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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 rely on 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. Precious 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 institutional 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 reframe the long-term services and supports system toward a greater use of home and community-based settings.

FUNDER
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