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ABSTRACT

ASSOCIATION BETWEEN COMMUNITY TRANSITION AND INDEPENDENCE AND CONTROL OVER LIFE: ANALYSIS OF GEORGIA'S MONEY FOLLOWS THE PERSON PROGRAM

By

FARAH NAZ SULAIMAN

April 24, 2017

INTRODUCTION: The growing proportion of the elderly population and individuals with disabilities is increasing the demand for institutional long-term care. The majority of nursing home residents desire to exercise control over their lives and to have independence in activities of daily living, but nursing home care is often associated with loss of control and independence among its residents. Money Follows the Person (MFP) is a rebalancing strategy to contain cost for long-term care and enhance consumer choice for elderly individuals and individuals with disabilities. The MFP program helps qualified individuals living in institutions make the transition to life in the community.

AIM: This study is aimed to explore the association of community transitions and the measures of independence and control over life among MFP participants who have relocated from institutions to the community.

METHODS: Data from Georgia's MFP participant survey from 2008 to 2015 were used to examine the association between community transition and measures of control and independence before transition and 12 months after transition. McNemar's test was used to measure the before and after transition differences. Odds ratios and 95% confidence intervals were reported to determine the correlation of study measures with age, sex and disability type.

RESULTS: The analysis for 664 MFP participants (54.4% male and 45.6% female) surveys in the state of Georgia found a significant increase in 13 out of 15 measures of independence and control over life (e.g., being able to pick the place of residence, go to bed when want to, choose the type of food to eat, have privacy to talk on telephone, do paid/voluntary work and others) after transition, attributed to community transitions (p-value <0.05). Correlations between age and disability type and measures of independence were statistically significant whereas sex of the participant was not.

DISCUSSION: Results suggested that relocating individuals with disabilities into the community can help increase perceived control and independence and reduce the limitation of choice, providing insight for policy makers to strengthen programs that can have a meaningful impact on cost-containment and quality of life for elderly people and for individuals with disabilities.

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CONTROL OVER LIFE: ANALYSIS OF GEORGIA'S MONEY FOLLOWS THE PERSON
PROGRAM

by

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APPROVAL PAGE

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Author's Statement Page

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FARAH NAZ SULAIMAN
Signature of Author

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1. INTRODUCTION

1.1. Background

Nearly 40 million people in the United States have some form of age-related, physical or developmental disability that restricts their participation in daily life activities (Field & Jette, 2007). And 1.8 million people from this group receive some form of long-term care in a nursing home or any other type of institutional facility in the country (Kaye, Harrington, & LaPlante 2010). With the advancement in medical technology, there has been an increase in the life expectancy of all people, including individuals with disabilities which enables people to not only live longer but become sicker with age, increasing the demand for long-term care and support (Bengtson, Settersten et al. 2016; Fries, 2003; National Health Interview Survey, 2012).

1.2. Long-term Care

Long-term care refers to a continuum of services to support chronically disabled individuals with their activities of daily living (ADL), rehabilitate or compensate for loss of their independent physical or mental functioning (Stone, 2000). The services range from assistance with ADLs (bathing, eating, dressing) to instrumental activities of daily living (meal preparation, shopping, transportation) and provision of assistive devices and housing and home modifications. These services are either provided in an institutional facility such as nursing homes or community residential setting such as personal homes, group home or any other community living setting.

70% of adults aged 65 years and above need nursing home care at some point in their lives that may last for an average of 3 years (Alkema, 2013). Of overall adults in nursing homes, nearly 16% are under the age of 65 while 8% are over the age of 95 years and the remaining 76% are between the ages of 65 and 95 (CMS, 2015). This heterogeneity of the needs of nursing home

residents in terms of their age differences, disability and personalized care may cause difficulties in promoting independence and control over life among these individuals and may also have negative health outcomes (American Psychological Association, 2014; Thompson & Thompson, 2001).

Institutional long-term care, in particular nursing home care, has often been associated with loss of control and independence among its residents (Bengtson, Settersten et al. 2016). Majority of nursing home residents desire to exercise control over their lives and independence in activities of daily living (Boelsma, Baur et al. 2014; Shearer, 2009).

1.3. Olmstead Ruling and Independence and Choice

The Olmstead ruling involved the enactment of Title II of the American Disability Act (ADA) which prohibits any kind of discrimination against individuals with disability by any state or local government (Olmstead v. L. C., 1999). The ruling resulted from a court case brought by two women in 1999 with intellectual disabilities who needed community long-term care but remained institutionalized for years in violation of ADA as state failed to provide community long-term care. The case considered whether individuals with disabilities should receive long-term care in the community. The Olmstead court found that community long-term care must be offered if appropriate, if a person with a disability is willing to move into a community setting, if the state can accommodate the placement within its available resources (Musumeci and Claypool 2014).

Therefore, as implied by Olmstead ruling, an individual's independence and control over life should not be superseded by the disability he/she has. Therefore, long-term care should be planned in a way to promote independence and personal choice and control over life and during

past years states have started programs to enable individuals receive long-term care in the community.

1.4. Medicaid and Long-term Care

Medicaid is the largest payment source for long-term care services and is considered to have an institutional bias of covering services mostly attained in a nursing home facility and less in the community (Musumeci and Claypool 2014). With the growing proportion of individuals with disabilities and the increased demand for long-term care, Medicaid has been facing skyrocketing expenditures for nursing home care. Therefore, initiatives have been started to rebalance the system by shifting focus towards Home and Community Based Services (HCBS) which is less expensive and preferred by beneficiaries (Reinhard, 2010; Musumeci & Claypool 2014). Money Follows The Person (MFP) Program is one such initiative funded by Center for Medicare and Medicaid Services (CMS) – a federal agency that administers the Medicare program and works in partnership with state governments to administer Medicaid in the form of demonstration grants – to the participating states.

1.5. Money Follows the Person across the United States

The program is being implemented in 43 states and the District of Columbia as of 2016 (Medicaid.gov, 2016) and aims to (Rall & Mason, 2013):

- Assist individuals with Medicaid coverage to relocate back into the community from nursing homes while maintaining their coverage through HCBS programs
- Contain the increasing burden of institutional long-term care services through successful community transitions of aged and people with disabilities from nursing homes
- Improve the quality of life of these individuals by developing more sense of independence and personal choice and strengthen their ties to the community

Nationally, approximately 52,000 individuals were transitioned from nursing homes to the community as of 2014 across all participating states. It includes 37 percent of older adults, 38 percent under the age of 65 with a physical disability, 18 percent with intellectual disability, 6 percent with mental illness, and 2 percent with some other type of impairment (Mathematica, 2015). These numbers show the growing demand and preference for community long-term care in their preferred home settings.

1.6. Money Follows the Person – Georgia

The state of Georgia received its MFP Rebalancing Demonstration grant in 2007 for five years by, to relocate individuals with disabilities from institutional care settings to qualified community residences. Expanding on Georgia's Olmstead Initiatives under the Americans with Disabilities Act (ADA), MFP is administered by Department of Community Health (DCH) in the state of Georgia (Policies and Procedures for Money Follows The Person, 2010). The programs enroll qualified Medicaid beneficiaries residing in an institutional setting for a minimum of 90 days. Through HCBS waiver services participants receive services such as mental health services, non-Medicaid federally funded services, State funded programs and local community funded services for which they are eligible per their needs. Potential participants are identified through referrals from nursing homes, family members or social workers. Once the eligibility is determined, the transition coordinator meets with the individual and/or representative to obtain informed consent for participation in the program and determine the level of services needed in the community. Once the transition arrangements are complete in the community, the participant is discharged from the nursing facility and relocated in the community aiming that they will feel more secure and socially included in the community.

The paradigm of long-term care started to shift towards the community with the

independent living movement in 1970s and got more reinforcement with the Olmstead ruling v. L.C. (1999). MFP is providing an opportunity for individuals with disabilities to relocate into the community and to best exercise their independence and regain the control over their lives in a least restrictive environment. Research is needed on the outcomes of these moves to ascertain whether the program is achieving its intended goals. The data gathered from program participants can be a great source of information to study the relationship of community transitions or long-term care in the community and increased independence and control over life among old age individuals or individuals with any kind of disability.

The purpose of this study is to explore whether relocating individuals with disabilities from nursing homes to the community relates to changes on the measures of independence and control over one's life.

2. REVIEW OF LITERATURE

2.1. Theoretical Framework

Independence and control-over life are matters of human right (Putnam & Frieden, 2014). Often overlooked in the medical model for long-term care and support services (LTSS), the control and decision making power for disabled individuals is given to medical providers and professionals in institutional care settings (Bengtson, Settersten et al. 2016). However, begun in the 1970s the independent living movement started a paradigm shift from a medical model of institutional care to more social care model of community-based care, promoting consumer choice and control in the process of care. These social models are person-centered and focus on disability as a ‘mismatch of person’s capabilities to the environment’s characteristics rather than a medical condition (Bengtson, Settersten et al. 2016). Based on Person-in-Environment theory, individuals and their social environment are two separate yet contagious units which can communicate and influence each other (Kondrat, 2002). Emphasizing a similar notion, the International Classification of Functioning, Disability and Health framework describes functioning and disability as a dynamic interaction between health status and contextual factors, both personal and environmental (WHO, 2011). Developed by Gerben DeJong in 1978 the “Independent Living Paradigm” described that the problem with existing medical model is that it is a dependency-creating model and promoted the new paradigm of advocacy, self-help, consumer-control over services, and independent and integrated community living (Shreve, 2011). Therefore, consumer choice and preference are crucial in planning and providing for long-term care for aging and individuals with disabilities for them to be more self-acting and independent in their day-to-day lives (Jacobs-Lawson, Waddell, & Webb, 2011; Shearer, 2009).

Central to Person-centeredness, Person-in-Environment theory and Independent Living Paradigm, policy changes and care frameworks emerged that support consumer choice, control, and independence in a least-restrictive environment for old-age and individuals with disabilities under the Administration of Community Living (ACL), The Aging and Disability Resource Connection (ADRC) and the Affordable Care Act (ACA) (Bengtson, Settersten et al. 2016).

Defining “community living” and “person-centeredness” in all HCBS programs, CMS with the help of Center for Excellence in Assisted Living (CEAL) introduced a structural framework of PC attributes that should be found in all HCBS settings, as well as specific and measurable indicators for each (CEAL, n.d.). It is focused on the core principles of maximizing privacy, autonomy, choice, and meaningful access to the surrounding community. The framework is comprised of nine practice domains:

- 1) Core values and philosophy (personhood; respect & dignity; autonomy, choice & independence; and privacy)
- 2) Relationships and sense of community (belonging)
- 3) Governance / ownership
- 4) Leadership
- 5) Workforce practices
- 6) Meaningful life and engagement
- 7) Services
- 8) Environment
- 9) Accountability

Based on this framework, MFP program is an approach of maintaining balance between individual needs and the independence and control over life by modifying the environment to

enhance individual choice and control (Coffey, 2008). Per Zimmer et al. (2014), the HCBS person-centeredness framework defines independence and choice and control as follows and marks it as the most important domain in creating and operationalizing person-centeredness in community long-term care.

2.2. Definition

“Each individual freely chooses and decides matters affecting him/her (e.g., health care decisions, schedules, what and when to eat, interesting and meaningful activities tailored to interests and preferences). Residents can, to the best of their abilities, describe their daily life in terms of control over decisions with personal preferences honored.” (Zimmer et al. 2014)

2.3. Supporting Literature

Individuals who acquire a disability may never make the switch from ‘patient’ to ‘participant’ (Rimmer, 2016). According to CMS, as of December 2014, 15.5% of the nursing home residents are under the age of 65 and although residents have cognitive and functional impairments, 19.8% of the residents had no Activities of Daily Living (ADL) impairment. Further 11.1% had no ADL impairment and little or no cognitive impairment and the percentage of those with severe functional impairment being only 14.9% of the nursing home population (CMS, 2015). 46-86% of individuals in institutional settings have a desire to live in the community, but due to limited resources only a relatively small proportion have the means to achieve this desire (Arling et al., 2011; Arling, Kane, Cooke, & Lewis, 2010; Nishita, Wilber, Matsumoto, & Schnelle, 2008; Winkler et al., 2011). However, with the growing share of HCBS in the market, nursing home care has been declining steadily over the last 25 years. HCBS are either “upstream”, meaning avoiding unnecessary nursing home admissions – or “downstream”,

meaning selecting and helping nursing home residents to return to the community with support also known as “community/nursing home transitions” (Reinhard, 2010).

Long-term care in a community residential setting is considered to enhance feeling of security, community participation, higher self-esteem, resilience, activity and independence and control among individuals with disabilities and old aged (Vasara 2015; Winkler, et al. 2011). When these individuals are living in a nursing home their level of control and personal choice over their decisions are mostly determined by the medical professionals creating a feeling of dependency and limitation of control and self-esteem (Hedgpeth, 2012). Therefore, once they relocate into the community from a nursing home it enables them to exercise greater control over their lives, explore their strengths and skills and utilize them in a way that will bring a positive change and add value to their lives and community (Gutierrez, Parsons, & Cox, 1998); thus, moving from a state of powerlessness and inability to one of active control and independence (Hooyman, Mahoney et al. 2016).

The literature supports the role of community living in enhancing independence and control among individuals with disabilities. A qualitative study of young adults with acquired brain injury conducted by Winkler et al. (2011) in Australia, explored the transition experiences of participants from aged care facilities into the community. Semi-structured interviews were conducted with individuals, family caregivers and disability support workers. Researchers reported 9 key outcomes of the transition grouped into three categories, 1) independence (improved continence, getting around, speaking and eating), 2) well-being (happier and less stressed and less difficult behavior), and 3) social inclusion (having things to do, being known in the community and friends/family involvement). Participants reported an increase in the level of each outcome category.

Researchers in Minnesota studied personal control and the ecology of community living among individuals with disabilities (Stancliffe, Abery, & Smith 2000). Their study was aimed to find out any differences in personal control by living-unit size and residence type. The study hypothesized that both self-determination – a person having the degree of control over what happens in their day to day lives – and environment variables i.e. characteristics of living facility, staff characteristics and lifestyle would be significant predictors of personal control. A sample of 74 (40 male and 34 female) were recruited from seven private residential facilities of which 15 were with semi-independent living support, 38 in community intermediate care facilities (ICFs) and 21 in supported living facilities funded by Medicaid’s HCBS waivers. Study findings confirmed that personal control does vary by size and type of community living setting. The highest level of personal control was exercised by individuals with semi-independent living support followed by those in supported living and ICFs respectively.

In Ireland, Kilroy et al. (2015) were interested in exploring staff perceptions of the quality of life of individuals with an intellectual disability who transition from an institutional facility to community living. The researchers aimed to study the quality of life of these individuals and whether it changed after their transition into the community. Using the thematic approach, interviews with eight workers who worked with these individuals who transitioned recently into the community were analyzed. Results showed that independence, choice and social opportunities were perceived to have improved for many highlighting the importance of individual space, privacy and freedom.

Using the data from Connecticut’s Money Follows the Person program, Robinson et al. (2015) discusses more than 2,000 individuals who transitioned from nursing homes to the community during 2008-14, their quality of life, global life satisfaction, and health services use

after transition. Examining the changes in indicators for each quality-of-life domain from before transition to six, twelve, and twenty-four months after transition, Robinson et al. (2015) found improvement in all measures of quality and access to care, being treated well by providers, independence and control, satisfaction with living arrangement and community involvement. Studying the predictors for life satisfaction, they also found that participants with greater choice and control over their daily lives and people with higher levels of community integration were also significantly more likely to report life satisfaction, compared to those with less choice or integration, respectively (Odds ratio =1.18, p-value: <0.05, 95% CI = 1.04 – 1.34).

2.4. Study Rationale

Community transitions are meant to make individuals more connected to their community, enabling more meaningful connections with their living environment (Kosciulek, 1999). However, given the diversity of needs of people of old age and individuals with disabilities, flexibility within the array of institutional long-term care is the least, with greater restriction in independence, personal choice and decision making. Therefore, this study may help to explain the association of measures of control and independence and limitations on choice before and after transition to a community setting, and may indicate areas of improvement for the program.

2.5. Research Question

In this study, we aim to answer the following questions:

1. To what extent is community transition associated with increased independence and control over life among MFP participants in the state of Georgia?
2. Which measures of independence and control seem to be most affected?

3. METHODS

3.1. Data

The MFP Quality of Life (QoL) survey comes from the national evaluation protocol of the program funded by CMS, and designed and managed by Mathematica Policy Research. The survey is currently used in all MFP demonstration states to track and evaluate program performance and outcomes which is designed to collect information on participants' quality of life before and after the transition, which will be used to improve the program design and provide the best possible services to beneficiaries in the community. The MFP QoL instrument is derived from widely used Participant Experience Survey (PES, Version 1.0, 2003) – developed by MEDSTAT Group, Inc. under a contract with CMS to assess quality of life Medicaid HCBS recipients (Stanton, 2004) – with several modifications reflecting the need for additional information for MFP not included in PES. The instrument covers seven quality of life domains:

1. Participant's freedom of choice and control over life
2. Satisfaction with housing, care, and life in general
3. Access to care and unmet needs
4. Feelings about being treated with adequate respect and dignity
5. Ability to engage in and enjoy community activities
6. Health status

Data about MFP participants' demographics, personal and family information, housing, financial status, health and functional needs are gathered and entered in a data system as part of screening process before transition. The MFP QoL baseline survey and a transition challenges checklist is filled for each transitioning participant 30 days to two weeks prior to discharge from nursing facility. The follow-up surveys are then conducted at twelve and twenty-four months

after transition. The survey is typically administered through in-person interview by the participant's transition coordinator at baseline and then via telephone call with a member of the research team at follow-ups. Interviews are either conducted with the member participant alone, with assistance of a family member or with a proxy (a person other than the participant who provides information about the participant on his/her behalf) to get information for the surveys. This study includes data at baseline and follow-up at twelve months after transition, from 664 MFP participants who transitioned from nursing homes before December 31, 2015 in the state of Georgia and completed a 12 months' period in the community.

3.2. Measures

All the study variables come from national MFP survey instrument. Out of forty-three MFP QoL survey questions, a total of fifteen questions which pertain to the domain of independence and control over life were used for analysis (Table 1), while others are excluded being out of the scope of study. In addition, three demographic measures: age, sex, and disability type were included (Table 2).

Table 1.
Measures of Independence and Control over Life

Variable	Survey Question	Response Choices
Picked the place of residence	Did you help pick this place to live?	Yes, No, Don't know, Refused
Can go to bed when want to	Can you go to bed when you want to?	Yes, No, Sometimes, Don't know, Refused
Can be by self when want to	Can you be by yourself when you want to?	Yes, No, Sometimes, Don't know, Refused
Can eat when want to	When you are at home, can you eat when you want to?	Yes, No, Sometimes, Don't know, Refused
Can choose the type of food to eat	Can you choose the foods that you eat?	Yes, No, Sometimes, Don't know, Refused
Have the privacy to talk on phone	Can you talk on the telephone without someone listening in?	Yes, No, Sometimes, No Access, Don't know, Refused
Can watch TV when want to	Can you watch TV when you want to?	Yes, No, Sometimes, No Access, Don't know, Refused
Get allowance to pay for extra	Some people get an allowance from	Yes, No, Don't know,

help or equipment	the state to pay for the help or equipment they need. Do you get an allowance like this?	Refused
Can pick the help providers	Do you pick the people who are paid to help you?	Yes, No, Don't know, Refused
Can see friends/family when want to	Can you see your friends and family when you want to see them?	Yes, No, Don't know, Refused
Can get to places need to go	Can you get to the places you need to go like work, shopping, or the doctor's office?	Yes, No, Don't know, Refused
Can go out independently	When you go out, can you go out by yourself or do you need help?	Go out independently, Need help, Don't Know, Refused
Can do paid work	Are you working for pay right now?	Yes, No, Don't know, Refused
Can do voluntary work	Are you doing volunteer work or working without getting paid?	Yes, No, Don't know, Refused
Can do fun activities in community	Do you go out to do fun things in your community? Such as, going to church, the movies or shopping.	Yes, No, Don't know, Refused

Table 2.
Demographic Variables

Characteristic	Categories
Age	<65 years
	65-74 years
	75-84 years
	85+ years
Sex	Male
	Female
Disability Type	Physical Disability
	Developmental Disability
	Old Age

3.3. Analysis

Data analysis was performed using IBM SPSS Statistics 22. A matched data set of baseline and follow-up at twelve months was used for this analysis. Descriptive statistics indicated the frequency of each measure and the demographic variables of age, sex and disability type. To look at the statistical differences in independence and control over life indicators from before to after transition, each of the fifteen categorical study measures were dummy coded into

a dichotomous binary variable (Yes/No) to use McNemar's test. Phi coefficient was used to test the intervariable degrees of association (such as correlation between being able to pick the place of residence with other study measures) with a level of significance determined as $p\text{-value} < 0.05$ along with bivariate risk estimate model (Odds Ratio with 95% confidence interval) to determine the likelihood of each measure of independence based of participant's age, disability type, sex and ability to pick the place of residence.

4. RESULTS

4.1. Demographic Characteristics

The total of 664 individuals who participated in the MFP completed the baseline and follow-up survey at 12 months after transition in the state of Georgia. Of these participants, 54.4% identified as male and 45.6% as female (Table 3). Per type of disability, 44.1% of the participants were with physical disabilities (and/or Acquired Brain Injuries), 40.5% had old age related disabilities, while the remaining 15.4% had some form of developmental disability. Participants' age range was 75 years, where youngest was 19 years old and the eldest was 94 years. The majority of the participants (75%) were less than 65 years of age (Mean=55.29, Median=55 years).

Table 3.
Demographics

Characteristic	Categories	Frequencies	
		n (N=664)	%
Age	<65 years	498	75.0
	65-74 years	99	14.9
	75-84 years	34	5.1
	85+ years	13	2.0
Sex	Male	361	54.4
	Female	303	45.6
Disability Type	Physical Disability	293	44.1
	Developmental Disability	102	15.4
	Old Age	269	40.5

4.2. Difference in Measures between Baseline and Follow-up

McNemar test determined that there were statistically significant differences in thirteen out of fifteen measures of independence and control over life before and after transition among MFP participants which can be attributed to their transition from nursing homes into the

community (p -value <0.05) (Table 4). The measures of independence and control that were affected by transition were: participants' ability to eat whenever they wanted (% increase: 45.8%, p -value 0.00), pick their place of residence (% increase: 43.5%, p -value 0.00), choose the type of food to eat (% increase: 41.5%, p -value 0.00), and pick their care provider (% increase: 31%, p -value 0.00). The measure with least proportion change was the ability to do paid work which increased by 1.9% where only one person (0.2%) had a paid work before the transition, which increased to 14 individuals (2.1%) being able to have a paid work. Therefore, despite the least point percent change, the relative percent change showed that it had increased significantly by 1300% (p -value 0.01). Although change was demonstrated on most measures, the measures of being able to see family/friends and do leisure activities in the community did not show any statistically significant differences and remained unaffected.

4.3. Correlation between Sex and Measures of Independence

There was no statistically significant correlation between participants' sex and most of the measures of independence except one. With a correlation (Phi) coefficient of 0.11 (p -value 0.005), participants who were male were 1.8 (95% CI: 1.2-2.9, p -value 0.005) times more likely to go out independently than participants who were female.

4.4. Correlation between Age Group and Measures of Independence

Age was found significantly correlated with participants' participation in community leisure activities (Phi: 0.14, p -value 0.00), making those who were above 65 years of age 1.9 times less likely to go out and participate than those who were below 65 (95% CI: 1.4-2.8, p -value 0.00).

Table 4.
Difference in Measures of Independence before and After Transition

Measures	Baseline		At 12 months		Point Percentage Change	Relative Percentage Change	Test Statistic (McNemar) <i>p</i> -value
	%	n (N=664)	%	n (N=664)			
Picked the place of residence	18.1	120	61.6	409	43.5%	241%	0.000*
Can go to bed when want to	76.5	508	94.4	627	17.9%	23.4%	0.000*
Can be by self when want to	52	345	76.7	509	24.7%	47.5%	0.000*
Can eat when want to	36.3	241	82.1	545	45.8%	126%	0.000*
Can choose type of food to eat	32.1	213	73.6	489	41.5%	129.5%	0.000*
Have the privacy to talk on phone	52.1	346	70.2	466	18.1%	34.6%	0.000*
Can watch TV when want to	79.5	528	96.5	641	17%	21.4%	0.000*
Get allowance	3.2	21	35.7	237	32.5%	1028.5%	0.000*
Can pick provider	4.7	31	35.7	237	31%	664.5%	0.000*
Can see friends/family when want to	83	551	83.7	556	0.7%	1%	0.758
Can get to places need to go	80.6	535	90.1	598	9.5%	12%	0.000*
Can go out independently	11.9	79	15.7	104	3.8%	32%	0.022*
Can do paid work	0.2	1	2.1	14	1.9%	1300%	0.01*
Can do voluntary work	0.2	1	9.2	61	9%	6000%	0.000*
Can do fun activities in community	66.6	442	67.2	446	0.6%	1%	0.838

* Significant difference at 12 months from the baseline, *p*-value <0.05

4.5. Correlation between Disability Group and Measures of Independence

Each of the three disability groups were found to have significant correlation with most of the measures of independence. Developmental disability was found to be correlated with several measures of independence. Those with developmental disabilities were 2.3 times less likely to eat when they wanted to, 2 times less likely to choose the type of food they wanted to eat, 7 times less likely to have the privacy for a telephone conversation, 2.5 times less likely to watch television when they wanted to and 4 times less likely to get to the places they wanted to visit than individuals with age-related or physical disabilities. They were 17.2 times less likely to go out without any help, 7.9 times less likely to get a paid work and 5.8 time less likely to go out for any leisure activity than those with other disability types with a level of significance <0.05 (Table 5).

Physical disability was found to have statistically significant correlation with most of the measures. They were 5.1 times (95% CI: 3.4-7.8, p -value 0.00) less likely to have the privacy for a telephone conversation, 4.9 times (95% CI: 3.1-7.7, p -value 0.00) less likely to go out independently and 4.2 times (95% CI: 1.0-18.8, p -value 0.04) to get a paid work than developmental disability and old-age group. There was no statistically significant correlation found between physical and developmental disabilities and being able to pick the place of residence, go to bed when wanted to or be by self, pick the provider or see friends and family and being able to do voluntary work.

While the other two disability types had no correlation with being able to pick the provider, be by self when wanted to and see friends and family, old-age related disabilities had shown significant correlation. Participants with age-related disabilities were 1.8 (95% CI: 1.0-3.1, p -value 0.04) times less likely than developmental and physical disability group to be by

self, 1.7 times less likely to pick their care provider (95% CI: 1.0-2.7, *p*-value 0.03), and 1.8 less likely to see friends and family when wanted to (95% CI: 1.0-2.9, *p*-value 0.03).

4.6. Correlation between Being Able to Pick the Place of Residence and Other Measures

Nine out of fourteen measures of independence and control were found to be significantly correlated with the ability to pick the place of residence for all program participants. Participants who picked their place of residence, after transition were 6.4 (95% CI: 2.9-14.1, *p*-value 0.00) times more likely to go to bed when they wanted to, 5.4 (95% CI: 2.4-12.0, *p*-value 0.00) times more likely to do voluntary work, 3.6 (95% CI: 2.5-5.2, *p*-value) times more likely to pick their care provider, 3.4 (95% CI: 2.4-4.9, *p*-value 0.00) times more likely to have their privacy while on phone and 2.8 (95% CI: 1.8-4.1, *p*-value 0.00) times more likely to be able to choose the type of food they eat than those who were not able to pick their place of residence at follow-up (Table 6).

Table 5

Participant Characteristics and Correlation with Measures of Independence and Control.

Measures of Independence and Control	Sex (Male/Female)			Age (Above 65/Below 65)			Developmental Disability (No/Yes)			Physical Disability (No/Yes)			Disability due to Old Age (No/Yes)		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
Picked the place of residence	1.2	1.2-1.6	0.38	1.4	1.0-2.0	0.06	1.0	1.3-1.4	0.93	1.1	1.3-1.5	0.59	1.2	1.2-1.8	0.39
Can go to bed when want to	1.4	1.4-2.8	0.29	1.1	1.8-2.4	0.77	1.0	1.9-2.0	0.91	1.1	1.7-2.2	0.73	1.2	2.2-3.0	0.74
Can be by self when want to	1.0	1.4-1.5	0.88	1.2	1.2-1.9	0.31	1.4	1.0-2.05	0.05	1.1	1.3-1.6	0.60	1.8*	1.0-3.1	0.04
Can eat when want to	1.3	1.2-1.9	0.25	1.1	1.4-1.7	0.59	2.3*	1.6-3.5	0.00	1.7*	1.1-2.6	0.01	2.2*	1.1-4.4	0.02
Can choose type of food to eat	1.1	1.3-1.5	0.73	1.3	1.1-1.9	0.20	2.0*	1.4-2.9	0.00	2.1*	1.4-3.0	0.00	1.1	1.5-1.7	0.83
Have the privacy to talk on phone	1.3	1.1-1.8	0.15	1.2	1.2-1.8	0.37	7.0*	4.8-10.3	0.00	5.1*	3.4-7.8	0.00	2.8*	1.6-5.0	0.00
Can watch TV when want to	2.3	1.6-5.5	0.06	1.1	2.4-2.7	0.90	2.5*	1.0-5.8	0.04	1.9	1.3-5.0	0.15	1.9	2.2-8.4	0.36
Get allowance	1.1	1.2-1.6	0.44	1.2	1.2-1.7	0.42	1.8*	1.3-2.4	0.00	1.7*	1.2-2.3	0.00	1.2	1.3-1.9	1.31
Can pick provider	1.3	1.1-1.7	0.15	1.3	1.1-1.9	0.17	1.0	1.3-1.4	0.92	1.3	1.1-1.8	0.09	1.7*	1.0-2.7	0.03
Can see friends/family when want to	1.4	1.1-2.1	0.15	1.5	1.1-2.3	0.09	1.3	1.2-1.9	0.23	1.1	1.4-1.7	0.70	1.8*	1.0-2.9	0.03
Can get to places need to go	1.3	1.2-2.2	0.25	1.7	1.0-2.9	0.05	4.0*	2.1-7.6	0.00	1.9*	1.1-3.1	0.01	2.3*	1.3-4.1	0.00
Can go out independently	1.8*	1.2-2.9	0.00	1.1	1.5-1.7	0.80	17.2*	7.4-40	0.00	4.9*	3.1-7.7	0.00	1.7*	1.0-2.9	0.04
Can do paid work	1.5	1.9-4.6	0.45	4.4	1.7-34.0	0.11	7.9*	1.7-35.5	0.00	4.2*	1.0-18.8	0.04	1.0	1.0-1.01	0.11
Can do voluntary work	1.1	1.6-1.8	0.80	1.2	1.4-2.8	0.58	1.2	1.5-1.9	0.57	1.1	1.5-1.9	0.64	1.1	1.9-2.2	0.89
Can do fun activities in community	1.0	1.3-1.4	0.97	1.9*	1.4-2.8	0.00	5.8	3.9-8.6	0.00	2.3	1.7-3.2	0.00	3.6	2.4-5.6	0.00

* Significant correlation, Odds Ratio within 95% Confidence Interval, p-value <0.05

Table 6.

Participant Ability to Pick their Place of Residence and its Correlation with Other Measures

Measures of Independence and Control	Ability to Pick Place of Residence		
	OR	95% CI	<i>p</i> -value
Can go to bed when want to	6.4*	2.9-14.3	0.00
Can be by self when want to	1.5*	1.0-2.1	0.03
Can eat when want to	2.8*	1.8-4.1	0.00
Can choose type of food to eat	3.4*	2.4-4.9	0.00
Have the privacy to talk on phone	1.8*	1.3-2.5	0.00
Can watch TV when want to	1.8	1.3-4.1	0.17
Get allowance	1.7*	1.2-2.3	0.00
Can pick provider	3.6*	2.5-5.2	0.00
Can see friends/family when want to	1.0	1.5-1.6	0.92
Can get to places need to go	1.4	2.3-13.3	0.22
Can go out independently	1.6	1.0-2.5	0.05
Can do paid work	1.2	2.4-3.5	0.73
Can do voluntary work	5.4*	2.4-12.0	0.00
Can do fun activities in community	1.5*	1.1-2.1	0.01

* Significant correlation, Odds Ratio within 95% Confidence Interval, *p*-value <0.05

5. DISCUSSION

This study investigated the association of measures of control and independence and limitations on choice of Money Follows the Person program participants before and after transition from a nursing home to a community setting, 2008-2015, the state of Georgia. The study found that community transition is positively associated with almost all the measures of control and independence and limitation on choice at twelve months after the transition.

The wide range of measures tell a consistent story of improvement and enhanced control and independence over lives of those who transitioned to community living which is in congruence to the existing body of evidence (Kilroy et al. 2015; Robinson et al. 2015). A significant increase in the proportion of participants who experienced more independence and control and less limitation of choice in their day-to-day activities of life after twelve months of spending in a community living highlights the importance of community living as a less restrictive living environment for persons with disabilities (Stancliffe et al. 2000). Boelsma et al. (2014) shared the perspective of old nursing home residents that for them the facility looks like a well-run industry, that makes sure residents are doing well but at the same time has nothing to do with the individuality and personhood of residents get lost amid too many staff and rules and regulations. This may well explain why participants experienced more independence and control over their lives because they could have a place of their own, where they could make their own choices, do things the way they wanted to, be themselves and not be bound to rules or fixed schedules. For example, in this study there was a 45.8% increase in the proportion of participants who had the choice to eat whenever they wanted to and 41.5% increase in those who had the choice to choose the type of food they wanted to eat after twelve months of transition. Food is not just a necessity to nourish the body, but it connects an individual with a lifestyle and social

identity and culture (Boelsma et al. 2014). Therefore, such a finding does suggest by living in a community setting individuals can experience more choice and control in matters as small as being able to eat when one desire that may have larger impact on maintaining one's identity.

Moreover, institutional long-term care facilities are mostly designed to provide care and accommodate frail and older people at the end stage of their lives and not adequately resourced to do so for younger people (Winkler et al. 2011). The data set for this study included 75% of participants under the age of 65 years. Therefore, a community living setting which is more person-centered combined with the provision of disability specific care for the majority group of younger participants could be an explanation to the significant increase in the level of independence and control after transition.

This study looked at the correlation between being able to pick the place of residence and other measures of independence. And the findings suggest that it has a significant impact and can be a predictor for other measures of control and independence of a participant after transition. To enhance person-centeredness in long-term care and community transition programs, individual and family involvement, individual's unique needs, strengths and personal circumstances play an important role in planning the process of discharge and transition from a nursing home (Leedahl et al. 2015). Picking a place in the community to live in is the first step in the process and if an individual or family does not have a say in where and how will the individual want to live in the community, then it may be difficult to contemplate control and independence in other matters of their care provisions later.

Looking at the correlation between participant age, sex and disability type, study findings suggest that sex has no significant correlation with control and independence after transition in the community. However, participants below 65 years of age were more likely to be able to

participate in community activities and go out independently without help, which can be suggestive of them being younger and less physical restriction to be involved in such activities. Moreover, each disability type was found to be linked with different measures of independence. Such as, individuals with developmental disabilities were found to be less likely independent in their day-to-day life activities of being able to eat, go to bed, or choose the type of food they want to eat; while very old participants were less likely to go out without help, see family and friends or be alone.

Hence, to enhance control and independence and remove the limitation of choice, planning transition or deinstitutionalization should focus on person-hood of individuals, based on their health needs and preferences to ensure that they have the choice and control over their lives. 5-12% of 1.8 million long-term nursing home residents have the functional ability and clinical state that is manageable in a community setting enabling them to live in the community with appropriate support (Mor et al. 2007). MFP is providing numerous such individuals an opportunity to be discharged from nursing homes and once again live a more independent life with less restriction and limitation of choice.

5.1. Limitations

The study had several limitations. First, the data analyzed came from Georgia's MFP participants and did not include a comparative perspective from other states' MFP program; therefore, the results may not be generalizable to all other transition programs in other states. Yet, the study provides a prediction of the relationship between the variables that can be explored and tested further in other states as well. Second, the data set included only participants who have completed the twelve months' period in the community after and those who were transitioned and had not completed the twelve months' period were not included. Their inclusion

might have had an impact on the findings. Third, there was a remarkable number of interviews conducted with a proxy respondent (interview with a family member). 14% of the interviews were conducted with a proxy respondent at baseline while the percentage increased to 35% at follow-up. This might have added some respondent bias to the study, especially because proxy responses could differ from actual participants' responses. Fourth, due to limitation of time and resources the data for the race/ethnicity of the participants could not be attained to see its correlation with the study measures, as this information was not part of the MFP survey.

5.2. Implications and Future Directions

Study findings suggest several implications for future research and practice. The next step should explore the differences in outcomes of measures of independence for specific sub-groups per their disability types, type of community living unit, and age. For example, do people older than 65 years of age experience different level of independence and control after transition than their counterparts? Or do people who live with a family member experience more independence than those living in group homes? Comparison can also be made between MFP participants and other transition programs so see whether the difference in outcomes are attributed to the program design or community living.

6. CONCLUSION

The results of this study demonstrate that MFP program in the state of Georgia is significantly found to be associated with enhanced control, independence and choice among its participants post transition. It provides insight to the policy makers, advocates, nursing home residents and their families that the program is successful in meeting the goal of improving person-centeredness in the long-term care arena. Therefore, with the insight from further research and evaluation of the program, national and state policy makers can improve the program design to better meet the needs of the participants and make the program more efficient. By doing so, not only individuals with disabilities get another chance of once again living in a community among friends and families with more control over their lives, but also the burden of high cost from institutional care can be re-balanced with Home and Community Based Services.

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