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6-11-2018

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Recommended Citation

Fuller, Kristi; Derricho, Chandrika; and Landers, Glenn, "The Journey to Community Living Through the Lens of the Money Follows the Person Program Participants" (2018). *GHPC Materials*. 81. https://scholarworks.gsu.edu/ghpc_materials/81

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THE JOURNEY TO COMMUNITY LIVING THROUGH THE LENS OF THE MONEY FOLLOWS THE PERSON PROGRAM PARTICIPANTS

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RESEARCH OBJECTIVE

The Money Follows the Person (MFP) program, established in 2008, is a Medicaid demonstration grant sponsored by the Centers for Medicare & Medicaid Services that provides states with the opportunity to rebalance long-term care services and supports by transitioning individuals from institutional to community settings. Photovoice was added to an existing evaluation in Georgia to better understand participants' perceptions of the impact of the program on their quality of life. Previous evaluation activities included analyses of administrative data and responses to a standardized national survey.

STUDY DESIGN

As described by Wang and Burris (1997) "Photovoice is a process by which people can identify, represent, and enhance their community through a specific photographic technique." From June 2015 to August 2016, five participants used photovoice to document their quality of life since transitioning from institutional settings to the community. The group met a total of four times to discuss the intent of the project, receive photography and ethics training, discuss the participants' photographs and narratives, and plan an exhibition. For each photo, participants decided what they wanted to capture in an image, titled it, and wrote a narrative to describe the back story. The work culminated in a photo exhibition in November 2016 that showcased the journeys of the five MFP participants. Each participant shared their disability story and exhibited five photos with narratives that they felt best captured their experience.

POPULATION STUDIED

At the time of the study approximately 2,500 individuals had transitioned from institutions to community settings with the support of MFP. The final study sample included five participants, three females and two males, ranging in age from 38 to 64, and one individual had a developmental disability while the others had physical disabilities.

PRINCIPAL FINDINGS

Themes from participants' photographs and narratives identify programmatic successes, as well as the importance of continued support of long-term services and supports provided in home and community-based settings. Each participant described a unique set of health conditions and life circumstances which necessitated the receipt of care in an institution. After transitioning, the participants reflected on important supports and opportunities for greater independence that they did not have in institutions. The participants determined the term "freedom" best represented their quality of life as a result of the program, which led to the exhibition's title—Gaining Freedom, Coming Home.

CONCLUSIONS

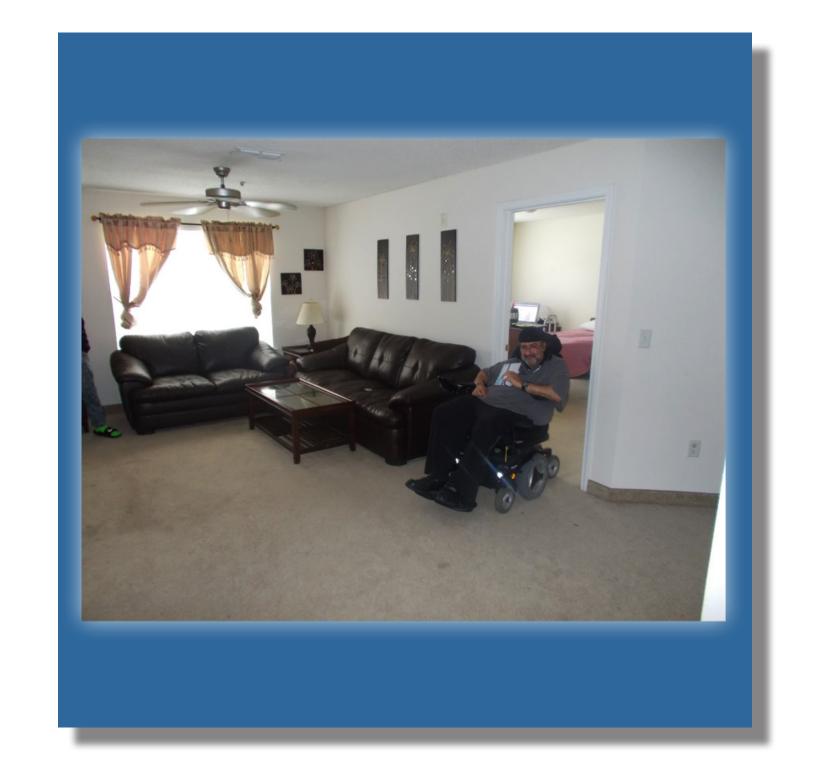
The participants documented first-hand the drivers for transition, positive outcomes, and continuing challenges that reflect their perspectives on quality of life in the community. The photographic images and narratives developed by persons with developmental and physical disabilities enhanced insights into their disability journey, identified the value of the MFP program in enabling community living, empowered participants to develop critical assessments of their realities, and induced stakeholders and decision makers to thoughtfully consider program sustainability recommendations. The use of photovoice was effective in ensuring that the evaluation of the program included the voice of the participants in a way that the existing survey data had not.

IMPLICATIONS FOR POLICY OR PRACTICE

Including participatory action research methods such as photovoice can add a level of richness to an evaluation that is able to reach stakeholders and decision makers in a way that other methods typically are not. The results from this evaluation support continued policy initiatives that seek to rebalance the long-term services and supports system toward a greater use of home and community-based settings.

FUNDER

The Georgia Department of Community Health through grant funding received from the Centers for Medicare and Medicaid Services.



MFP Budget

This is my spacious living room and apartment. Thank you Jayson Wright and Karen Lucas! Money Follows the Person really helps with it comes to living accommodations. I was able to rent with the Home Choice Voucher a 2 bedroom 2 bath no barriers all open 988 sq. ft. apartment that I can reasonably afford. The MFP Budget (CAP) given also applies to furniture of my choice, washer and dryer, an upgrade for an electric bed, start-up funds, and medical supplies.

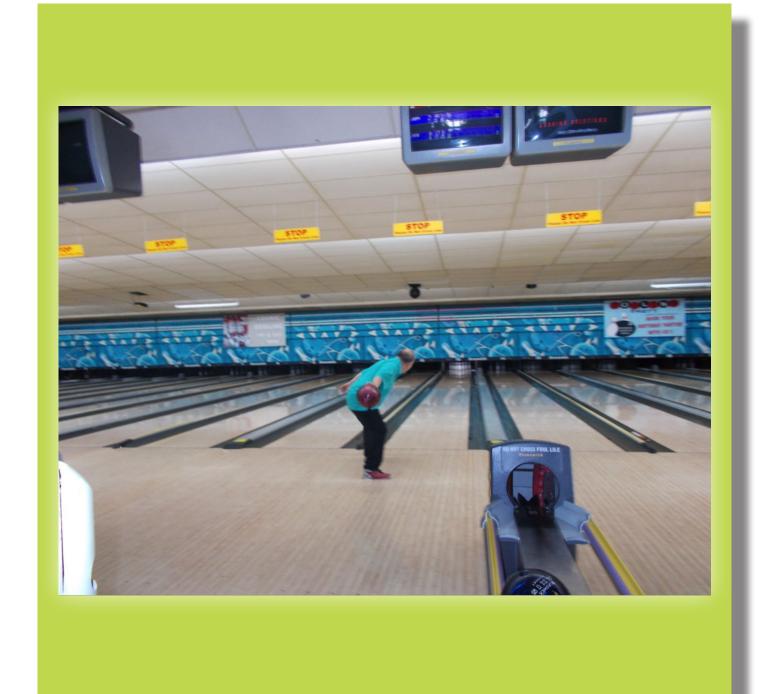
-Yaser



Cooking Passion

I renewed my passion for cooking and found a way to do it regardless of my disability. They served chicken every day at the nursing home for 2.5 years and the rest of the food was awful. I lived on cereal grilled cheese sandwiches, and eggs. This you can't mess up. I wanted a balanced diet and variety.

-Patricia



Bowling Alley

I wanted to show I go out into the community for fun. It's a hobby for me to bowl. I enjoy it. I like to get scores, winning, and feel good because it gives me exercise. I get excited when I win.

-Danny



Vera

Vera is an amazing system that allows me to control my home environment with my iPad or iPhone. Being able to control my homes gives me much more independence since I've been disabled. I no longer have to depend on others for minute things such as: adjusting the thermostat or the lights. I am able to lock and unlock my front and back doors. I'm now living on my own thanks to MFP and their modifications.

-Michelle



My Comfort Zone

I want to share this photo because I love to cook. I like sitting on my patio, and I am happy! It feels good to have my own kitchen because I like to cook and I enjoy sitting on my patio, having a good cup of coffee, and gathering my thoughts. I now have good health, a peace of mind, my very own apartment, and perfect teeth. I can honestly say that I have something to smile about thanks to the MFP program!

-Tammy



Failure to Comply

This courthouse has caused more heartache than you could ever imagine. Not only has the courthouse failed to comply with ADA regulations with the only courtroom on the second floor and a gate style elevator that is unusable, they also have no handicap accessible restrooms. The worst part though is their beliefs in that disabled parents are unfit to care for their children regardless of what they have to offer them.

-Michelle



