



# **PROXY INTERVIEWS:** The Effect on Quality of Life Results for MFP Participants Brittney Romanson, M.P.H.; Glenn Landers, Sc.D.; Kristi Fuller, M.S.W.; Mohammad Khalaf, M.P.H.; and Elizabeth Kauss, M.S.W.

#### BACKGROUND

Since 2008, Georgia has been 1 of 46 sites that participates in the Money Follows the Person (MFP) rebalancing demonstration program funded by the Centers for Medicare and Medicaid Services. It seeks to shift Medicaid long-term care spending by transitioning individuals from institutional to community settings. The program is unique in that it provides services to Medicaid eligible participants that may not otherwise had been covered, like home modifications and rental deposits. The Georgia Health Policy Center works as the external evaluator of the state's MFP program and conducts one- and two- year post-transition interviews with MFP program participants or their proxies.

## **RESEARCH OBJECTIVE**

When examining the Quality of Life (QoL) survey results, we found that some participants were experiencing quality of life differently post-transition. This study explores the association between respondent type and reported quality of life.

### STUDY DESIGN

Matched QoL surveys from a longitudinal panel of MFP program participants' were analyzed. MFP participants are interviewed three times: prior to leaving an institution (baseline), one yearafterleaving an institution (year-one followup) and two years after leaving an institution (year-two follow-up). At all three time points, the QoL survey may have been completed by the sample participant alone, the participant with assistance, or a proxy on behalf of the participant. This study examines participants who completed both a baseline and one-year follow-up between January 2009 and July 2013. Two quality of life measures assessed overall happiness and quality of care. Bivariate analyses calculated potential relationships between QoL and respondent type (sample member alone versus proxy).



#### POPULATION STUDIED

The initial sample of the study included 404 matched surveys of subjects who completed pre- and post-transition surveys from January 2009 to July 2013. Participants ranged from age 19 to 94 and were broken out into three target populations: physically disabled (PD) (32%), developmentally disabled (DD) (56%), and older adults (OA) (12%). At the year-one follow-up interview, more surveys were completed by a proxy than at baseline. Specifically, persons with a DD had a proxy complete a survey on the clients' behalf 79% of the time at the follow-up. A sub-analysis was conducted with 42 persons with a developmental disability who answered supplemental questions phased into the QoL survey in November 2012.

Demographic Data at First Year Follow-Up			
Age (mean)	58.5		
<u>Sex</u> Male [n (%)] Female [n (%)]	226 (55.9%) 175 (43.3%)		
<u>Target Population</u> Older Adult [n (%)] Physically Disabled [n (%)] Developmentally Disabled [n (%)]	48 (12%) 118 (32%) 186 (56%)		
<u>Respondent Type</u> Sample Member Alone [n (%)] Sample Member with Assistance [n (%)] Proxy [n (%)]	160 (41.3%) 13 (3.4%) 214 (55.3%)		

### PRINCIPAL FINDINGS

There is a significant association between respondent type and survey answers. Being a proxy was associated with happiness (r = 0.276, p < 0.000) and stating that people who helped with care listened carefully to what was asked of them (r = 0.261, p < 0.000). Within target populations, a proxy answering the survey on behalf of a person with a developmental disability was correlated with happiness (r = 0.312, p < 0.000) and the quality of care (r = 0.400, p < 0.000). Finally, being a proxy who was a service provider responding on behalf of a person with a developmental disability was associated with reporting that the people who helped listened carefully to what was asked (r = 0.535, p = 0.040), but there was no significant association with happiness.

Bivariate Correlations Between Respondent Type and Quality of Life Measures at First Year Follow-Up			
	n	Happiness Person r	Quality of Care Person r
Proxy Respondent	404	0.276***	0.261***
DD Proxy Respondent	42	0.312***	0.400***
DD Service Care Provider Proxy Respondent	15	-0.113	0.535***

### CONCLUSIONS

Results extend previous work that suggests proxy respondents do not report QoL experiences the same as participants. Specifically, this study indicated that being a proxy responding on behalf of a person with a developmental disability is associated with happiness and reporting that the people who helped listened carefully to what was asked.

#### IMPLICATIONS FOR POLICY, DELIVERY, OR PRACTICE

Findings have important implications for the immediate task of how QoL in MFP participants who cannot speak for themselves is assessed and in the larger context of how proxy responses should be interpreted. It is nearly impossible to reject using proxies. However, one may mitigate their impact by conducting interviews with a family member instead of a direct service provider and completing in-person interviews for non-verbal clients with alternative modes of communication.

In the larger context of proxy interviews, it is suggested that proxy respondents might best be used to report on tangible events that may have been directly witnessed rather than QoL, which is personal and primarily subjective.

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> For more information, please contact the Georgia Health Policy Center at 404.413.0314 or visit us online at www.gsu.edu/ghpc.



