Title: Comparisons of Self and Proxy Report On Health-Related Factors in People with Intellectual Disability

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Introduction: Clinicians, researchers, and policy makers rely heavily on information gathered directly from people that they are studying. Self-report on a wide variety of topics is collected in all manner of medical and psychological assessments, research studies, and evaluation of policy and procedure. There are some populations for which obtaining self-report may be more challenging, such as people with intellectual disabilities (ID). The cognitive demands inherent in self-reporting are complicated and may present stumbling blocks for people with ID at each step in the process (Fujiura, 2012). A common way to address these issues in the past was to use a proxy reporter to collect information about people with ID. However, as research and policy have shifted to an inclusive model, there has been an increased effort to obtain information directly from the person with ID whenever possible. A better understanding of how self-report compares to proxy report can lead to better interpretation of proxy data in situations when self-report is not available. The current study compares proxy and self-report for several health-related factors commonly used by medical professionals and service providers. These factors were selected for their relationship to health and QOL outcomes and range from very subjective (stress and social support) to fairly objective (types of physical activity).

Method: Participants with ID were 90 adults receiving services in one of three Midwest counties who were interested in participating in a study about health and well-being. Each participant with ID nominated a caregiver who “knew him/her well” to participate. Information was collected from both the person with ID and their caregiver on stress, social support, physical activity, and subjective health.

Results: Overall, self and caregiver report were significantly related for subjective health (ICC=.46, p<.001). Self and proxy report of stress were not significantly correlated (ICC=.077, p=.23). When caregivers were divided into family members and paid staff, the family member proxy report did significantly correlate with self-report (ICC=.49, p=.046) but staff report did not (ICC=.10, p=.21). Proxy and self-report were significantly related for support from family and significant others but not significantly related when it came to rating support from staff or friends. In terms of physical activity, reliability between raters was significant for the number of activities endorsed (ICC=.26, p<.01) but not for the composite score that took into account both number of activities and exertion level (ICC=.06, p=.30).

Discussion: While there are some people with ID who are unable to self-report in any capacity, the results of this study and other recent studies (Stancliffe, Tichá, Larson, Hewitt, & Nord, 2015) demonstrate that it is possible to obtain information directly from many adults with ID on a variety of topics. Given the results of this study, it is recommended that concentrated effort should be made in both research and practice to obtain self-report from any person with some capacity for communication. When proxy reports must be used, they should be used with caution, particularly when dealing with subjective subject matter. Proxy reports from staff members may be particularly concerning as staff often have known a person for a limited amount of time and may only see that person in one context. When self-report is not feasible, it is recommended to gather proxy report from more than one source if possible, especially if the only sources available are staff.

References/Citations: