

Who Should Speak for Individuals with Intellectual Disabilities? Evaluating Quality of Life at Community Providers¹

by Gordon Scott Bonham, Ph.D.
Bonham Research, Baltimore, Maryland
gbonham@BonhamResearch.com
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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.

Introduction

Research since the late 1980's has asked people with intellectual disabilities to express their own views about their quality of life (Schalock and Verdugo, 2002). Quality of life is the primary outcome of programs that support people with intellectual disabilities. Evaluating quality of life outcomes involves several problems in both policy and practice. At the policy level, good evaluation involves stakeholders and participatory action research emphasizes the involvement of those being studied, but it also raises many questions. What does involvement mean when stakeholders have very different agendas and resources? What does involvement mean when those being studied have limited abilities to understand and participate? Who decides what is a desired outcome and how it is measured? Who determines when a person has enough intellectual ability to provide information for themselves that is reliable and valid? How does an evaluator get around the well-documented problem of acquiescence? When others provide even objective information about people with intellectual disabilities, how can the evaluator separate out the true situation from the limited perspectives and biases of those providing the information? These questions involve four basic issues: 1) who determines the capability of people to respond for themselves, 2) can self-respondents provide valid information, 3) can

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proxies provide valid information, and 4) how should those who cannot respond for themselves be represented?

This paper primarily addresses the first issue of who determines the capability of people to speak for themselves, and presents findings from a statewide project that involves government regulators, service providers, self-advocates, and their families. The Ask Me! Survey in Maryland pioneered using peers to obtain informed consent and to interview thousands of adults with intellectual disabilities supported through Medicaid. It includes interviews with two proxy respondents with differing relationships to a sampled individual who is unable to respond for him or her self. Its data help to understand reliability and bias in collecting measures of the quality of life of people with intellectual disabilities. While findings do not solve the problems of collecting outcome data for individuals with limited intellectual abilities, it discusses ways to adjust for limited abilities, limited knowledge, and stakeholder bias.

There are several ways to determine if a person is capable of being interviewed. Sometimes staff or families who support people with intellectual disabilities decide if they can understand and answer questions (Rapley, Ridgway and Beyer, 1997; Stancliffe, 1999). Frequently non-disabled interviewers make the decision of who can respond for themselves, whether these are professional interviewers of the general population (Research and Training Center on Community Living, 2004) or interviewers specifically trained to interview people with intellectual disabilities (Sigelman, et al., 1980). Perry and Felce (2004) found that an interviewer with intellectual disabilities could collect information as effectively as a person without intellectual disabilities. Sometimes the decision-maker has a set of pre-interview questions to help them determine who can adequately respond for themselves (Sigelman et al., 1980; Perry and Felce, 2002; Stancliffe, 1995). Often the basis for deciding who can respond is not specified (Research and Training Center, 2004). The explicit or implicit decision criterion about who is able to respond for themselves affects the information that will be obtained for those individuals. Sigelman, et al. (1980) found that only three of twenty people with profound retardation could respond at all to interviews, and dropped those with profound retardation from the study. Perry and Felce (2002) determined that none of those with the least intellectual ability could respond for themselves, while all those with average ability could. The National Health Interview Survey had responses for 60% of people with mental retardation before interviewers were allowed to use proxies (Research and Training Center on Community Living, 2004). After interviewers could use proxies, representation increased to 90% but only 41% responded for themselves. Rapley (2000) suggests that quality of life is a social construct and its measurement is an interaction between the interviewer and interviewee. Participatory action research calls for involvement of people in research affecting them (Whitney-Thomas, 1996): (1) the subjects of research should identify the specific issues that are important to them, (2) subjects should be asked directly about their own lives, (3) they should be involved in the collection of data, and (4) the research should be used to empower the subjects of the research.

A number of researchers have studied the reliability of answers given by people with intellectual disabilities (Chung, Yu, Martin, Havapiak and Garinger, 2000; Heal and Sigelman, 1996; Perry and Felce, 2002; Sigelman et al., 1980; Stancliffe, 1995). They have looked at acquiescence,

first and last response bias, and stability of answers over time. Suggestions to reduce these problems involve simple wording in questions, having more than two fixed responses, balance between positive and negative wording, and use of pictures and aids (Finlay and Lyons, 2002; Heal and Sigelman, 1996; Sigelman, Budd, Winer, Schoenrock and Martin, 1982). Antaki and Rapley (1996) suggest the problems lie with the interview context, rather than just the person with intellectual disabilities, as both interviewers and respondents work and rework questions and answers. Sigelman et al. (1982), Heal and Sigelman (1996), and Perry and Felce (2002) applied four tests in determining validity of self-responses: 1) the proportion of questions answered, 2) the correspondence between answers to the same question on two occasions, 3) the consistency of answers with the same meaning but with different words or format, and 4) the agreement of information from various sources.

Studies on the reliability of responses by people with intellectual disabilities often compare them to responses of proxies, without first testing proxy responses for reliability (Chung et al., 2000; Heal and Sigelman, 1996; Stancliffe, 1995; Perry and Felce, 2002). Lunsky and Benson (1997) found that staff members did not respond any more consistently across a number of instruments than did people with mild mental retardation. The National Health Interview Survey (Research and Training Center, 2004) found self-respondents skipped questions less frequently than proxies, particularly on subjective questions. Lunsky and Benson (1997) and Stancliffe (1999) found that staff members tended to agree more with each other than with consumers. Gaudet, Pulos, Crethar and Burger (2002) found low correlations between family members and provider staff, similar to the low correlations between self-responses and proxy-responses. Umb-Carlsson (2005) found relative and staff proxies contributed dissimilar information. Cummins (2002), Dudley (2001), and Perry and Felce (2002) found that the more subjective the measure, the lower the correlation between self and proxy respondents. Cummins (2002) reviewed the literature about proxies responding for subjective well-being and concluded that proxy responses for people with severe disabilities “cannot be regarded as valid under any circumstances.” Proxies have limited information on how individuals who cannot respond to questions and express themselves think. In these situations, proxies cannot escape projecting their own thoughts and prejudices. Cummins argues that any reported reliability between self-respondents and proxies, or among proxies, is a result of shared cognition and life experiences rather than specific response validity. As a result, staff and caregivers may be the least reliable proxies in those areas that reflect upon their responsibilities. Two proxies are frequently used, and Stancliffe (1999) found that the average of two staff proxies agreed better with self-response than a single staff response. Cummins (2002), however, argues that two proxies double the response effort without increasing validity.

Cummins (2002) argues that proxy responses are least valid for people who cannot respond for themselves and should not be used to make decisions concerning a person’s life. Stancliffe (2000) also cautions against projecting findings on the validity of proxy reporting from people who can respond for themselves to those who cannot respond for themselves. Parsons, Baum and Johnson (2000), however, argue that a proxy respondent is preferable to complete non-response, especially when the person with intellectual disabilities is willing to participate. Cummins (2002) concedes that proxy responses may be acceptable when the primary objective is

to reflect generally shared views. Rapley et al. (1997) suggest that simple regression adjustments can be made in some domains for proxy responses, while Stancliffe (2000) cautions that not enough is known to assume a simple linear adjustment is adequate. The Ask Me! Survey was designed to influence system change and provide agencies with information on consumers' quality of life to help them enhance programs. It was also intended to help people with intellectual disabilities and their families select the most appropriate service providers. Not collecting proxy information would provide a limited view of the quality of life in Maryland, would not help agencies that support large numbers of people with the most severe disabilities, and would not help families, of those with the most severe disabilities, choose service providers.

Development of The Ask Me! Survey

The Ask Me! Survey began in 1996 with a broad-based consortium of key stakeholders in Maryland: the Developmental Disabilities Administration (DDA), the Maryland Disability Law Center, the Maryland Developmental Disabilities Council, People on the Go of Maryland, The Arc of Maryland, and the Maryland Association of Community Service for Persons with Developmental Disabilities. The Maryland Disability Law Center had provided the impetus for a survey through litigation regarding quality-of-community programs. The DDA agreed in the resulting consent decree to conduct a consumer satisfaction survey. The consortium identified satisfaction with quality of life as a more important focus than satisfaction with services, and adopted the approach of Schalock and his colleagues (Schalock and Keith, 1993; Schalock, 1996). The Ask Me! Project was developed based on the following premises:

1. People with developmental disabilities are in a better position to elicit more meaningful responses from other individuals receiving services than are interviewers who do not have developmental disabilities.
2. By directly asking people how they view their lives, the project has the potential to increase the empowerment of people with developmental disabilities who are receiving services.
3. Because the interviewers themselves have disabilities, the experience they gain in working as interviewers may open professional paths for them within the project or elsewhere.
4. Agencies are keenly interested in the views of the individuals they support and how to address those views.
5. State public policy and funding priorities can be derived from better understanding the views of people who receive services.

Participatory Action Research

The Ask Me! Survey embodies the Whitney-Thomas (1996) concepts of Participatory Action Research. (See **Figure 1**.) The first step is to have survey subjects involved in developing the content. The Maryland statewide self-advocacy organization published a booklet, *Signs of Quality: Words to Serve By*, that highly influenced the Ask Me! Project (People on the Go, 1996). They developed the booklet “to help everyone working with and advocating for people with developmental disabilities.” The name for the project came from their first

litmus test question, “Did you ask me?” The initial pilot used the words in the booklet as a guide to simplify the language of the Schalock and Keith (1993) questionnaire, but the pilot also identified that the Schalock and Keith *Quality of Life Questionnaire* that it did not touch areas important to self-advocates. When the Ask Me! Survey was developed, three-fourths of the questions came almost verbatim from *Signs of Quality*. The remaining questions were primarily related to the domain of employment and material well-being, an area that was gaining in importance. Revisions to the survey, currently underway, will ask more about friend and romantic relations, and about involvement in planning. The survey uses direct and simple language; provides favorable, neutral and unfavorable fixed responses for each question; and uses happy, neutral and sad facial representation as an interview aid for the three responses. The Ask Me! Survey has 56 questions, six for each of eight quality of life domains (physical well-being, emotional well-being, material well-being, interpersonal relations, social inclusion, personal development, self-determination, and rights). Five questions relate to the perceived

Participatory action research

- Subjects develop content
- Subjects asked directly
- Subjects involved in data collection
- Subjects empowered by research



Figure 1

availability of transportation, identified by initial interviewers as very important, and three repeated questions check internal consistency of responses.

Most people participate and respond for themselves

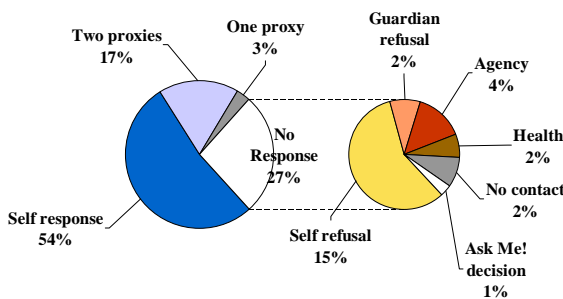


Figure 2

The second step of participatory action research is to ask subjects directly. Half (54%) of the people selected for the Ask Me! Survey respond for themselves. (See **Figure 2**.) An additional 20% are represented by proxies, primarily by two proxies. However, over one-fourth (27%) of the selected people are not represented by interview data. Over half of these people are not represented because they

refused, or reported by their agency to have refused, to participate. An additional 2% could not be contacted to schedule an interview. These may have made an indirect decision to not respond by repeatedly failing to answer the phone, schedule interviews, or show up for interviews. Guardians made the decision that no one could speak for 2% of the individuals. The agency directly contributed to no one speaking for 4% of the individuals by not having current contact information for someone the state had assigned to them for services, but may have contributed to all the preceding reasons for non-response. The remaining 3% of the individuals were not represented in the survey due to survey logistics—sick or away during the survey period, or were too inaccessible for peer interviews.

The third step of participatory action research has subjects involved in data collection. The Ask Me! Survey has been a pioneer in employing peer interviewers, discussed in depth in later sections of this paper. The fourth step of this type of research is to empower subjects by the research. This aspect of Ask Me! is included in the final discussion section of the paper.

Researcher Selects the Respondent

The Ask Me! Survey involves a number of individuals in deciding who answers the interview questions. The researcher makes the initial decision on who can speak for themselves. (See **Figure 2.**) The Ask Me! sample is designed to provide estimates for each community agency supporting people with intellectual and other developmental disabilities, and for the state of Maryland as a whole. It uses a two-stage probability sample design. The first stage involves the selection of agencies to be interviewed during a year based upon the numbers of people they support. The ten largest agencies in the state (350 or more individuals) are included in the survey every year. The next twenty-two large agencies (135-349 individuals) are randomly assigned be interviewed during even or odd years. Agencies supporting 10-134 individuals are randomly assigned for interviews in one of the four years of a four-year cycle. State institutions and community agencies supporting 1-9 individuals are not included in Ask Me!, so approximately 2% of individuals supported only by these providers have no chance of being selected. In the second stage of sampling, forty adults from each selected agency are randomly selected, with the experience that information will be obtained for approximately 30 of them. Data analysis at the agency level does not require weights, as all respondents have an equal probability of selection. Analysis that involves people from more than one agency involves weights that take into account the probability of an agency being selected, the probability of a person within an agency being selected, the response rate at the agency, and the number of different agencies through which an individual can be selected. The two-stage sample



Figure 3

selects about 2,000 individuals each year at about 45 community agencies to represent the approximately 12,500 people 18 years of age or above supported by approximately 150 community agencies with funds through the DDA. The researcher draws a new sample of individuals each year without regard to selection in prior years, so he does not guarantee that every individual will eventually be able to speak for him or her self, and a small number may speak for themselves more than once in a four-year cycle.

Agency Secures Participation

The Arc of Maryland, the prime contractor for the Ask Me! Survey, sends the agency contact person a list of the 40 people selected for interviews, and schedules several days for interviews at the agency. The agency contact person is responsible for securing an agreement to participate from each selected individual, or the consent of the guardian if the person has a guardian. The Ask Me! Survey provides standard letters and consent forms for the agencies to use, but does not monitor how the agency goes about securing cooperation. The average response rate among the 43 agencies in FY2008 was 73%, but has varied from 23% to 97% for the 109 agencies included in the survey over the past four years (FY2005-FY2008). An average of half of the non-response is due to the reported refusals by selected individuals to participate, and while the Ask Me! Survey accepts, without question, the right of people to refuse to be interviewed, it strongly suspects that an agency’s approach to people affects the rate of refusal. People with intellectual and developmental disabilities are more known for their acquiescence to requests than for their nay-saying. Agency approaches to guardians and to scheduling interviews may contribute to guardian refusals and may increase the number of no productive contacts with individuals.

The reported quality of life varies among community agencies, and may be associated with the response at agencies. Average physical well-being ranged from a low of 7.07 to a high of 9.72 on a scale of 0 to 10, with scores below 5 representing negative quality of life and scores above 5 representing positive quality of life. (See **Figure 4.**) The physical well-being averages of seven

out of ten agencies fell within the range of 7.82 to 9.46 (shaded box in the figure) and are not statistically different from the overall state average. The physical well-being scores for the 20% with an average above 9.46 (represented by the line above the box) were statistically different from the 10% with average scores below 7.82 (represented by the line below the box). All agencies had positive average quality of life scores in five of the eight domains. Some agencies, however, had negative quality of life scores in the domains of social

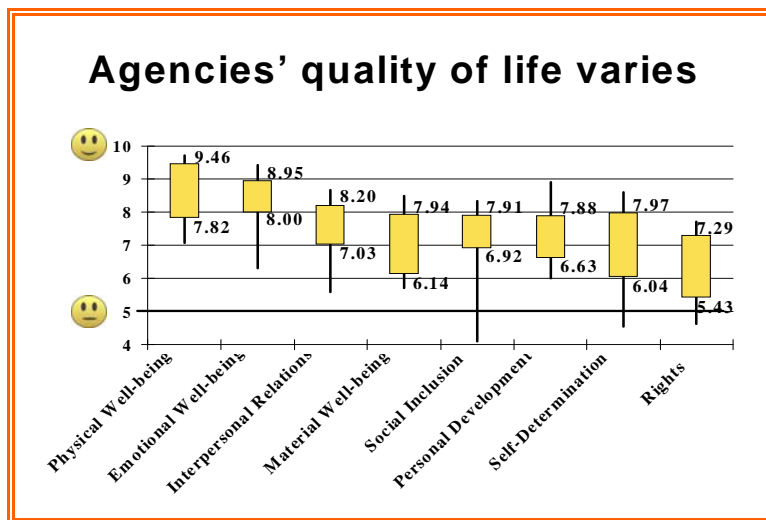


Figure 4

inclusion, self-determination, and rights. While the middle 70% of the agencies had social inclusion scores that clustered closely together, their scores on self-determination and rights varied greatly.

Peer Professionals Determine Ability to Consent

The Ask Me! supervisor gives a general explanation of the survey to the selected individuals and supporting staff at the beginning of each interview session, and then assigns each individual to a peer interviewer team. The team takes the individual to a private room and asks for their consent to be interviewed. Peer interviewers determine ability to consent by asking six questions approved by the DDA institutional review board. (See **Text Box 1**.) If the interviewers believe that the respondents understand and respond to these screening questions, the interviewers sign the form and proceed with the interview. If they believe the respondent cannot understand and cannot communicate responses, they notify their supervisor who identifies (with the agency’s help) two proxies to interview. Overall, 73% of the people willing to be interviewed do respond for themselves, but this varies from 24% to 100% among agencies, reflecting differences in the intellectual abilities of the people they support.

1. Do you understand you will be answering questions? (Yes, no)
2. Do you understand you can skip questions if you do not want to answer them? (Yes, no)
3. Do you understand you can stop the interview at any time? (Yes, no)
4. Let me ask you a question from the interview. Would you say that you are a happy person? (Yes, sometimes, no)
5. Would you like to answer more questions? (Yes, no)
6. Do you understand that you will be answering questions about your life? (Yes, no)

Text Box 1

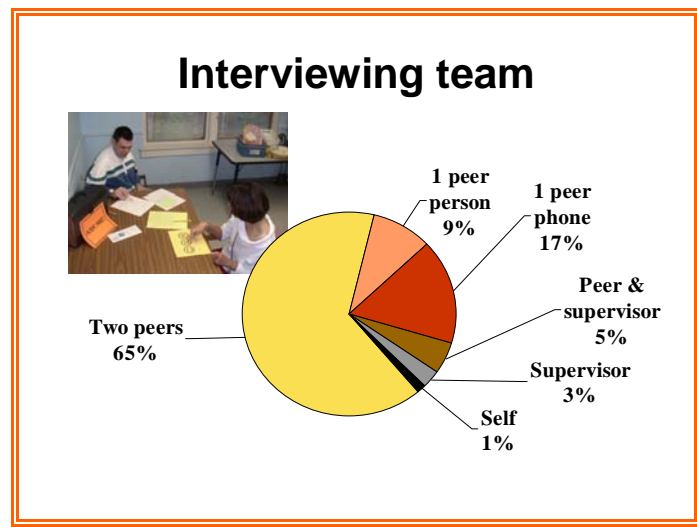


Figure 5

Two-thirds (65%) of the individual and proxy interviews were conducted face-to-face by two-person interview teams in FY2007,. (See **Figure 5**.) Illness or scheduling conflicts sometimes result in an uneven number of interviewers at an interviewing location, and a peer interviewer will conduct the face-to-face interview by her or his self (9%) or with the assistance of the Ask Me! supervisor (5%). Seventeen percent of the interviews are conducted over the telephone by one interviewer. Most telephone interviews are with family members or residential staff as second

proxies, although a few individuals respond for themselves over the telephone. Only when the possibility of an interview will be lost (3%) does an Ask Me! supervisor or coordinator conduct the interview. Individuals, generally proxies, read and mark the surveys themselves 1% of the time.

Supervisor Selects Proxies

Survey protocol requires two proxies for people who cannot respond for themselves, and gives first preference to day staff, second preference to family members or friends, third preference to residential staff, and then to any other support staff or service coordinator who knows the person. Most interviews are scheduled during the day at the agency. Generally, the individual is brought to the interview by a day program direct support staff member. When a person cannot respond for him or her self, the supervisor asks the day staff member to provide a proxy interview at that time. When an interview is scheduled at the individual’s residence, the residential staff or family member is asked by the supervisor to provide a proxy interview as soon as the interviewers determine that an individual cannot respond for themselves. The supervisor also asks the agency’s contact for the names and telephone numbers of other people, who would know the individual well, for later contact by the telephone interviewer. The most frequent combination in FY2007 was a day staff member and a residential staff member (13% of all surveyed people and 46% of proxy combinations), followed by a day staff member and a family member (6% of all surveyed people and 20% of proxy combinations). Almost as many (5% of all surveyed people and 19% of proxy combinations) were two similar staff members. The remainder (4% and 15% respectively) was a single proxy.

Peers Who Conduct the Interviews

Three-fourths (73%) of the approximately 150 interviewers ever employed by Ask Me! can be identified as supported by the DDA for at least some of the time between July 2001 and July 2007. The DDA-supported interviewers are similar to all people supported by DDA in some ways, and different in others. The majority of the interviewers were women (63%) while the majority of individuals supported by DDA were men (58%). (See **Text Box 2**.) The average age of Ask Me! interviewers was 35.6 years. Interviewers tended to be younger than all the people supported by DDA: 36% of the

| | <i>DDA supported interviewers</i> | <i>All DDA supported individuals</i> |
|---|-----------------------------------|--------------------------------------|
| <i>(Number)</i> | <i>(112)</i> | <i>(12,615)</i> |
| Total | 100% | 100% |
| <i>Sex</i> | | |
| Female | 63% | 42% |
| Male | 37% | 58% |
| <i>Age</i> | | |
| 18-24 | 15% | 13% |
| 25-34 | 36% | 23% |
| 35-44 | 26% | 23% |
| 45-54 | 19% | 24% |
| 55+ | 5% | 20% |
| <i>Disabilities (can be multiple)</i> | | |
| Mental retardation | 69% | 80% |
| Cerebral palsy | 23% | 12% |
| Epilepsy, seizures | 20% | 20% |
| Orthopedic | 20% | 12% |
| Speech, language | 13% | 27% |
| <i>Support Services (can be multiple)</i> | | |
| Residential | 35% | 38% |
| Day/Employment | 68% | 69% |

Text Box 2

interviewers were 25-34 years of age compared with 23% of the individuals supported by DDA. Only 24% of the interviewers were 45 years of age and over compared to 44% of DDA supported people. Two-thirds (69%) of the interviewers had a classification of mental retardation, lower than the 80% of the general DDA population with this classification. One-fourth (23%) of the interviewers had cerebral palsy, about twice the percentage as all people supported by DDA. Interviewers were about as like to have epilepsy and seizure disorders as the general DDA population, more likely to have orthopedic impairments, and less likely to have speech and language disorders. Interviewers were just as likely as all people supported by DDA to receive residential support services and day/employment support services.

Interviewers primarily work in teams of two, with a lead interviewer reading the questions and the other team member pointing to the response categories on the flash card and helping with any problems. Either of the interviewers can record the answers. The team approach allows flexibility in adjusting to any difficulties that one of the team members might have; for example, a team member who cannot read can perform the tasks that do not require reading, such as achieving rapport and pointing to the flash card. Gender composition is not an important factor in the team composition, and does not affect the outcome of the interviews as measured by the number of questions completed, the percentage of questions receiving the most positive response, or the quality-of-life scale scores. The project has standardized protocols for conducting interviews, reporting suspected abuse or neglect, terminating interviews, and ensuring confidentiality, in addition to the procedures for obtaining informed consent and interviewing proxies. The Ask Me! interviewers are able to handle all these protocols, and they bring the project to life.

Who Asks and Who Answers Makes a Difference

In Ask Me! with peer interviewers, 73% of the people had the ability to respond for themselves (or with some help from others), higher than reported in other surveys. One-fourth (25%) of those classified with profound retardation responded for themselves, one-half (49%) of those with severe, and almost all of those with moderate (88%), mild (97%), or borderline or less retardation (94%) responded for themselves. (See **Figure 6**.) Since peer interviewers made the determination in a uniform manner of who was able to respond for themselves, self-response is a good indicator of intellectual ability, probably better than the agency-provided level of retardation as discussed later in this paper.

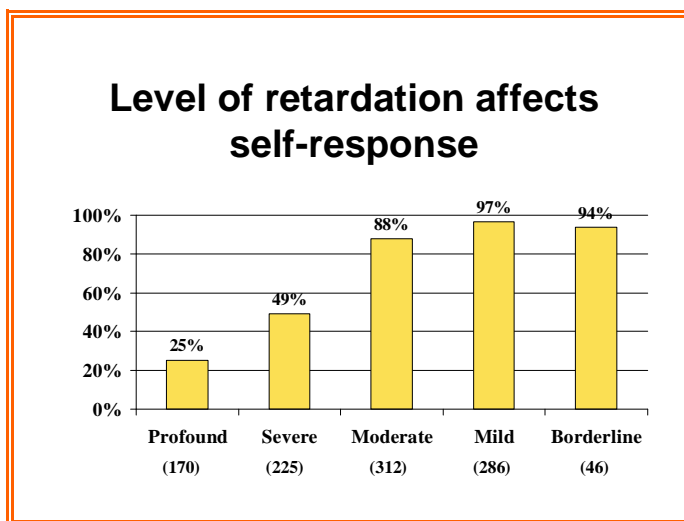


Figure 6

Researcher

The initial selection of agencies and individuals by the researcher on the survey determines who can potentially speak for themselves. The sampling uses industry-established procedures to ensure that all people have equal opportunity to participate in the survey, and no bias is introduced at this point. However, certain basic decisions influence who can speak for themselves. First of all, the sample frame is based on the files of the DDA. Individuals with developmental disabilities who receive no state-funded services are therefore excluded from the survey. Maryland has a substantial waiting list, and none of these who are outside the system are included in Ask Me! Further, the small number of individuals in the system, but for whom all services are provided through one of the four state-run institutions or through an organizational entity supporting fewer than ten people are excluded. Finally, current Ask Me! interviewers are excluded. While all DDA-funded individuals supported in the community by a provider of services to ten or more individuals has the opportunity to be selected, not all individuals have the same opportunity. Agencies are selected first, and then individuals within the agency. An individual supported by more than one agency has more opportunity to be included than an individual supported by only one agency. People supported by small agencies have opportunity for selection only once in four years, but then have an almost certain selection in the year their agency is included. On the other hand, an individual supported by one of the largest agencies has a small opportunity to be selected every year. Individuals are selected without regard to whether they have been interviewed in previous years, so although one-eighth of the people supported with DDA funds are selected for the sample each year, not all will have opportunity to speak for themselves during an eight-year period. Some will be selected multiple times, and others will not be selected any time. To ensure that everyone is equally represented in the final analysis, the information each respondent provides is given a weight inversely proportional to their probability of being selected. In FY2007, individual weights ranged from 1.00 to 38.00, with an average weight of 9.96.

Peer Interviewers

Rapley (2000) suggests that quality of life is a social construct and its measurement is an interaction between the interviewer and respondent. Therefore, who conducts the interview affects the responses. A study at one agency during the second fiscal year (1999) of the pilot had individuals randomly assigned to one of three groups of interviewers. The first group consisted of paid peer interviews (who worked alone). The second group was agency staff who volunteered to conduct interviews as part of their regular job. The third group was volunteers from the Quality Assurance Committee of the Board of Directors. The paid peer interviewers completed 48 interviews, the staff completed 38 interviews, and the board volunteers completed 52 interviews. The responses to the agency peer interviewers were very similar to the responses to the regular Ask Me! peer interviewers the previous year. The peer interviewers, however, received different responses than did agency staff or board volunteers in the domain of dignity. (See **Figure 7.**) Respondents expressed significantly lower levels, and greater variation, of “dignity” to their peers (2.5) than to staff (4.3, $t(81)=1.83, p=.07$) or to board volunteers (6.0, $t(92), p<.01$), on a scale that could range from -10 to +10. They expressed lower levels, and

greater variation, to their peers than to board volunteers in work satisfaction (4.3 vs. 5.9, $t(67)=1.74$, $p=.09$) and lower levels of life satisfaction (2.3 vs 4.1, $t(95)=2.16$, $p=.03$). While the average scores on the remaining domains did not differ statistically, responses to peer interviewers had greater variance in community integration than did responses to either staff or board volunteers.

As the peer interviewers collect the data on site, they increase staff awareness of the competence of people with developmental disabilities in their role as interviewers, and effectively present the importance of quality-of-life issues. A side benefit of the peer interviewers making the determination is that agencies cannot be accused of selecting those individuals they think will express a high quality of life.

Proxies

Some characteristics of individuals have strong relationships with the quality of life they report, or are reported for them. Other measured characteristics do not. Two measures of intellectual ability significantly relate to most quality of life domains: self-response and level of retardation. People's ability to answer survey questions for themselves generally showed a stronger relationship to their quality of life than agency-reported levels of retardation. While both are measures of intellectual ability, both have their limitations for analysis. Agencies did not report information on level of retardation for one-fourth of the sample, and the information reported probably represents an assessment at the time the person first obtained services, or the best guess of staff, and not a current professional assessment. Self-respondents report their perceptions of quality of life, while proxies report their perceptions of the perceptions of people who cannot communicate well with anyone, including their proxies. Therefore, the self/proxy measure cannot distinguish differences due to intellectual ability of the target individual, and differences due to second-hand reporting. For example, self-respondents report lower levels of physical well-being than proxies report. (See **Figure 8**.) Does this mean that people with the ability to respond for themselves really are (1) worse off physically than those without ability to respond to others, (2) have different concepts of physical well-being than staff and family, or (3) do staff and family tend to exaggerate the physical well-being of those entrusted to their care (or entrusted to others' care) either consciously or unconsciously? The reverse occurs in the domain of rights; self-respondents report substantially higher levels than do proxies. It seems reasonable that a person able to understand what others are saying and to express themselves will acquire more rights than a person unable to understand and respond to others. Some proxy bias, however, must be present as different types of proxies report different levels of rights. Family

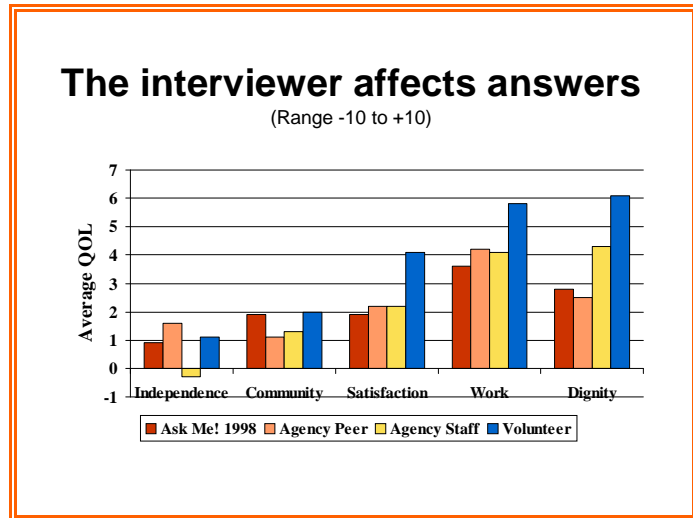


Figure 7

members, on average, report a negative level of rights (below 5 is negative, above 5 is positive), whereas residential staff report positive levels of rights. These differences in reporting are found even when the two proxies are reporting for the same individual.

Agency

The response rates at agencies had significant correlations ($p < .05$) with ten agency characteristics. (See **Figure 9**.) Two of these related to the intellectual abilities of the people the agency supported, and one to physical abilities.

Three related to the types of services provided by the agencies. Four related to the quality of life domains. Many of these are inter-related, and multiple stepwise regression showed that two of them had significant independent relationships with survey response, and explain about one-fifth of the variation among agencies ($R^2 = .20$). The greater the intellectual ability of the people the

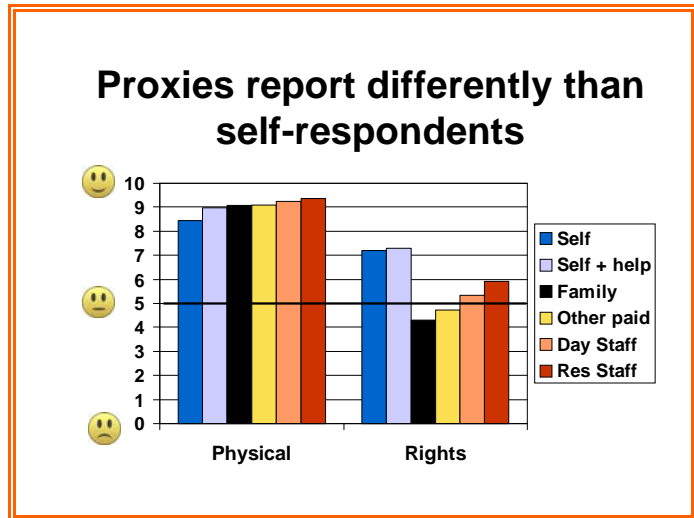


Figure 8

| | Correlation | Regression |
|------------------------|-------------|------------|
| • Self-response | -.40 | -.35 |
| • Intellectual ability | -.41 | ns |
| • CSLA services | -.27 | -.20 |
| • Residential services | .29 | ns |
| • Day services | .20 | ns |
| • Seizures | .23 | ns |
| • Physical well-being | .21 | ns |
| • Emotional well-being | .21 | ns |
| • Social inclusion | .21 | ns |
| • Rights | -.21 | ns |

Figure 9

agency supports, as defined by proportion peer interviewers attested that had the ability to consent to the interview and answer questions, the lower the response rate at the agency ($\beta = -.35, p < .001$). Additionally, the greater the proportion of individuals the agency supported in their own home or apartment (Community Assisted Living Arrangements, or CSLA), the lower the response rate at the agency ($\beta = -.20, p = .03$). An agency has less contact with people supported in CSLA who frequently work in the community and live independent of staff, requiring support only occasionally or in certain areas (e.g., medical appointments, grocery shopping).

A study in 2004 found that the goals agencies submitted to the DDA around 2002 were related to changes in the quality of life between 2002 and 2004 (*Ask Me! 2004*, p.28). Agency goals of improving physical well-being, personal development, self-determination, and rights resulted in increased quality of life among the people they support. Agency goals of improving emotional well-being, consumer satisfaction, or staff satisfaction resulted in decreased quality of life. Goals to improve agency processes had no direct effect on quality of life.

Data also suggest that the value agencies place on research-based information from the people they support affects quality of life. The greater the participation rates that the agencies are able to achieve from self-respondents or their proxies on the Ask Me! Survey, the higher the quality of life is at the agency (*Ask Me! FY2005*, pp. 41, 82). Additionally, the more times agencies attend training on Ask Me! and analyze Ask Me! data for themselves, the greater the value they saw in the data (*Ask Me! FY2003*, pp.48-51).

Discussion

People with intellectual and other developmental disabilities should be involved as possible in research that potentially affects them. Not everyone with profound retardation can speak for themselves, but most individuals with mild or less severe retardation can if given the opportunity. The Ask Me! Survey has been successful in allowing more people to speak for themselves than most other research by following the principles of Participatory Action Research. People with intellectual and developmental disabilities had substantial input into the content and wording of the survey, peers determine if they have the ability to give informed consent and respond to an interview, only peers are in the interview room providing them with the time and support they need to speak for themselves, and people benefit from the research in a number of ways—agencies change based upon the information provided, people see peers in professional roles that they can aspire to, and peer interviewers find meaningful paid work that can become a career, a stepping stone to other types of work, and an inspiration to self-advocacy. Some people cannot respond for themselves, and proxy voices represent them better than no voices at all. However, the ability to respond for himself or herself is not a fixed attribute of the person. Initial analysis of a set of agencies interviewed four years apart showed that agencies with high levels of personal development in the FY2002 Ask Me! Survey had increases in the percent of individuals able to respond for themselves in the FY2006 survey. (See **Figure 10**.) That increase in self-response also caused an increase in the reported level of personal development. This suggests that agencies which focus on personal development can increase self-respond in a cycle that need not end.

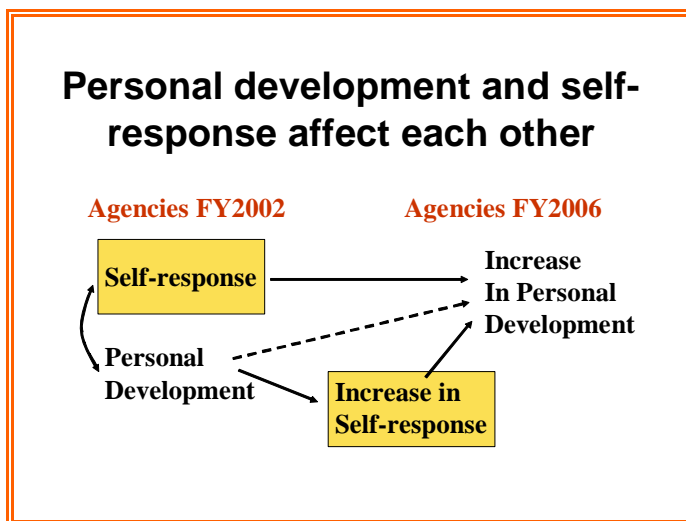


Figure 10

While self-response can increase, there will remain the question about what to do with people who will not be able to speak for themselves. Although self-respondents and proxy respondents report different levels of quality of life, they generally agree on what relates to quality of life. Separate regressions show that both self-respondent and proxy reporting of self-determination are the major predictors of the reporting of rights. (See relative thickness of the arrows in **Figure**

11.) Both suggest that the reporting of personal development has an independent direct prediction of the level of reported rights as well as an indirect contribution through its strong relationship with self-determination.

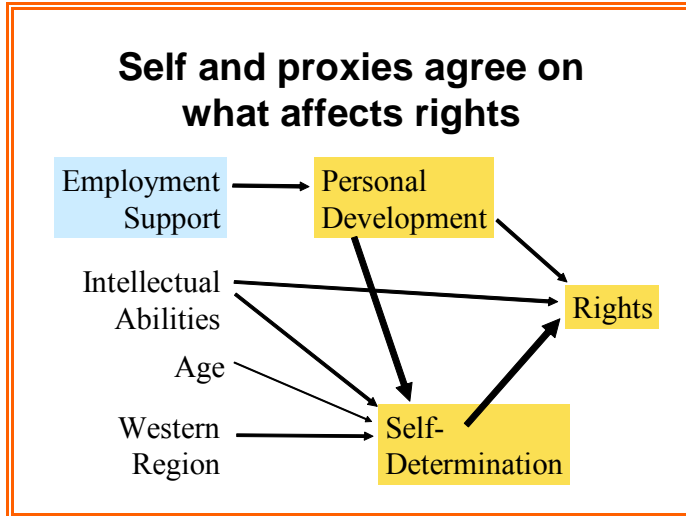


Figure 11

Both suggest that employment support does not directly affect rights, but will do so indirectly as employment is associated with a greater sense of personal development. The greater the intellectual ability (less severe retardation), the greater the rights reported by both self-respondents and proxies. Age and geographic regions also have similar significant relationships for both self and proxy respondents. Since these relationships do not change by the source of reporting, self-responses and proxy responses can be combined, as long as who responded to the interview is statistically controlled during analysis.

Statistically controlling for who answers, however, does not solve all problems. A study on the incidences of unplanned hospital trips, serious injuries, medication errors and unauthorized use of restraints found statistical relationships with the levels of emotional well-being and physical well-being reported in the Ask Me! Survey. The reasons for these relationships are not clear. Higher levels of physical well-being are associated with higher rates of hospital trips, while higher levels of emotional well-being are associated with lower rates of hospital trips. Higher levels of emotional well-being are associated with higher rates of medication errors. If quality of life affects incidences, or incidences affect quality of life, the direction would all be expected to be the same for the different domains and the different measures of incidences. Physical and emotional well-being are the two domains with the highest reported levels of quality of life overall, with the least variation among agencies, and in which proxies report higher quality than do self-respondents. The more people with intellectual and other developmental disabilities can speak for themselves, the more confident we can be that observed relationships are not due to measurement problems.

References

- Antaki, C., & Rapley, M. (1996). Questions and answers to psychological assessment schedules: Hidden troubles in 'quality of life' interviews. *Journal of Intellectual Disability Research, 40*, 421-437.
- Basehart, S., Marchand, C., & Bonham, G.S. (2003.) "Ask Me!sm" A survey on quality of life designed by and for people with developmental disabilities. In Bradley, V. J., & Kimmich, M. H., Ed., *Quality Enhancement in Development Disabilities*. Baltimore MD: Paul H. Bookes Publishing Co., 163-177.

- Bonham, G. S., Basehart, S., & Marchand, C. B. (2000.) *Quality of Life of Marylanders with Developmental Disabilities Participating in the Robert Wood Johnson Self Determination Initiative: Final Report*. Baltimore, MD: Bonham Research.
- Bonham, G. S., Basehart, S., & Marchand, C. B. (2003.) *Ask Me!sm Year FY2003: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., & Marchand, C. B. (2004.) *Ask Me!sm Year FY2004: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., & Marchand, C. B. (2005.) *Ask Me!sm Year FY2005: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., & Marchand, C. B. (2006.) *Ask Me!sm Year FY2006: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Volkman, J., & Basehart, S. (2007.) *Ask Me!sm Year FY2007: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Chong, I., Yu, D., Martin, G., Harapiak, S. & Garinger, J. (2000). Response switching to repeated questions by individuals with developmental disabilities during interviews. *Developmental Disabilities bulletin*, 28, 56-67.
- Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation*, 25, 183-207.
- Dudley, J. R. (2001). When staff and consumers disagree about consumer satisfaction. *The NADD Bulletin*, 4,(6), 103-106.
- Gaudet, L., Pulos, S., Crethar, H., & Burger, S. (2002). Psychosocial concerns of adults with developmental disabilities: perspectives of the self, family member, and provider [Abstract]. *Education and Training in Mental Retardation and Developmental Disabilities*, 37. Retrieved March 15, 2005 from the World Wide Web: <http://www.addceec.org/etmrddv/TOC/etmrddv37n1.html>.
- Heal, L. W., & Sigelman, C. K. (1996). Methodological issues in quality of life measurement. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Volume I: Conceptualization and measurement* (pp. 91-104). Washington, DC: American Association on Mental Retardation.
- Keith, K. D., & Bonham, G. S. (2005.) The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research*, 49(10):799-805.
- Lunsky, Y., & Benson, B. A. (1997). Reliability of ratings of consumers with mental retardation and their staff on multiple measures of social support. *American Journal on Mental Retardation*, 102, 280-284.
- Parsons, J. A., Baum, S., & Johnson, T. P. (2000). Inclusion of disabled populations in social surveys: review and recommendations. Chicago, IL: Survey Research Laboratory, University of Illinois at Chicago for The National Center for Health Statistics.
- People on the Go. (1996). *Signs of Quality*. Annapolis, MD: The Arc of Maryland.

- Perry, J., & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias and resident:proxy concordance. *Mental Retardation*, 40, 445-456.
- Perry, J., & Felce, D. (2004). Initial findings of the involvement of people with an intellectual disability in interviewing their peers about quality of life. *Journal of Intellectual & Developmental Disability*, 29, 164-171.
- Rapley, M. (2000). The social construction of quality of life: The interpersonal production of well-being revisited. In K. D. Keith & R. L. Schalock (Eds.), *Cross-cultural perspectives on quality of life* (pp. 155-172). Washington, D.C.: The American Association on Mental Retardation.
- Rapley, M., Ridgway, J., & Beyer, S. (1997). Staff:staff and staff:client reliability of the Schalock & Keith (1993) Quality of Life Questionnaire. *Journal of Intellectual Disability Research*, 42, 37-42.
- Research and Training Center on Community Living. (2004). Response patterns among adult respondents with mental retardation in the National Health Interview Survey, 1997-2002. *DD Data Brief*, 6(2). Institute on Community Integration (UCEDD). Retrieved March 18, 2005 from the World Wide Web: www.rtc.umn.edu/nhis/databrief10/dddb62.pdf.
- Schalock, R. L. (1996.) *Quality of Life*. Washington, D.C.: American Association on Mental Retardation.
- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008.) The concept of quality of life in program planning and evaluation. *Evaluation and Program Planning*.
- Schalock, R. L., & Keith, K. D. (1993.) *Quality of Life Questionnaire Manual*. Hastings, NE: IDS Publishing Corporation.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.
- Sigelman, C. K., Schoenrock, C. J., Spanhel, C. L., Hromas, S. G., Winer, J. L., Budd, E. C., & Martin, P. W. (1980). Surveying mentally retarded persons: Responsiveness and response validity in three samples. *American Journal of Mental Deficiency*, 84, 479-486.
- Stancliffe, R. J. (1995). Assessing opportunities for choice-making: A comparison of self- and staff reports. *Mental Retardation*, 99, 418-429.
- Stancliffe, R. J. (1999). Proxy respondents and the reliability of the Quality of Life Questionnaire Empowerment factor. *Journal of Intellectual Disability Research*, 43, 185-193.
- Stancliffe, R. J. (2000). Proxy respondents and quality of life. *Evaluation and Program Planning*, 23, 89-93.
- Umb-Carlsson, O. (2005). Living Conditions of People with Intellectual Disabilities: A Study of Health, Housing, Work, Leisure and Social Relations in a Swedish County Population. Uppsala, Sweden: Uppsala Universitet, *Digital comprehensive summaries of Uppsala Dissertations from the Faculty of Medicine* 89.
- Whitney-Thomas, J. (1996). Participatory action research as an approach to enhancing quality of life for individuals with disabilities. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Volume II: Application to persons with disabilities* (pp. 181-197). Washington, DC: American Association on Mental Retardation.