

RESEARCH BRIEF

An update on HDI's research in the field of developmental disabilities

My Room or Yours? Home vs. Institutional Living and the Relationship to Quality of Life

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Fundamental to the movement toward full inclusion of people with disabilities in their communities is the belief that people should have the right to choose where they live and receive services. The National Council on Disability emphasized this fundamental right in their 2011 Disability Progress Report, and suggested that “no disability policy is in greater need of reform than the antiquated Medicaid rules that favor institutional settings over home- and community-based services (HCBS)” (National Council on Disability, 2011). The Money Follows the Person (MFP) Rebalancing Demonstration Grant is an important means of addressing this issue. This Research Brief describes the MFP grant program and its effectiveness nationally and in Kentucky. We then present data on Kentucky participants and consider the impact of residential choice on quality of life.

Background

Money Follows the Person Rebalancing Demonstration Grants

First authorized by Congress in 2005, and then extended by the Patient Protection and Affordable Care Act of 2010, MFP funding was designed to rebalance state Medicaid long-term care spending to give Medicaid beneficiaries living in long-term care facilities increased choice about where they live, and to strengthen state systems of long-term services and supports (LTSS) so that they can serve more people in community settings (Denny-Brown,

Hagen, Bradnan, & Williams, 2015). MFP grant funds can be used to support a range of transition activities, including pre-transition planning, residential and environmental modifications, and home- and community-based services (Denny-Brown et al., 2015). Currently, 44 states and the District of Columbia participate in MFP demonstration grants. Targeted populations include the aging population, people with physical disabilities, and people with intellectual disabilities. As of December 2014, over 51,000 people had transitioned through MFP programs across the country (Denny-Brown et al., 2015).

In 2007, Kentucky was awarded an MFP Rebalancing Demonstration Grant from the Centers for Medicare and Medicaid Services (CMS). The MFP Program in Kentucky, Kentucky Transitions (KYT), serves to facilitate transition and provide sustainable community based services to Kentuckians who choose to move from Medicaid-funded long-term care settings (Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) and nursing facilities) to the community.

Among the major barriers faced by MFP participants is the insufficient supply of affordable, accessible housing nationally. In the 2013 annual report of data obtained from all states with MFP grants, the lack of accessible and affordable housing was the most frequently reported barrier, representing 62% of challenges (Morris et al., 2014). In Kentucky, the Human Development Institute (HDI) plays an important role in ensuring that people transitioning back into the community have access to an environment that meets their needs. Since 2008, KYT has contracted with HDI to implement home assessment services for MFP program participants. That is, for those persons living in ICF/IID or a nursing facility who wanted to move back into their community, HDI staff conducted

assessments of the proposed community residence, including an onsite assessment of the residence; identification of barriers throughout the residence, access to interior circulation throughout the home, and; implementing home modification services for MFP program participants. Typical elements of home modifications include installation of ramps, widening of doorways, bathroom safety modifications, and other adaptations of the residence. In addition, HDI has completed Housing Quality Standards inspections on all transition homes since 2014.

Choice in Residence and Quality of Life

HCBS are well established as less expensive than institution-based service (Musumeci & Claypool, 2014) and are clearly more consistent with the principles of self-determination (Wehmeyer, 2001) and the fundamental right to choose where one lives. Yet relatively little research has evaluated the impact of living in the community on quality of life (QOL; Neely-Barnes, Marcenko, & Weber, 2008). In this research brief, we report the results of an analysis of this relationship in the Kentucky transitioned population.

As noted by Gulick (1997), quality of life for people with disabilities is made up of the same factors and relationships that have been shown to be important to people without disabilities. It results from getting one's basic needs met and having the opportunity to pursue and achieve goals in important areas of life (Goode, 1994, as cited in Gulick, 1997). Although QOL may be defined and measured in different ways, Schalock, Verdugo, Bonham, Fantova, and Loonis (2008) noted that QOL is generally seen as being: (1) multidimensional, (2) influenced by the interaction of personal and environmental factors, and (3) affected by self-determination, inclusion, and purpose in life. According to these and other researchers (e.g., Sheppard-Jones, Prout, & Kleinert, 2005), many of the personal and environmental changes involved in the transition from institutional to community living are directly related to commonly identified QOL indicators. These indicators include personal development, self-determination, social inclusion, human and legal rights, interpersonal relationships, material well-being (including housing), and emotional well-being (Schalock et al., 2008). We also explored changes in several of these indicators pre- and post-transition as measures of QOL among those transitioning to community living.

Method and Research Questions

KYT is responsible for administering a quality of life survey with each transitioning participant; therefore, we obtained secured access through KYT to the QOL survey data for all individuals who have transitioned through the program. KYT surveys participants at three points in their transition: pre-transition to establish baseline levels; one year post-transition; and two years post-transition. The results in this study represent the first two rounds of surveys, the pre-transition and one-year post-transition surveys completed between June 2008 and April 2015. In this study, we present data related to the following research questions:

1. Are there differences in self-reported emotional well-being pre- and post transition?
2. Are there differences in pre- and post transition levels of personal choice?
3. Are there differences in pre- and post transition levels of community access and inclusion?

Participants

All Medicaid eligible individuals receiving Medicaid services in an ICF/IID or a nursing facility and who had been in the institutional setting (or a combination of hospitalization and institutionalization) for a minimum of ninety consecutive days (excluding Medicare covered days for short term rehabilitation) were eligible to transition. Medicaid waivers provided transition and community based services to individuals who fell into one of the following groups: individuals who were elderly and/or physically disabled; individuals who had an intellectual and/or developmental disability; or individuals who had an acquired brain injury after the initial year of MFP community based services. For this analysis we reviewed QOL data for a total of 587 baseline respondents and for 301 respondents who were one-year post-transition.

Survey Instrument

The survey instrument included questions about program participants' experience across seven domains: (1) living situation, (2) choice and control, (3) access to personal care, (4) respect and dignity, (5) community integration and inclusion, (6) satisfaction, and (7) health services. We focused on selected items related to post-transition QOL.

Results

With respect to emotional well-being, participants were asked "Are you happy with the way you live your life?" Pre-transition, only slightly more than half responded

affirmatively (52.6%). At one-year post-transition, the percentage that said they were happy with the way they lived their life had risen considerably, to 86.9%.

Several questions addressed issues of personal choice. In response to the question “Do you like where you live?” 35.9% of participants responded “Yes” pre-transition, compared to 93.7% post-transition. Participants were also asked if they were happy with the way they live their life. The percentage indicating “Yes” rose from 52.6% pre-transition to 86.9% post-transition. When asked if they could see friends and family when they want to see them, the “Yes” response went from 72.7% pre-transition to 95.7% post. Concerning transportation, when asked if they could get to the places they need to go, 94.3% of respondents said “Yes” post-transition, compared to 80.5% of those still living in facilities.

While there was a consistent increase in choice post-transition, some results indicated more significant differences. When asked if they helped pick the place they live, the “Yes” response increased from 20.7% pre-transition to 74.2% post-transition. The percentage of respondents reporting that they could go to bed when they wanted increased from 78.7% to 90%. While less than half (48.8%) indicated that they could be by themselves when they wanted to be while living in a facility setting, the percentage rose to 88.1% post-transition. There were significant differences with respect to the abilities to choose what to eat and when to eat. Participants reporting that they eat when they want increased from 38.2% to 92.9%, and the percentage choosing the foods that they eat went from 33.5% to 92.3%. The results for several of these key QOL indicators are provided in Table 1.

We also looked at questions related to community access and inclusion. First, participants were asked if they could go out to do fun things in their community. As we anticipated, there was an increase in post-transition affirmative responses to 78.2% compared to 49.5% pre-transition. As a follow-up question, the participants were asked if they are able to just go places, without making arrangements or planning many days ahead and asking people for help. The percentage of pre-transition “Yes” responses to this question was 5.4%, which increased post-transition to 28.6%. While this is a positive increase, this relatively low percentage even post-transition indicates an area of need in community living. On a related question, however, participants were asked if there are things they want to do outside that they cannot currently do. Whereas 60.8% of participants responded affirmatively pre-transition, the percentage dropped to 14.8% post-

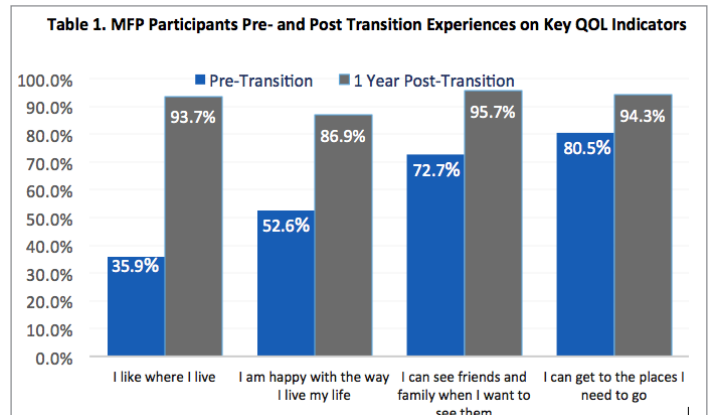


Table 1

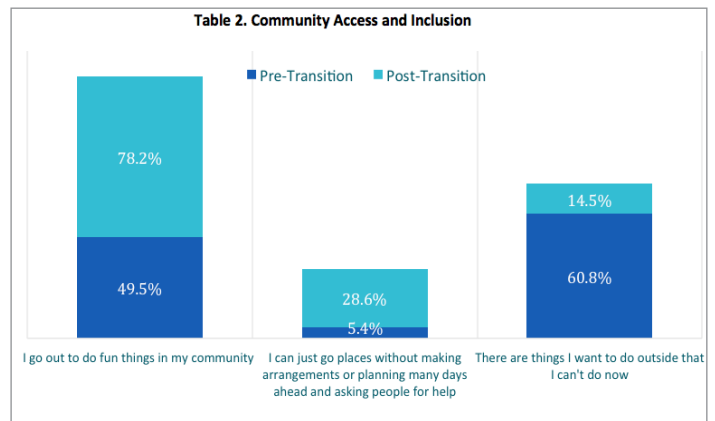


Table 2

transition. The results for the community access and inclusion questions are provided in Table 2.

Conclusion

The transition work done through the MFP federal demonstration continues to strengthen the movement toward community and independent living. In this brief, we attempted to solidify the assumption that QOL is better when living independently than living in facilities. QOL measures and fiscal analyses show that supporting people to live in non-institutional settings is both less costly and results in significantly increased quality of life. Both the general population of people with disabilities and the aging population are growing rapidly, and the present results underscore the importance of restructuring the current system of institutional and nursing facility care. Next steps would also include providing the supports needed to keep people living in their homes, thus avoiding the process of entering into and transitioning out of nursing or ICF/IID residential facilities. Through the demonstration of these nationwide projects, our hope is that private and subsidized insurers begin to transition their policies to support people living in their community of choice with the highest level of independence possible.

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About HDI Research Briefs

HDI Research Briefs were initiated to highlight the research activities at HDI. Projects at HDI focus on individuals with disabilities and include projects with emphases in early childhood, school age persons, adults, and issues across the lifespan. Many of these projects have significant research components and involve HDI staff, students in graduate programs, and other faculty at UK. With each issue of **HDI Research Briefs**, we will try to provide a cross-section of HDI's research activities. The brief reports are typically "mini" versions of more involved studies. The brief reports are intended to give an overview of the research project and emphasize the implications of the studies.

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