

# **Measuring Quality of Life - ‘The Maryland Ask Me!<sup>sm</sup> Experience’**

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## **Abstract**

The state of Maryland is home to a unique and valuable approach to quality enhancement for services for people with intellectual and other developmental disabilities. Known as the Ask Me! Project, this effort consists of face-to-face interviews conducted by individuals who themselves have developmental disabilities. A total of 154 peer interviewers, for 11 years, have assessed the quality of life of consumers who receive publicly provided services and supports. Evidence suggests that peer interviewers achieve higher levels of self-response with less bias than non-peer interviewers. The Ask Me! Project findings are being used statewide to move policy and services toward greater self-determination and rights, and provide people with intellectual and other developmental disabilities information to make more informed choices about agencies to support their desired quality of life.

## **Background**

Quality of life is both an important concept in program planning and in evaluating outcomes (Schalock, Bonham, and Verdugo, 2008). The Ask Me! Survey began in FY1998 as a pilot, using the early work of Schalock and Keith (1993). It modified the quality of life domains in FY2001 to reflect newer developments in the field that Schalock and Verdugo subsequently documented (2002). It pioneered the use of peer interviewers (Basehart, Marchand, and Bonham, 2003). Ask Me! findings have been used at the organization and system level to guide change (Keith and Bonham, 2005), and Maryland is one of only a few states to make comparable agency-level quality of life scores available to the public (Bonham, Basehart, and Marchand, 2005; Bonham, Volkman, and Basehart, 2007).

### *Organizational Structure*

The Maryland Developmental Disabilities Administration (DDA) sponsors the Ask Me! Project through a line item in the state budget that is matched by federal Medicaid funds. DDA contracts with The Arc of Maryland, the primary advocacy organization in the state for people with intellectual and other development disabilities, to conduct the annual survey. The Arc of Maryland administers the project with a project supervisor, three regional coordinators, and an administrative assistant. It hires, trains, and supervises the peer interviewers. It tracks and maintains all paper documents and supervises keying of data by one of the peer interviewers. The Arc of Maryland subcontracts with Bonham Research to develop the survey content and procedures, to draw the annual sample of agencies and individuals for interviews based on DDA data files, to develop and maintain the database, to process the data for each agency, to prepare the annual report summarizing and analyzing the information, and to provide other technical support.

## *Purpose and Time Line*

The concept for the Ask Me! Project began in 1996 with a broad-based consortium of key stakeholders in Maryland: DDA, Maryland Disability Law Center, 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 is based on the following premises:

- 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.
- 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.
- 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.
- Agencies are keenly interested in the views of the individuals they support and how to address those views.
- State public policy and funding priorities can be derived from better understanding the views of people who receive services.

The most effective quality enhancement mechanism is an informed constituency. Individuals who understand their rights, have the opportunity to express their views, and are encouraged to speak out can enhance the quality of their own individual services and supports and the entire professional array of services. A consumer survey on quality of life provides important outcome measures to complement other quality enhancement efforts in the state: individual planning, inspections by state and local licensing authorities, state regulations governing health and safety and quality supports, consumer appeal rights, self-advocacy, and effective enforcement mechanisms. As one of the most direct uniform methods to elicit personal responses from consumers, the Ask Me! Project is an important, integral part of the quality enhancement system in Maryland.

The Maryland DDA and Maryland Developmental Disabilities Council cooperated to fund Ask Me! as a pilot project for the first four years. The first survey was conducted in the fall of 1997 (fiscal year 1998) with ten participating community agencies and interviews with 237 people. It measured consumers' perceived quality of life using an adaptation of Schalock and Keith's (1993) *Quality of Life Questionnaire*. This adaptation simplified question wording in the four domains (work, independence, integration, and satisfaction) of the *Quality of Life Questionnaire*

so peer interviewers could read the questions and respondents could better understand them. The adaptation also added questions that a booklet prepared by the state self-advocacy organization had identified as important to them (People on the Go, 1996.) Combining the six additional questions into a single dimension, labeled “Dignity,” did not prove statistically satisfactory. In fiscal year 2000, a completely new Ask Me! Survey was developed, with the help of Dr. Robert Schalock, that measured the eight dimensions of quality of life he subsequently published in Schalock and Verdugo (2002): physical well-being, emotional well-being, material well-being, interpersonal relations, social inclusion, personal development, self-determination, and rights. The new Ask Me! Survey was pretested in fiscal 2000 at four agencies (Bonham, Basehart, and Marchand, 2000), and used for in all 35 agencies that volunteered for the fourth pilot year in fiscal 2001.

Fiscal 2002 marked the beginning of state-mandated participation in the Ask Me! Project. The DDA budget did not permit the interviewing of all twelve to thirteen thousand individuals every year who are funded by DDA, nor even a sample of people at each of the approximately 150 community agencies. Therefore, Ask Me! adopted a four-year cycle for including almost all agencies and a sample of people at each agency. Initially, the DDA budget was sufficient to include only a few agencies supporting fewer than fifty individuals. A budget increase in fiscal 2004 permitted all agencies supporting 10-49 people to be included, but still excluded entities supporting fewer than ten people. This limit only excludes less than 0.5% of the people that DDA supports in the community. The Ask Me! Project also does not interview individuals who receive all their services in state-operated institutions, although plans are underway to conduct before and after interviews with people moving into the community as the state institutions close.

*Sample:*

The sample is designed to provide estimates for Maryland as a whole and to provide estimates for each community agency. It is a two-stage probability sample. The first stage involves the selection of agencies based upon the number of people they support. Ten agencies supporting 350 or more individuals are included in the survey every year of the four-year cycle. Twenty-two agencies supporting 135-349 individuals are randomly assigned be interviewed during even or odd fiscal years. Agencies supporting 10-134 individuals are randomly assigned for interviews in one of the four years. Forty people from each selected agency are randomly selected in the second stage of sampling, with the expectation 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. Data analysis above the agency level 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. (Adults receive support from an average of 1.25 agencies.) The two-stage sample includes about 1,500 individuals each year at about 45 community agencies and represents all people 18 years of age or above and who are funded by the Maryland DDA.

### *Dissemination and Use of Information*

The Ask Me! Survey is useful for quality management on three levels: provider-level for continuous program improvement; state-level for establishing goals and monitoring the mental retardation and developmental disabilities' system; and advocacy-level for choice of supports and self-determination. The agencies participating in the Ask Me! Survey receive the aggregate and anonymous detailed responses of the people they support. This information is designed to help them enhance their programs, and can be used to measure achievement of outcomes included in the quality assurance plans they submit to the DDA. DDA uses the Ask Me! results as part of its budget submission to the state legislature to demonstrate how it is "Managing for Results" in achieving its mission. Its mission of fostering "personal growth, independence, and productivity," is effectively measure by the Ask Me! quality of life domains. Individuals, families, and service coordinators have Ask Me! quality of life findings available as a resource in seeking the most appropriate agency for providing support services. The Arc of Maryland uses Ask Me! results to guide its advocacy and training programs.

### **Participatory Action Research**

Participatory action research calls for involvement of people in research that affects them (Whitney-Thomas, 1996). People with intellectual and other developmental disabilities want greater choice and control over the services and supports they receive (Basehart, Marchand, and Bonham, 2003). They want opportunities to express their views about the services they receive and to be part of efforts to improve them. Yet, consumer satisfaction surveys have often been developed and administered by professionals and authority figures. The Ask Me! Survey involves four premises of participatory action research: (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. People on the Go of Maryland, the Maryland statewide self-advocacy group for people with intellectual and other developmental disabilities, along with its sponsor, The Arc of Maryland, initially proposed the consumer-directed approach to assessing consumer satisfaction and quality of life. They had a major input into the survey development and have been joined by other individuals with intellectual and other developmental disabilities in conducting interviews and in using information to promote self-determination and knowledge of rights.

### *Content Development*

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, and to identify areas that it did not touch. When the new survey was developed, three-fourths of the questions came from *Signs of Quality* with only minor revisions. The survey was designed to maximize the probability of self-

response and reduce the probability of unreliable responses in several ways: (1) using peer interviewers, (2) asking questions important to self-advocates, (3) using direct and simple language (average of 9.9 words per question, 1.3 syllables per word, and rated at a 3.6 school grade level with the lowest possible verbal complexity score); (4) providing three fixed responses for each question (favorable, neutral and unfavorable); and (5) associating happy, neutral and sad facial representation with the three responses. The Ask Me! Survey has 56 questions, six for each of the eight quality of life domains defined at the top of page 3, five questions on the perceived availability of transportation (identified by initial interviewers as very important), and three repeated questions to check internal consistency of responses. Each question can be answered with a positive response (☺ 1), a neutral response (☹ 2) or a negative response (☹ 3). Respondents can answer with words, by general gesture, or by pointing to a face on a card associated with their answer.

### *Peer Interviewers*

Antaki and Rapley (1996) suggest that many of the problems in collecting information from people with intellectual disabilities lie within the interview context as both interviewers and respondents work and rework questions and answers. Peer interviewers are frequently used in types of survey research to reduce possible bias, and Perry and Felce (2004) found that interviewers with intellectual disabilities could collect information as effectively as interviewers without intellectual disabilities. Experience on the Ask Me! Project suggests that survey results are more valid and meaningful because of peer interviewers. The interviewer is more likely to understand and be understood by the interviewee, as they typically share more common experiences than those who do not receive services.

The project requires standardized protocols for obtaining informed consent, conducting interviews, reporting suspected abuse or neglect, terminating interviews, ensuring confidentiality, and interviewing proxies for individuals who cannot understand the survey. The Ask Me! interviewers handle all these protocols and bring the project to life. As they 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. An extremely important part of their job is to make the determination of whether a person is able to respond for themselves. In some studies, the staff or families who support people with intellectual disabilities decide if they can understand questions and express themselves (Rapley, Ridgway, and Beyer, 1997; Stancliffe, 1999). Other times non-disabled interviewers make the decision as to 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). 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. 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.

### *Consent for interviews*

The project sends each agency a list of people selected for interviews so the agency can make the necessary arrangements. This includes informing the individuals about the survey and asking them to participate. If an individual had a guardian, the agency sends the Ask Me! permission form to the guardian to sign to allow participation. At the interview session, the Ask Me! supervisor gives a general explanation of the survey to the selected individuals and supporting staff, 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, and if granted, they conduct the interview. The institutional review board for the DDA requires each person to be interviewed to have the ability to consent to the interview. Peer interviewers determine ability to consent by asking six pre-interview questions:

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)

These questions effectively determine who can respond to the interview for themselves. If the interviewers believe that the respondent understood and answered these screening questions, the interviewers sign the form and proceed with the interview. If they believe the respondent cannot understand and cannot communicate, they notify their supervisor to identify (with the agency's help) two proxies to interview. Overall, 73% of the people willing to be interviewed respond for themselves, but this varies from 24% to 100% among agencies, reflecting differences in the intellectual abilities of the people they supported.

### *Interview setting*

Most peer interviewers work in pairs and conduct interviews face-to-face with the selected person or the person's proxy. A few interviewers conduct telephone interviews. Interviewers conducted 48% of interviews face-to-face with the person at the person's weekday program or employment site. They conducted 6% of the interviews face-to-face with the person in their home or other location, and 9% of the interviews with the person by telephone. Interviewers conducted 21% of the interviews face-to-face with staff members at weekday program or employment sites, 4% face-to-face with proxies at other locations, and 13% with proxies by phone (mostly second 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. The most frequent combination 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.

### *Confidentiality*

Interviewers conduct interviews in private and they guarantee confidentiality for anything said during the interview. The only time another person is in the room is at the request of the respondent, who may ask for a staff or advocate to help or translate for them, or a third peer interviewer observing the interview for quality control purposes. One question on the survey asks if people in the home hit or hurt the respondent. At the infrequent times that the answer is “yes,” the peer interviewers ask if the respondent would like to talk to the Ask Me! supervisor about it. If not, the interviewers give the individual a paper with telephone numbers they can call to report abuse if they should later choose to do so. The interviewers are granted legal immunity from requirements to report suspected abuse. If the person wants to talk, the interviewers summon their supervisor who informs the individual that the supervisor is legally required to report any abuse they describe. After any abuse or neglect is described, the supervisor leaves to report to the appropriate person at the agency, and the interview continues. This has resulted in a few interventions over the history of Ask Me!, but more frequently the abuse has already been dealt with, although still remembered by the individual. Interviewers sign a pledge of confidentiality and know that breaching that trust is grounds for dismissal.

Each selected individual is assigned a project identification number at the time of sample selection. The person’s name and their number appear together only on the master spreadsheets maintained by the supervisor and coordinators. The supervisor records only the number on the survey form. The person’s name without the number appears on the Consent Form, and the Transportation Form that is completed by the agency. During data processing, Bonham Research assigns different unrelated record identification numbers for any eventual public release. No data is provided that could identify any group containing fewer than five individuals. The Ask Me! Project considers confidentiality so important to accurate reporting for agency and state program enhancement that the data are not made available for individual planning or individual service quality control.

## **Interviewers**

### *Recruitment*

Interviewing teams are based in four geographic areas of Maryland. The Arc of Maryland conducts annual recruitment for interview positions through People on the Go, local self-advocacy groups, service coordination, vocational rehabilitation, and service provider agencies. The project had no experience in selecting peer interviewers for the first year of interviewing, and only a little bit more by the second year. The results were generally not very successful,

although one of the original interviewers is still interviewing eleven years later. While formal recruitment announcements are still distributed, most applicants have heard about the position through friends or staff, or decided at the time they themselves were interviewed that they could be, and wanted to be, an interviewer. Currently, only a few peer interviewers are new each year as most continue for several years. Current interviewers average 4.7 years on Ask Me!

Necessary qualities for interviewers include listening skills, understanding the project's goals and expectations, ability to conduct objective interviews and follow protocols, interest in traveling, sensitivity, self-motivation, dependability, and self-advocacy skills. A key quality of a good peer interviewer is the ability to make the respondent feel comfortable and confident in the interview setting. The ability to read or to mark answers are not requirements, since an interviewer without these abilities can be paired with an interviewer who has those abilities. Neither is the ability to communicate verbally a requirement, as accommodations are made for interviewers who require augmentative or alternative communication strategies and technologies.

### *Training*

Interviews must be conducted according to the project protocols to preserve the integrity, reliability, and validity of the survey. Training is the first quality enhancement measure. All interviewers participate in initial centralized training each year, and then in monthly regional training sessions designed for continuous quality enhancement. Another quality enhancement measure involves videotaping an actual interview. Interviewers and project staff view the videotape together, enabling the interviewers to see themselves in an actual interview. Staff encourages interviewers to draw their own conclusions about improving their skills. A third quality enhancement measure involves pairing experienced interviewers with new interviewers so quality can be demonstrated and not just taught. A fourth measure involves an experienced peer interviewer observing a pair conducting an actual interview, and providing feedback afterwards.

The annual statewide training for all new and experienced interviewers includes (Basehart, et al., 2003):

- Information on the prior year's survey results and recommendations
- Qualities of good interviewers
- The Ask Me! Project's goals
- The role and responsibilities of interviewers
- Interview protocols to ensure reliability and validity
- Confidentiality requirements
- Problem-solving techniques to deal with potential on-site challenges
- Protocol for reporting abuse and neglect
- Protocol for terminating an interview
- Opportunities to practice team interviewing techniques
- Opportunities to build teamwork.

Regional training sessions tend to focus on various subsets of these topics. They also provide additional opportunities to practice interviewing techniques and to build teamwork.

### *Employment*

The Arc of Maryland hires 35-40 peer interviewers each year as part-time employees. Interviewers receive \$11 for each face-to-face interview in which they participate. This includes payment for the consent process, even if the individual is unable to give informed consent and is not interviewed. They are then paid for proxy interviews in which they participate. Interviewers may work a couple of days a month, or as much as several days a week, depending on the number of interviews to be conducted in their region and on their availability. Interviews are generally conducted on the same days of the week so interviewers can schedule another job or activity on other days. The Arc of Maryland office telephone interviewer/data entry clerk is paid at an hourly rate. Interviewers are paid stipends for attending training sessions. Interviewers make their own arrangements for transportation in the major metropolitan areas where public transportation is available. The Ask Me! coordinators provide transportation or make special arrangements when public transportation is not available. Interviews are scheduled as far in advance as possible and interviewers are expected to be present and on time. Interviewers are expected to exhibit standard job skills and a professional attitude and appearance.

### *Professional growth*

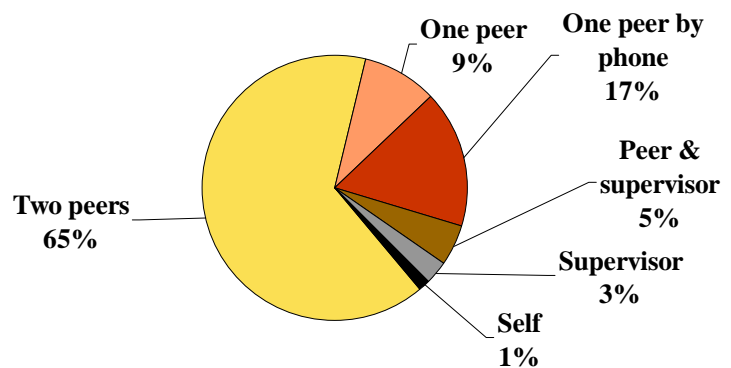
The Ask Me! Survey has and does affect the 154 past and present interviewers as well as the respondents. It has offered some individuals their first opportunity to have paying jobs outside of sheltered workshops, and offers others a second chance at working after an unsuccessful placement. One-fifth (19%) of the individuals no longer on the payroll are known to have quit in order to go to school or to take a job offering higher income and benefits. One of these interviewers was promoted to become a full-time Ask Me! regional coordinator. Not everyone hired became a successful interviewer. One-sixth (16%) is known to have resigned because of the work hours, transportation difficulties, health reasons, or changing residence to another state. An additional 36% are known to have been terminated, or not asked to return the next year, due to problems with their interviewing skills or work ethic. However, only one person has been terminated for a breach of confidentiality. The reasons the remaining interviewers are no longer part of Ask Me! have not been determined, but at least one interviewer quit because the job was paying too much money for her to retain her medical benefits. Anecdotes suggest that interviewing on Ask Me! increases individuals' self-esteem and self-advocacy. A couple of non-reading interviewers decided that they could learn to read and started taking lessons. Another former interviewer set up a website and organized a self-advocacy group in a part of Maryland without one.

### *Teamwork*

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.

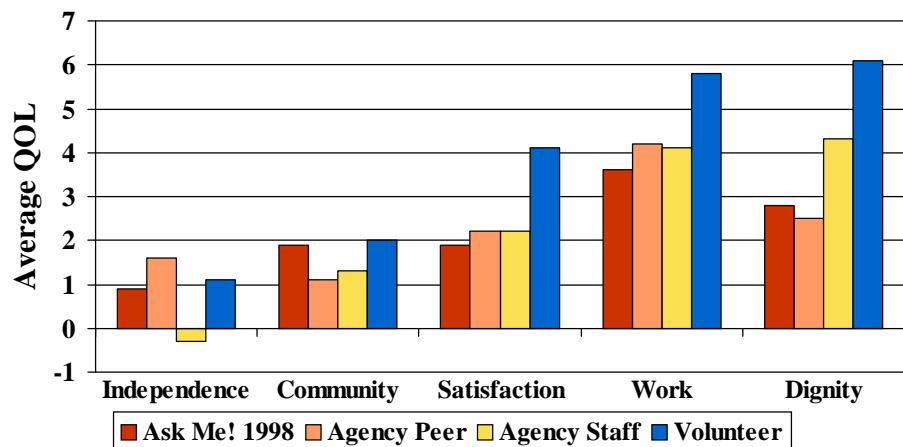
In FY2007, two-thirds (65%) of the individual and proxy interviews were conducted face-to-face by two-person interview teams. (See **Figure 1.**) Illness or scheduling conflicts sometimes result in an uneven number of interviewers at an interviewing location, and a peer interviewer will conduct the face-to-face 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.



**Figure 1.** Who Conducts the Interview?

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 (working individually) completed 48



**Figure 2.** Average Quality of Life Reported to Peer, Staff, and Volunteer Interviewers

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 2**.) 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 remaining other average scores did not differ statistically, responses to peer interviewers had greater variance in community integration than to either staff or board volunteers.

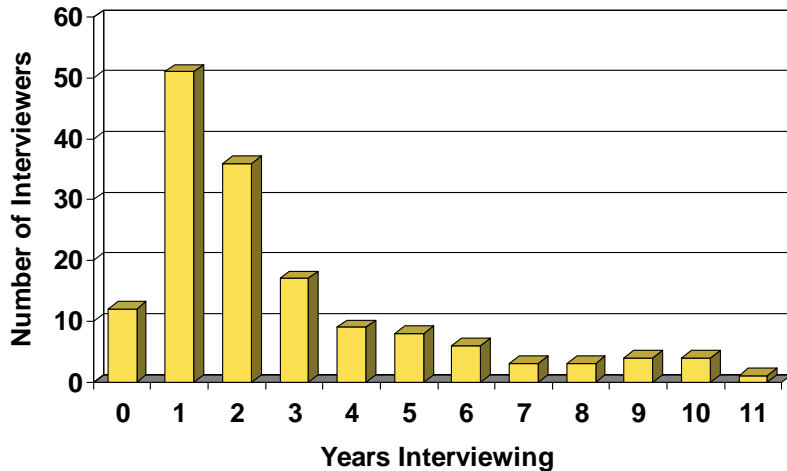
*Characteristics of Peer Interviewers*

Three-fourths (73%) of all the interviewers employed 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 **Figure 3**.) 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 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.

	<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%

**Figure 3.** Characteristics of Interviewers and All People Supported by DDA

Although interviewers in the most recent year average 4.7 years of experience, all interviewers since the beginning of Ask Me! averaged 2.7 years. Twelve of the 154 interviewers resigned or were terminated prior to conducting any interviews, and one-third (51) of the interviewers conducted interviews during only one fiscal year. (See **Figure 4.**) One-fourth (36) interviewed for two years. However, one-fifth (29) has interviewed for five or more years.



**Figure 4.** Number of Interviewers by Number of Years Interviewing on the Ask Me! Survey

The Ask Me! Survey has employed about the same number of interviewers during each of the eleven fiscal years. However, the average number of interviews they completed generally increased with each succeeding year. The project hired 33 interviewers during the first pilot year to interview 280 individuals and proxies. (See **Figure 5.**) Most of the interviews involved two peer interviewers and/or two proxies, for a sum of 421 interviewer involvements for which they were paid. On average, each interviewer conducted 12.8 interviews. This small number of interviews per person did not allow interviewers to become skilled in interviewing, and raised concern about quality and efficiency. While the number of interviewers increased over the next two years, they did not increase as rapidly as the number of people interviewed, so the average number of interviews doubled. In addition, some of the interviewers in the subsequent years had experience from previous years. Ask Me! soon found that 35 interviewers were about the right number to interview a sample of 1,500 individuals, and the average number of interviews per interviewer steadily increased to 79.3 in fiscal 2008. Exceptions occurred in fiscal years 2004 and 2005 when the state obtained additional resources and requested that all agencies supporting more

Fiscal year	Number of interviewers	Average number of interviews	Total interviews paid	Total people interviewed
1998	33	12.8	421	280
1999	40	21.7	869	590
2000	52	23.1	1,202	743
2001	42	37.0	1,554	1,065
2002	40	40.1	1,603	1,030
2003	40	52.6	2,104	1,351
2004	34	83.6	2,841	1,855
2005	36	68.6	2,470	1,735
2006	37	63.6	2,352	1,462
2007	34	68.8	2,339	1,495
2008	30	79.3	2,379	1,549

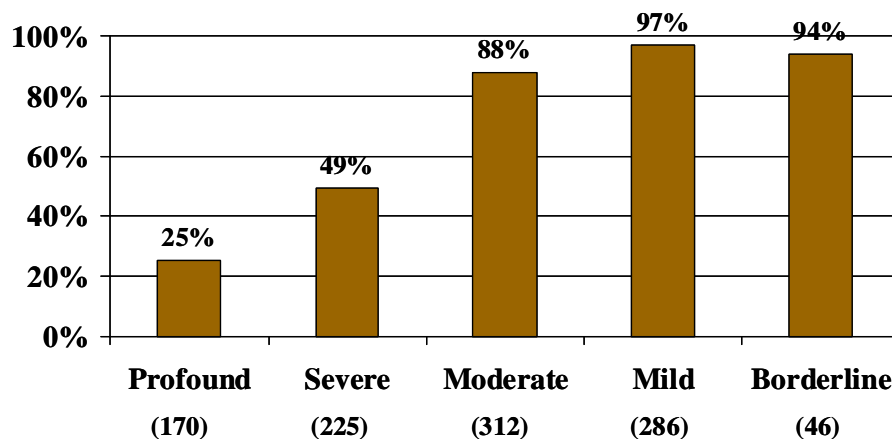
**Figure 5.** Number of Interviewers and Interviews by Year

than ten people be interviewed within the first four-year cycle. Numbers of interviews are not evenly distributed across all interviewers, however. During the most recent year (2008), one interviewer (requiring a lot of support and living in an area with poor transportation) conducted only six interviews while another field interviewer conducted 190 interviews, and the central office telephone interviewer conducted 322 interviews. Over the eleven years of the project, interviewers have conducted 130.7 interviews on average. One interviewer has conducted 1,339 interviews during eight years of interviewing.

*Response to Peer Interviewers*

Sigelman, et al. (1980) found that only three of twenty people with profound retardation could respond at all to their interviews, and dropped all 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 dropped to only 41% responding for themselves. In Ask Me! with peer interviewers, 73% of the people had the ability to respond for themselves,<sup>1</sup> higher than reported in these 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.** Percent Self-Response, by Level of Retardation

Not everyone selected for the survey participates, either themselves or through proxies. The overall survey non-response rate in 2007 was 27%, with over half of non-response due to refusal to participate by the selected individuals (15%) or their guardians (2%). The next most likely reasons for non-response were agency lack of knowledge about the people DDA thought they

<sup>1</sup> The project classified people who responded with the help of another person as self-respondents, and these constituted 7 of the 73 percentage points.

were supporting (4%), and failure of the person to show up for interviews or be available for contact by interviewers even though they had initially agreed. A few (3%) individuals had moved out of state, were in the hospital, had health problems, did not understand English or American Sign Language, or had other reasons the project decided they could not be interviewed. Non-response at agencies ranged from 0% to 84%, indicating agency interest had substantial effect. The agency with the 84% non-response rate was closed several months after the interview sessions, but before any release of Ask Me! data, when state investigation of a newspaper story confirmed staff abuse of residents.

## **Quality of Data**

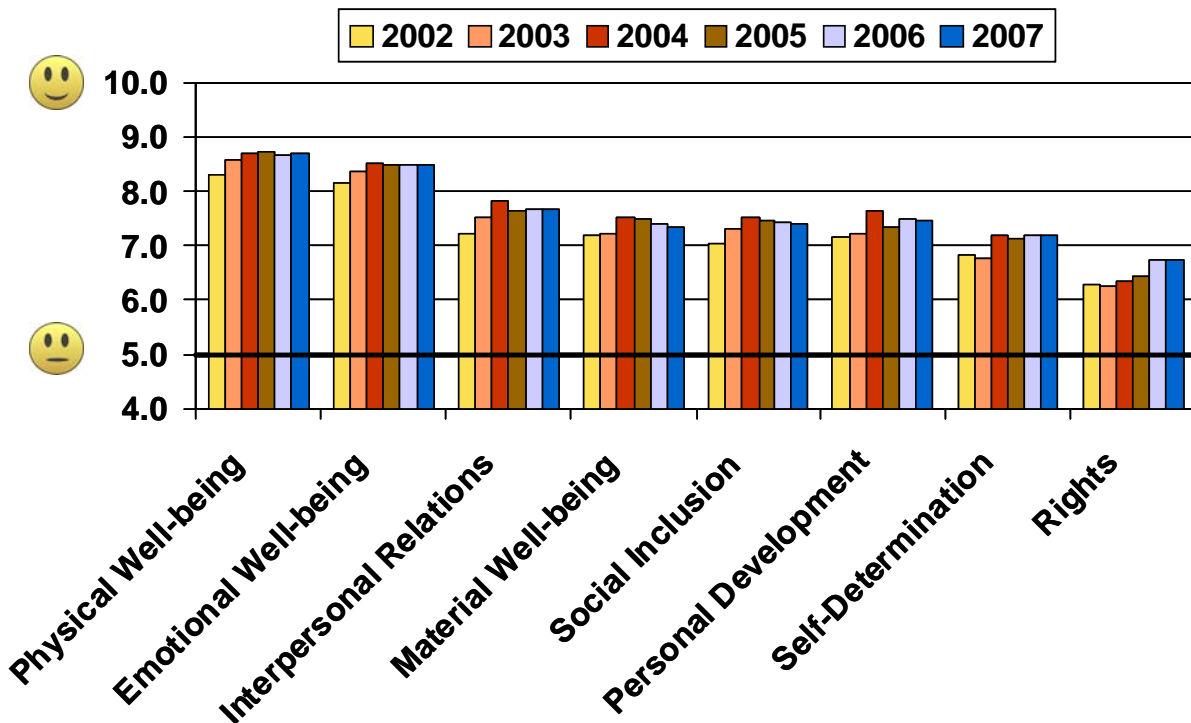
Quality of life represents outcomes that are person-defined and are valued aspirations. No sources external to the individual are available to verify the reliability and validity of the data. Studies on the reliability of responses by people with intellectual disabilities have often compared them to responses of proxies, without first testing proxy responses for reliability (Chung, Yu, Martin, Harapiak, and Garinger, 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.” He argued 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 primary tests for reliability and validity of data from people with intellectual and developmental disabilities, therefore, are the reasonableness and usefulness of the information. The Ask Me! Survey embedded three duplicate questions to test consistency of response, but this primarily showed that agency staff is no more consistent in answering questions than people with

intellectual and other developmental disabilities. This section discusses a number of findings from the Ask Me! Survey that suggest that the data are reliable, valid, and useful.

*Statewide Change*

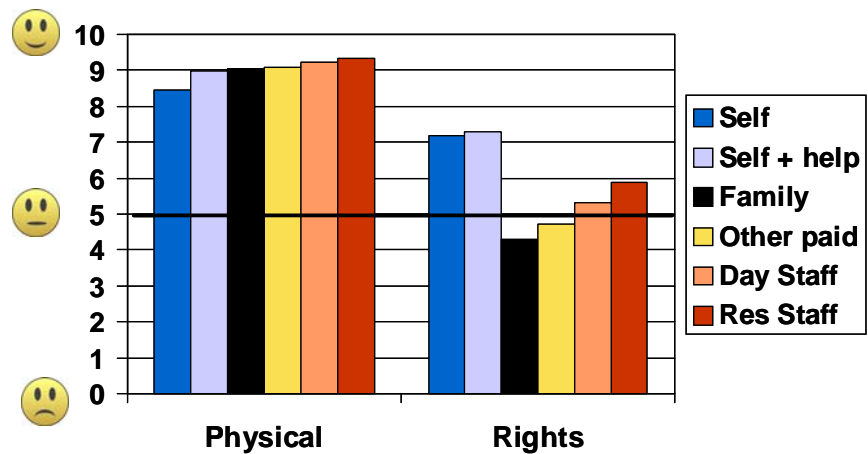
The changes between fiscal years 2002 and 2007 in the quality of life of adults in Maryland with developmental disabilities suggest that the Ask Me! Survey has had some effect by giving a voice to people supported by Maryland community provider agencies. The DDA started using Ask Me! results in FY2002 for its “Managing for Results” submission to the state legislature as part of its budget request. It set a goal, based on the 2001 pilot, of increasing the average quality of life in the domain of personal development, while maintaining the quality of life in the other seven domains as measured both by the average and the percent of individuals who reported a positive quality of life (above a threshold of a neutral quality of life). DDA achieved these goals in fiscal 2002 and 2003, except in the domains of self-determination and rights. (See **Figure 7.**) Therefore, the *Ask Me! FY2003* report recommended that DDA (and the community agencies) shift their focus to self-determination and rights. Although DDA did not change its “Managing for Results” goals, it did change agency training to emphasize self-determination and rights. The Arc of Maryland also used these Ask Me! results to focus its self-advocacy training to these two areas. Substantial increases had occurred in self-determination by 2004, and substantial increases had occurred in rights by 2006.



**Figure 7.** Average Quality of Life in Maryland, by Year

## Individuals' Quality of Life

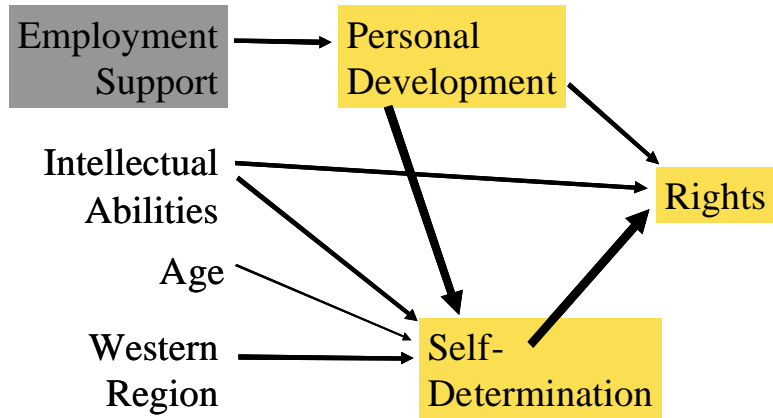
Some characteristics of individuals have strong relationships with the quality of life they report, or are reported for them. Other measured characteristics do not. Two measures of intellectual ability significantly relate to most quality of life domains: self-response and level of retardation. People's 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. Information on level of retardation was missing for one-fourth of the sample. The level may represent a recent professional diagnosis, but more probably represents the assessment at the time the person first obtained services or the best guess of staff. Self-respondents report their perceptions of quality of life, while proxies report their perceptions of the perceptions of people who cannot communicate well, even with them. Therefore, the self/proxy measure cannot distinguish differences due to intellectual ability 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) 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 is evident as different types of proxies report different levels of rights. Family 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.



**Figure 8.** Average Quality of Life in Domains of Physical Well-being and Rights, by Respondent

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 is the major predictor of the reporting of rights. (See relative thickness of the arrows in **Figure 9**.) 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. 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.



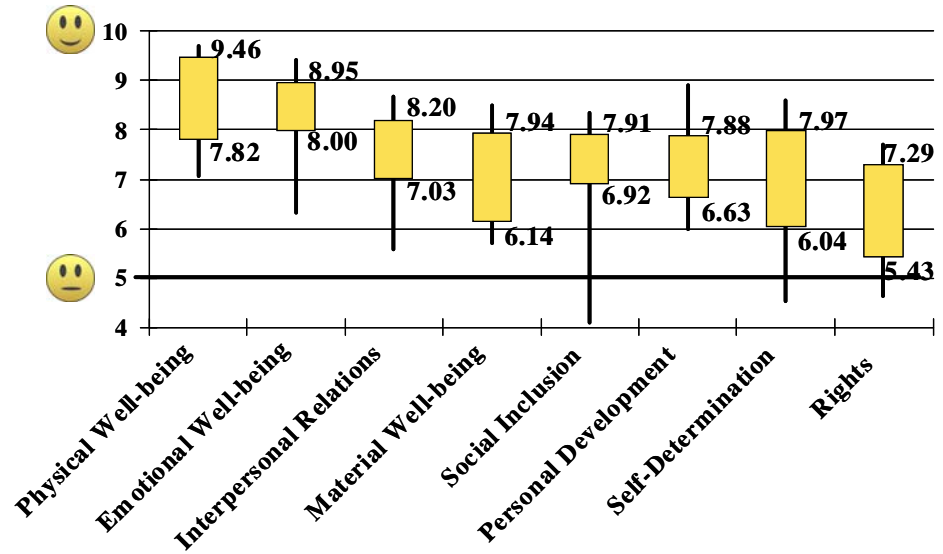
**Figure 9.** Individuals and Proxies Agree on What Affects Quality of Life

Regression analysis at the individual level shows that men and women do not differ in their reporting on any of the quality of life domains. A few physical conditions and impairments may relate to quality of life, but which condition or impairment depends on whether individuals or proxies respond to the survey. When no causal relationships among quality of life domains are assumed, and they are individually regressed on personal and service characteristics, people with supported employment services have higher quality of life in all eight domains than people with day habilitation services, independent of physical and intellectual abilities. Whether or not people received residential services supported by DDA does not directly relate to their quality of life in any of the domains. Individuals' perceptions of the availability of transportation have strong relationships with quality of life in all eight domains. The frequency family and friends provide transportation is the only objective measure that relates both to perception of availability of transportation and perceptions of quality of life. Although it does not affect the perceived availability of transportation, the frequency that an agency provides transportation to employment or day programs and to other activities directly affects quality of life. Whether or not people have service coordinators (who is independent of agencies providing direct support) is not reflected in their quality of life (Bonham, et al., 2005). However, the type of relationship they have with the service coordinator (chosen, available, listens, identifies new services, etc.) does affect quality of life (Bonham, et al., 2000).

*Quality of Life and Agencies*

The reported quality of life varies among community 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 10.**) 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 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 the most of any domains.



**Figure 10.** Average Quality of Life Scores Among Agencies, 2007

Individuals receiving supported employment report higher quality of life than individuals not receiving supported employment, controlling for physical and intellectual abilities. Similarly, agencies that provide supported employment have higher average quality of life reported in six of the eight domains than do agencies that provide other types of support, controlling for the average physical and intellectual abilities of the people they support. Agencies that provide support to individuals living in their own homes have higher average reporting of material well-being and social inclusion than agencies with few individuals living independently, a finding not seen at the individual level (Bonham, et al., 2005). Independent of whom they support, the value agencies placed on consumer data, as measured by the Ask Me! response rate (agencies asked consumers to participate, arrange for their presence at the interview site, and identified proxies for those who could not respond for themselves), the higher the reported quality of life at the agency. Additionally, the more times agencies attended training on Ask Me!, and analyzed the data for themselves, the greater the value agencies said they found in the data (Bonham, et al., 2003).

Additional value of Ask Me! Survey data has come from linking it with other data reported by agencies to the DDA. The DDA began requiring agencies to submit Quality Assurance Plans about the same time that Ask Me! moved from a pilot to a required survey. Agencies that submitted quality assurance goals of improving physical well-being, rights, self-determination, and personal development had statistically significant increases in two, three, or four quality of life domains between Ask Me! Surveys two years apart. (See **Figure 11.**) Goals in the domains of personal development and interpersonal relations, however, resulted in quality of life declines during the first year at agencies interviewed every year, but this was more than overcome by the end of the second year. Agency goals of improving emotional well-being, increasing consumer satisfaction, and increasing staff satisfaction resulted in statistically significant decreases in three

or five of the eight quality of life domains over the next two years. Consumer satisfaction with services is not the same thing as quality of life. Staff satisfaction may be desirable, but only when it can be translated into improved quality of life for the supported individuals. Quality Assurance Plan goals to improve interpersonal relations, social inclusion, material well-being, and several agency processes had little effect on changing quality of life (Bonham, Basehart, and Marchand, 2004).

• <b>Physical Well-being</b>	<b>4+</b>	• Organizational	1+
• <b>Rights</b>	<b>3+</b>	• Other process	1+
• <b>Self-Determination</b>	<b>2+</b>	• Consumer process	0
• <b>Personal Development</b>	<b>4-/2+</b>	• Staff process	0
• Interpersonal Relations	1-/1+	• <b>Consumer Satisfaction</b>	<b>3-</b>
• Social Inclusion	0	• <b>Staff Satisfaction</b>	<b>5-</b>
• Material Well-being	0		
• <b>Emotional Well-being</b>	<b>5-</b>		

**Figure 11.** Number of Quality of Life Domains Affected (+/-) by Quality Assurance Plan Goals

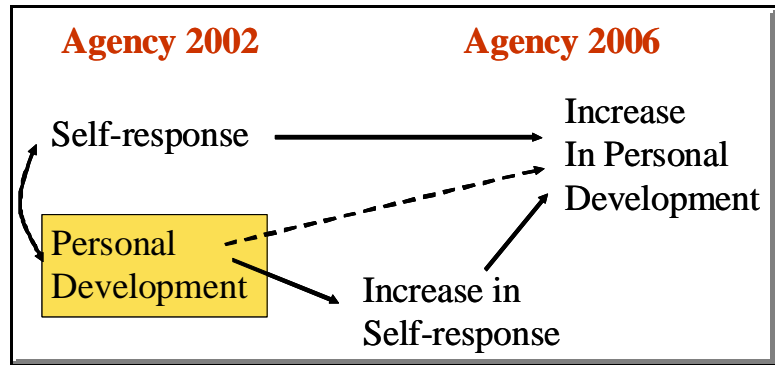
Characteristics of agency staffing at the midpoint of the four-year cycle are reflected in the quality of life of the people they support. In a regression equation controlling for characteristics of people supported (self-reporting and seizures) and characteristics of the agency (supported employment, survey response rate, and region), the more direct care staff for whom a first line supervisor has responsibility, the lower the quality of life in the domains of personal development and self-determination. (See **Figure 12**, shaded area.) The higher the turnover rates of direct support staff, the lower the personal development and rights. The higher the average wage paid to direct support staff, the higher the personal development independent of staff turnover (Bonham, et al., 2005). These cross-sectional relationships may or may not show up as causal in longitudinal analysis, but preliminary analysis of about 40 agencies suggests that the turnover rate of first line supervisors has a significant negative effect on changes in agency quality of life over four years (Bonham, Basehart, and Marchand, 2006).

<b>Agency Characteristics</b>	<b>Personal development</b>	<b>Self-Determination</b>	<b>Rights</b>
Direct staff/supervisor	<b>-.18</b>	<b>-.18</b>	..
Direct staff turnover	<b>-.22</b>	..	<b>-.17</b>
Direct staff wage	.22	..	..
% Supported employed	.36	.27	.23
Ask Me! response rate	.24	..	..
Western DDA region	..	.40	.26
% Self-reporting	..	.43	.43
% Seizures	..	..	<b>-.22</b>

**Figure 12.** Standardized Multiple Regression Coefficients of Agency quality of Life, by Agency Characteristics

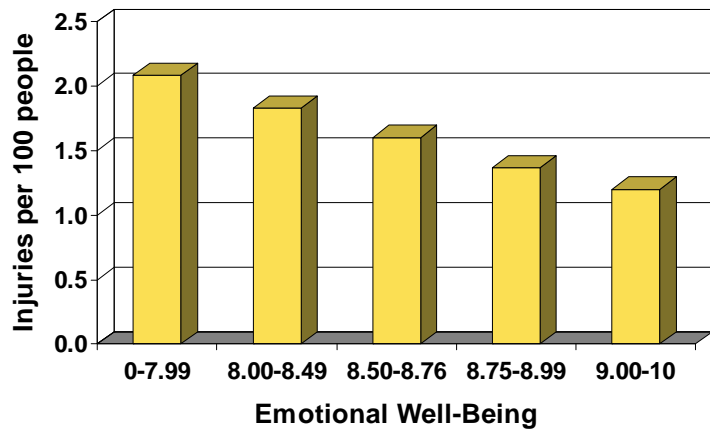
Preliminary longitudinal analysis shows that the ability of people to respond for themselves is not static, but can increase with personal development. Each year of the Ask Me! Survey has shown that self-respondents report a higher quality of life in the domain of personal development than do proxies. Causality, however, can not be determined from cross-section data. At the beginning of the second cycle of interviews in 2006, 38 agencies had data four years apart. These data indicate that causality operates in both directions. The greater the percent of self-respondents in an agency in 2002, the greater the increase in personal development over the next

four years that was reported at the agency, independent of the 2002 level of personal development. (See **Figure 13.**) Similarly, the higher the level of personal development reported in 2002, the greater the increase in the percent of self-respondents over the four years. In addition, the increase in the percent of people who respond for themselves over the four years affected the increase in the level of personal development reported by an agency. The increase in the percent of self-respondents in the four years was not constrained by the initial level of self-response, suggesting that what agencies can do to increase people's perceived level of personal development will increase people's functional intellectual ability, which in turn increases their perceived personal development in a continuous cycle. Agencies with initially high reported levels of personal development are mathematically constrained in the amount of increase in personal development that can occur in the next four years (represented in the dashed arrow). Agencies with low levels of personal development, however, have opportunities to greatly increase their level of personal development.



**Figure 13.** Personal Development and Self-Response at Agencies Increase Each Other

The Ask Me! Survey data has the potential to identify agencies that may need assistance or may need different levels of monitoring. While the DDA has promised agencies that it will not use Ask Me! data as criteria for licensing or sanctions, Ask Me! data are being used to identify areas of training needs, particularly in areas of self-determination and rights. The DDA also now requires new agencies to state in their applications how they plan to use their Ask Me! data. In order to assist a committee seeking to understand and reduce agency reports of accidents and injuries, the rates of incidences were linked at the agency-level with Ask Me! data. Four characteristics of agencies and the people they support predicted 40% of the variability in injury rates, with emotional well-being the most important of these. (See



**Figure 14.** Rates of Injury Predicted by Agency Emotional Well-being

**Figure 14)** Agencies with emotional well-being scores below 8.0 reported 2.1 injuries per one hundred people supported in a six-month period, while agencies with emotional well-being

scores of 9.0 or above reported about half (1.2) the rate of injuries. The independent contribution of each characteristic is shown in the following predictive (regression) equation:

$$\begin{aligned} \text{Reported injuries per 100 individuals supported} &= 12.293 \\ &+ 0.026 \text{ percent receiving residential services} \\ &+ 0.044 \text{ percent males} \\ &- 0.013 \text{ percent self-response on Ask Me! Survey} \\ &- 3.730 \text{ emotional well-being score.} \end{aligned}$$

This equation, if confirmed and calibrated with field investigation, might suggest a way to triage reports so the Office of Health Care Quality, which licenses and monitors community provider agencies, can allocate its limited inspection staff efficiently.

## Discussion

The Ask Me! Project is completing its second four-year cycle of interviewing people with intellectual and other developmental disabilities who are living in the community with support from the Maryland Developmental Disabilities Administration. Interviews take place at all community agencies in the state supporting ten or more individuals at least once every four years. Interviews are completed each year with about 1,500 individuals at about 45 agencies (about 30 interviews per agency) selected through a two-stage probability sample of approximately 12 to 13 thousand individuals supported by about 150 agencies. Four pilot years helped develop the survey instrument, protocols, and procedures.

The Ask Me! Project pioneered the use of peer interviewers for face-to-face interviews of individuals with intellectual and other disabilities. The principles of participatory action research were central in the initial conceptualization of the project. Members of People on the Go, the state's self-advocacy organization, helped pretest an adaptation of the *Quality of Life Questionnaire* developed by Schalock and Keith (1993), and then helped pretest the new *Ask Me! Survey* based upon the questions they had developed several years earlier to help everyone working with people with disabilities understand what was important to them. People on the Go sent a representative to the project advisory committee meetings, and provided a pool for recruiting interviewers. Peer interviewers, working privately in pairs, provide a safe and comfortable environment for people, determine whether the individuals understand enough to give informed consent, interview individuals, and record their responses. They also interview proxies when people do not understand enough to give informed consent, as well as key data, promote the use of Ask Me! results, and to train other self-advocates and staff.

A study using the pilot adaptation of the *Quality of Life Questionnaire* found that peer interviewers had different completion rates and received different responses than did staff members or interested volunteers from the board. This study has not been replicated with the *Ask Me! Survey*, but similar results would be expected. No other studies have reported self-response rates higher than those obtained by peer interviewers in Ask Me! This suggests that peer interviewers can obtain meaningful responses from people whom non-peer interviewers cannot, even though none of these studies are exactly comparable in procedures. Other studies

have demonstrated that peer interviewers can be effective interviewers (Perry and Felce, 2004) and that the results of an interview are the product of interaction between interviewers and respondents (Rapley, 2000). It can reasonably be assumed that Interviewers interact with respondents and filter responses through the interviewer's lenses of experience and beliefs, since proxies are known to provide filter responses (Cummings, 2002; Stancliffe, 2000). Ask Me! has found that the presence of a helper, during the interview with a self-respondent, results in answers that fall between those provided by self-respondents alone and those provided by proxies alone. The Ask Me! Project, therefore, believes that peer interviewers elicit more reliable and valid information than other any other type of interviewer can by allowing more people to respond for themselves, and by reducing potential bias of non-peers in the interview setting.

Ask Me! allows people with intellectual and other developmental disabilities the opportunity to speak for themselves in a way that will enhance the disability support system. Ask Me! has a more direct effect on the peer interviewers and those that interact with them. Interviewing has given a number of individuals with disability their first paid employment, and the confidence that they can do productive work even if they have been told in the past that they could not. Some have found careers in Ask Me!, with one individual advancing to the regional coordinator position and others moving into quality control responsibilities. Current interviewers have an average of 4.7 years of experience, and one has been interviewing for all eleven years of the project. One-fifth of those no longer interviewing on Ask Me! are known to have resigned in order to go to school or take a better paying job. It has inspired interviewers to become stronger self-advocates and to promote self-advocacy. It has inspired non-reader interviewers to learn to read. Peer interviewers have inspired some of their respondents to become better self-advocates and to believe that they could do a job like interviewing. Peer interviewers have also impressed agency staff as they talk about the importance of Ask Me! and also its data, and in the way they conduct proxy interviews.

The usefulness and value of data from Ask Me! reflects the value of peer interviewing. Ask Me! has shown general improvement in the quality of life in Maryland over the past seven years, and has shown where to target resources when improvement was not occurring. It has demonstrated that specific initiatives at the state and agency levels can enhance people's quality of life. It has confirmed widely held beliefs, such as low staff turnover contributes to quality of life. It has also disproved other beliefs, such that improving staff satisfaction with their jobs will directly translate into improved quality of life of the people staff support. It also provides data about agency strengths and weakness that people can consider in choosing an agency to provide support. While aggregated perceptions of people with disabilities about their quality of life should not be the only basis for judging an agency, data resulting from peer interviews in Ask Me! have been found to correlate with reports by agency management and findings by the state licensing administration. Discussions on further appropriate uses of Ask Me! are underway in Maryland, and Ask Me! has been sharing its experiences and promoting the value of peer interviewing to enhance quality of life.

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