describes changes for specific subpopulations, including those who transitioned from an intermediate care facility for the mentally retarded (ICF-MR), those who are aged (defined as age 65 or older) and transitioned from a nursing facility, and those who are younger than 65 and also transitioned from a nursing facility.³ Subsequently, we refer to these target populations in the report as individuals with intellectual disabilities (ID), the aged, and individuals with physical disabilities (PD), respectively.

Focusing on target populations reflects how many MFP programs operate in practice. Grantees typically tailor their transition programs to the target population, partnering with different organizations (such as Area Agencies on Aging, Centers for Independent Living, and the state agency for developmental disabilities for individu-

² The first follow-up survey is to be conducted approximately 11 months after transition; the second follow-up survey is to be conducted 24 months after transition. When necessary, survey respondents may use either the interpretive assistance of another or a proxy respondent to provide answers. See the Data and Methods box for more details regarding the survey instrument.

³ A fourth category—those who transitioned from institutions for mental diseases (IMDs)—represents a much smaller and more specialized segment of the MFP program's participants, and not enough observations for this target population were available for this report.

als with intellectual disabilities), using different targeting strategies, and placing different target populations in different HCBS waivers (Lipson and Williams 2010). We examined how the following broad dimensions of participants' experiences changed between the time they were in institutional care and one-year post-transition: (1) satisfaction with life (or life satisfaction), (2) quality of care, and (3) quality of community life.

Data for this report include survey and administrative data submitted to CMS through November 2010, representing surveys conducted through September 2010. We included only participants with both pre-transition (or baseline) and follow-up survey data.⁴ All pre-post transition changes reported as statistically significant were tested using paired t-tests and are significantly different at $p < .01$. We examined change in participant quality of life regardless of enrollment or institutionalization status at the time of the one-year follow-up survey. Subsequent reports on participant experience will examine how changes in quality of life vary with MFP program components and individual characteristics (such as age, physical functioning, and health care utilization).

An earlier examination of MFP participant experience before transition identified several key findings that affect the analysis of how quality of life changes after the initial transition to the community (Irvin et al. 2010).⁵ First, most MFP participants reported

⁴ Baseline surveys were conducted between January 2008 and December 2009. To ensure that follow-up surveys captured experience at one year, follow-up surveys conducted between 8 and 16 months after the baseline survey were included in the study sample.

⁵ The earlier findings were based on analyses of responses to the initial or baseline survey, conducted through December 2009, and included 1,890 MFP participants from 25 of 30 grantee states.

high levels of happiness with the way they lived their lives and the care they received in the weeks and days before transitioning. In addition, before transition, participants with intellectual disabilities reported relatively high levels of life satisfaction (74 percent) compared with aged participants and participants with physical disabilities (57 and 56 percent, respectively). These findings suggest that the transition to community living will have differential effects on the quality of life of different target populations and that some participants entered community living with relatively high levels of satisfaction with their lives. For example, because of their relatively high level of baseline satisfaction with life, participants with intellectual disabilities may be less likely than other participants to show improvement.

Characteristics of the Study Sample

In the sample of MFP participants represented in this report, aged participants (17 percent), participants with physical disabilities (27 percent), and participants with intellectual disabilities (28 percent) comprised nearly three-quarters of the study sample (Table 1). The rest represented those transitioning from another site of institutionalization (2 percent) or those who could not be classified due to missing data (26 percent). Data from 22 of the 30 grantees are included, with data from Connecticut, Missouri, Ohio, and Oregon representing 54 percent of the analytic sample.

Most of the sample (60 percent) was younger than age 65, which is consistent with the overall profile of MFP participants (Lipson and Williams 2010). Approximately 21 percent of the study sample are those age 65 and older (Table 2). Children and young adults (those younger than 21) represented a small percentage (2 percent), but for the balance of the

TABLE 1. STUDY SAMPLE, BY TARGET POPULATION

Target Population	Number	Percentage
Total	803	100.0
Aged	138	17.2
Participants with physical disabilities	217	27.0
Participants with intellectual disabilities	228	28.4
Other	14	1.7
Unknown	206	25.7

Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

TABLE 2. CHARACTERISTICS OF MFP PARTICIPANTS IN STUDY SAMPLE

Characteristics	Number	Percentage
Total	803	100.0
Age Distribution at Time of Transition		
<21	18	2.2
21-44	152	18.9
45-64	313	39.0
65-74	88	11.0
75-84	49	6.1
>=85	33	4.1
Unknown	150	18.7
Sex		
Female	399	49.7
Male	395	49.2
Unknown	9	1.1
Reinstitutionalized		
Yes	54	6.7
No	749	93.3

Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

Note: Reinstitutionalizations of 30 days or longer are reported in the MFP Program Participation data.

sample, age was not reported by the grantee. Table 2 also shows the percentage of the population who were ever reinstitutionalized.⁶

Does Quality of Life Improve After the Transition to Community Living?

One year after transition to the community, MFP participants reported improvement in the quality of their lives across all domains considered. Table 3 displays the magnitude of improvement overall and by target population for key indicators across six domains of participant quality of life.⁷ Participants reported the largest improvement in satisfaction with their living arrangements, with satisfaction among participants with physical disabilities increasing by 50 percentage

⁶ Approximately 5 percent of participants in the sample were surveyed while institutionalized. Grantees are to conduct both follow-up surveys, regardless of the participant's institutional status.

⁷ Areas of choice and control also demonstrated improvements of similar relative magnitude. However, a different unit of measurement was used: average number of areas of choice and control reported. Figure 8 shows information for choice and control.

points between pre-transition and one-year post-transition to community living.

How Does Transition to the Community Affect MFP Participants' Quality of Life?

The MFP-QoL survey reflects the concept that an individual's quality of life is multidimensional and is a function of overall life satisfaction, quality of care received, and community life.

Overall Life Satisfaction. For the MFP program to be successful, satisfaction with life must be maintained or improved in community-based settings. As Figure 1 shows, MFP participants across all target populations reported a significant increase in their satisfaction with the way they lived their lives.⁸ Among all target populations, nearly 60 percent of participants reported being satisfied with the way they lived their life while still in institutional care. This percentage increased to 81

⁸ The survey question was: "Taking everything into consideration, during the past week, have you been happy or unhappy with the way you live your life?"

TABLE 3. SUMMARY OF FINDINGS, BY TARGET POPULATION

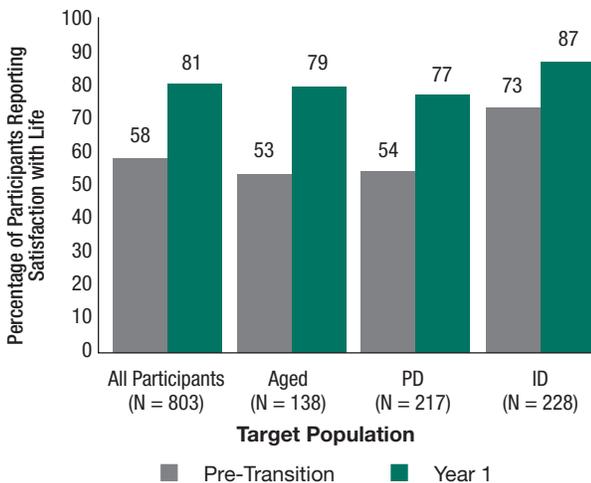
Domain Indicator ^a	Total	Aged	PD	ID	Other/ Unknown
Satisfaction with life	++	++	++	+	++
Unmet personal care needs	+	+	+		+
Respect and dignity	++	++	++	+	++
Satisfaction with living arrangements	++++	++++	+++++	++	+++++
Community integration	+	++	+	+	+
Mood status		+			+
N	803	138	217	228	220

Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

^a For aspects of participant experience where a single, key question can be identified, that question is used to represent the domain. For example, we use the question assessing whether participants felt “sad or blue” to represent the domain of mood status.

- + Indicates improvement of 10 to 19 percentage points.
- ++ Indicates improvement of 20 to 29 percentage points.
- +++ Indicates improvement of 30 to 39 percentage points.
- ++++ Indicates improvement of 40 to 49 percentage points.
- +++++ Indicates improvement of 50 or more percentage points.

Figure 1. Percentage of MFP Participants Reporting Satisfaction with Life, Pre-Transition and Post-Transition



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

percent one year after the transition to community-based care.⁹

The high rate of satisfaction with life after one year in the community is attributable to broad improvement in satisfaction. That is, when the analysis was restricted to those who were not satisfied with their lives while in institutional care, 72 percent reported being satisfied with life at the one-year follow-up. Despite these favorable outcomes, some MFP participants became less satisfied with their lives. Among those who were satisfied with their lives while in institutional care, 13 percent reported they were no longer satisfied a year

⁹ Analyses of proxy respondents were also conducted to determine the influence proxies might have had on the results. Unlike earlier analyses of the quality of life of MFP participants before they transitioned to community living, the use of a proxy respondent was not associated with satisfaction with life (Irvin et al. 2010). For the study sample presented in this report, proxy respondents provided quality of life information for 23 percent of pre-transition interviews and 16 percent of post-transition interviews. At both time points, ratings of satisfaction with life did not vary by the type of respondent (the participant or a proxy). This finding contrasts with our earlier examination, which found that proxies reported higher rates of satisfaction with life than what MFP participants themselves reported. This contrast between the different analyses is most likely related to how the study samples were defined.

later. Among those experiencing a decline in their satisfaction, 13 percent were in institutional care at the time of the one-year follow-up survey.

Satisfaction with life increased across all target populations. The percentage of aged and those with physical disabilities reporting overall satisfaction with life increased by 26 and 23 percentage points, respectively, at the one-year assessment. Although participants with intellectual disabilities had the smallest increase over time, a greater percentage were satisfied with their lives at baseline when they were still in institutional care, compared with nursing home residents.

The finding that about 8 of 10 participants reported satisfaction with the way they live their life one year after transition compares favorably with the rate reported by Beauchamp et al. (2006) in their report on overall life satisfaction for participants in the Program of All-Inclusive Care for the Elderly (PACE) and HCBS users (2008). Using an item identical to the one in the MFP-QoL survey, Beauchamp and colleagues surveyed PACE participants and HCBS users between 18 months and five years post-enrollment and reported overall satisfaction rates of 71 percent for HCBS recipients and 74 percent for PACE participants.

We conducted additional analyses of specific subgroups to determine the relationship between satisfaction with life and reinstitutionalization. Overall, 5 percent of the study sample had returned to institutional care at the time of their one-year follow-up survey.¹⁰ Among those reinstitutionalized, only 49 percent indicated they were satisfied with the way they lived their life a year after their initial transition to community living, approximately 30 percentage points lower than what is observed in the overall study sample. Satisfaction with life among reinstitutionalized populations ranged from 43 percent for aged participants to 67 percent for participants with intellectual disabilities. These rates of satisfaction among reinstitutionalized participants were lower than the pre-transition rates for each target population.

Quality of Care. Some stakeholders express concern that a potential consequence of community living is poorer-quality care due to diffusion of accountability among a wider range of community-

¹⁰ Nearly seven percent of the analytic sample were reinstitutionalized during their first year of MFP participation.

based providers. To assess care quality, the quality-of-life survey uses reported satisfaction with care, unmet need for personal care assistance, and treatment by providers.¹¹

For all groups of participants, after the first year of community living, all three areas of care quality improved from pre-transition levels. MFP participants were more satisfied with the care they received, had fewer reports of unmet personal care needs, and more reported their caregivers treated them with respect and dignity.

Satisfaction with Care. Although nearly three-quarters of participants (71 percent) were satisfied with the help they received in an institutional setting, an even larger proportion (90 percent) were satisfied with the assistance they received in the community. Satisfaction with care increased across all target populations.

Unmet Need for Personal Care Assistance. A prominent feature of institutional care is assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Although a community residence offers greater freedom, obtaining personal care assistance in the community may be difficult if paid and unpaid caregivers who provide essential assistance with ADLs and IADLs are not always available when needed. Therefore, respondents to the MFP-QoL survey were asked to report unmet needs in the areas of (1) bathing, (2) meal preparation, (3) medication management, and (4) toileting.¹²

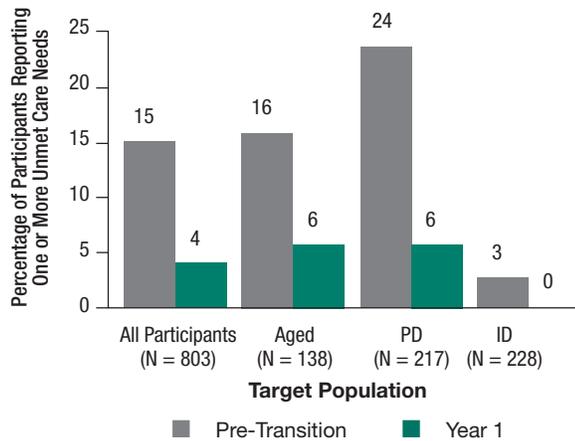
Despite concerns that the transition to a community setting could lead to an unintended decrease in meeting personal care needs, we found evidence to the contrary. Figure 2 shows that the percentage of participants reporting one or more unmet care needs significantly decreased between the pre- and post-transition periods (15 to 4 percent), and this finding was consistent across target populations.

To further assess the post-transition unmet care needs of MFP participants more generally, the survey asked respondents about post-transition support. Nearly half of all participants (47 percent) indicated they had

¹¹ To assess satisfaction with care, the survey asks: "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?"

¹² Unmet needs are defined as ever going without a particular activity because of a lack of assistance.

Figure 2. Percentage of MFP Participants Reporting One or More Unmet Care Needs, Pre-Transition and Post-Transition



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

spoken with a case manager or support coordinator about the need for special equipment or changes to the home that would make life easier.¹³ Of these, most (85 percent) said they received the desired equipment or changes. When asked whether they needed more help with tasks around the house, such as cooking and cleaning, fewer than one in six (15 percent) acknowledged such a need. In addition, more than one-third of respondents (37 percent) indicated they received help from family and friends with such tasks, suggesting that informal support outside the MFP program exists and provides supplemental benefits.

Treatment by Providers. Respectful treatment by paid caregivers is a key component of quality of life for any recipient of institutional or home- and community-based long-term care. In institutional settings such as nursing homes, CMS maintains standards of care that focus on treating residents respectfully and with dignity. These safeguards, however, are less systematic and enforceable for community-based care. Therefore, MFP participants’

¹³ Special equipment was defined as items such as wheelchairs, canes, vans with lifts, and automatic door openers.

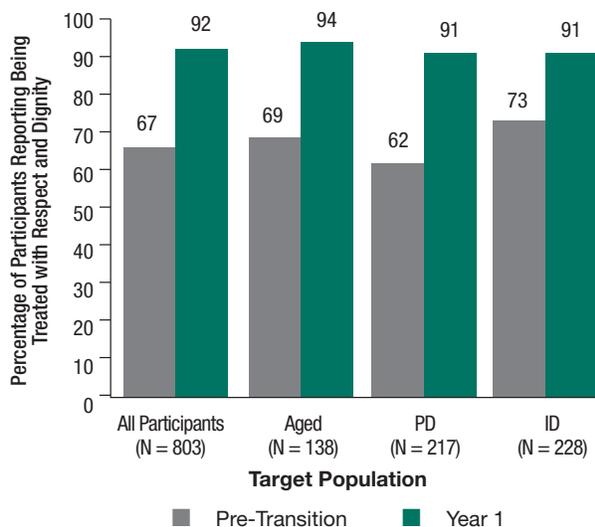
assessments of how they are treated once they live in the community and receive services there are a vital component in measuring quality of life.

Despite the concern about reduced safeguards, Figure 3 shows that MFP participants experienced a significant improvement in their treatment, increasing from 67 percent reporting treatment with respect and dignity during the pre-transition period to 92 percent a year after they transitioned to the community.¹⁴ Findings also demonstrated significant increases for each component of the measure independently, though neither component alone (82 to 96 percent for being treated well and 79 to 96 percent for being listened to) demonstrated the magnitude of improvement that the combined measure did.

Findings also revealed that reported physical abuse (an optional question designed to detect mistreatment by staff) decreased significantly post-transition (2 percent

¹⁴ The results combine responses to two questions asked of MFP participants who have caregivers who help them with everyday activities: “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?”

Figure 3. Percentage of MFP Participants Reporting Treatment with Respect and Dignity, Pre-Transition and Post-Transition



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

of participants reported physical abuse, compared with 6 percent pre-transition).¹⁵ Among target populations, participants with intellectual disabilities and aged participants reported significantly less abuse after transitioning (1 and 2 percent, respectively) compared with the rates reported while institutionalized (5 and 8 percent, respectively).

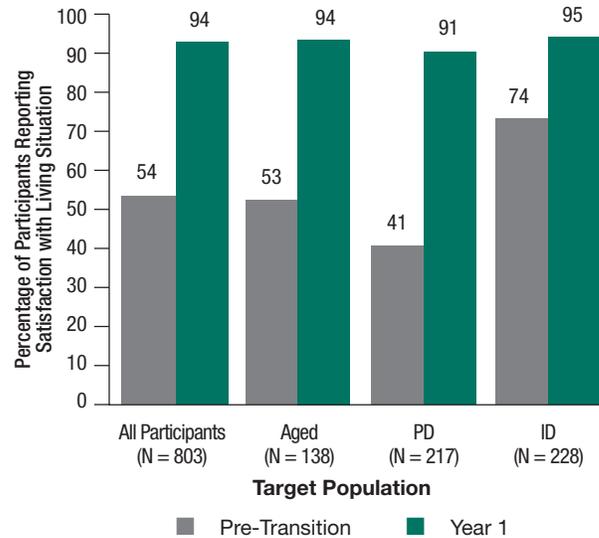
Community Life. A fundamental expectation of transitioning from institutional to community living is that participants will have enhanced community experiences. The MFP-QoL survey measures satisfaction with living arrangements, community engagement, work status, and degree of choice and control as proxies for participants' quality of community life.

Satisfaction with Living Arrangements. Most MFP grantees report difficulty finding appropriate housing for participants (Denny-Brown et al. 2011). The environments into which MFP participants transition vary, from homes and apartments (sometimes with family) to group homes of four or fewer residents. As Figure 4 shows, nearly all MFP participants (94 percent) reported liking where they lived nearly one year after transitioning, an increase large both in magnitude (compared with the 54 percent who reported liking their living arrangement while institutionalized) and significance. Improvement was significant for each target population. Likewise, improvement was widespread; among all participants not satisfied with their living situation in an institutional setting, 92 percent reported being happy at the one year follow-up (information not shown). Just 5 percent reported a decline in their satisfaction with living arrangements, and 18 percent of these participants were in institutional care at the time of the one-year follow-up survey.

Community Integration and Inclusion. Integration and inclusion in one's community can help minimize the potential for depression and loneliness that some people may experience transitioning from group settings to independent living. MFP participants report a high level of community integration and inclusion after transitioning to community living. For example, interactions with family and friends remained high after participants left institutional settings. Furthermore, most MFP participants reported an ability to see friends and family when they chose to, with the proportion doing so post-transition (90 percent) slightly

¹⁵ This question was answered by 481 respondents pre-transition and 470 respondents post-transition.

Figure 4. Percentage of MFP Participants Reporting Satisfaction with Living Situation, Pre-Transition and Post-Transition

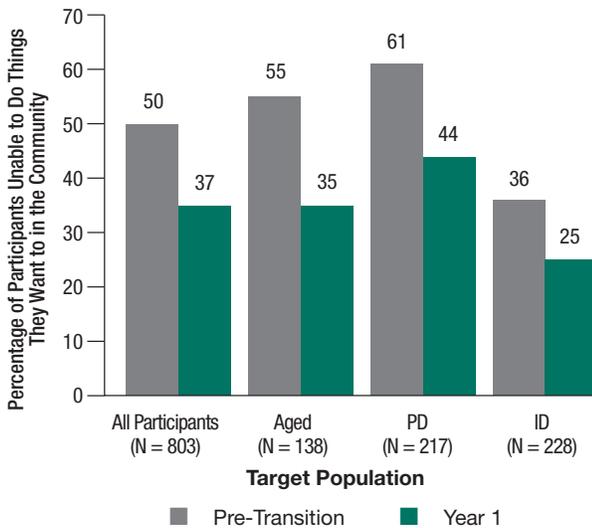


Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

greater compared with the period before transition (85 percent). Nearly all participants reported an ability to get to needed places such as work, shopping, or the doctor's office pre- and post-transition (89 and 95 percent, respectively). Only participants with physical disabilities experienced a significant increase in their ability to get around the community (93 percent post-transition compared with 81 percent pre-transition).

A substantial change in community integration associated with transition was participants' ability to participate in activities outside their homes. Figure 5 shows that half of all MFP participants (50 percent) were unable to participate in community activities while in institutional care, but this proportion declined to 37 percent one year after the initial transition to community living. This limitation generally varied among the target populations, with the proportion of participants with physical disabilities who were unable to participate in community activities after transition to community living (44 percent) exceeding the rate for aged participants (37 percent) and participants with intellectual disabilities (25 percent).

Figure 5. Percentage of MFP Participants Reporting Barriers to Community Integration Pre-Transition and Post-Transition^a



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

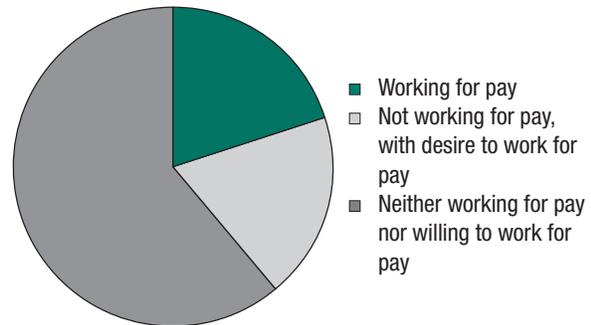
^a Assessed through the question: “Is there anything you want to do outside of your home that you cannot do now?”

We assessed post-transition outcomes related to paid employment and work on a volunteer basis.¹⁶ Nearly one-fifth of all MFP participants (19 percent) reported working for pay (Figure 6). As Figure 7 shows, participants with intellectual disabilities represented the greatest proportion of paid workers (72 percent). Fewer than one in ten (9 percent) participants reported doing volunteer work after transition (data not presented). One-fifth of participants (20 percent) did not report working for pay but indicated a desire to do so. Participants with physical disabilities represented the greatest proportion not working but willing to work for pay or on a volunteer basis (44 and 35 percent, respectively) (data not presented).

Choice and Control. Program participants should expect increased autonomy after they transition to community living. The MFP-QoL survey assesses six

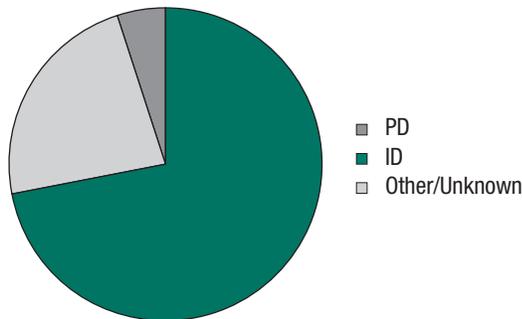
¹⁶ Questions related to employment and volunteer status were administered at the one-year follow-up survey only.

Figure 6. MFP Participants’ Paid Work Status After One Year of Community Living (N = 787)



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

Figure 7. MFP Participants Who Worked for Pay After One Year of Community Living^a (N = 148)



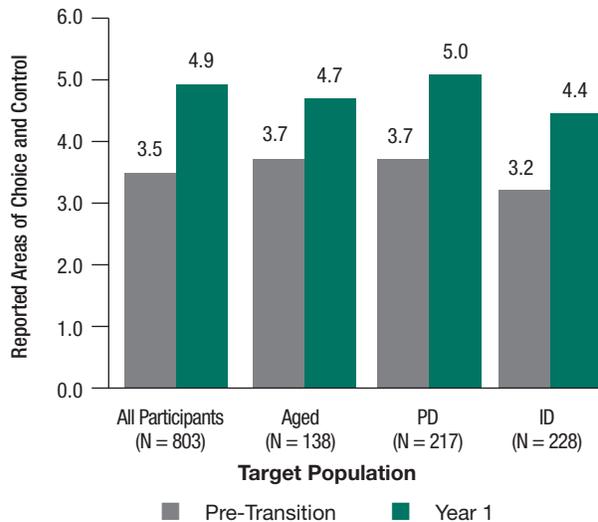
Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

^a Aged participants did not report working for pay.

areas of choice and control: being able to go to bed when one desires, the ability to be alone when one chooses, the ability to eat food of one’s choice and when one chooses, and the ability to use the telephone or watch television when one chooses.

As Figure 8 shows, MFP participants’ choice and control increased significantly between the pre-transition

Figure 8. Average Number of Areas of Choice and Control Reported by MFP Participants, Pre-Transition and Post-Transition



Source: Mathematica analysis of MFP-QoL survey and Program Participation data files submitted through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010.

Note: The MFP-QoL survey assesses six areas of choice and control: being able to go to bed when one desires, the ability to be alone when one chooses, the ability to eat food of one's choice and when one chooses, and the ability to use the telephone or watch television when one chooses.

period and one year post-transition (from an average of 3.5 areas of choice and control to 4.9 areas). Moreover, results revealed that autonomy among each of the six individual measures of choice and control increased significantly, although most gains were modest. Trends in increased choice and control were similar across the different target populations.

Implications of Participant Quality of Life One Year After Transition to Community Living

This early assessment of MFP participants' experience a year after their initial transition to community living suggests that participants experienced significant improvement in their quality of life. Should the trends reported here continue throughout the demonstration, then most MFP participants can be expected to experience an enhanced quality of life once outside

the institutional setting. Other preliminary findings show that MFP had a broad effect across all target populations, with each quality-of-life domain showing statistically meaningful change from pre-transition levels. These early findings also suggest that MFP is doing more than simply facilitating transitions to the community, as participants reported increased levels of community integration, as well as reduced levels of unmet care needs and expanded choice and control in community settings. Global ratings of quality of life increased significantly and, given our inclusion of the small but significantly less satisfied institutionalized population, may be a slight underestimate of satisfaction among participants who successfully transition to the community.

We observed the largest relative improvements for satisfaction with living arrangement and the percentage of participants reporting any unmet care needs; both measures improved by 74 and 73 percent, respectively. Although mood status improved significantly at one-year post-transition, this domain showed the least improvement; still, the percentage of participants reporting they felt sad or blue fell 19 percent between pre-transition and one-year follow-up. However, in spite of this improvement, more than one-third of MFP participants (38 percent) reported feeling sad or blue over the past seven days following transition to the community.

The paradoxical finding that 8 of 10 participants indicated they were satisfied with the way they lived their life post-transition, yet a substantial minority reported depressed mood, warrants further attention. It is possible that respondents overstate their satisfaction ratings or that their reported mood levels are biased in some way. Regardless, the overall magnitude of reported depressed mood suggests that providers and HCBS programs should carefully monitor mood for participants who make the transition from institutional care to community. Although a participant may be happy to move to the community, the transition to community living has the potential for isolation or for community living not matching a participant's expectations. Future analyses of the quality-of-life data collected by MFP grantees will include additional assessments of mood and its relationship to critical outcomes such as satisfaction and reinstitutionalization.

Our findings may have been influenced by the availability of informal support networks for MFP partici-

pants. Beyond the linkages to the formal services MFP provides, participants transitioning to a community setting rely upon informal social and care supports. The contribution of such informal networks to enhanced quality of life is unknown, but their economic value within the U.S. health care system is estimated to exceed those of the formal health care and nursing home care sectors combined (Arno et al. 1999). We observed that about one-third of sample participants received informal support from family and friends. The extent of these informal supports, exogenous to the MFP program, may play an important role in maintaining participant quality of life. Monitoring the provision of such services will increase in importance following the 365-day period of MFP participant service provision (that is, when formal MFP supports are no longer available). Family and friends play a vital role in this regard, but so do other forms of social networks, such as faith-based institutions and congregations, community centers, and volunteer organizations.

Identification of, and access to, appropriate housing is a frequently reported barrier for many MFP grantees (Denny-Brown et al. 2011). However, our findings indicate that, after housing is secured, respondents are overwhelmingly satisfied with their living arrangements (94 percent). This finding also implies that grantees have largely been successful in meeting the housing needs of the participants represented in this analysis.

About one in five MFP participants reported working for pay during the first year living in the community, although employment varied widely by target population. Overall, 48 percent of all participants who wanted to work for pay reported doing so.¹⁷ Nearly half of all participants with an intellectual disability reported paid work experience, while no aged participants and very few participants with physical disabilities (4 percent) worked for pay. Among those not working, the desire to work was most common among participants with physical disabilities.

Although the findings of this report are largely positive, we note several areas where participant experience can be improved. First, many participants who are not currently working, particularly participants with physical disabilities, would like to be. The high level of interest

¹⁷ Calculated as the number working divided by the number working plus the number not working but reporting that they wanted to work.

in, and low reported rates for, paid work, represents an important opportunity for grantees to further enhance the integration of MFP participants into their communities. Second, about a third of all participants report barriers to community integration, with more than 4 in 10 participants with physical disabilities reporting they were unable to participate in community activities. Third, 6 percent of aged and participants with physical disabilities reported unmet care needs. Because the survey focuses on assistance with such tasks as bathing, meal preparation, medication management, and toileting, not receiving assistance with these activities greatly diminishes quality of life and may introduce unnecessary risk for the participant. Finally, depressed mood continues to be reported for a noteworthy portion of participants, and more attention to mood status may be necessary to ensure that the participant has a successful transition to community living.

Study Limitations

Several important limitations of our analysis warrant consideration and caution concerning the overall positive findings presented in this report. The information in this report should be considered preliminary before our findings can be taken as representative of the program, as our findings need to be replicated for a larger proportion of participants, and baseline characteristics of participants need to be controlled for in the analyses.¹⁸

Compared with recent reports on the number and types of MFP participants who transitioned through MFP, our analytic sample under-represents aged and physically disabled participants (Lipson and Williams 2010). The sample reflects participants who had data submitted on their behalf and where a linkage between the pre- and post-transition surveys could be established and both could be linked with administrative data records. In addition, the data set includes participants from 22 of the 30 grantees. Given that MFP transitioned approximately 5,600 participants through December 2009, our study sample represents fewer than one in six of all transitions that could have an associated follow-up one-year assessment by September 2010, the last month of data included in this report. Not having data on these participants may bias the results if excluded participants were systematically different from those in our sample. To assess differences between this

¹⁸ Future reports will address these issues.

group of participants and participants not represented in this analysis, we compared pre-transition ratings of global satisfaction for the participants in this analysis with those of a larger group of MFP participants not included in this study (N = 1,779) and found that baseline global satisfaction scores were not significantly different. However, we caution that our findings will require replication in a larger group of participants before we consider them representative.

Another important data limitation was lack of institutionalization site and age data for approximately one-quarter of the respondents. These variables are missing on grantee-submitted MFP Program Participation Data files; however, they will be available through follow-up with the grantees and linking these data to Medicaid eligibility records, which will be conducted at later stages in our analysis.

The method of survey administration is also a potential source of bias for these data. Because grantees administer the MFP-QoL survey, and surveys are often conducted by MFP transition coordinators, consumers may feel compelled to overstate satisfaction if they felt a need to provide positive information or believed that reporting problems could result in negative outcomes for themselves. Although there is no evidence that this occurred, this phenomenon cannot be ruled out as a bias in the data in terms of absolute values. However, if the bias is similar between the pre- and post-transition surveys, the change in improved outcomes should not be affected.

Another possible confound to our findings is that quality of life and ratings of participant experience are, by their very nature, subjective entities. Participant expectation of transition at the time of the pre-transition survey may color ratings of participant experience. However, given the significant increases in participant-rated quality of life at follow-up, this confound does not appear to have a strong effect on our findings. Should it exist, the changes we can document with these data may understate the true change in quality of life.

We acknowledge this analysis excludes a range of unmeasured program and individual factors that are likely to affect participants' first-year experience. For example, we plan to explore program characteristics such as model of caregiver employment (agency versus self-direction). Similarly, we are interested in understanding how the type and volume of HCBS received affects participants' experience. Furthermore,

grantees have identified specific activities to rebalance long-term care by expanding the availability of HCBS; providing transition services (for example, case management, housing assistance, or one-time transition expenditures); or providing other innovations, such as investing in assistive technology (Denny-Brown et al. 2011). Finally, we plan to control for differences in participant characteristics at discharge using Minimum Data Set data for participants who transition from nursing homes. Many of these activities and characteristics are likely to affect participant quality of life and will be explored in future reports.

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DATA AND METHODS

Data Sources

The statistics presented in this report are derived from two data sources: (1) MFP-QoL surveys, and (2) Program Participation Data files. All MFP participant experience data are obtained through administration of the MFP-QoL survey by grantees. The MFP-QoL was developed by Mathematica staff and is based largely on the Participant Experience Survey, with several items drawn from other instruments.¹⁹ The MFP-QoL instrument captures seven aspects of participants' quality of life: (1) overall satisfaction, (2) satisfaction with living arrangements, (3) unmet need for personal care needs, (4) respect and dignity, (5) choice and control, (6) community integration and inclusion, and (7) mood status.

Data from the MFP-QoL were matched with MFP Program Participation Data files; both file types are submitted by grantees quarterly. The participation files confirm participant eligibility status and provide information on qualified institutional stays, qualified residence, and reinstitutionalization. This analysis used MFP-QoL and participation data submitted to CMS through November 2010, representing transitions through December 2009 and 1-year follow-up surveys through September 2010. We included individuals' baseline and one-year follow-up survey records that could be matched with a record in the MFP Program Participation Data files.

To classify the MFP target populations, we used information on the qualified institution and age as reported at the time of an individual's initial transition to the community to construct MFP target group assignments for enrollees (both are reported in the MFP Program Participation Data files). The aged were individuals 65 years or older who transitioned from a nursing home; individuals with physical disabilities were younger than 65 who transitioned from nursing homes; and individuals with intellectual disabilities were participants of any age who transitioned from an ICF-MR. Individuals transitioning from any other type of institutional care were assigned to "other," and individuals without complete age or qualified institution data were categorized as "unknown."

The analytic sample includes 803 people with institutional (baseline) and one-year follow-up MFP-QoL surveys that could be matched with a participation record. To ensure that follow-up survey data reflected participant experience at one year, we included data for participants with a follow-up survey conducted between 8 and 16 months after their institutional assessment. The sample includes participants from 22 of the 30 grantees, although data from four states (Connecticut, Missouri, Ohio, and Oregon) make up 54 percent of the sample.²⁰

¹⁹ Those instruments include ASK ME! Cash and Counseling, National Core Indicator Survey, Quality of Life Enjoyment and Satisfaction Questionnaire—Short Form, and the Nursing Home Consumer Assessment of Health Plans Survey.

²⁰ Grantees with no data in the sample are Delaware, Illinois, Indiana, Louisiana, Michigan, North Carolina, North Dakota, and Virginia.

(continued)

DATA AND METHODS (continued)

To assess participant experience, we selected key indicators for each domain on the MFP-QoL instrument. For aspects of participant experience where a single, key indicator question can be identified, we selected that indicator to represent the quality-of-life domain. For example, we used the item assessing whether participants felt sad or blue to represent the domain of mood. In domains where we selected a single item to represent participant experience, we also examined other related items to ensure consistency. For example, for the domain of choice and control, information from all six questions assessing participant choice was summarized to yield a count of areas of reported choice and control.

QoL Survey Administration

Grantees are responsible for survey administration, data entry, tracking, quality assurance, and transmission of the data to CMS. The survey, which takes about 20 minutes to administer, consists of 41 questions and is designed to be conducted in person and in a private setting. Grantees are instructed to collect MFP-QoL survey data for *all* participants before the transition to the community, and again at one and two years after transition. Methods and staff used to administer the survey vary by state. Grantees reported using one of four staff types to administer the instrument and collect MFP-QoL data: (1) transition coordinators; (2) private contractors (such as universities); (3) office-based staff (for example, people employed by the state Medicaid office); and (4) volunteers. Use of transition coordinators is the most common approach, followed by use of office-based staff and private contractors. Use of proxy respondents was permitted, and the survey was completed by proxy respondents for 23 percent of pre-transition interviews and 16 percent of post-transition interviews.

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