

# Who Should Speak for Individuals with Intellectual Disabilities? Evaluating Quality of Life at Community Providers<sup>1</sup>

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## Abstract

*Quality of life of people with intellectual disabilities is difficult to measure. Questions arise about both self response and proxy response. The Ask Me! Survey collects data annually for 1,200 individuals with developmental disabilities. Peer interviewers encourage three-fourths of the selected people to respond for themselves. Two proxies provide information for each person who cannot respond. Self-respondents answer more questions, produce more reliable scales, and have nearly the same internal consistency as proxies. Self-respondents report lower physical well-being and higher self-determination than do proxies. Two proxies agree most on emotional well-being and least on self-determination. Two day staff agree the most; family and staff proxies agree the least. Self and proxy responses can be combined for many analysis with appropriate statistical controls. Participatory evaluation policy can be put into practice, but doesn't resolve all the problems in collecting information to better support people with differing intellectual abilities.*