

Using Medicaid Data to Identify Factors that Predict Reinstitutionalization of Mississippians with Disabilities and Elderly People

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Background: Mississippi Bridge to Independence (B2I) was Mississippi's Money Follows the Person (MFP) program seeking to rebalance the state's long-term care system by transitioning Medicaid beneficiaries from institutional living to home- and community-based settings (HCBS). Success of initial transitions has been documented in state cost-savings and participants' quality of life increases. However, reinstitutionalization poses a challenge to sustaining a positive outcome for the initiative. *Purpose:* Therefore, the purpose of this research is to identify the underlying causes of participants' reinstitutionalization. *Methods:* The Quality of Life (QoL) survey designed by Mathematica Policy Research was used to measure variables in 7 categories. Data was collected from 399 participants in face-to-face interviews over a 4-year period (2012–2016). *Results:* Among participants, 71.9% (n = 287) completed the B2I program successfully, whereas 8.27% (n = 33) were reinstitutionalized. Utilizing the logistic regression model, results determined elderly people were 15 times and those with physical disabilities were 5 times more likely to be reinstitutionalized than those with intellectual disabilities. Among 7 QoL variables, 2 were found to be significant: "Happiness" and "Choice and Control." *Conclusion:* Implications from this study can be important to sustaining the project, developing new policies, and advancing community-supportive infrastructure in Mississippi.

Keywords: disability study, reinstitution, quality of life, independence, logistic regression

Introduction

In the last three decades, the United States has had an increasing trend of long-term care in facilities such as nursing homes as the aged population has increased. This trend is likely to continue due to the increasing number of people surviving to 65-plus years of age. In 2016, around 49.2 million Americans were ages 65 or older, and that number is expected to rise to 98 million by 2060 (U.S. Department of Health and Human Services, 2017). According to the Centers for Disease Control and Prevention (CDC), around 5.8 million people ages 18 or older had limitation in activities of daily living, and more than 106 million had limitation in instrumental activities of daily living in 2016 (National Center for Health Statistics, 2016).

To reduce the burden of states' long-term care cost and to increase beneficiaries' quality of life, various federally funded programs have provided home-and community-based services (HCBS) over the last decade. Some studies reported that these programs can reduce their expenditure if the participants stay at HCBS for a 12-month period (Bohl, Schurrer, Miller, Lim, & Irvin, 2015). Programs like Money Follows the Person (MFP) can be successful if the participants experience better quality of life and higher quality of care with no additional costs than they would have if they remained in institutional care. However, many of the participants return to the institutions after transitioning to HCBS for various reasons, such as low quality of care, poor medication system, language barriers, and so forth (Hostetter & Klein, 2012). In Mississippi, MFP was implemented from 2012 to 2016 under the name Bridge to Independence (B2I).

Prior to the mid-20th century, it was common in the U.S. to institutionalize people with disabilities who required long-term care, excluding those who were labeled "abnormal" from normal social interaction (Burrell & Trip, 2011). In 1977, it was estimated that 83.7% of people with intellectual disabilities/developmental disabilities (ID/DD) using residential services lived in institutional settings with 16 or more residents, representing more than 200,000 people with ID/DD (Lakin & Stancliffe, 2007). More and more research studies found that alternative, community-based care was more effective than hospital care for patients with mental disabilities in terms of treatment results, living arrangements, and expenses (Kiesler, 1982). This coincided with a shift in the philosophical approach used for those who required long-term care (Burrell & Trip, 2011). Across the world, societal treatment of people with disabilities began to be seen as a human rights issue, focusing more on quality of life and encouraging individualization of needs-response and treatment programs (Mental Welfare Commission for Scotland, 2003).

As research continued and community-based residential programs began to develop, those patients who did not require acute treatment began to be deinstitutionalized, shifting the care of people with disabilities from a hospital setting to smaller, community-based settings (Dorwart & Hoover, 1994). This process of deinstitutionalization began to significantly reduce the populations in state-run hospitals (Fisher et al., 2001). By 2005, a mere three decades later, only

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16.3% of people receiving residential services lived in large-scale institutional settings (Lakin & Stancliffe, 2007).

This applies not only to those with ID/DD but also those with physical disabilities and elderly people who require long-term care. As civilization moved from the large, extended-family model to the nuclear model, it became atypical for the elderly to be cared for at home and led to higher rates of institutionalization. But studies have shown that receiving even small amounts of help in the home setting may prevent the elderly from needing institutionalization (Yamada, Siersma, Avlund, & Vass, 2012). Those who utilized available home- and community-based services, especially respite care and rental services for assistive devices, were less likely than non-users to be institutionalized (Tomita, Yoshimura, & Ikegami, 2010). Studies also found that supplementing family or informal care with home-based formal care might reduce the risk for hospitalization in community-living older adults who were eligible for long-term care (Li, Chi, & Xu, 2010). In addition, hospitalization rates significantly decreased after non-institutionalized, disabled elderly people were provided with help for activities of daily life (ADL) disabilities, through community-based, long-term care services (Sands et al., 2006). Community-based services could have a very positive effect on the lives of those who might have otherwise been hospitalized or institutionalized.

These changes in both philosophy and execution of approach represent an advantage in cost and treatment effectiveness, as well as in the quality of life experienced by those in long-term care. In 2001, O'Brien, Thesing, Tuck, and Capie found that, after deinstitutionalization,

the positive changes and advantages discerned for [those receiving long-term care] were further encapsulated in how the person's current quality of life was perceived. Both staff and family indicated there had been significant increases in satisfaction levels related to the extent and type of material possessions, the person's health, meaningful daily activities, safety, the person's place in the community and emotional well-being (p. 78).

The same study also reported an increase in social and adaptive skills among those with long histories of institutionalization. Community-based care provided a sense of community that usually was not possible in hospital and institutional settings.

However, it was not a simple matter of moving patients from one building to another. In order for deinstitutionalization to be effective, it had to be a proactive and self-aware process. Programs had to be in place to ensure that patients continued to receive appropriate levels of health care and that they were given the tools needed to succeed in a community-based setting. Research showed that inadequate preparation before discharge left a significant number of patients with mental disabilities homeless or in prison (Eikermann, 2000). In some cases, community services provided insufficient levels of treatment for patients with disabilities (Lamb,

2001). Even after deinstitutionalization, many patients with severe illnesses were still without work, had few social contacts, and lived in sheltered environments (Fakhoury & Priebe, 2007). This lack of social integration for patients following their discharge from institutional settings was still far from the desired full integration (Eikermann, Reker, & Richter, 2005). The challenge ahead was to develop an adequate supply of high-quality, community-based service systems to successfully sustain deinstitutionalization (Vladeck, 2003).

The Mississippi Bridge to Independence (B2I) program was focused on the transitional period after deinstitutionalization. It helped to remove barriers to home- or community-based living for people with physical, intellectual, or developmental disabilities, as well as older adults (65 years and older). It was an MFP initiative funded by the Centers for Medicare and Medicaid Services (CMS). B2I provided transition services for qualified individuals after their discharge from an institutional setting. These services included transition care management, housing start-up costs, transportation, extended pharmacy benefits, durable medical equipment, caregiver and peer support, life skills training, and safety planning.

Schurrer and Wenzlow (2011) studied the post-transition outcomes (from institutionalized to home- or community-based settings) of MFP participants in 25 states and found that 9% of the participants were reinstitutionalized during the first year of transition. They concluded that those participants who re-entered the institution did so mostly within the first 3 to 6 months after transition. This was the period when the responsibility of the MFP services was moved from transition experts to care coordinators. Researchers concluded that it was essential to have a smooth transfer process to ensure the continuity of services during the first, most vulnerable months of participants' integration into the community (Schurrer & Wenzlow, 2011). A decline in the individual's mental or physical health was the main factor for reinstitutionalization. Other reasons included short-term hospitalization, lack of family or other support systems within the community, and loss of housing (Denny-Brown, Lipson, Kehn, Orshan, & Stone, 2011).

Though researchers have suggested a few factors that might lead to reinstitutionalization, there was no definitive explanation in the literature. But this was a situation that could not be ignored: with the maturation of the so-called baby boomer generation, the need for adequate and effective long-term care was becoming more urgent with each passing year. By 2050, the U.S. population aged 65 and over is predicted to reach 83.7 million, nearly twice its estimated population of 43.1 million in 2012; similar increases are expected in all developed countries (Ortman, Velkoff, & Hogan, 2014). A large portion of the global population would need long-term health-care services, and it would be important to ensure that we have programs in place to help patients transition from an institutional setting to a community-based service model. Therefore, the purpose of this research was to determine the factors affecting reinstitutionalization among the Mississippi B2I program participants at 12 months post-transition from institutions to HCBS in an effort to lessen the likelihood of reinstitutionalization. Findings could lead to new policy

development, long-term care cost-effect rebalancing, program and practice improvement, and enhancement of beneficiaries' quality of life.

Methods

Participants and Process

According to the eligibility criteria provided by the Centers for Medicare and Medicaid Service's Money Follows the Person (Mathematica Policy Research Report, 2017a), Mississippi Medicaid beneficiaries who were willing to transition from institutionalized care to home- and community-based settings were referred to the B2I program from local nursing homes or Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) across the state. Qualified B2I participants were those who had lived in an institution for at least 90 days and were either 18 years of age or older with a disability or 65 years of age or older. Based on the program procedure, each B2I participant was given a personal interview using a survey instrument to determine quality of life pre- and post-transition. From January 2012 to December 2016, a total of 399 beneficiaries had transitioned to the community or enrolled in B2I. Data collected by Medicaid program staff from these individuals were used as a cohort for the study. Of the 399 participants, 232 completed a 12-month follow-up survey using an identical survey instrument (Mathematica Policy Research Report, 2017a). According to U.S. Department of Health and Human Services (HHS) regulations for the protection of human subjects in research (Office for Human Research Protections, 2018), this study did not require approval by the Institutional Review Board.

Instrument

The Quality of Life (QoL) survey was developed by Mathematica Policy Research to measure MFP implementation. Using the same instrument, B2I was evaluated and this study conducted. The QoL contains 41 multiple-choice and short, open-ended questions in seven modules, plus two follow-up questions. The seven modules used to measure the quality of life of participants include Living Situation, Choice and Control, Access to Personal Care, Respect and Dignity, Community Integration and Inclusion, Overall Life Satisfaction, and Health Status.

The instrument was administered to the program participants at three points in time: just prior to transition, 12 months after transition, and about 24 months after transition. Trained Medicaid personnel administered the questionnaire. To ensure a consistent data-collection procedure and high-quality data, the process followed the protocol and instructions provided by Mathematica Policy Research.

Socio-demographic variables. The following socio-demographic variables were included: gender, age, kinds of disability (physical, intellectual, and elderly), race/ethnicity (Caucasian, African American, and other), living with family (yes/no), and residence type

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(family/participant-owned home, leased apartment, and group-home living with four or more people).

Quality of life variables. The items in the seven modules for the quality of life measurements were summed up as total score. The seven modules were Living Situation (0–4), Choice and Control (0–12), Access to Personal Care (0–4), Respect and Dignity (0–5), Community Integration and Inclusion (0–13), Overall Life Satisfaction (0–10), and Health Status (0–6). Aggregated higher scores indicated more positive or optimistic outcomes of B2I participants' quality of life. The detailed scores for the seven modules are in the Appendix.

Outcome variable. Researchers recorded and followed the B2I participants who remained in the community-living setting and those who were reinstitutionalized. Reinstitutionalization is defined as any admission to a hospital, nursing home, intermediate-care facility, or institution for the same diseases after transitioning to a community-living setting. Reinstitutionalization is one of the key success indicators of B2I transitions. A lower rate is a better indicator of transition success.

Statistical Analysis

After the descriptive analyses of the socio-demographic and quality of life variables, we evaluated the relationships between each variable and the outcome variable (reinstitutionalization) using chi-square independence tests, Cochran-Mantel-Haenszel chi-square tests, and Fisher's exact tests at 5% significance level. Continuous variables were checked for a normality assumption and assessed using independent two sample t-tests for continuous variables and chi-square independent tests for categorical variables. We performed multivariate logistic regression models to attempt to identify which socio-demographic and disaster-related factors were associated with an increased likelihood of being reinstitutionalized.

Results

Sample Characteristics

This study included 399 B2I program beneficiaries in Mississippi from 2012 to 2016. Among them, 232 participants responded to the 12-month follow up. Since all reinstitutionalization happened within a year of the transition, we used the 12-month follow-up data as the study sample. During the year, nine participants were deceased, nine moved to other regions, 11 no longer needed services, and three were suspended from eligibility. Two participants were removed from the sample pool for health reasons. After the transition to home- or community-based settings, 33 were readmitted to institutional facilities (8.3%), while 287 completed the program (71.9%) and remained in the communities.

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Among 399 participants, about 57% were people with intellectual/developmental disabilities, 28% had physical disabilities, and 14% were elderly. The participants were 59% male and 53% Caucasian. Participants' ages ranged from 4 to 91, with a median of 43 years old. The type of residences participants were transferred to included 23% homes owned by participants or families, 34% leased apartments, and 43% group homes. Only about 26% of participants were living with their families. Table 1 summarizes the characteristics of the participants. The descriptive analysis performed on outcome variables indicated the reinstitution rate was 8.3% (n = 33).

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Table 1
Participants' Demographic Characteristics (N = 399)

Variables	N	%	Mean (SD)
Benchmark			
Elderly	57	14.29	
Physically disabled	114	28.57	
Intellectually or developmentally disabled	228	57.14	
Gender			
Male	237	59.40	
Female	162	40.60	
Age			44.36 (18.85)
Age group			
Less than 25 years old	74	18.55	
25 to 34 years old	77	19.30	
35 to 44 years old	42	10.53	
45 to 54 years old	80	20.05	
55 to 64 years old	63	15.79	
More than 65 years old	63	15.79	
Race/Ethnicity			
African American	184	46.12	
Caucasian	212	53.13	
Other	3	0.75	
Residence			
Family/participant-owned home	90	22.56	
Group home, four people or fewer	136	34.09	
Participant-leased apartment	173	43.36	
Living with family			
Yes	102	25.69	
No	295	74.31	
Program completion			
Reinstitutionalized	33	8.27	
Completed B2I program	287	71.93	
Dropped	79	19.80	

Bivariate Analyses

To explore which variables were significantly associated with reinstitutionalization, bivariate analyses were performed (Table 2). The chi-square test of independence was conducted with significance level at 0.05 for the nominal-scale variables, and an independent two-sample t-test was conducted for the continuous variable. For the ordinal-scale variables, the Cochran-Mantel-Haenszel test for linear association was performed. Results indicated that the control variables, such as disability type, living status after the transition, and age, were significantly associated with reinstitutionalization.

Among the QoL variables, the total score of living situation, happiness, community integration and inclusion, and choice and control were statistically significant at $\alpha = 0.05$. These variables were included in the final model to explain reinstitutionalization by multivariate analyses.

Table 2

Bivariate Analyses Between Reinstitutionalization and Other Variables

	Test	Test Statistic	P
Socio-demographic variables			
Benchmark	χ^2	22.82	< 0.001
Residence	χ^2	17.42	< 0.001
Gender	χ^2	0.02	0.883
Age	<i>t</i>	4.76	< 0.001
Race/Ethnicity	χ^2	1.76	0.415
Living with family	χ^2	1.10	0.294
Quality of life variables (1-year follow-up)			
Respect and Dignity Score	CMH	1.64	0.200
Living Status Situation Score	CMH	7.967	0.005
Health Status Score	CMH	1.615	0.203
Happiness Life Satisfaction (Happiness) Score	CMH	13.714	< 0.001
Community Integration and Inclusion Score	CMH	3.930	0.047
Choice and Control Score	CMH	9.758	0.002
Access to Personal Care Score	CMH	0.131	0.717

Multivariate Analyses

Prior to applying the logistic model, multicollinearity was checked among independent variables. Only two variables were strongly correlated (disability type and age), which had more than two variance influence factors (VIF). Therefore, one of these variables was dropped from the model to avoid redundant information and to allow confounding factors among the remaining variables.

The multivariate logistic regression was used to determine which socio-demographic and quality of life factors were associated with an increased likelihood of reinstitutionalization (Table 3). The first model included only socio-demographic variables such as gender, race, disability type, age group, post-transition residence type, and whether or not participants were living with family. The global model likelihood ratio test indicated that the overall model was statistically significant ($\chi^2 = 30.42$, $df = 3$, $p < .001$). Among the socio-demographic variables, age and residence were significantly associated with reinstitutionalization. If a participant's age increased by 1 year, the odds of reinstitutionalization increased by 3.4% ($OR = 1.03$, 95% CI: 1.01–1.06, $p = .003$). If a participant lived in a leased apartment or a home owned by the participant or the participant's family, the odds of reinstitutionalization were five times more than those who lived in a group home ($OR = 5.14$, 95% CI: 1.40–18.79, $p = .013$, $OR = 5.06$, 95% CI: 1.28–19.94, $p = .021$, respectively).

Secondly, seven quality of life variables were added to the model to detect the relationship between reinstitutionalization and those variables, considering socio-demographic variables simultaneously. The global model likelihood ratio test indicated that the overall model was statistically significant at $\alpha = 0.05$ ($\chi^2 = 34.92$, $df = 4$, $p < .001$).

Compared to the group of people with intellectual or developmental disabilities, the elderly group had more than 15 times the chance of reinstitutionalization ($OR = 15.26$, 95% CI: 4.55–51.13, $p < .001$); the group with physical disabilities had about 5 times the chance of being readmitted into institutions ($OR = 5.22$, 95% CI: 1.56–17.47, $p = .007$). Among the QoL variables, the total score of happiness showed the statistical significance at $\alpha = 0.05$. Those who reported being happy after the transition were about 25% less likely to be reinstitutionalized ($OR = 0.75$, 95% CI: 0.59–0.96, $p = .023$). Furthermore, participants who had more chance to interact in the community or to have job/work opportunities in their communities were 24% less likely to be reinstitutionalized ($OR = 0.76$, 95% CI: 0.57–0.99, $p = 0.046$).

Table 3
Multivariate Logistic Regression Model

	Socio-demographic variable model			
	B	<i>p</i>	OR	95% CI
Socio-demographic variables-only model				
Age	0.033	0.003	1.034	1.011–1.057
Residence				
Participant-leased apartment	1.636	0.013	5.135	1.404–18.785
Family/participant-owned home	1.621	0.021	5.059	1.284–19.940
Participant-leased apartment				
Benchmark				
Elderly	2.725	< 0.001	15.259	4.554–51.129
Physically disabled	1.652	0.007	5.216	1.557–17.472
Happy score	-0.287	0.023	0.751	0.586–0.961
Community score	-0.270	0.046	0.764	0.586–0.995

Discussion

The Mississippi Division of Medicaid B2I project, Mississippi's Money Follows the Person initiative, was implemented (2012–2016) through grant support from the Centers for Medicare and Medicaid Services (CMS). The project has made positive impacts on rebalancing the state's long-term care system, strategizing Medicaid money-saving practices, and changing clients' quality of life through transitioning Medicaid beneficiaries from institutional facilities to home- and community-based settings (HCBS). The success of the project implementation has been well documented in program reports and evaluations throughout the awarded states, including Mississippi. To sustain the impact of the initiative, one of the challenges is to reduce the number of program participants being re-admitted to institutional facilities after transitioning to HCBS. In this study, we used seven variables from an established quality of life (QoL) survey instrument to identify the factors that may contribute to B2I participants' reinstitutionalization using descriptive analyses, bivariate analyses, and multiple logistic regression.

Among 399 B2I participants, the reinstitutionalization rate was 8.3% at 1-year post-transition sample follow-up, which is higher than the national rate. For all states participating in the program, about 5% of participants were reinstitutionalized for more than 30 days in 2016

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(Mathematica Policy Research Report, 2017a). Significant indicators for reinstitutionalization were identified as follows:

- Age of the participants: It appears advanced age of the participants is associated with likelihood of reinstitutionalization, which is concordant with the results of the national report.
- Type of disability: People with physical disabilities are more likely to be readmitted to institutions compared to the group of people with intellectual or developmental disabilities, which is also concordant with the results of the national report.
- Type of residence (after transition): Participants living in a group home (four or fewer people) seem to have a smaller risk of reinstitutionalization than those who transition to leased apartments or homes owned by participants or families.
- Satisfaction and happiness (after transition): Participants who have a higher level of satisfaction (happiness) with their life after transition show a reduced risk for reinstitutionalization.
- Community integration and inclusion: Participants who lack family and community support after transition or who live in social isolation have higher rates of reinstitutionalization.

Factors impacting B2I participants' reinstitutionalization rates were identified from this study as age, type of disability, level of community integration and inclusion, and type of housing. These findings agree with the literature for increasing the risk of reinstitutionalization. Community integration and inclusion was identified as one of the key factors of success for the program by many states, including Mississippi, through separate quantitative and qualitative studies (Mathematica Policy Research Report, 2017b). In this study, we confirmed that increased involvement and support from the community, such as job or volunteer opportunities, community organized activities, and so on, reduced Medicaid beneficiaries' risk of return to institutions. In addition, our results highlight the importance of community involvement and its subsequent effects on people's happiness or life satisfaction. Housing is also a crucial factor for the success of the program, according to the national MFP evaluator (Mathematica Policy Research Report, 2017b). We found type of housing could affect sustainability of transition. Specifically, we found better outcomes for participants who transitioned to group homes (defined as "community homes where a small number of unrelated people in need of care, support, or supervision can live together with supports and services") than for those who took part in supported living (defined as "services designed to help persons with disabilities live in their own home or live in a home that they share with roommates of their choosing"). Further investigation is suggested to determine if group homes affect the reinstitutionalization rate for the elderly and people with physical disabilities whose higher institution returning rate has been detected.

In our investigation, we are unable to identify the relationship between three of the seven variables and reinstitutionalization ($p > 0.05$). They are: Respect and Dignity, Health Status, and

Access to Personal Care. It is our belief that some of the questions from the survey are not accurate, precise, or specific enough to reflect the true perception. Better instrument development to fulfill the study purpose is recommended for a future study. In addition, confounding factors are suspected in this study. Interactive effects could be considered for further research using factorial analysis. Structural equation modeling may be used to explore more intricate relationships among the factors.

We realize identified factors in this study are limited by the variables derived from the QoL survey instrument. Factors associated with B2I participants' reinstitutionalization rate should be multi-faceted and include participants' socio-economic status; education level; level of support received from health-care providers, family, and community; and ability to live independently. Further investigation may result in a better understanding of reinstitutionalization risk indicators if redesigned variables with clear-cut specificities are applied to a survey instrument and subsequent test methods.

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Appendix

Quality of Life Variable Score Range

Modules	Score Range
Module 1: Living Situation	0–4
Module 2: Choice and Control	0–12
Module 3: Access to Personal Care	0–4
Module 4: Respect and Dignity	0–5
Module 5: Community Integration and Inclusion	0–13
Module 6: Overall Life Satisfaction	0–10
Module 7: Health Status	0–6

Aggregated higher scores indicated more positive or optimistic outcomes of B2I participants' quality of life.

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