Ask Me!sm FY 2002

The Quality of Life of Marylanders With Developmental Disabilities

Receiving DDA Funded Supports

Prepared for the
Maryland Developmental Disabilities Administration

by
Gordon Scott Bonham, Ph.D.
Bonham Research

Sarah Basehart, BA, Cristine Boswell Marchand, MS,
The Arc of Maryland

Noember 10, 2002

Authors

Gordon Scott Bonham has been the project's researcher from the initial development of the questions to the present. He is President of Bonham Research, a private human services research and evaluation company. His 29 years of developing and analyzing surveys have included research at Towson University, the University of Louisville, and the National Center for Health Statistics. Dr. Bonham received his Ph.D. in sociology from the University of Michigan (Ann Arbor) and has a wide range of experience in surveys, social research, and program evaluation. The social health and well being of the individual in society has been the primary subject of his research, including a number of studies involving services to people with cognitive and other developmental disabilities. Dr. Bonham serves on the Board of BARC and chairs its Quality Assurance Committee.

Sarah Basehart is Assistant Director of The Arc of Maryland. Ms. Basehart holds a Bachelor's Degree in Economics and Political Science from the University of Maryland Baltimore County, and is currently pursuing a Master's Degree in Policy Sciences. In addition to coordinating the Ask Me![sm] Project, she facilitates the statewide self-advocacy group, People On the Go, and works on policy issues of concern to persons with developmental disabilities and their families. She also directs the "Know Your Rights" Project, which trains individuals with developmental disabilities on their rights as they receive services and current policies in Maryland. Over the past year she worked with self advocates to develop training methods and techniques, including creating individual training styles for each self advocate presenter.

Cristine Boswell Marchand is the Executive Director of The Arc of Maryland, a position she has held for thirteen years. Ms. Marchand has been associated with disability rights organizations at the local, state and national levels over the past twenty-two years in Maryland, Colorado, Minnesota and Washington, D.C. She received her Masters' Degree in Policy and Mental Retardation from Minnesota State University-Mankato. She provided the concept for the survey, general supervision and overall direction to the Ask Me![sm] Project.

Committed and skilled interviewers, who themselves have received services funded by the DDA, make The Ask Me![sm] Project possible. In FY2002, 39 consumer interviewers worked for The Arc of Maryland. They demonstrated that people with developmental disabilities can learn and use professional interviewing skills to collect quality information. FY2001 was the fifth year of interviewing for 5 and the fourth year for 6. They were joined by 8 new interviewers. (Years interviewing are indicated in parentheses). Two interviewers also served as Quality Assurance Consultant (QA). Linda McKinley, a former interviewer, worked for Bonham Research as Data Entry Clerk. Ask Me![sm] FY2000 interviewers included:

Alexander Donovan (1)
Angie Elzey (2)
Angie Lepore (1)
Betsy Partrige (3)
Brian Platen (1)
Bridgette Pressley (4, QA)
Bruce Franklin (2)
Carlo Harris (5, QA)
David Wissinger (2)
Emma Thomas (4)
Fran Appold (5)
Greg Gray (1)
James Devore (5)
Jonathan Koplowitz (4)
Kenice Fleming (1)
Kenny Barnes (2)
Kevin Duckworth (3)
Kim Witt (3)
Kimberly Smith (3)
Leslie Tatum (1)
Linda Cooper (1)
Lori Powell (4)
Michael Danzig (5)
Michael Johnson (1)
Michael Macneal (2)
Michael Raidt (3)
Missy Perrott (1)
Paty Woff (3)
Robert Haburchak (5)
Robin Rice (2)
Rose Marie Hancock (3)
Rusty Bruner (2)
Scott Heim (4)
Simone Thomas (2)
Theresa Dillman (4)
Theresa Thomas (2)
Tracy Wright (2)
Vernon DeHaven (3)
Viki Mills (2)

Ask Me![sm] now has available a training manual for organizations interested in replicating the project in other states. The manual provides all necessary materials and information to conduct the survey. The manual is available at cost and includes the survey, interview protocol and interviewer training information. All documents are also on a diskette. To protect the integrity of the project, The Arc of Maryland has developed a licensing agreement for entities that wish to become certified to use the survey.

Executive Summary

The Ask Me![sm] Project in FY2002 collected information about the quality of life of a sample of the 11,556 adults in Maryland supported through the Developmental Disabilities Administration (DDA) through 117 community providers. People associated with all community providers serving 55 or more people will be included in a four-year cycle, along with people served by a random sample of smaller providers. The *Ask![sm] Me Survey* in FY2002 included 958 people served by 33 community providers. People who themselves received services conducted the interviews, allowing 77% of those surveyed to respond for themselves.

This report includes data from a representative sample of all people supported by DDA: 61% were men, 78% were 25-54 years of age, and 30% classified with severe or profound retardation (50% of those with severe and 20% of those with profound retardation answered for themselves). DDA supported residential services for 49% of the people, employment services for 35%, day habilitation for 54%, individual or family support services for 13%, community supported living assistance for 9%, and behavior consulting services for 9%. Three-fourths of the people received services from a single provider.

The findings from the project provide information to help support systems understand what contributes to the quality of life of people with developmental disabilities, to guide the state an individual providers as they improve services, and to persons to make ;informed choices about services. The findings provide the basis for the following recommendations:

1. A life of quality has many dimensions that are interrelated, and enhancement of people's quality of life should be the goal of all components of the developmental disability system.
    a. Physical well-being, emotional well-being and material well-being appear foundational, relating to each other and to at least two other quality of life domains
    b. Interpersonal relations and rights appear central, relating to each other and to at least five other quality of life domains
    c. Social inclusion, self-determination and personal development are outcome goals defined by the Maryland Developmental Disabilities Administration (DDA), with personal development having a strong impact on the other two

2. People supported by the Maryland Developmental Disabilities Administration have a very positive view of their physical and emotional well-being. While these foundational domains of a life of quality should be maintained, greater attention needs to be given to other domains, particularly personal development and interpersonal relations.
    a. 90% of people receiving services reported positive scores on their physical and emotional well-being
    b. People showed the least variability in reporting physical and emotional well-being
    c. Physical well-being relates to the fewest other quality of life domains, and the higher people report their physical well-being, the lower they report their rights

d. Personal development is the DDA goal that related to all the other quality of life domains when personal and service characteristics were controlled
e. Interpersonal relations related significantly to all other domains as a central part of a life of quality, and was the strongest predictor of personal development

3. Rights (involving respect, dignity, equality, citizenship, access and due process) is the quality of life domain least understood, yet central to a person's well-being. The reasons the whole development disability system (internationally, Maryland and individual providers) does least well in this area needs to be explored in all possible ways.
   a. The domain of rights had the lowest scale reliability of the eight domains
   b. Rights received the lowest average rating by people (2.4) and had the second highest variability
   c. People served by four of the 33 providers gave negative average scores to rights
   d. Rights, along with self-determination, showed the greatest regional differences
   e. Providers with higher scores on physical well-being, higher average reimbursement rates for residential services, and higher average reimbursement rates for day services had lower average scores on rights than did providers with lower scores on physical well-being and lower reimbursement rates
   f. Rights, highly related to self-determination, was affected by day reimbursement rates in the opposite way as self-determination.

4. Transportation availability and employment services offer the greatest predictions of people's quality of life, and are therefore logical areas to consider for service enhancements.
   a. Perceived availability of transportation had significant relationships with five of the eight quality of life domains
   b. Transportation provided by the sampled agency increased people's sense of social inclusion and interpersonal relations
   c. Transportation by other agencies positively increased material well-being, but decreased the sense of personal development

5. The disabilities people may have do not determine their quality of life, and no one should be overlooked in the pursuit of quality of life enhancements.
   a. People with higher cognitive ability reported higher quality of life than people with lower cognitive ability in six of the eight domains, particularly rights
   b. Cognitive ability offered less prediction of people's quality of life than did the availability of transportation
   c. Men reported slightly lower quality of life than women in three domains, and slightly higher in one
   d. No other personal characteristic offered prediction of people's reported quality of life, except cerebral palsy and seizures that related to single domains each

6. The mere presence or absence of services offer little prediction on the quality of people's lives. The focus should be on the quality of those services as judged from the perspective

of recipients.

a. DDA supported employment services predicted slightly higher material well-being and rights than the lack of employment services
b. DDA supported residential services predicted slightly higher rights, but lower self-determination, than the absence of residential services
c. CSLA services were slightly related to higher physical well-being, but lower personal development
d. DDA supported day habilitation services and individual support services did not directly affect quality of life at the individual level, although agencies with a greater percent of their people in day habilitation services had higher scores on personal development

7. Service providers have potential to increase the quality of life of the people they serve. They should set and pursue goals informed by data from the people they serve, and should be held accountable for outcomes.
   a. People served by different agencies express significant differences in their quality of life in all domains, with variability among agencies greatest in personal development, self-determination and right
   b. The same relationships among the quality of life domains were observed when providers were the units of analysis as when individuals were the units of analysis
   c. The quality of life of people served by 20 agencies surveyed in both FY2001 and FY2002 increased in the domains of physical well-being, emotional well-being and material well-being
   d. In the domains where quality of life did not increase overall, agencies with low scores in FY2001 had low scores in FY2002, and agencies with higher scores in FY2001 had higher scores in FY2002, especially in the domains of self-determination and personal development
   e. Provider enhancements in any domain except physical well-being will potentially increase people's quality of life in all other domains; enhancement of physical well-being appears at the expense of rights
   f. Agencies serving many people with mental retardation and with seizures had lower agency scores on rights and interpersonal relations, but other characteristics of their consumers did not directly affect agency scores
   g. Large proportions of consumers in employment services related to high levels of personal development and emotional well-being, but high proportions in residential and support services had no relationship
   h. Size of the agency and the proportion served by other providers had no association with quality of life
   i. Self-respondents could answer more questions than could proxies (primarily staff), and reported differently than proxies for five of the eight domains
   j. Only 9% of the people sampled for interview refused to participate

PAGE INTENTIONALLY BLANK

Table of Contents

List of Figures

List of Tables

PAGE INTENTIONALLY BLANK

Project Overview

The *Ask Me!sm Survey* collects information from people receiving services funded by the Maryland Developmental Disabilities Administration (DDA) to determine their satisfaction with the quality of their lives. Quality of life is the ultimate goal of services provided to persons with developmental disabilities and reflects on the nature and quality of services received, although mediated by people's values, perceptions and other experiences. Satisfaction with quality of life may be missed in a focus on providing specific services to meet specific needs, or satisfaction with a particular service may be mistaken as satisfaction with overall life quality. It would be hoped that provision of specific services, satisfaction with those specific services, and overall satisfaction with quality of life are interrelated. However, different people may view quality of life differently, and the *Ask Me!sm Survey* allows people with developmental disabilities to define quality of life for themselves. People with developmental disabilities helped develop the survey instrument and procedures. People with developmental disabilities promote the survey. People with developmental disabilities conduct the interviews. People with developmental disabilities have the opportunity to answer questions for themselves. People with developmental disabilities key data into the computer. People with developmental disabilities share their experiences as providers seek to understand how to use the survey information to improve services. The Ask Me!sm Project demonstrates that people with developmental disabilities elicit and provide data on quality of life that are valid, reliable, and useful for program enhancement.

This report presents and analyzes data from the FY2002 Ask Me!sm Project. FY2002 is the first year of a four-year cycle during which 99% of the people supported by DDA will be represented, all agencies serving 55 or more people will be involved at least once, and a sample of agencies serving 10-54 people will be included. Only the smallest agencies (serving fewer than 10 people) and the people served only by those agencies will not be included. DDA's objectives are to survey consumers about satisfaction with their quality of life, to improve services funded by the Developmental Disabilities Administration in order to enhance the quality of life of Marylanders with developmental disabilities, and to provide Maryland consumers with information to support informed choice.

The FY2002 Ask Me!sm Project followed a four-year pilot study with funding through cooperation between DDA and the Maryland Developmental Disabilities Council. The Arc of Maryland, People on the Go, and Bonham Research developed the interview instruments and procedures, hired and trained consumer interviewers, conducted the interviews, processed the data, and produced the reports. The first year of Ask Me!sm successfully piloted the *Ask Me!sm Survey* instrument adapted from Schalock and Keith's *Quality of Life Questionnaire* (1993). It piloted the use of interviewers with developmental disabilities and the training and support they needed to become professional interviewers. The first year also piloted the information and support needed by interviewees to participate, and the information and support needed by agencies to facilitate the participation of the people they support. The FY1998 pilot included interviews for 237 consumers served by ten providers.

The FY1999 Ask Me!sm pilot further tested the instrument and procedures among 535 consumers served by 21 providers. It extended the project to the deaf community and re-interviewed a sample of people to test stability of responses over time. The second year of the pilot also developed more complete orientations for providers' staffs about the *Ask Me!sm Survey*, gave technical assistance to providers to help them understand and use their data for planning, engaged its Advisory Committee on the issues of statewide expansion and publication of agency-specific results.

The third year of the Ask Me!sm pilot in FY2000 interviewed 735 people served by 28 agencies with the same instrument as in the first two years. This pilot year also included the development of a new version of the *Ask Me!sm Survey* based on *Signs of Quality* written by People on the Go of Maryland. The questions reflected more recent research that had identified eight dimensions of well-being: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. The new questions had three pretests for readability and length in English and one pretest in American Sign Language.

The final year of the Ask Me!sm pilot in FY2001 used the new English survey instrument to interview 923 people served by 33 agencies. The new instrument included internal quality checks, and additional quality control measures were introduced in the interview fieldwork. It used the new American Sign Language instrument used to interview 56 people served by two agencies. The Arc of Maryland copyrighted the Ask Me!sm Project to ensure its integrity became required in Maryland and available for other states and organizations that completed appropriate training.

The FY2002 Ask Me!sm Project represents the first non-pilot year in what is expected to be an ongoing project with four-year cycles. It used the survey instrument developed for the FY2001 pilot. For FY2002, people were sampled from DDA's list of all people for whom they have authorized support, rather than from independent lists of people served by the participating providers. Everyone had a known probability of being included in the two-stage sample and weights were applied for sate-wide analysis. The selection of people from DDA files allowed analysis of survey non-response and the currentness of the DDA files. It also provided data on all DDA-authorized services whether or not they were provided by the agency through which the person was selected. The FY2002 project interviewed 958 people from 33 agencies, representing 11,556 people served by 117 provider agencies.

Survey Background

The quality of services provided to people with mental retardation and other developmental disabilities is judged by how appropriate the services are in helping the consumers of these services to live as independent and satisfying lives as possible. Measuring independence and satisfaction, however, is challenging. Quality of life became a major theme within the field of developmental disabilities as both a general philosophy and a guide to evaluate habilitation efforts (Schalock, 1996). Schalock and Keith (1993) developed a survey instrument with four dimensions of quality of life organized around general satisfaction and the three major service delivery principals of independence, productivity and community integration. The survey instrument used during the first three years of the Ask Me![sm] Project was based upon the Schalock and Keith instrument, with the addition of a new dimension labeled as dignity. However, Hughes and Hwang (1996) identified fourteen dimensions of the quality of life that had been studied by researchers, and Schalock and Verdugo (2002) now argue that there are eight basic dimensions to quality of life that are fairly well agreed upon cross-culturally. Social inclusion has been discussed most in the developmental disability literature, and rights has been discussed least. (See **Figure 1**.) The Ask Me![sm] Project developed a new survey to measure these eight dimensions, with questions based upon *Signs of Quality* written by the statewide self-advocacy organization (People on the Go, 1996). This survey instrument is part of the copyrighted Ask Me![sm] Project.

- **Social Inclusion**: The integration into and participation in one's community, the expression of valued social roles, and the receipt of social supports from community members
- **Physical Well-Being**: The level of health experienced (physical functioning, disease symptoms, pain, fitness, energy, nutrition); the performance of activities of daily living (walking, dressing, self feeding) and leisure activities; and/or the receipt of health care
- **Interpersonal Relations**: The experiencing of social interactions and relationships (with family, friends, peers) and/or receiving support (emotional, physical, financial, feedback) from family, friends, peers or agencies
- **Material Well-Being**: The presence of adequate financial status, employment (a job), and adequate housing
- **Emotional Well-Being**: The condition of being contented (satisfied, happy) having a positive self-concept, and/or being relatively free of stress
- **Self-Determination**: The expression of autonomy and personal control, the pursuit of personal goals an values, and the opportunity to make decisions
- **Personal Development**: The level of education received, personal competence expressed, and/or performance exhibited (includes creativity and personal expression)
- **Rights**: The expression of human rights (respect, dignity, equality) and the guarantee of legal rights (citizenship, access, due process)

Figure 1. Dimensions of Quality of Life by Frequency of Discussion

Measuring the quality of life of people with disabilities presents several challenges. The first is how to obtain valid information. Self-completed questionnaires are beyond the ability of many people with developmental disabilities, so quality of life instruments are typically administered during face-to-face interviews. An interviewer who does not know the respondent may not know how to communicate the question, may not be able to elicit a response, or may not be able to understand a response when one is given. On the other hand, an interviewer very familiar with the respondent may assume he or she knows the respondent's answer, may not give the respondent time to respond, or may influence the respondent's answers through nonverbal clues. If a provider/client or some other authority relationship exists, the respondent may give answers intended to please the interviewer rather than accurately reflect the respondent's own attitudes. Another problem exists when people cannot understand and communicate for themselves. Can proxies accurately answer for people with limited cognitive abilities, and who should be proxies? Should they be service providers, family members, or independent observers? Should one proxy or more than one proxy, with some combination of answers, provide responses? The Ask Me!sm Project carefully designed and tested questions that could be answered by most people with developmental disabilities. It employed people with developmental disabilities to conduct the interviews in a confidential environment to increase the likelihood of people being able to respond for themselves and to express their true feelings. It carefully trained the interviewers to make people feel comfortable, patiently ask them the questions, and carefully identify their answers. The project leaves the determination of who can and cannot answer the questions up to the people themselves and their interviewers, and developed a protocol for proxy interviews when people really could not respond for themselves.

The basic theory underlying the Ask Me!sm Project is that a person's quality of life may be affected by the individual's objective life conditions, but not determined by them. Objective life conditions are mediated through subjective well-being and personal values and aspirations (Felce and Perry, 1996). In the FY2002 Ask Me!sm Project, objective life conditions were recorded by agency staff on separate background forms, and derived from data in the DDA files. They were tested to see how they might influence subjective quality of life in the eight dimensions. Ask Me!sm focuses on people's long-term qualities of life rather than short-term satisfaction with service provision. However, the *Ask Me!sm Survey* measures one short-term outcome for all people, the perceived availability of transportation. The American Sign Language version of the *Ask Me!sm Survey* (not used in FY2002) includes a second short-term outcome for deaf people, the ease of communicating with others.

The consistency and reasonableness of the findings are the strongest indication of the reliability and validity of the *Ask Me!sm Survey* and procedures. The quality of life reported by an individual during interviews a year apart was fairly similar (Bonham, et al., 1999). The average quality of life among samples of an agency's consumers during three subsequent years was generally within sampling variability (Bonham, et al., 2000a). Significantly, the quality of life reported by people themselves was more consistent over time than the reports of proxies (family members, friends or staff) about them (Bonham, et al., 1999). The Ask Me!sm procedures have consistently allowed at least 77% of people to respond for themselves. Most people with disabilities can answer all of the survey questions if they can answer any questions at all. Few

people give the same answer to all the survey questions, either the positive (first) answers to suggest acquiescence or to the negative (last) answer to suggest nay-saying (Bonham, et al., 2000). About three-fourths of both proxies and people responding for themselves gave the same answers to the same questions repeated in two different places in the survey. Although proxies report differently than self-respondents, Ask Me![sm] statistically controls for proxy bias rather than excluding people who cannot respond for themselves. Ask Me![sm] has found that interviewers who themselves have disabilities make good interviewers and elicit information from people with disabilities at least as well as (and probably better than) staff, and definitely better than volunteers from an agency's board (Bonham, et al., 2001). Ask Me![sm] has shown that interrelationships identified during one interview time period represent causal effects measured in a longitudinal survey, and provide insight into the value of services (Bonham and Basehart, 2000).

PAGE INTENTIONALLY BLANK

Project Description

Sample

The FY2002 Ask Me![sm] Project collected for 958 people with developmental disabilities served by 33 agencies between August 2001 and June 2002. (Interviews at two agencies serving people who are deaf had to be postponed to fall 2002.) These people represent 11,556 supported by DDA, and 117 of the 136 agencies that provide them services. The DDA file of about 25,000 person-service-agency authorizations in July 2001 formed the basis for sampling. The first sampling step involved stratifying agencies by size and then assigning them for interviews according to a four-year cycle. (See **Figure 2**.) The second stage involved randomly selecting 40 people from each agency, or all the people if the agency served fewer than 40 people. Sample people were replaced if they turned out to be less than 18 years of age, no longer receiving services by the time of interview (including deceased), or was an Ask Me![sm] interviewer.

Strata 1 (300+ people)
- 10 agencies serve 37% of people
- Sampled every year, 10 in FY2002

Strata 2 (130-299 people)
- 21 agencies serve 27%
- Sampled every 2 years, 11 in FY2002

Strata 3 (55-129 people)
- 40 agencies serve 25%
- Sampled every 4 years, 11 in FY2002

Strata 4 (10-54 people)
- 46 agencies serve 10%
- Random every year, 3 in FY2002

Strata 5 (1-9 people)
- 31 agencies serve 1%
- Not included in sample

Figure 2. Agency Sample Frame

Weights have been applied to most data presented in this report so they accurately reflect the total population of people receiving DDA-supported services. The weights reflect the probability of selecting the agency, the probability of selecting a person within the agency, and the response rate within the agency (ranged from 63% to 92%). Some surveyed people represent 3 people in Maryland while some others represent 39 people in Maryland. Details of the sampling and weighting procedures are provided in **Appendix 1**.

Interviewers

The project employed interviewers who themselves had received services supported by DDA. Interviewers were selected on the basis of listening skills, understanding of 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. Accommodations were made for interviewers who required augmentative communication strategies and technology.

A centralized one-day training occurred at the beginning of the survey period for both new and experienced interviewers. (See **Figure 3**.) Following the centralized training, interviewers meet regionally for additional interviewing practice prior to their first actual on-site interview session.

Figure 3. Interviewer Training Session

Monthly regional training also occurred throughout the interviewing period to provide interviewers with opportunities for continuous quality improvement. Quality assurance measures included videotaping of actual interviews for self and peer evaluation, observation and standardized feedback from quality assurance consultants (experienced interviewers from prior years), and monitoring by project staff.

The Ask Me!sm Project employed 39 individuals with developmental disabilities as interviewers in FY2002. They averaged 1.7 years of prior experience. Five interviewers had on all four prior years of the project. (See **Figure 4**.) They conducted two-thirds of the interviews 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 the lead interviewer with any problems. Either of the interviewers could record the answers. The team approach allowed a number of consumers who could not read to be involved as interviewers. The team functions, however, could be redistributed among the team members to compensate for any difficulty one of the members might have. Sometimes scheduling problems required interviewers to conduct the interview alone with consumers. Interviewers conducted an average of 46 interviews. Five interviewers conducted fewer than ten interviews, while three interviewers conducted 110 or more interviews (maximum of 160).

Figure 4. Interviewers with 5 Years Experience: Appold, Harris, Devore, Project Director Basehart, Haburchak and Danzig

Interview Preparation

The project team offered orientations to every participating provider. The orientations provided information about the process and goals of the project. The orientations could be for the individuals receiving services, their family members, or provider staff and management. The majority of providers requested orientations, and these usually were for staff. Providers reported that the survey process ran more smoothly when staff had been fully informed about the *Ask Me!sm Survey*. Informed staff were then able to share information with the individuals selected for interviews and encourage their participation in the survey. Informed staff were also less concerned about the *Ask Me!sm Survey* measuring their performance.

An Ask Me![sm] interviewer presented at each orientation along with a project staff. The interviewer shared his or her experiences interviewing individuals with developmental disabilities with the *Ask Me![sm] Survey*. The interviewer also shared his or her perspective about the involvement of self advocates in quality assurance and control over supports. Feedback from individuals, family and staff indicated that people responded positively to hearing directly from the interviewer. Some providers reported that the interviewer's *Ask Me![sm] Survey* presentation helped encourage staff to support individuals' efforts to speak up for themselves.

When interviewers arrived at the interview site, they signed in and recorded the time they arrived. A short, pre-interview meeting followed. They were introduced to project staff that would be assisting during the interview sessions. The session coordinator then divided the interviewers into their teams and assigned interview locations to each team. Next, the session coordinator discussed the agenda for the day and the expected number of individuals to be interviewed and any accommodations they might require. The project staff distributed the supplies for the day to each interview location: blank surveys, pencils, happy/neutral/sad face cards, and a sheet providing numbers to call to report abuse or neglect.

Survey Procedures

Agency coordinators contacted the selected individuals or their guardians to explain the survey and to secure initial agreement to participate. The agencies then made the necessary arrangements to get the consumers to the interview sites. After the respondents arrived, the session coordinator gave the respondents information about the Ask Me![sm] Project and the interview process. They were told about the role self-advocates had in developing the survey, given assurances of confidentiality, and told about their right to not answer any or all questions if they did not want to answer. The respondents were then asked to sign a consent form (unless they had a guardian who had already signed one) for their agencies to provide background information about them to the Ask Me![sm] Project. These signed permission forms were later sent to the agencies along with Consumer Characteristics Forms containing the respondents' names. The project identification number was added to the returned Respondent Characteristics Forms by the Ask Me![sm] Project staff.

The interviews were conducted in conference rooms and empty offices provided by the participating agencies. No staff from the agency was in the room during the interviews unless a respondent asked someone to accompany them. Interviewers consistently noted that interviewees seemed less concerned about breach of confidentiality and better focused when interviews were conducted in private offices with only the interviewer team and respondent present. Ask Me! staff was available in a central area to answer specific questions, problem-solve, or offer suggestions if an interviewer needed assistance or a respondent needed additional accommodations to complete the interview. Consumers were told that they did not have to answer a question if they did not want to--it was strictly voluntary. The consumers were also told their answers would remain private, and that no one providing services or members of their families would see their answers.

The interview team assisted the respondent by pointing to "happy," "neutral," and "sad" faces as the multiple choice responses were read. Ask Me!sm Project staff were available in the main room to answer specific questions, problem-solve, or offer suggestions if an interviewee needed additional accommodations to complete the interview. As interviews ended, the Ask Me!sm Project Coordinator thanked the respondent for his or her time and asked for feedback about the interview process and the respondent's thoughts about specific questions.

Interviews generally took 15-45 minutes, with an average of 30 minutes. Interviews with proxies took about as long as interviews with self-respondents.

Sample Selection and Response

The Ask Me! Survey selected 1,399 people for interview from 33 agencies. It also selected 88 people from two agencies supporting deaf people, but interviewer problems kept these people from being interviewed in FY2002 and are not discussed further in this report. Half (53%) of the people selected for interviews responded to the survey for themselves. (See **Figure 5**.) An additional 15% agreed to participate in the survey, but did not have the ability to answer the questions for themselves and proxies provided information for them. A few (9%) of the selected people were not appropriate for the sample. These included children that would have been removed prior to sampling if their age had been known, people who died or left DDA support prior to interviews, people hired as interviewers after they had been selected, and people selected through two different agencies. These people were subsequently excluded from the sample for purposes of calculating response rates. The non-respondents included 3% whose guardians refused to let them participate, 9% who themselves refused to participate, and 5% reported by the selected agencies as no longer received services from them although still supported by DDA. The remaining 6% were not interviewed for a variety of reasons (illness, language problems, inability to contact, failure to keep appointments) and for whom specific procedures had not been developed to follow up on them. Procedures will be implemented in FY2003 to reduce the percentages in the last two groups.

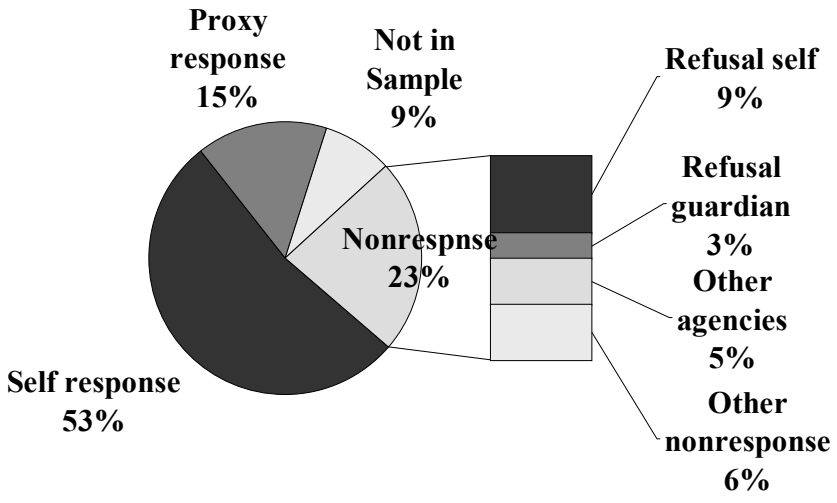


Figure 5. Survey Response of Sample People

Overall, Ask Me! obtained information for 958 people, or 75% of the people eligible for interviews. (See **Table 1**.) Among those for whom information was obtained, 77% provided the information themselves. Thus, 55% of the selected people participated in the FY2002 Ask Me!

for themselves. The initial sample included forty people from each selected agency, with the expectation that at least thirty people from each agency would provide information. Eight

Table 1. Ask Me!sm Response Rate by Agency: FY2002					
Agency	% of Sample Complete	Self-response as % of Complete	Self-response as % of Sample	# Surveys Completed by People Served	
				At this Agency	All Agencies
TOTAL	75	77	55	958	1066
Abilities Network	65	96	63	26	26
ACCFX Gallagher	92	53	49	34	41
Alliance	65	100	65	26	28
Ardmore Enterprises	91	68	62	31	36
Athelas Institute	70	82	58	28	30
Bayside Community Network	77	81	63	31	31
Benedictine School	88	93	82	30	30
CHI	84	87	73	31	40
Chimes, Inc	73	64	47	33	44
Community Living, Inc	74	79	58	28	28
CSAAC	90	61	55	36	37
DBA Horizon Goodwill	74	52	38	25	25
Dove Pointe, Inc	88	77	68	30	30
eMerge	76	83	63	29	30
Jubilee Association of MD	72	86	62	28	31
Kent Center, Inc	64	84	54	25	25
Melwood	76	82	62	28	31
Opportunity Builders	64	92	59	25	26
PennMar	72	69	50	29	30
Providence Center	70	81	57	26	28
Rehabilitation Opportunities	84	94	78	31	35
SEEK	82	67	55	27	29
Spring Dell Center	76	72	55	29	30
The Arc of Baltimore	71	63	44	32	44
The Arc of Carroll County	88	82	72	38	38
The Arc of Frederick County	63	97	61	29	29
The Arc of Montgomery Co	69	89	62	27	39
The Arc Northern Chesapeake	73	92	67	36	36
The Arc of Prince George's Co	76	56	42	25	33
The Arc of Washington County	64	68	43	28	35
The Caroline Center	71	67	47	27	28
UCP Central Maryland	69	63	43	24	37
Worchester Co Development	70	85	59	26	26

agencies had sufficient number of people classified as not in the sample that supplemental samples were drawn for them. The survey collected information on 24 to 38 people through each agency, with at least 30 interviews completed through one-third (12 of 33) of the agencies. The number of interviews completed and the response rate varied among the agencies. The project obtained survey data for 92% of the eligible people selected through ACCFX Gallagher, although only 53% of these people were able to respond for themselves. While the Benedictine School had a slightly lower overall response rate of 88%, 93% of the responding people answered the survey questions for themselves. The Arc of Frederick County had the lowest overall response rate of 63%, although 97% of their people responded for themselves.

Many people receive services from more than one agency, and the random selection process within each agency resulted in eight individuals selected twice for interviews. Although interviewed only once, the information provided by these people was included in the information related to both agencies. The information provided by people served by two sample agencies but randomly selected for only one agency was likewise included in the information related to both agencies. The 109 people in the sample served by more than on agency increases the number of interviews for 22 of the 33 agencies, as shown in the last column of the table. Statistics for each agency, however, are calculated using only the data for people in the original sample for the agency and without weight adjustments.

One characteristic of agencies and five characteristics of people significantly affected the response to the survey. (See **Figure 6**.) Agencies in the southern DDA region had a 9 percentage point (B=.09) higher rate of response of individuals and proxies than agencies in the central DDA region (the category omitted from the list), while those in the western and eastern regions did not have significantly different response rates than agencies in the central region. Agencies new to the Ask Me! Project had about the same response rate as agencies that had voluntarily participation in the prior pilot years. The size of the agency did not affect response rates.

Characteristics	B	sig
Agency		
DDA southern region	.09	**
DDA western region	.06	
DDA eastern region	.01	
New to Ask Me! this fiscal year	.04	
Number of people served	.00	
Person		
Receives day services	.20	**
Receives residential services	.12	**
Receives support services	-.07	**
Number of provider agencies	-.09	**
Receives service coordination	.05	
Deafness and hearing impairments	-.20	**
Autism	-.03	
Behavior problems	-.04	
Blindness and visual impairments	.05	
Cerebral Palsy	.01	
Head injury	.05	
Mental disorder	-.01	
Other neurological impairments	-.07	
Orthopedic impairments	-.06	
Epilepsy and seizure disorder	-.00	
Specific learning disability	-.05	
Speech and language impairment	.02	
Male	.01	
Age	.01	
** p<.01		

Figure 6. Multiple Regression Coefficients of Agency and Person Characteristics on the Probability of Survey Response

The Ask Me! Project tried to arrange interviews at people's day programs when possible, and people receiving day services had a 20 percentage point higher self or proxy response rate than did people who did not receive day services. Independent of day services, people receiving residential services responded more frequently than did people not receiving residential services. In contrast, people who had support services, instead of or in addition to day and residential services, responded less frequently than did those without support services. The greater the number of agencies that provided services to the person, the less likely the person responded to the survey. These findings may reflect either the difficulty of the project making contact with people, disinterest of these people in the survey, or both. The significantly low response by people with deafness and hearing impairments can be explained by problems the project had with its deaf interviewer's conduct of interviews. Together, the characteristics shown in the table explain 14% of the variation in people's rate of response.

Proxy Responses

Preferably, at least one proxy was an advocate: family member, friend, or service coordinator. Interviewers frequently conducted face-to-face interviews with attending staff when people could not respond for themselves, and telephoned other proxy respondents. They asked the proxy to answer the question as if they were the person. Two proxies responded for half of those who could not respond for themselves, but one proxy was all that was available for the other half. Responses from two proxies were averaged, an approach that has been shown to result in both reliable and valid information (Rapley & Beyer, 1997; Rapley & Hopgood, 1997; Schalock & Keith, 1993; Stancliffe, 2000). Staff provided 68% of the proxy responses.

Two proxies responded to the survey for 72 people who could not answer for themselves. The proxy pairs included an advocate and a staff member for 48 people, and two staff members for 24 people. On average, both proxies answered 52 of the 53 questions in the survey, and answered 34 of them the same way. It did not make much difference whether both proxies were staff members or one was an advocate in the number of questions they answered the same. (See **Figure 7**.) One proxy gave a neutral response and the other gave the positive or negative response for an average of 14 questions, and they gave opposite responses for an average of 4 questions. When an advocate and a staff member answer the survey for a person,

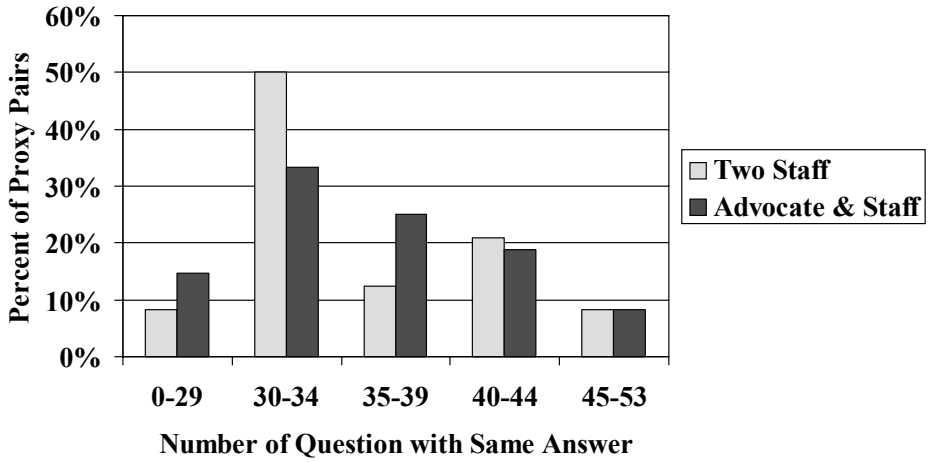


Figure 7. Percent of Proxy Pairs by Number of Same Answers

the advocate gave significantly lower quality of life scores than the staff member in the areas of interpersonal relations, social inclusion and rights. (See discussion on proxies in Appendix 1 for more details.) The average quality of life scores provided by two staff proxies also differed significantly in the area of interpersonal relations, suggesting two proxies observe different types of interpersonal relations, regardless of their relationship with the person unable to respond for her or himself. The two staff proxies also disagreed significantly on the availability of transportation.

Quality of Data

The survey included three pairs of questions to check upon internal validity of responses. Two questions on earnings were worded exactly the same and placed 13 questions apart ("Do you have the chance to earn good money?"). Two questions on general happiness had only slightly differences in wording and were placed 43 questions apart ("In general, how happy are you with you life?" and "How happy are you with your life overall?"). Two questions about house-mate choice addressed the same concept using different words and placed 23 questions apart ("How much choice did you have in whom you live with?" and "Did you pick who you live with?"). About three-fourths of the self-respondents and proxies answered both questions with the same or similar wording in the same way. (See **Figure 8**.) Three-fifths of the self-respondents and proxies answered the questions with similar concepts the same way. Self-respondents provided as consistent answers as did proxy-respondents. The eight quality of life domain scales contained six questions each. The scale reliability among people who responded for themselves was higher than the scale reliability among proxies for the seven of the eight domains. (See Appendix 1 for details.)

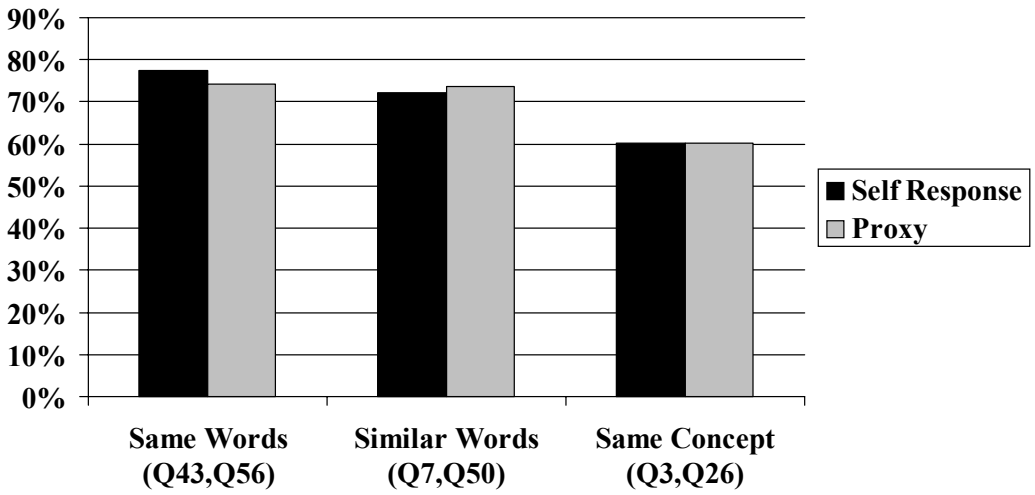


Figure 8. Percent Giving the Same Response to Duplicate Questions

Respondents

Survey respondents in Ask Me![sm] FY2002 represent a random sample of individuals receiving services from 33 participating providers. These providers served as few as 32 people funded by DDA, and as many as 1,176 people. The agencies participating in the study represent one-fourth of the organizational units receiving DDA funds and serve half of the people funded by DDA.

Self and Proxy

The procedures and instruments enabled 70% of the selected people to respond for themselves unassisted, and an additional 7% to respond for themselves with some assistance. (See **Figure 9**.) The interviewer, generally in consultation with the interviewing supervisor, made the decision that the others did not have sufficient understanding of the questions to provide meaningful answers. Two different types of proxies (staff and family/advocate) provided responses to the interview for 5% of the people and two staff members (generally a residential and a day program staff member) provided responses for 3% of the people. The information for 14% of the people was provided by a single staff member, and by a single advocate for 1%. The earlier **Table 1** showed large differences among agencies in who responded to the survey. All (100%) of the people interviewed for served by Alliance could respond for themselves, while half (52%) of the people served by Hagerstown Goodwill could respond for themselves. This reflects the different populations served by the agencies, as ability to respond was determined by the Ask Me![sm] interviewers and supervisors, not agency staff.

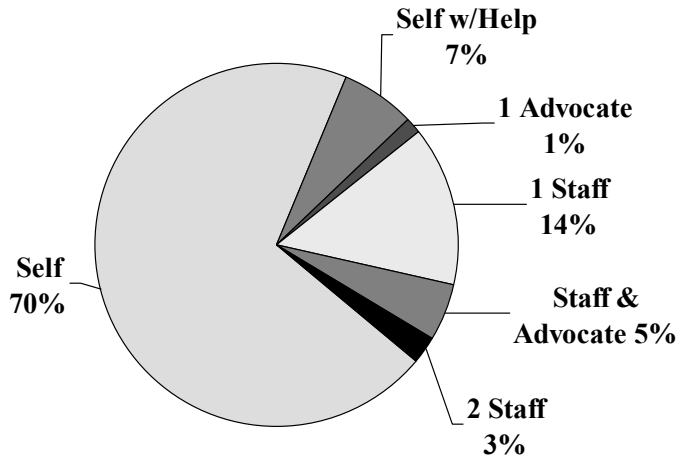


Figure 9. Percent of People by Who Responded

Survey protocol counted an interview as completed if a person could answer at least five of the first ten questions. If they could not answer that many, the interviewer terminated the interview and the project arranged to interview proxies. Most (86%) self-respondents answered more than 90% of the questions. (See **Figure 10**.) Proxies have the disadvantage that they do not and cannot know all the feelings and opinions of the people for whom they are responding. Fewer (82%) of the proxies than self-respondents could answer more than 90% of the questions. While no proxies answered 30% or fewer of the questions, proxies were more likely than self-respondents to answer 61% to 90% of the questions.

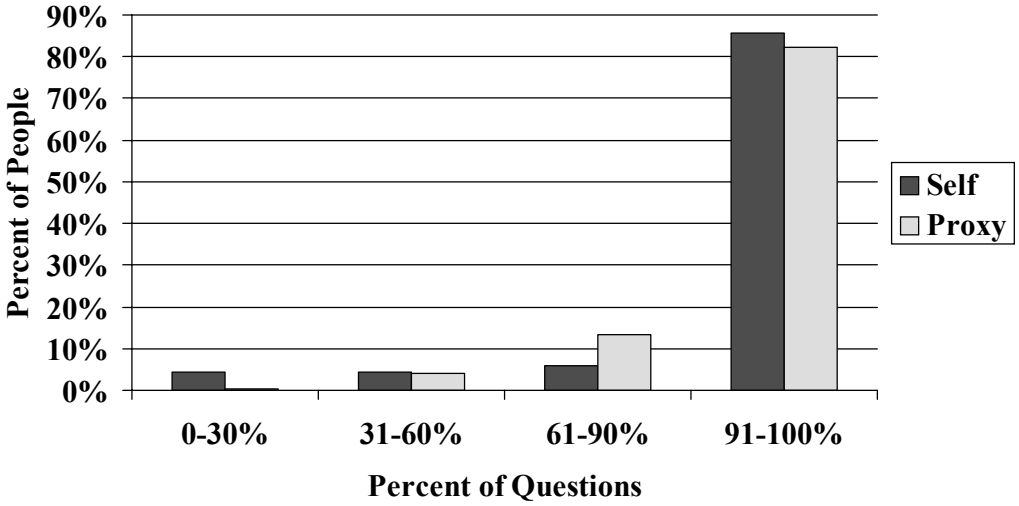


Figure 10. Percent of People by the Percent of Questions They Answered

Demographics

People selected for the Ask Me![sm] Project in FY2002 represented a random sample of adults receiving residential, employment, day or supported services from community providers supported by the Maryland Developmental Disabilities Administration (DDA). Excluded were children, adults receiving all services within an institution, and adults receiving service coordination only. The majority (61%) of adults served in the community with DDA supports were men. Three-fourths of them were 25-54 years old, with 10% under age 25, 12% 55-64 years old and 5% 65 years and over. (See **Figure 11**.) A greater percent of the adults supported

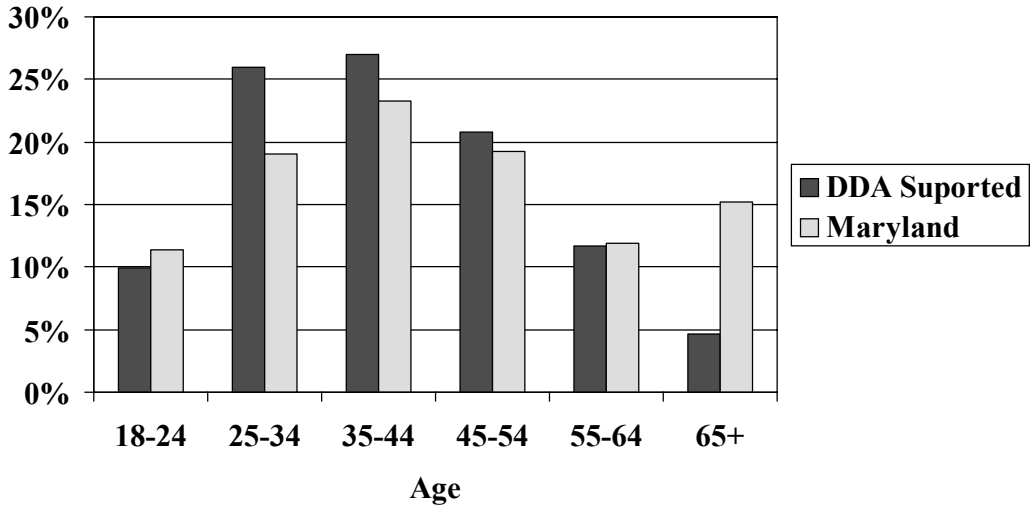


Figure 11. Percent of People with DDA Supports by Age

by DDA in the community are between the ages of 25 and 44 than in the general adult population of Maryland (Maryland State Data Center, 2002). People with developmental disabilities supported in the community are substantially less likely than the Maryland adult population as a whole to be 65 years and over.

Disabilities

The DDA files identify 87% of the people served in the community as having mental retardation without indicating the level of retardation. Agencies provided information on the Ask Me![sm] Background Forms on the numeric IQ scores when available, and a six-category classification of level of retardation when an IQ score was not available. It appears that the DDA files are incomplete in their identification of people's retardation. While 96% of the people classified with mental retardation on the DDA files were classified with mild to profound retardation based on provider information, 77% of the people not classified with mental retardation on the DDA files were classified with mild to profound retardation by providers. Agency-provided information shows that 39% people supported by DDA in the community have mild retardation, and 25% have moderate retardation. (See **Figure 12**.) Few people supported by DDA were reported by agencies to have borderline retardation (4%) or normal levels of cognitive abilities (2%). However, agency reports may not be accurate either. The DDA files indicated mental retardation for 52% of the people reported by providers as having normal cognitive abilities or abilities that only bordered on retardation. The majority of people classified in neither data system with mental retardation had autism, cerebral palsy, head injury or other neurological disorder.

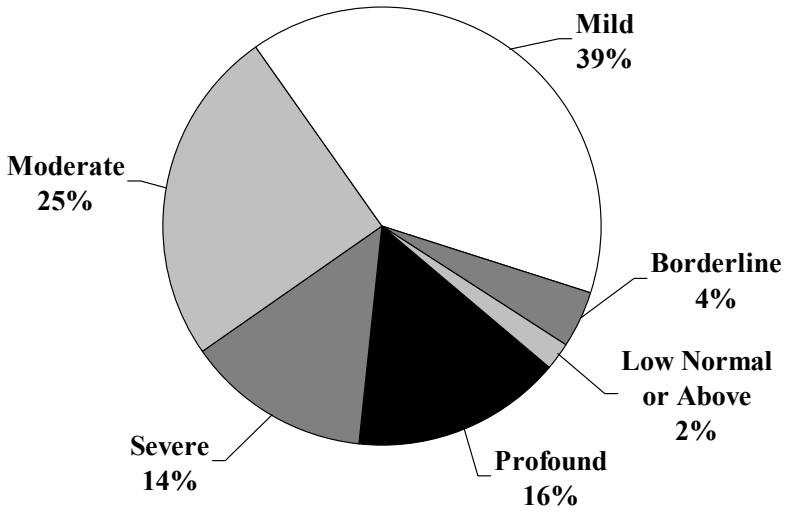


Figure 12. Percent of People by Level of Retardation

The ability of people to respond to the survey for themselves was affected by their level of retardation. All of the people with low-average or average level of cognitive abilities responded for themselves, as did most of those with borderline, mild or moderate retardation. (See **Figure 13**.) Only 50% of people with severe retardation and 20% of those classified with profound retardation could respond for themselves. This follows the pattern shown during the pilot years except for people with profound retardation. Their self-response rate was as low as 6% and as

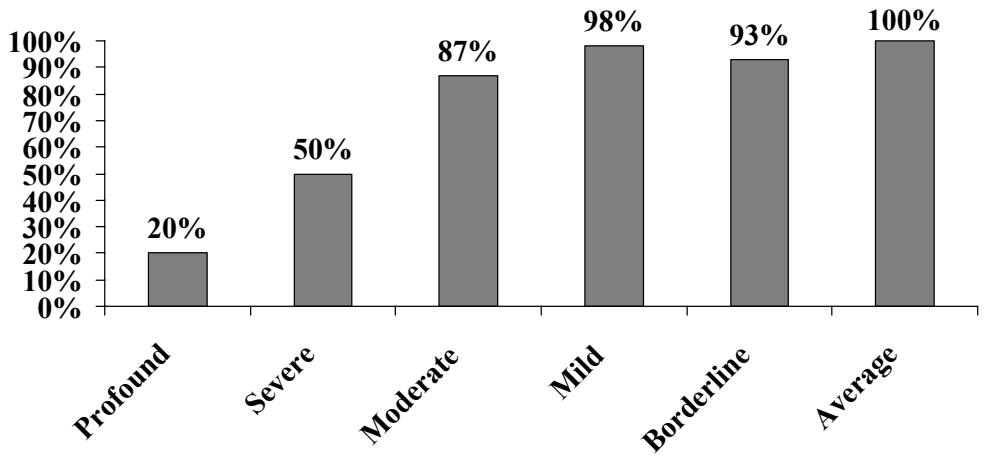
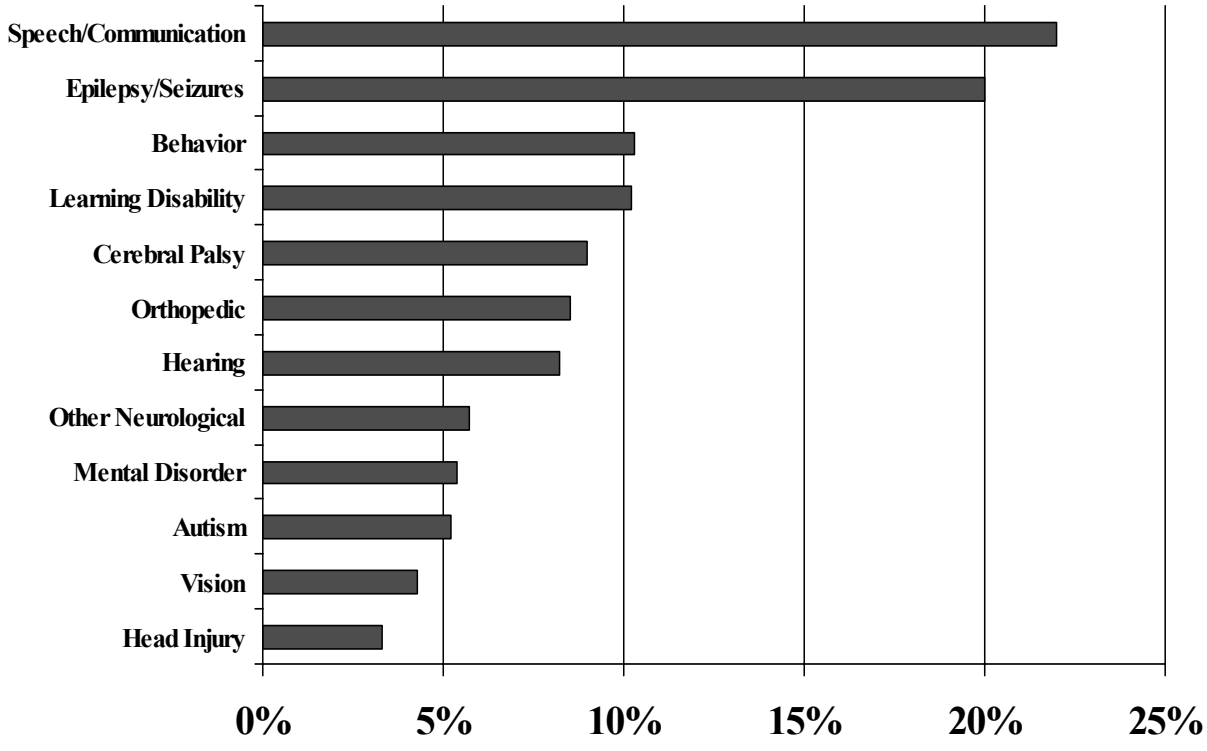


Figure 13. Percent Responding for Themselves, by Level of Retardation

high as 67% during the pilot years. After each interview, the interviewers recorded how well they thought the respondents understood the questions. This was subjective and reflected interviewer perceptions as well as respondent perceptions. Nevertheless, interviewers in FY2002 thought that 74% of the respondents understood the questions "very well," 17% understood the questions "some," and 9% understood the questions "not very well."



The DDA files indicate the presence of many conditions or impairme

Figure 14. Percent of People with Impairments Other Than Mental Retardation

nts other than mental retardation. (See **Figure 14**.) One-fifth or more of the people supported by DDA in the community have speech and language impairments (22%), and have epilepsy and seizure disorders (20%). About one out of 10 had behavior problems, specific learning disabilities or cerebral palsy. Fewer than 5% had blindness and visual impairments, or had head injury. These complicating conditions are not mutually exclusive, and many consumers had more than one.

Services

Half of the people in the DDA files did not receive supported residential services. Most of these (38%) lived with their families and the rest (13%) lived alone or with non-relatives. (See **Figure 15**.) One-sixth (17%) received DDA residential support that the providers said involved 40 or fewer hours of services during a week. Another 18% lived in the community and received more than 40 hours of services a week, but do not require services 24 hours per day. The remainder received services 24 hours per day seven days per week. Most of these (12%) live in the community, but a few (2%) live in institutions and only go into the community for day services. (The project does not currently include people who receive all their services in an institution.)

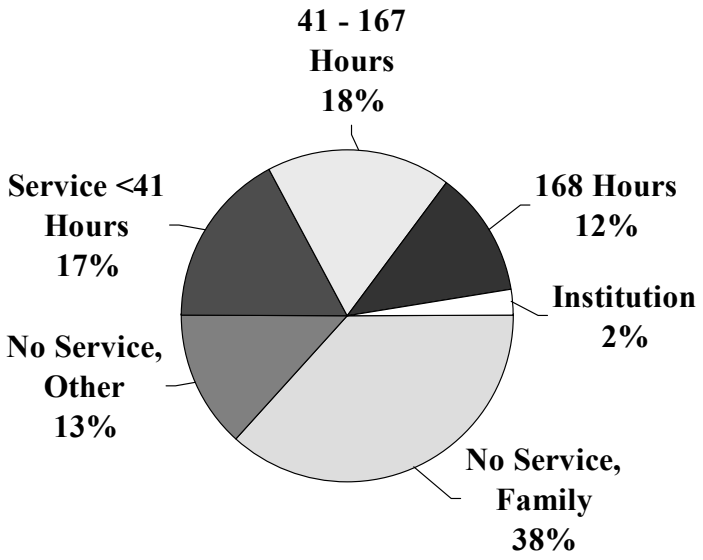


Figure 15. Percent of People by Residential Services

Almost all of the people receive day services supported by DDA. (See **Figure 16**.) Of the 11% receiving no services, only 3% were employed. Slightly more than half

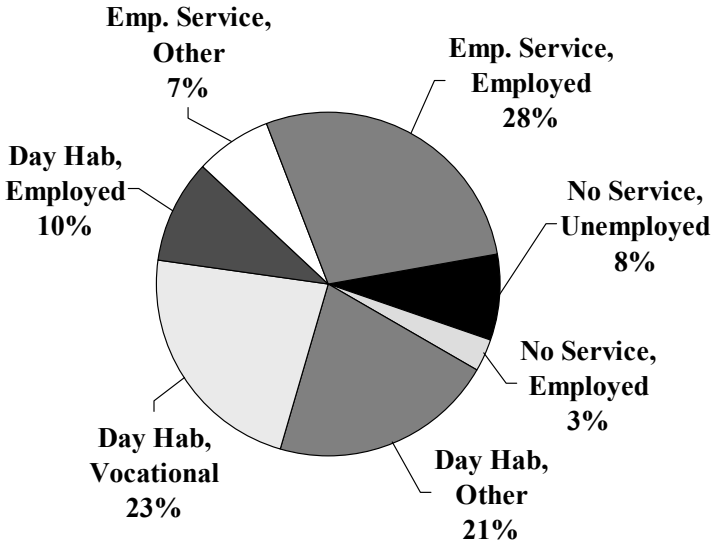


Figure 16. Percent of People by Day Activity

(54%) had DDA support for day habilitation, including 10% who the agency reported as employed, 23% who received vocational training during the day, and 21% received other types of day habilitation services, including medical day care. DDA support employment services for one-third of the people, including 28% who providers reported were employed at the time of the survey. The other 7% were not employed at the time of the survey.

One-third of the people received DDA-funded support services: 13% received individual or family support services, 9% received community supported living assistance (CSLA), and 9% received behavior consulting services.

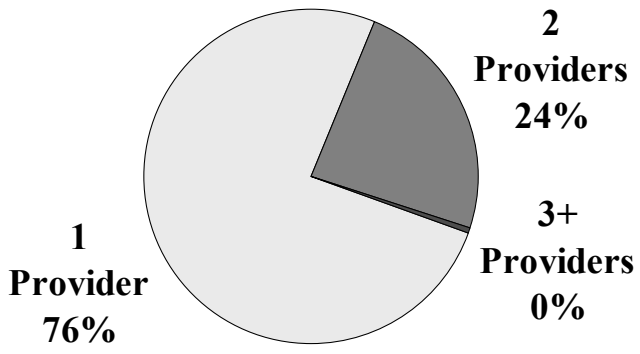


Figure 17. Number of Service Providers (excluding service coordination and institutions)

Three-fourths (76%) of the people supported by DDA in the community receive all their services from a single provider. (See **Figure 17**.) Almost all the others receive services from two different providers. Fewer than one-half of one percent receive services from three or more community providers. This, however, does not include service coordination, authorized for 45% of the people supported by DDA.

People had been with the agencies through which they were sampled for different lengths of time. One in twenty (5%) had been with their providers less than one year, while twice as many (11%) had been with their providers twenty or more years. (See **Figure 18**.) Thirty-four percent

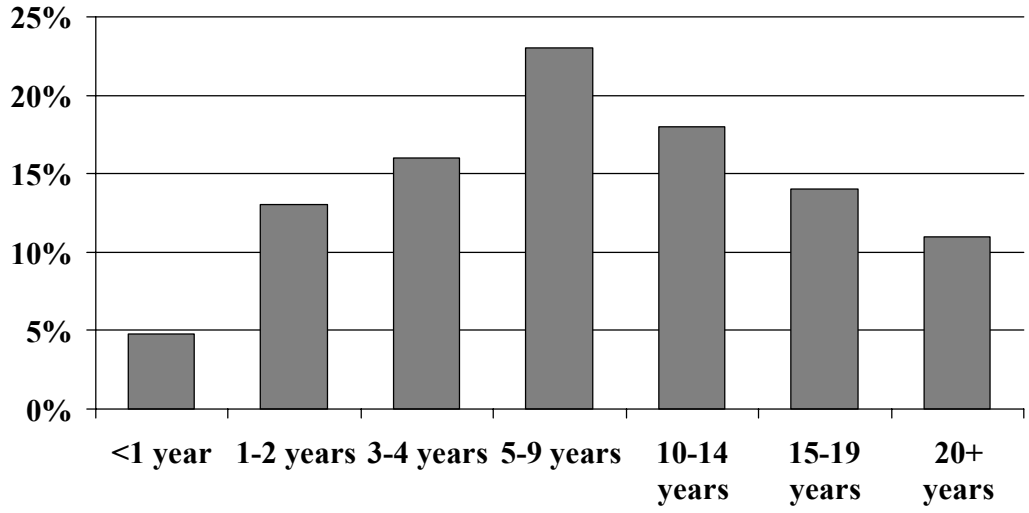


Figure 18. Percent of People by Years with Participating Provider

had been with their providers less than five years, and 43% had been with them 10 or more years. The median length of time was slightly more than 8.6 years.

Transportation is a major expense for service providers. Three-fourths (79%) of the people were transported by their providers (though whom they were surveyed) three times or more per week. (See **Figure 19**.) Only 10% of the people received no transportation from their providers, although the providers did coordinate transportation for 3% of these.

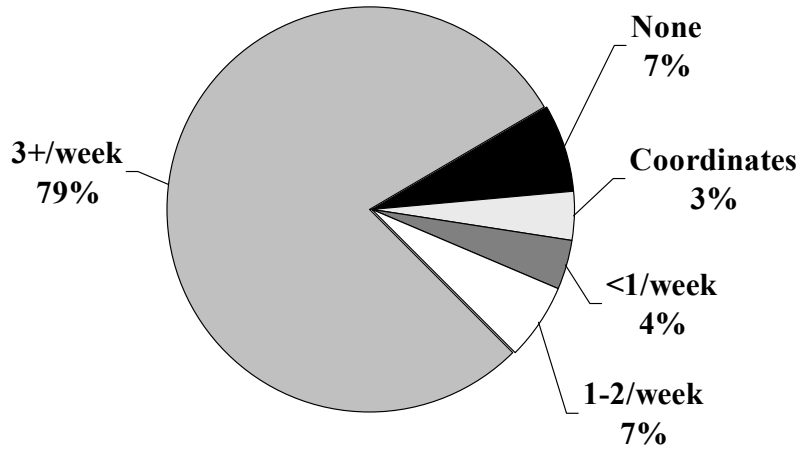


Figure 19. Percent of People by Days Agency Provided Transportation

Agencies reported that 43% of the people used either their own or their family's vehicle at least once a month, and 16% used transportation provided by another agency. (See **Figure 20**.) A few used public transportation: 12% used public transit, 8% used a para-transit service like Access or Mobility, and 5% used taxis. Over one-quarter of the people had no transportation other than that provided by their primary agency.

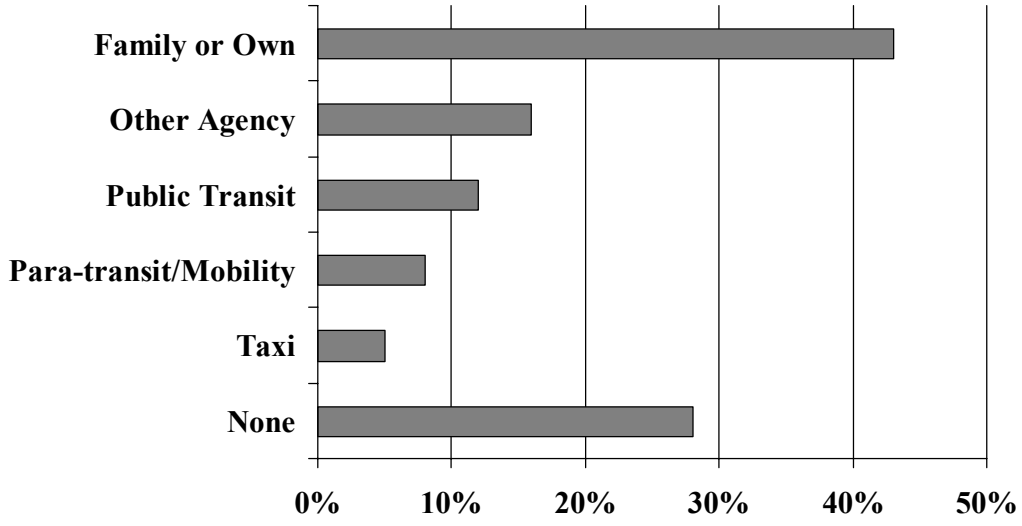


Figure 20. Percent of People Using Non-Agency Transportation in Past Month

PAGE INTENTIONALLY BLANK

Quality of Life Findings

Question Responses

The survey instrument included six questions as indicators for each of the eight quality of life domains. Other questions could also serve as indicators, but the questions included in Ask Me![sm] were generally derived from questions self-advocates identified as signs of quality to be asked providers of services. All six questions are indicators of the domain, and dropping any question reduces the reliability of the scale score. However, the question whose elimination reduced the reliability of the score the most can be considered the single best representative of the domain. These are shown below with their distribution of responses:

Social Inclusion: 13. How often do you see your friends on weekends?

34%	☺1	Every weekend
42%	😑2	Some weekends
24%	☹3	Not on weekends

Personal Development: 24. Do you get the information you need about sexuality?

36%	☺1	Yes
14%	😑2	Sometimes
50%	☹3	No, don't know meaning

Self-Determination: 26. Did you pick who you live with?

49%	☺1	Yes
17%	😑2	Some
34%	☹3	No

Rights: 49. How often do you vote in government elections?

23%	☺1	Often
15%	😑2	Sometimes
62%	☹3	Never

Interpersonal Relations: 18. How many close friends do you have?

43%	☺1	A lot
29%	😑2	Some
28%	☹3	Few

Emotional Well-Being: 1. Would you say that you are a happy person?

80%	☺1	Yes
15%	😑2	Sometimes
5%	☹3	No

Physical Well-Being: 37. Do staff or people you live with hit or hurt you?

85%	☺1	No
8%	😑2	Sometimes
7%	☹3	Often

Material Well-Being: 39. How often do you worry about having enough money?

63%	☺1	Never
22%	😑2	Sometimes
15%	☹3	Often

At least 73% of the respondents gave the most positive answer to seven of the questions on the survey. (See **Figure 21**.) Three of the questions with the most positive answers concerned physical well-being: 85% said the people they lived with never hit or hurt them, 75% had regular checkups with a dentist, and 75% felt that people had the right level of concern about their health. Three questions related to emotional well-being: 80% said they were a happy person, 73% liked themselves, and 73% felt they got the services they needed.

#	*Question*	*% Positive*
37.	Do staff or people you live with hit or hurt you?	85%
1.	Would you say that you are a happy person?	80%
32.	On health, are people concerned the right amount?	75%
35.	Do you have regular check-ups with a dentist?	75%
5.	Do you like yourself?	73%
4.	How safe do you feel in your neighborhood?	73%
25.	Do you get the services you need?	73%

Figure 21. Questions with the Most Positive Responses

Five questions received a negative response by 30% or more of the people. (See **Figure 22**.) Almost two-thirds (62%) of the people said they never voted in governmental elections, and half said they did not get the information they needed about sexuality. About one-third said they did not pick who they lived with, could not lock the bathroom door, and had to make a lot of advance preparation if they wanted to go somewhere.

#	*Question*	*% Negative*
49.	How often do you vote in government elections?	62%
24.	Do you get the information you need about sexuality?	50%
26.	Did you pick who you live with?	34%
52.	Have to plan days ahead and ask for transportation	33%
45.	Can you lock the bathroom door if you want to?	30%

Figure 22. Questions with the Most Negative Responses

Most (75%) of the questions are objective, with the subjective ones concentrated in the domain of material well-being. Objective questions provide clearer guides to program enhancement than do subjective questions. The responses to all of the questions in the *Ask Me!sm Survey* are shown

in **Table 2** on the following two pages.

Table 2. Percent Giving Each Response to Survey Questions: Ask Me! FY2002

	1 ☺	2 😐	3 ☹	Total
Emotional Well-Being				
1. Would you say that you are a happy person?	80	15	05	100
2. How do you feel about your home where you live?	65	29	06	100
4. How safe do you feel in your neighborhood?	73	15	12	100
5. Do you like yourself?	73	21	06	100
6. Do you feel that others treat you the same as any other person?	58	28	14	100
7. In general, how happy are you with your life?	68	25	07	100
Social Inclusion Scale				
8. Do people help you to be part of your community?	69	22	09	100
9. Do you go to fun things in your community?	63	23	14	100
10. When you go to fun things, are you active?	62	24	14	100
11. Do you think your neighbors like you?	64	27	09	100
12. How many friends.....from church, synagogue & comm. orgs.?	44	33	22	100
13. How often do you see your friends on weekends?	34	42	24	100
Interpersonal Relations Scale				
14. Do people help you learn how to do things for yourself?	58	31	11	100
15. When you make a mistake, do people help you?	63	26	11	100
16. When you set goals, do people help you reach them?	70	21	09	100
17. How often do you see or talk with your family?	55	28	17	100
18. How many close friends do you have?	43	29	28	100
19. Does what you do most days let you look good to others?	63	27	10	100
Personal Development Scale				
20. Does your job or what you do most days make you feel important?	68	20	12	100
21. Are you getting the training that will help you get a job/better job?	56	21	22	100
22. Do others give you a chance to become what you want to be?	60	27	13	100
23. Are you learning things that will make you a better person?	71	21	08	100
24. Do you get the information you need about sexuality?	36	14	50	100
25. Do you get the services you need?	73	17	11	100
Self-Determination Scale				
26. Did you pick who you live with?	49	17	34	100
27. Can you be alone when you want to?	58	20	22	100
28. How much choice do you have in the food you eat?	49	29	23	100
29. Do you get a chance to say what you think?	54	28	18	100
30. Do you pay for things you buy with your own money?	66	17	16	100
31. Did you choose your job or what you do most days?	58	23	19	100

Table 2. Percent Giving Each Response to Survey Questions: Ask Me! FY2002 – Continued

	1 ☺	2 😐	3 ☹	Total
Physical Well-Being Scale				
32. On....health, are people concerned, too concerned, not care?	75	16	10	100
33. Is your health good, fair or poor?	71	19	10	100
34. Would you say your eating habits are good, fair or poor?	71	21	08	100
35. Do you have regular check ups with a dentist?	75	13	13	100
36. Can you get the sleep you need without being disturbed?	70	19	12	100
37. Do staff or people you live with hit or hurt you?	85	08	07	100
Material Well-Being Scale				
38. How many things do you own, like furniture, TV, etc.?	52	37	11	100
39. How often do you worry..money pay rent or buy food?	63	22	15	100
40. On money, do you feel that you are well off, problems, poor?	59	26	15	100
41 Do you have money each week to spend on what you want?	67	21	12	100
42. Do you save money every time you get paid, sometimes, or never?	53	28	19	100
43. Do you have the chance to earn good money?	59	20	21	100
Rights Scale				
44. Do staff ask before they come into your home or room?	56	23	21	100
45. Can you lock the bathroom door if you want to?	57	13	30	100
46. Can you talk on the telephone in private?	62	14	24	100
47. Can you spend time by yourself if you want?	67	15	17	100
48. When you have a gripe against staff, is it easy to say something?	53	25	22	100
49. How often do you vote in government elections?	23	15	62	100
Transportation Scale				
51. When you want to go somewhere, do you have transportation?	66	24	10	100
52. Can you just....go, have to plan some, or many days ahead & ask?	30	37	33	100
53. If you set up a ride, can you depend on it?	69	20	11	100
54. Do you miss ...have to change plans because of transportation?	50	34	16	100
55. Do transportation problems make you feel separate from others?	58	25	17	100

NOTES:

a) When proxies differed, they were included in the percent with the less favorable score (e.g. proxy 1 gave code 1 and proxy 2 gave code 2, the average code 1.5 was included in this table as part of the percent for code 2).

b) Each percent is independently rounded, so the three numbers shown in the table may sum to 99, 100 or 101 percent.

c) Questions 3, 50 and 56 are not shown as they duplicated other questions and are used for methodological purposes only.

Quality of Life in Maryland

The Ask Me![sm] Project calculated quality of life scores for 954 people on emotional well-being from questions at the beginning of the survey. (See **Figure 23**.) It calculated scores for 842 people on material well-being from questions near the end of the survey. The highest scores occurred in the domain of physical well-being, in which 90.3% of the people had positive scores. The sampled people had an average score of 6.594, reflecting a population well-being score between 6.320 and 6.868.[1] Emotional well-being scores varied the least, as measured by the standard deviation, and self-determination scores varied the most. The Maryland Developmental Disabilities Administration establishes its goals based upon both the percent with a positive score and the average score.

Domain	*% Positive*	*Average Score*	*Std. Error*	*Std. Dev.*	*# People*
Social inclusion	79.8	4.200	.152	4.634	926
Self-determination	72.0	3.515	.177	5.315	898
Personal development	78.4	4.288	.161	4.812	897
Rights	62.9	2.417	.178	5.206	851
Interpersonal relations	84.1	4.637	.148	4.474	919
Emotional well-being	90.0	6.272	.124	3.825	954
Physical well-being	90.3	6.594	.140	4.158	886
Material well-being	78.0	4.406	.155	4.501	842
Transportation availability	76.4	3.887	.157	4.573	847

Figure 23. Statistical Properties of Quality of Life Scores

Interrelationships Among Domains

One quality of life domain is not necessarily more or less important than any other. Yet it is hard to focus on all eight at one time. As discussed in the background section, some domains have received more attention in the literature than have others, but this attention does not mean they are more important. The Maryland DDA has clearly defined social inclusion, personal development, and self-determination as desired outcomes from services and support programs for persons with mental retardation/developmental disabilities. These desired outcomes provided the conceptual framework for developing a path analysis. (See **Figure 24**.) The variables on the right side of a path analysis are assumed to be predicted, or caused by, those on the left. The variable at the tail of the arrow is hypothesized to affect the variable at the head of the arrow. No arrow exists between two variables when no statistically significant relationship was found between them. The numbers on the arrows are path coefficients (standardized

[1]The 95% confidence interval is the average +/- 1.96 times the standard error of the mean. The standard error of the mean is equal to the standard deviation squared divided by number of people - 1.

multiple regression) and indicate the strengths of the relationships.[2]

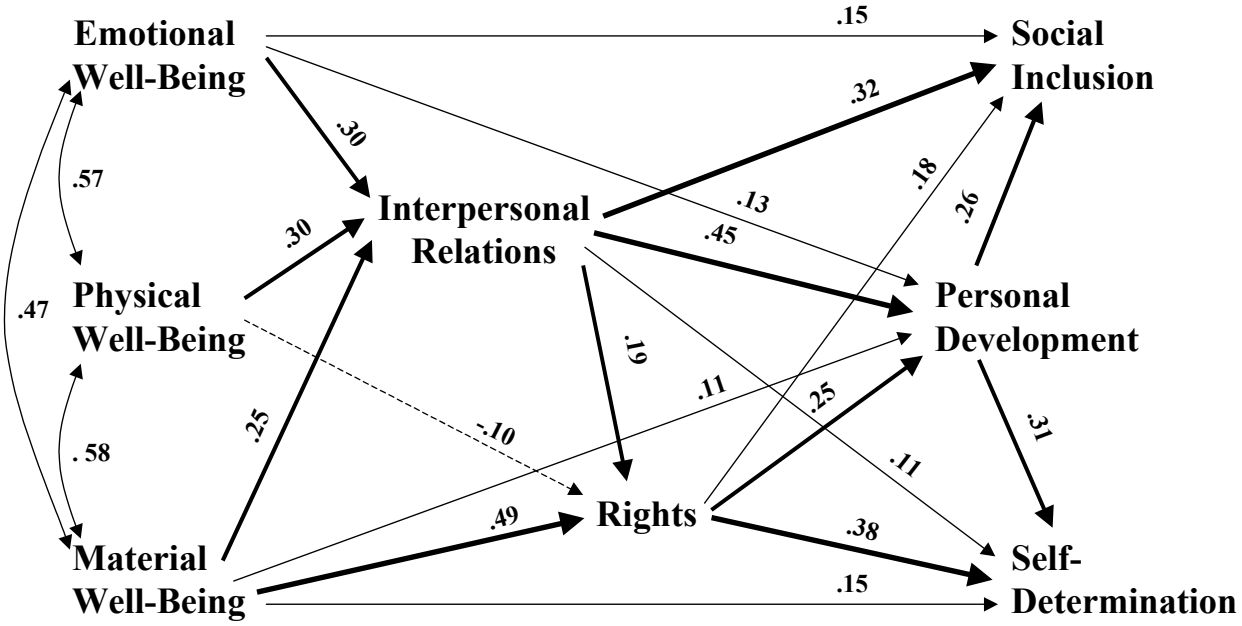


Figure 24. Path Model of the Relationships Among Quality of Life Domains

The unweighted data from FY2001 suggested that among the three DDA objectives, personal development affected social inclusion and self-determination, and not vice versa. In addition, social inclusion and self-determination had no causal impact on each other. The weighted data for FY2002 did not so clearly show the direction of causality between personal development and social inclusion, and between personal development and self-determination. The FY2002 weighted data also showed a marginal relationship between social inclusion and self-determination independent of their association with personal development. These differences, however, did not suggest discarding the model from FY2001, which the weighted FY2002 data fit remarkably well. The arrows pointing at social inclusion show the predictive value of the variables to the left, and suggest that the best way to increase social inclusion would be to increase interpersonal relations (path coefficient of 0.32). The weighted FY2002 data suggest the next best way to increase social inclusion would be to increase personal development, rather than emotional well-being as suggested by the unweighted FY2001 model. The current data show that material well-being had no direct effect on social inclusion, whereas it had a minor effect in the previous year. In both years, the best way to increase self-determination would be to increase rights and personal development. Personal development appears central in quality of life, related to six of the other seven domains. The only domain that did not have a direct independent relationship with personal development was physical well-being, a change from the previous year's model. However, the FY2002 weighted data show a much stronger effect of interpersonal relationships on personal development than did the earlier data. The current data

[2]A coefficient of 1.0 indicates a perfect direct relationship, -1.0 a perfect inverse relationship, and 0.0 indicates no relationship.

also shows a strong effect of material well-being on rights than did the earlier data. A difference in the models for the two years, however, is the reversal of the effect of physical well-being on rights. The FY2002 data suggest that physical well-being increases at the expense of rights, a phenomenon now being discussed within the disability community.

Personal development is the goal of DDA that is most related to the overall quality of life of the individual. The above path analysis shows it related to six of the other seven domains. When characteristics of services and the family were considered in regression equations, personal development was shown to be related to all seven domains. (See **Figure 25**.) The strongest predictor of people's feelings on personal development was their feeling about the interpersonal relationships they had. Next strongest was their feeling about having rights. Other quality of live areas had small but significant impact, as did three other factors. The greater the person's cognitive ability, as measured by IQ scores and level of retardation, the greater their reported

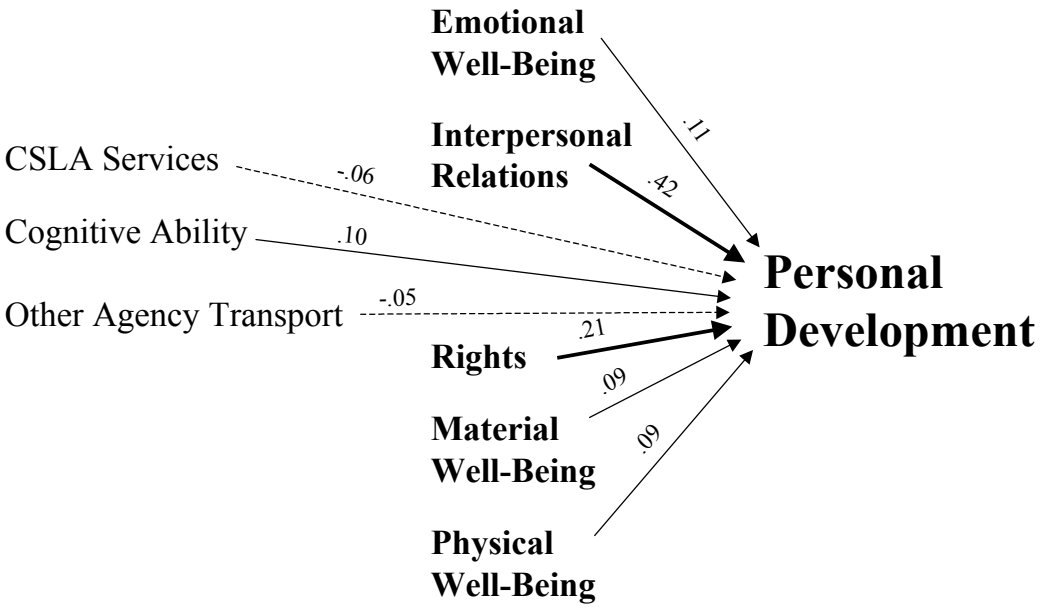


Figure 25. Predictors of Life Quality in the Domain of Personal Development

satisfaction in the domain of personal development. Transportation had some importance as reflected by a negative path associated with transportation provided by agencies other than the one through which the person was interviewed. DDA funding for community supported living assistance (CSLA) also had a small negative effect on people's perceptions of personal development. This suggests that the current way CSLA services are supported and carried out be reviewed to see if they are meeting their objectives.

An argument has been made that interpersonal relationships are most central to

> *"...our lives are all made more productive by social ties that we have with other people....We can increase the entire range of personal outcomes for people with disabilities and people with mental illness by increasing their social capital."*
>
> –James F. Gardner

people's quality of life. Gardner (2002), referring to Putnam and the literature on social capital that "demonstrates how our lives are all made more productive by social ties that we have with other people," states that, "We can increase the entire range of personal outcomes for people with disabilities and people with mental illness by increasing their social capital." The domain of interpersonal relations used in the *Ask Me!sm Survey* is close to the concept of social capital, as was the only domain that had a statistically significant relationship with all other quality of life domains when other characteristics and factors are not controlled. Although interpersonal relations is not an explicit goal of DDA, it appears to be a key means of achieving the DDA goals. The two strongest predictors of high satisfaction with interpersonal relationships were high levels of physical well-being and high levels of emotional well-being. (See **Figure 26**.) Next in importance was material well-being and the perceived availability of transportation. People with transportation provided by the agency three or more times a week reported higher levels of interpersonal relations than those receiving less transportation, independent of how available they through transportation was. People with higher cognitive ability reported greater

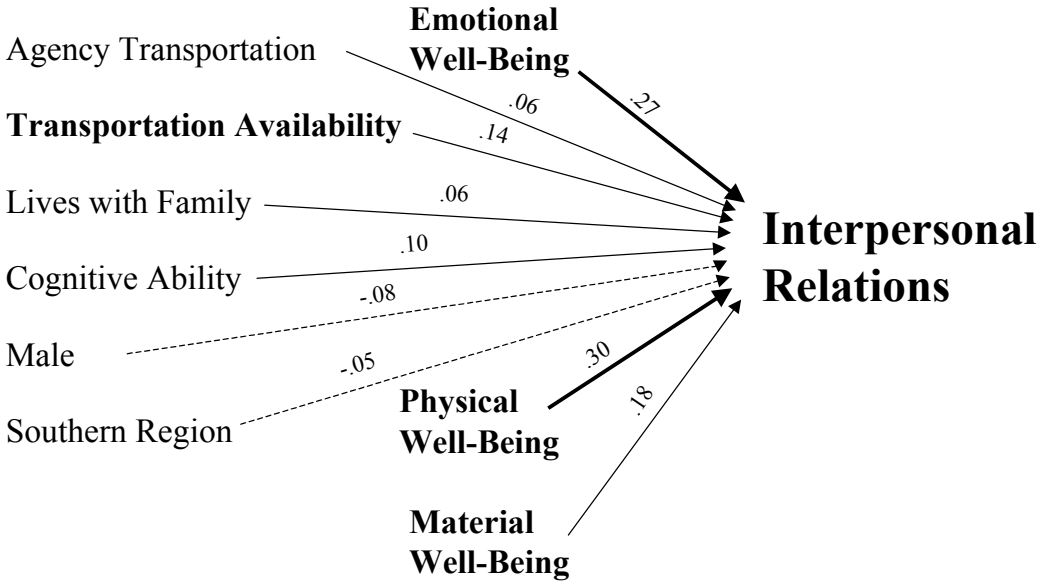


Figure 26. Predictions of Life Quality in the Domain of Interpersonal Relations

satisfaction with interpersonal relations than did people with lower cognitive ability, and men reported lower levels of interpersonal relationships than did women. People living with their families reported higher levels of interpersonal relations than did people living in other residential settings. People living in the Southern DDA Region reported slightly lower levels of interpersonal relations than did people living in the other three regions.

Services and Quality of Life

The Ask Me!sm Project had several characteristics of services available for analysis on how they related to people's quality of life. These measures came from the people themselves, from the service providers through which they were sampled, and from the DDA files. Transportation

Characteristic	Social Inclusion	Self-Deter.	Personal Develop	Rights	Interper. Relation	Emotion Well-be	Physical Well-be	Material Well-be
Quality of Life								
Personal development	.26	.27	na	na	na	na	na	na
Rights	.19	.31	.21	na	na	na	na	na
Interpersonal relations	.31	.08	.42	.13	na	na	na	na
Emotional well-being	.15	–	.11	–	.27	na	.32	.13
Physical well-being	–	.14	.09	–	.30	.41	na	.40
Material well-being	–	.12	.09	.33	.18	.16	.40	na
Services								
Transportation availability	–	–	–	.15	.14	.11	.11	.29
This agency transportation	.06	–	–	–	.06	–	–	–
Other agency transportation	–	–	-.05	–	–	–	–	.07
Employment services	–	–	–	.07	–	–	–	.07
Residential services	–	-.06	–	.10	–	–	–	–
CSLA services	–	–	-.06	–	–	–	.06	–
Behavioral services	–	–	–	-.09	–	–	–	–
Person								
Cognitive ability	–	.09	.10	.10	.11	.09	–	.11
Male	-.05	–	–	–	-.08	–	-.07	.06
Other								
Proxy	–	-.12	–	-.26	–	.11	.20	-.17
Lives with family	–	–	–	–	.07	.09	–	–
Southern region	–	-.07	–	-.10	-.05	–	.05	–
Western region	–	.06	–	.06	–	–	–	–
R-square	.55	.65	.58	.45	.53	.38	.52	.50

Figure 27. Significant Standardized Regression Coefficients on Individual Quality of Life

appears to most consistently related to people's quality of life. People's expressions on how available they thought transportation was for them significantly predicted their quality of life in five domains. (See **Figure 27**.) People's perception on the availability of transportation is more of a short-term outcome of service, rather than a service itself, and is therefore closer to the long-term outcomes of life quality. However, two direct measures of transportation services also offered some prediction on quality of life. People whose agencies provided transportation three or more times per week reported higher levels of social inclusion and interpersonal relations than people whose agencies did not provide transportation this frequently. When other than the sampled agencies provided transportation during the previous month, people reported lower levels of personal development.

Contrary to expectations, people receiving transportation three or more times per week from the agency through which they were sample reported that transportation was less available than did people who received transportation services less than three times a week. (See **Figure 28**.) People receiving DDA-supported employment services, however, reported greater transportation

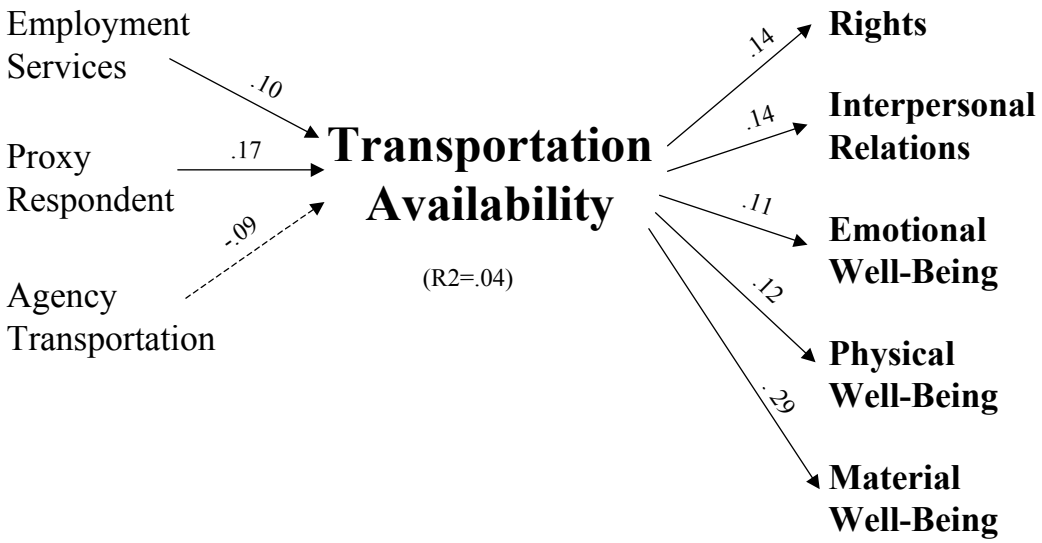


Figure 28. Predictors and Impact of Perceived Availability of Transportation

availability than did people not receiving employment services.[3] Agency-reported use of transportation during the past month provided by family, public transit, paratransit, or taxis did not have a significant relationship with how available people reported transportation to be. Proxies report greater availability of transportation than did self-respondents people. Since the majority of proxies were staff, this suggests that staff are more likely than consumers to feel that their agencies are making transportation available. Unfortunately, only 4% (R^2=.04) of the variation in the availability of transportation that people report can be explained by service and background characteristics currently available to the Ask Me!^{sm} Project.

Services other than transportation predicted people's reported quality of life. People receiving DDA-supported employment services reported higher levels of rights and material well-being than did people without employment services. (Refer back to **Figure 27**.) People receiving DDA-supported residential services reported higher levels of rights than people without residential services, but the also reported lower levels of self-determination. Community supported living assistance (CSLA) appeared to increase peoples' perceptions of physical well-being, but had a negative impact on their sense of personal development.

The data show that people in DDA's southern region reported higher levels of physical well-being, but lower qualities of life in the domains of self-determination, rights and interpersonal relations than did people in other parts of Maryland. This may be due to characteristics of people who live in the southern region or to general characteristics of the southern Maryland communities. However, it could also be that services provided by agencies in southern Maryland focus more on the physical well-being of people than do services provided in the rest

[3]Agency-reported employment of the person was a marginally better predictor than DDA-supported employment services, but is not as readily available a measure.

of the state, and overlook other domains on well-being. People in different regions of the state expressed the greatest differences in the domains of self-determination and rights, with people in DDA's western region reported the highest levels and people in the central and eastern shore regions in between those in the southern and western regions.

A number of service measures did not offer predictions of the quality of life people reported. These included DDA-supported day habilitation services, DDA-funded individual and family support services, and DDA-supported service coordination. (See **Figure 29**.) It may be that all of these services were well adapted to individuals' needs, or randomly adapted, so the fact that DDA provides support for these services was not the appropriate measure. It also appears to make no difference whether DDA supports different services through different agencies, or supports all the services for a person through a single provider agency.

Service Characteristics	Head injury
DDA day habilitation services	Mental disorder
DDA individual & family support	Orthopedic impairment
DDA Service coordination services	Other neurological impairment
Number of DDA service providers	Specific learning disability
Institutional residence	Speech and language impairment
Person Characteristics	Employed
Age	*Other*
Autism	Eastern Shore region
Behavior problems	Family provides transportation
Blindness and visual impairments	Uses para transit
Cerebral palsy	Uses public transit
Deafness and hearing impairment	Uses taxi
Epilepsy, seizures	

Figure 29. Characteristics Not Related to Quality of Life

Personal Characteristics and Quality of Life

The cognitive abilities of people had some affect on their quality of life. The higher their cognitive ability, the higher their reported their quality of life in the domains of self-determination, personal development, rights, interpersonal relations, emotional well-being and material well-being. (Refer back to Figure **27**.) Only people's sense of social inclusion and physical well-being seemed unaffected by their cognitive abilities. It should be noted, however, that cognitive ability did not affect the availability of transportation that people reported, and transportation availability predicted quality of life slightly better than did cognitive ability. None of the twelve non-cognitive disabilities or impairments recorded by DDA on their files offered any prediction of people's quality of life.

As discussed earlier, men reported lower levels of interpersonal relations than did women. They also reported lower social inclusion and physical well-being. However, in the domain of material well-being, men reported greater satisfaction than did women.

None of the other characteristics of people listed in Figure **29** had any statistical relationship to any quality of life measure. This suggests that people's perceived quality of life is limited very little by things that cannot change. There is the potential to improve every person's quality of life.

Proxy Effects

Proxies responded when people could not respond for themselves. Several factors predicted 41% ($R^2 = .41$) of proxy response. The most important factor was the cognitive ability of the person. (See **Figure 30**.) The higher the cognitive ability, the less likely proxies responded for people (or the more likely people responded for themselves). In addition, proxies were less likely to respond for people in the DDA western region than in other regions, for people who lived with their families than for people in other living arrangements, and for people receiving employment services. Proxies responded slightly more frequently for men than for women, even with the same cognitive ability. The path model shows that proxy respondents reported higher levels of transportation availability, higher levels of emotional well-being, and higher levels of physical well-being than did self-respondents with similar characteristics and services. On the other hand, proxy respondents reported lower levels of self-determination, rights and material well-being than did self-respondents. Since proxies responded for 80% of people classified as having profound retardation and 50% of those with severe retardation, the measure "proxy

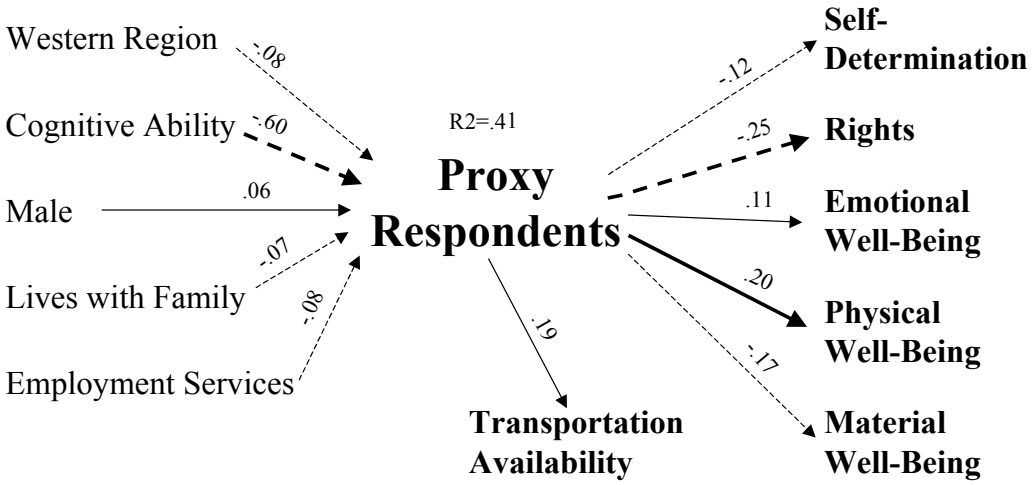


Figure 30. Predictors of and Effect of Proxy Response

response" may represent a special characteristic or disability of a person that is not completely captured by IQ tests. However, the measure "proxy response" may also represent the different perspective of outside people who are asked to guess what individuals who cannot respond for themselves are thinking and feeling. Some of the differences must be due to outside proxies not knowing what a person thinks and feels. Statistically different qualities of life in the domains of social inclusion, rights and interpersonal relations were reported by advocate proxies than by staff proxies for the same people. (See discussion of proxies in Appendix 1.) The qualities of life reported by two staff proxies for the same people did not differ as much, but were not always

the same. This suggests that staff should not rely on their perceptions of people's quality of life or need for services, but check their perceptions with the people they serve as much as possible. Other consumers could assist when individuals have difficulty communicating their feelings or desires. However, proxy responses are better than ignoring people who cannot respond for themselves as long as adjustments are made for bias.

Agency Variation

The Ask Me![sm] Project sought to interview 30 people (or their proxies when necessary) at each sampled service provider. The final number of people for with interview information varied from a low of 24 and as many as 38. (See **Table 3**.) Agencies differ in the types of services they provide, and the characteristics of the people included in the survey differ accordingly. Abilities Network does not provide residential services, and none of the people surveyed through them received DDA-funded residential services. Although Abilities Network provides employment support services, only a few of their surveyed people were funded by DDA for employment services. All but one were identified by DDA as receiving support services. In contrast, all but two of the people surveyed through the Benedictine Community received DDA-supported residential services, and all but one received DDA-supported employment services. Only a few were identified by DDA as receiving support services. As discussed earlier, 76% of the people surveyed received services from a single provider. This percent also varied among the sampled service providers, from Community Living, Inc. which was the sole provider of services to 32% of the people it served to Bayside Community Network which was the sole provider of services to 99% of its people. These characteristics, along with the overall response rate and the rate of self-response shown earlier in Table 1 should be considered in interpreting average quality of life scores of individual service providers.

DDA plans to publish the average quality of life scores in its *Guide to Services* after the first four-year cycle has been completed. These will be added to the information provided by each service provider. About half of the service providers included in this first year of the four-year cycle gave permission for their scores to be included with this annual report. These providers are indicated in the final column of Table 3, and a separate page for each is included in **Appendix 2**. The average score for a service provider is affected by specific people chosen for interviews. While the people were randomly selected by using the sampling procedure in SPSS, a different random selection of people would likely produce different average scores just by chance, and is statistically represented by the *standard error* of the estimate. There is less than five times out of a hundred that what any sample of 30 people produces will differ by more than two standard errors (t=2.045, 29 degrees of freedom) from what an interview with everyone would produce. For all eight domains except one, the difference between the highest 20% (7) of average scores and the bottom 10% (3) was greater than twice the standard errors of the scale scores. For the domain of self-determination, the difference was statistically significant only between the top 6 scores and the bottom 3 scores. To assist in interpreting the scores, Appendix 2 provides symbols to indicated if the average score for a service provider was in the highest 20%, the middle 70%, or the lowest 10%. In addition, information is included about the month during which half of the surveys were completed, the response rates, the proportion of people

served by other agencies, and the DDA-supported services received by the people surveyed. Average domain scores may be directly requested from service providers that did not choose to have them included in this report.

The average quality of life scores of people served by the 33 service providers included in the first year of the four-year cycle differed greatly. The average score on physical well-being for all people supported by DDA was 6.6, while the average score was 9.0 (10.0 is the maximum)

Table 3. Number of People with Surveys by Type of Service					Appendix
	Type of Service				
Agency	Residential	Emp/Day	Support	Total	
Total	341	742	217	960	
Abilities Network	0	4	25	26	
ACCFX Gallagher	25	17	2	34	
Alliance	0	23	4	27	
Ardmore Enterprises	7	32	0	32	
Athelas Institute	2	27	6	28	X
Bayside Community Network, Inc.	16	31	2	31	X
Benedictine School	28	29	5	30	X
CHI	9	25	2	31	X
Chimes, Inc.	13	26	2	33	
Community Living Inc.	25	5	3	28	
CSAAC	33	35	0	36	
DBA Horizon Goodwill Industries	0	25	0	25	
Dove Pointe, Inc.	11	27	8	30	X
eMerge	18	21	12	29	
Jubilee Association of MD	15	0	13	28	X
Kent Center Inc.	11	23	13	25	X
Melwood Horticultural Train Ct	4	24	5	28	X
Opportunity Builders	0	21	4	25	
Penn Mar	18	27	10	29	X
Providence Center	0	25	4	26	
Rehabilitation Opportunities	0	32	0	32	
SEEC	0	26	4	28	
Spring Dell Center	8	22	4	29	
The Arc of Baltimore	6	30	5	32	X
The Arc of Carroll County	16	29	5	38	X
The Arc of Frederick County	0	0	24	25	X
The Arc of Montgomery County	13	17	7	27	X
The Arc of Northern Chesapeake	16	29	6	36	X
The Arc of Prince George's County	9	18	5	25	X
The Arc of Washington County	13	22	10	28	
The Caroline Center	14	26	10	27	
UCP Central Maryland	8	20	12	26	
Worcester Co Developmental Ctr	3	24	5	26	

among people served by one provider and 3.0 (-10.0 is the minimum) among people served by another provider. (See **Figure 31**.) Both fall outside the 95% confidence interval of 1.6 (twice the standard error for a sample of 30 people), which says that the differences expressed by the people they serve cannot be explained by the particular sample drawn from their agency, but reflect true differences of expression by the people they serve. The 33 service providers had much less variation among the people they served in expressions of emotional well-being. While the average confidence interval of +/- 1.5 suggest that the highest average score is not statistically different from the Maryland average, the specific test for that specific provider shows that it is statistically higher than the state average.

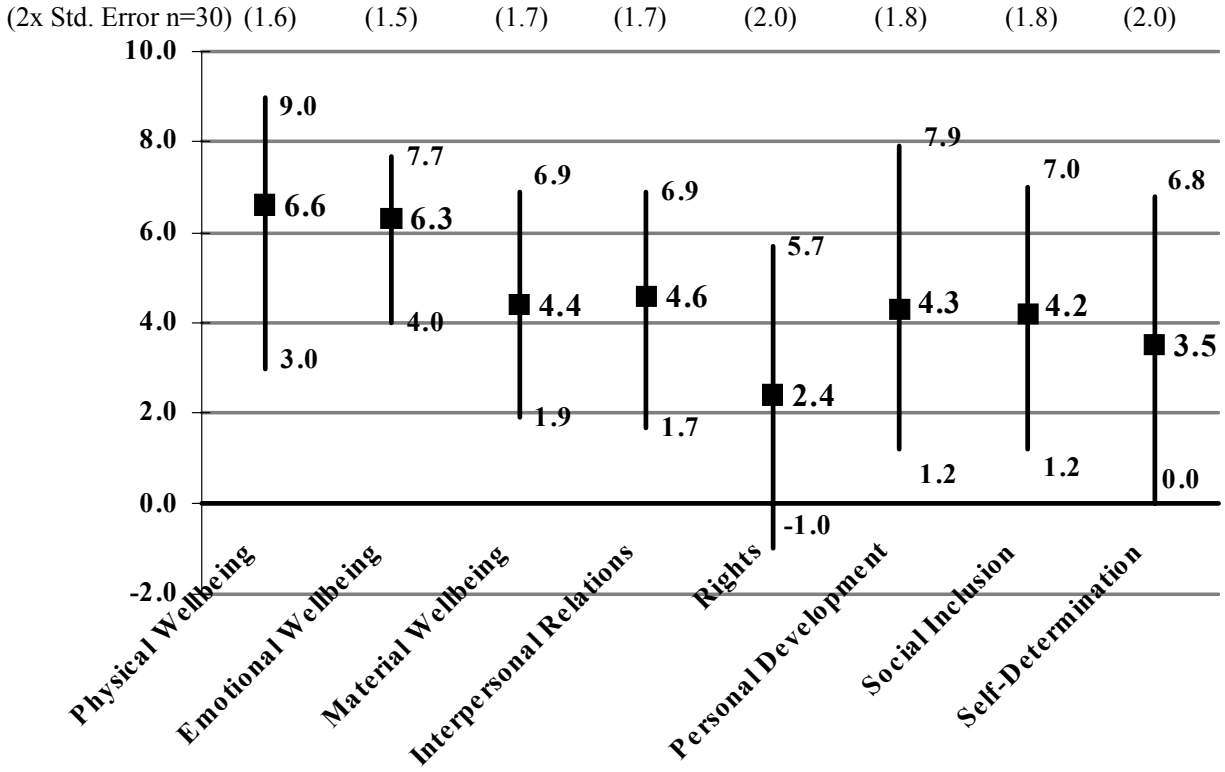


Figure 31. Average Quality of Life Scores Among 33 Service Providers

People were almost as positive about their emotional well-being as their physical well-being, and emotional well-being varied the least among agencies (4.0 to 7.7, a difference of 3.7 points). Rights was the only domain for which agencies (three) had average scores less than zero, meaning they had more negative responses to the six rights-indicator questions than they had positive responses. The greatest variation among agencies (6.7-6.8 points) occurred in the domains of self-determination, rights and personal development. It is probably not a coincidence that these three quality of life domains with the greatest inter-agency variation have received the least attention in the mental retardation and developmental disabilities' literature (order shown in Figure **1**). The low levels of rights has been found in other studies (Reinders, 2000) and may reflect that this domain is the most complex from a conceptual and measurement standpoint.

Twenty providers included in the FY2002 survey had also participated in the FY2001 pilot that used the same interview instrument. The quality of life of people served by these providers significantly increased over the year in three foundational domains: emotional well-being, physical well-being, and material well-being. (See **Figure 32**.) However, the scores at some providers changed more than the scores at other providers, so that providers with the lowest scores in FY2001 did not necessarily have the lowest scores in FY2002. People's quality of life did not increase overall in the other five domains, and the average scores of individual providers in FY2002 were about the same as in FY2001. The continuity was statistically significant for the domains of self-determination (correlation = .68) and personal development (correlation = .45). As a result, providers whose people had low self-determination and personal development scores in FY2001 had similarly low scores in FY2002, and providers whose people had higher scores in FY2001 had higher scores in FY2002. Six of the providers had higher scores in FY2002 than FY2001 in three or more domains, with no lower scores. Eleven providers had changes in one or two domains with increases about as frequent as decreases. Three providers had no statistical changes in any of the domain scores. These findings suggest that some providers attempted to enhance the quality of life of the people they served in the three foundational areas, and were successful. Unfortunately enhancements in the foundational domains do not necessarily translate into enhancement in all other quality of life domains.

Domain	*FY2001*	*FY2002*	*Corr.*
Social inclusion	3.9	4.8	.39
Self-determination	3.4	3.5	.68+
Personal development	4.0	4.3	.45+
Rights	2.5	2.4	.41
Interpersonal relations	4.0	4.7	.41
Emotional well-being	5.6*	6.3*	.35
Physical well-being	5.9*	6.7*	.15
Material well-being	3.8*	4.7*	.35

* FY2002 different from FY2001, p=.05
\+ Significant correlation between FY2002 and FY2001 agency scores, p=.05

Figure 32. Average FY2001 and FY2002 Quality of Life Scores for 20 Providers and Agency Correlation

An earlier path model showed the significant relationships among the quality of life domains reported by individual respondents. A similar path model was made for the 33 service providers in the project, showing the relationships among domains of the average scores of the people they serve. (See **Figure 33**.) The bold paths with path coefficients represent the significant relationships among the average agency scores on the quality of life domains, with the light lines without coefficients show the additional relationships among individual people that were not strong enough to be statistically significant based upon a much smaller number of aggregate observations. Most of the strong relationships observed among individuals were also observed among agencies. The path, however, from physical well-being to rights was much more dominant among agencies than among individuals. This emphasizes the tradeoff between physical well-being and rights. The agencies whose people report the highest levels of physical well-being tend to be the same agencies whose people report the lowest levels of rights. On the other hand, material well-being and rights have an almost perfect relationship at the agency level, with the higher the expressions of material well-being, the higher the expression of rights.

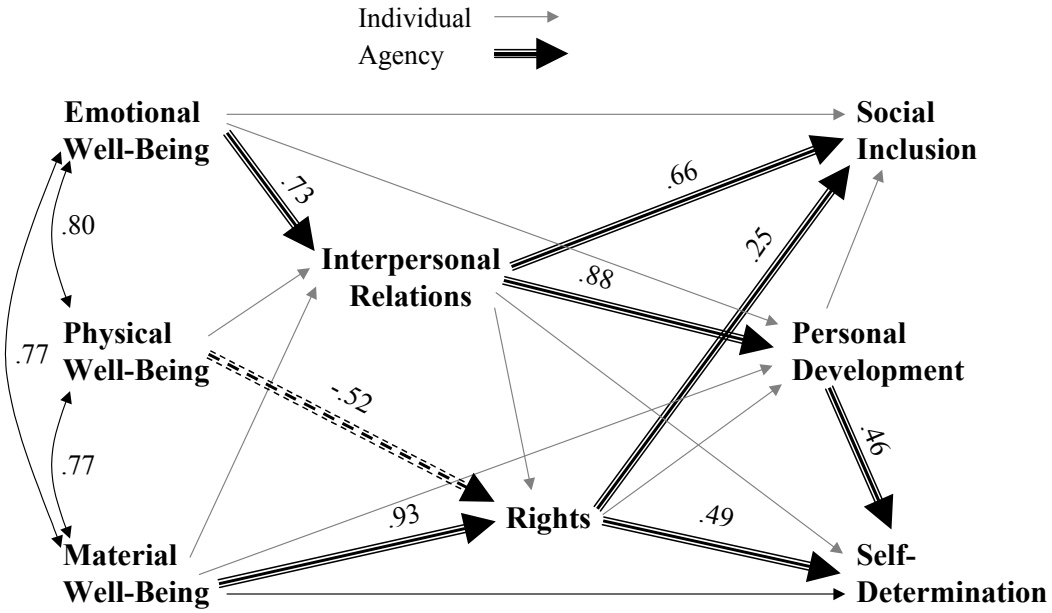


Figure 33. Path Model of Average Agency Scores on Quality of Life Domains

Regressing the average agency quality of life scores on agency characteristics identified some predictors of scores. (See **Figure 34**.) No characteristic of the service providers predicted the average scores their people gave in the domains of social inclusion or physical well-being--only the average scores in other quality of life domains offered predictions. For personal development, however, two provider characteristics combined with two other average domain scores to predict 88% (R^2=0.88) of provider variability. The greater the percent of people to whom the agency provided employment services, and the greater the percent to whom it provided day habilitation services, the higher the average score reported by the people served by the agency. Agencies with a high percent of their people receiving DDA-funded employment services also report high levels of emotional well-being. Transportation availability also predicted emotional well-being, but transportation availability was more important in predicting perceived material than emotional well-being among the people served. The average scores on rights, interpersonal relations, and material well-being were affected by the consumer population served by the agencies. The greater the percent of people served who were classified with profound or severe retardation, the lower the average scale score on rights and on interpersonal relations. Providers serving larger percentages of people with epilepsy and seizure disorders also had lower scores on rights. When these, along with the observation that providers in southern Maryland scored lower on rights than providers in other parts of the state, were taken into consideration, the previously observed negative relationship between physical well-being and rights became statistically insignificant. The greater the percentage of people in the agency who could not respond for themselves, the lower the level of material well-being that was reported by people served by the agency.

Characteristic	Social Inclusion	Self-Deter.	Personal Develop	Rights	Interper. Relation	Emotion Well-be	Physical Well-be	Material Well-be
Quality of Life								
Personal development	–	.49	na	na	na	na	na	na
Rights	.25	.51	.19	na	na	na	na	na
Interpersonal relations	.66	–	.82	–	na	na	na	na
Emotional well-being	–	–	–	–	.74	na	.52	–
Physical well-being	–	–	–	–	–	.55	na	.49
Material well-being	–	–	–	.51	–	–	.37	na
Person								
% Proxy responses	–	–	–	–	–	–	–	-.28
% Profound/severe retardation	–	–	–	-.50	-.37	–	–	–
% Epilepsy, seizures	–	–	–	-.27	–	–	–	–
Services								
Transportation availability	–	–	–	–	–	.28	--	.54
% Employment services	–	–	.70	–	–	.26	–	–
% Day services	–	–	.72	–	–	–	--	–
Other								
Southern region	–	–	–	-.30	–	–	–	
Western region	–	.22	–	–	–	–	–	–
R-square	.66	.74	.88	.71	.67	.78	.70	.83

Figure 34. Significant Standardized Regression Coefficients on Agency Quality of Life

A regression analysis (not shown) on the number of total percent of questions to which people gave positive answers on person and service characteristics emphasized the importance of transportation. The perceived availability of transportation was the single most important predictor of positive responses (beta=.46), with significant independent contributions of agency transportation three or more times per week (beta=.11) and para-transit in the past month (beta=.07). Also significantly predictive was proxy response (beta= -.18), cognitive ability (beta= .13), and DDA employment services (beta= .10).

Providers receive different average rates per day from DDA for providing day services and providing residential services. The different rates are intended to offset different costs of services for different groups of people. The rate of residential reimbursement for 25 of the 33 providers added additional prediction to the regression shown in Figure **34** on the average rights score. Regressed separately[4], the rate of day services reimbursement for 25 of the 33 providers added additional prediction. For both services, the higher the average rate of reimbursement, the

[4]Three agencies provided neither residential nor day services, 5 agencies provided residential services and not day services, 5 provided day services and not residential, and 20 provided both. Due to the small number that provided both, the daily reimbursement rates for residential and day services were not included in the same regression.

lower the average level of rights reported by the people served (betas of -.40 for residential and -.47 for day services). In contrast, the higher the rate of day services reimbursement, the higher the average score on self-determination (beta = .37).

Aggregate characteristic of agencies were not investigated when analysis at the person-level showed no relationship to quality of life. Other aggregate agency characteristics were investigated, but found to have no significant relationship to the average quality of life scores of providers. (See **Figure 35**.) Whether or not an agency provided residential services offered no prediction of the average quality of life scores of the people it served. Nor did the size of the agency not the percent of people who received all their services from the agency offer any predication on their consumers' quality of life.

Person Characteristics
% Cerebral palsy
% Orthopedic impairment
% Speech and language impairment
Service Characteristics
% Residential services
% Individual & family support
% No other service providers
Number of people served
Other
Response rate
Eastern Shore region

Figure 35. Agency Characteristics Not Predictors of Average Quality of Life

A relationship between agency characteristics and the average quality of life reported by people does not necessarily mean that the agency characteristic caused higher or lower quality of life among the people served. However, it does suggest that it might be useful to explore the relationship in more detail to identify if a causal relationship exists that could be modified through program enhancements. For example, at the individual level, people with DDA-supported employment services reported no higher or lower levels of personal development than people not receiving DDA-supported employment services. At the agency level, however, agencies that provide a large percent of their people with DDA-supported employment services had higher average scores on personal development than did agencies that provided a smaller percent of their people with DDA-supported employment services. Are agencies that focus on employment services more likely to also focus on personal development? Could personal development be identified only as a step toward employment rather than a goal for everyone, whether or not employed? An agency might be able to change average scores through redefining or training on personal development. On the other hand, people with lower cognitive abilities reported lower scores on rights and interpersonal relations. The lower average score on rights and interpersonal relations for agencies serving larger percentages of people with profound and severe retardation would be expected just based upon who was served. An agency would have to focus on how it can improve the perceptions of rights and interpersonal relations for individuals with the lowest cognitive abilities in order to affect their overall scores. These providers should continue serving this group of people, even if it keeps its average scores low.

The lack of a relationship does not mean that an agency cannot affect people's quality of life. It merely means that the measure of a characteristic currently available to the project does not show a relationship. Many of the service measures analyzed in this report were indications on the DDA file that the services were authorized, not necessarily that providers of record currently provided the services, nor the quality of service provision. Findings over the development of the

Ask Me![sm] Project suggest that the quality of services (the way they are provided) is more important than just the presence or absence of a service.

PAGE INTENTIONALLY BLANK

Discussion

Public and private health and human service organizations face two challenges: demonstrating fiscal and programmatic accountability, and using person and organization outcomes for continuous program improvement. Both managers and program evaluators have attempted to respond to these challenges through techniques and strategies such as total quality management and use-focused evaluation. They encounter four difficulties in using measured outcomes to produce meaningful programmatic change: the lack of clear and logically consistent methods, lack of effective guidance on aligning services to desired outcomes, ineffective use of information technology, and ineffective diffusion techniques.

The Ask Me![sm] Project, sponsored by the Maryland Developmental Disabilities Administration, provides system planners, program managers, and individual advocates help in overcoming these four difficulties. Program evaluation models in general have three essential characteristics: a standard of performance or value, a focus on the organization or the individual, and a specificity of goals or measurements. The intersections of these evaluation characteristics identify eight evaluation approaches (Schalock and Bonham, 2002):

1. *Organization performance goals* include program processes of service delivery, health and safety, financial stability, staff development, and organizational efficiency
2. *Organization value goals* are the desired outcomes that include access to services, consumer satisfaction, staff competencies, family/consumer supports, wraparound services, and community support.
3. *Individual performance goals* are the desired program outputs that include physical and mental health, functional abilities, financial well-being, residential status, and educational development.
4. *Individual value goals* include the long-term individual outcomes of self-determination, social inclusion, social relationships and friendships, rights and dignity, and personal development.
5. *Performance assessment* is the preferred measurement method for evaluating organizational program process. Specific methods include performance planning and reporting, licensure requirements, staff certifications, performance indicators (such as critical performance indicators and report cards), and financial accountability measures (such as financial audits).
6. *Consumer appraisal* is the preferred measurement method for evaluating organizational valued outcomes. Specific methods include consumer and staff satisfaction surveys, and measures reflecting fidelity to service delivery models, benchmarks and standards of excellence.
7. *Functional assessment* is the preferred measurement method for evaluating individual program outputs related to adaptive behavior and role status. Specific measures include rating scales, observation, objective behavioral measures, and status indicators (such as education, living, and employment status).
8. *Personal appraisal* is the preferred measurement method for evaluating individual value outcomes. Specific measures include quality of life evaluations obtained from personal interviews, surveys, or focus groups.

The Ask Me![sm] Project is a personal appraisal, clearly focused on individual value outcomes. It is responsive in a constructive way to the desires of people with developmental disabilities to be heard and understood. It developed a logically consistent tool to assess their quality of life across eight domains that are internationally discussed as important in the fields of developmental disabilities, health, mental health, aging and education. People with developmental disabilities participate in all aspects of the project, from the initial survey content, through interviewing, to panels on the value of the results for programmatic change and improvement.

The project's findings provide guidance on aligning services to desired outcomes. Managing for results requires understanding what program processes affect outcomes, and how. Since most health and human service programs are designed to meet the needs of people, they need to know the characteristics, needs and desires of the population they serve to effectively plan and adapt programs. Ask Me![sm] has demonstrated that quality of life is not determined by people's abilities or disabilities, while showing how some characteristics present program challenges. The project presents a causal model consistent with survey findings that identifies likely points of intervention or change to produce desired outcomes. A clear model, however, challenges agencies and providers to clearly define their goals for individual value outcomes and how they expect program enhancements to affect immediate program outputs, which affect short-term objectives, which in turn effect long-term quality of life. The model also offers guidance about the locus of program enhancement. That locus may be individual interactions with the people served, it may be organization environment and procedures, or it may be system priorities and resource allocation.

The project involves a scientific sample each year of service providers and the people they serve. It provides standard quantitative metrics for identifying goals and measuring progress toward reaching them. The openness of discussion it fosters provides both opportunities and threats as the same data support programmatic accountability as well as program improvement. The state is now accountable to the providers just as the providers are now accountable to the state, and both are accountable to the people served.

The Ask Me![sm] findings can help align services both vertically and horizontally. Vertical alignment involves staff understanding organization-wide goals and their role in achieving them. It energizes staff, provides direction, and offers opportunities for involvement. Horizontal alignment involves processes that cut across the different functions of the organization to create what the consumers most need and value. The Ask Me! Project provides organizations with consumer-referenced outcomes as they target organization resources and staffing patterns on significant predictors of desired outcomes, and implement funding patterns to focus on outputs that predict outcomes. During the four pilot years, the Ask Me! Project provided agency-level data only to the agency to give them opportunity to learn how to use data for program change without concern over the accountability component of evaluation. The FY2002 data are now provided to the DDA and to The Arc of Maryland. For some service providers, the data are available as part of this report. The Ask Me![sm] Project provides additional information, not all the information, to be used in program improvement and program accountability.

The Ask Me![sm] Project in FY2002 represents a stratified sample of the people receiving supports by the Maryland Developmental Disabilities Administration, and simple random samples of people served by 33 service providers in Maryland. The almost 1,000 people surveyed provide very accurate estimates of the quality of life of people receiving services in Maryland, and what predicts and likely affects their quality of life. Estimates for people served by individual providers cannot be as detailed and precise, since they are based on an average of 30 people. Promises of confidentiality prevent the data being used to define the quality of life for an individual person–that responsibility is left to the service provider.

Agency Use

The most important use of consumer-reported quality of life information is for continuous program enhancement at the agency level (Schalock, 2001). The data suggest that some agencies included in the FY2001 pilot used the data in this way, and the quality of life of the people they served increased in some of the domains. The project encourages the use of dat in this way by sending participating agencies their data once processing was completed. Data included frequencies of response by their 24-38 consumers to every question in the survey, summary scores for each quality of life domain, and an Excel spreadsheet file of each person's responses minus identification.. Data in this report provides comprehensive statewide analysis for comparative purposes. The Maryland Ask Me! Project also include a central quality assurance training session at the beginning of the year for participating providers. The training covered five topics:

- Importance the state places on the quality of life of people it supports
- Background on quality of life concepts and measurement
- Findings on the quality of life of Marylanders with developmental disabilities
- How to read and understand the data agencies receive
- Strategies to use information in program planning and service enhancement

The training suggested that providers first compare the average quality of life reported by their consumers to that of all consumers in the state, and hypothesize reasons why the people they support have higher, lower or the same scores as the state. For example, average quality of life scores for a provider with a significant share of the state's consumers might be expected. This may not satisfy a provider that believes it is a leader in quality services, so the second step is to compare the Ask Me! findings with the provider's goals. If the quality of life data do not reflect the goals of the provider, the provider should then ask how it might change its services to best enhance its consumers' quality of life?

As an example, a provider may determine that it wants to enhance the quality of life of the people served in the domain of personal development. This is a long-term goal and the agency should not expect to see immediate and dramatic changes, since outcomes regarding this goal are influenced by many other factors such as past experiences, the individual's personal value system, and services currently provided by other agencies. A more immediate outcome for the agency is the satisfaction that individuals have with their own personal development. However,

consumer satisfaction is an imperfect measure as it is primarily a value of the organization rather than the people served, but would be expected to increase if output objectives have been reached. A key output objective for enhancing personal development would be that consumers accomplish the goals that they have set for themselves. The agency processes that lead to consumers accomplishing their goals include helping consumers set meaningful goals during their individual planning meetings, assigning staff and other resources in ways that will help the people progress towards those goals, and monitoring progress. Planning works from the desired long-term outcomes back to detail program process. Accomplishment works the other way. Effective goal setting during individual planning, accompanied by the allocation of resources (responsibility, training, authority and support) and careful monitoring of achievement, should lead to goal-accomplishing outputs, which in turn should lead to consumer satisfaction with their accomplishment of specific goals, which should also lead to increased overall satisfaction with their quality of life in the domain of personal development.

State System Use

DDA uses the data to develop its goals and monitor their achievements as it manages for results, a requirement of the governor and legislature for all state agencies as part of the budgetary process. The Ask Me! results allows DDA to move beyond the traditional licensing approach to quality as meeting a minimum standard. It can focus on enhancing quality for all people while maintaining a minimum threshold. DDA's Managing for Results plan includes 16 specific targets, with a threshold standard and an average score standard for each of the eight quality of life domains. The threshold standard is a positive quality of life score (more positive than negative responses to the component questions) and the targets to be maintained or exceeded are the percent of people with positive scores for each domain at the baseline survey. This threshold ensures that the people whose quality of life is most problematic are not forgotten in the pursuit of enhancing quality of life for all people served. The focal target, however, is enhancing the quality of life for all people, measured by an increase in the average quality of life score. For its first year, DDA set its goal as increasing the average score in the personal development domain by 4%. Since personal development has strong statistical relationship to all the other quality of life domains, improvements in this focal domain will require, or result in, improvements in all the other domains. The goals for the other seven domains are to maintain or increase the average score. DDA encourages, but does not require, individual service providers to use Ask Me! data as they develop quality assurance plan and measure their achievement.

The Ask Me! Project provides DDA more than data to set goals and measure their achievement. The Ask Me! findings provide a causal model on how quality of life can be enhanced. The quality of life dimensions of physical well-being, material well-being and emotional well-being appear foundational for the other dimensions of quality of life. However, these are the dimensions that have received the most focus in the developmental disabilities literature and are the dimensions with the highest quality of life scores among people in Maryland receiving services. The literature has paid much less attention to personal development, self-determination and rights, and the Ask Me! data reflect this in lower average scores given by the people

interviewed. Among these, personal development appears central since it is affected by or affects the others. The empirical central role of personal development, combined with its explicitly mentioned in DDA's mission statement, led DDA to select this quality of life domain for its initial focus.

Advocacy Use

The Ask Me![sm] Project resulted from a consent decree following a suit by Maryland Disabilities Law Center that their views be consistently sought about the services supported by DDA. Rather than accept a typical consumer satisfaction approach, the State embraced a consumer-led approach and worked with The Arc of Maryland, People On the Go, the Developmental Disabilities Council, and interested provider agencies to develop Ask Me![sm]. The project fits well in the broader movement towards participatory action research and evaluation in which consumers participate actively in the design, implementation, analysis, and use of research. The *Signs of Quality* developed by the Maryland self-advocacy group several years before the project began gave rise to most of the survey questions. Consumers changed the survey as they pre-tested and then administered the survey. They conduct the interviews, implement quality control procedures, and key the data. They participate in panel presentations on the project and its findings. Some consumers have been with the project since its beginning, finding career opportunities in it. Some have learned to read so they can interview better. Some have moved onto other meaningful forms of paid employment. Beyond their personal development, Ask Me![sm] interviewers have served on many statewide policy committees and provided strong statewide leadership on issues important to individuals with developmental disabilities.

The willingness to participate by 91% of the sampled people demonstrates that people want to be heard, and the survey procedures allows more than three-fourths of them to speak for themselves. However, speaking and hearing is not enough. Programs need enhancements designed to increase the quality of life of the people they serve. These need to be identified and developed from the consumers' perspectives, requiring consumers' active involvement. Even knowledgeable and well-intentioned staff cannot know how consumers feel as well as the people themselves. People with disabilities and their advocates can insist that Ask Me![sm] findings be used to improve programs.

The average quality of life scores from people served by different providers can be useful in asking them questions and informing decisions. Although DDA will not publish the information from the surveys in its *Guide to Services* until after the FY2005 survey, the information from half of the providers included in the FY2002 survey is available in this report and can be requested from the remaining organizations. Decisions to use or change providers should not be made on this information alone, but the expressed quality of life of people currently served may be as important as any other single piece of information. More valuable, however, will be the use of the information by advocates to encourage change within current programs that are focused on enhancing peoples' quality of life.

PAGE INTENTIONALLY BLANK

References

Bonham, G. S., Basehart, S., and Marchand, C. B.(2001.) *Ask Me!sm Year FY2001: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Supports.* Annapolis, MD: The Arc of Maryland (November 30).

Bonham, G. S. and Basehart, S. (2000.) *Quality of Life of Marylanders with Developmental Disabilities Participating in the Robert Wood Johnson Self-Determination Initiative: Final Report*. Annapolis, MD: The Arc of Maryland (August 23).

Bonham, G. S., Basehart, S., and Marchand, C. B.(2000.) *Ask Me!sm Year FY2000: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Supports.* Annapolis, MD: The Arc of Maryland (December 22).

Bonham, G. S., Basehart, S., and Marchand, C. B.(2001.) *Ask Me!sm Year FY2001: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Supports.* Annapolis, MD: The Arc of Maryland (November 30).

Bonham, G. S., Pisa, L. M., Basehart, S., Marchand, C. B., Harris, C., Heim, S and Ingram, A.. (1999.) *Ask Me!sm Year 2: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Supports.* Annapolis, MD: The Arc of Maryland (November 4).

Bonham, G. S., Pisa, L. M., Marchand, C. B., Harris, C., White, D. and Schalock, R. L. (1998.) *Ask Me!sm The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Supports*. Annapolis, MD: The Arc of Maryland (February 10).

Felce, D. and Perry, J. (1996.) Assessment of quality of life. In R. L. Schalock, Ed. *Quality of Life*, Washington, D.C.: American Association on Mental Retardation.

Gardner, J. F. (2002.) Quality is about social ties and trust–for everyone. *Capstone*, 19(2):1ff, News from the Council on Quality and Leadership, Towson, MD (Summer/Fall).

Hughes, C..and Hwang, B. (1996.) Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of Life. Volume 1: Conceptualization and Measurement* (pp. 51-63). Washington, DC: American Association on Mental Retardation.

Maryland State Data Center. (2002.) Population by age and sex (P12/P13), *Census 2000, Summary File* 1, http://www.op.state.md.us/MSDC/census/cen2000/sf1/state/md_sf1.pdf (9/19/02).

Matikka, L. M. and Vesala, H. (1997.) Acquiescence in quality of life interviews with adults who have mental retardation, *Mental Retardation*, 35(2):75-82.

People on the Go. (1996.) *Signs of Quality*. Annapolis, MD: The Arc of Maryland.

Rapley, M., and Beyer, S. (1997). Daily activity, community participation and quality of life in an ordinary housing network: A two-year follow up. *Journal of Applied Research in Intellectual Disabilities*, 10 (4), 259-269.

Rapley, M., and Hopgood, L. (1997). Quality of life in a community-based service in Australia. *Journal of Intellectual & Developmental Disabilities*, 22 (2), 125-141.

Reinders, H.S. (2000). *The future of the disabled in liberal society: An ethical analysis*. Notre Dame, IN: The University of Notre Dame Press.

Schalock, R.. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Ed.), *Quality of Life: Volume 1: Conceptualization and Measurement* (pp. 123-139). Washington, DC: American Association on Mental Retardation.

Schalock, R. L. (in press). *Outcomes-Based Evaluation*, 2nd Edition. New York: Plenum Press.

Schalock, R. L. and Bonham, G. S. (In review). Does measuring quality outcomes lead to meaningful programmatic changes? Submitted to *Evaluation and Program Planning*.

Schalock, R. L. and Keith, K. D. (1993.) *Quality of Life Questionnaire Manual*. Hastings, NE: IDS Publishing Corporation.

Schalock, R. L. and Verdugo, M. A.. (2002.) *Handbook on Quality of Life for Human Service Practitioners*. Washington, DC: American Association on Mental Retardation.

Stancliffe, R. J. (2000). Proxy respondents and quality of life. *Evaluation and Program Planning*, 23, 89-93.

Appendix 1. Methods

PAGE INTENTIONALLY BLANK

Sample Procedures

The *Ask Me!sm Survey* is designed to produce statistically accurate estimates each year of the quality of life of Maryland adults supported by DDA in the community. FY2002 was the first of a four-year cycle that will also produce estimates for the average quality of life of people supported by all community agencies serving 55 or more individuals, and for a sample of smaller agencies. This design uses a two-stages process for selecting the sample each year to randomly select agencies and then randomly select people served by the selected agencies. During the four pilot years, agencies volunteered to be part of the Ask Me!sm Project. These agencies did not represent a scientific sample of all agencies providing services in Maryland, even though they represented a wide range or agencies in the four regions of the state. Additionally, while people were randomly selected within agencies, the procedures during the pilot years did not take into consideration how many agencies provided services to a selected person. Beginning in FY2002, agencies are randomly selected and required to participate in the Ask Me!sm Project, and people will be randomly selected in a way that accounts for the number of different agencies that provide them services.

Table 4. Number of People, Providers and People-Provider Records Receiving DDA Support, July 2001

	DDA File	Sample Frame*
Number of Service Provider IDs	171	136
Number of Person-Provider Records	24,960	13,225
Number of Persons Supported	12,469	11,539
Services from 1 provider	4,721	8,739
Services from 2 providers	3,881	2,747
Services from 3 providers	3,122	51
Services from 4 providers	620	2
Services from 5 providers	119	0
Services from 6 providers	6	0

* *Sample frame excludes institution and service coordination records*

Sample selection began with DDA records on the people and services it supported. The DDA supported about 25,000 person-provider-service combinations at the beginning of FY2002. (See **Table 4**.) These combinations involved 167 agency designations with up to four services for a person within a single agency. The person/agency service combinations involved 12,469 individuals. One-third (4,721) of DDA-supported people received services through a single agency designation, including 930 people who received only service coordination or received all their services from the four Maryland residential institutions. Another one-third received

services from two organizational designations. One-fourth received services from three organizational designations. A few people received services from four, five or six different organizational designations. The person/agency/service combinations in the State's database did not directly identify agencies and people for Ask Me![sm] sampling purposes. Ask Me![sm] excluded institutions and their services, combined multiple designations for the same agencies and excluded service coordination services. The final sample frame contained 13,225 person/agency records involving 11,539 people and 136 agencies. Unfortunately, this sample frame included children who had to be identified and removed at a later stage in the project. Ask Me![sm] interviewers were also later removed from the sample.

Agency Selection

The 136 community agencies providing support other than service coordination constituted the primary sampling units. The agencies were divided into five strata based on the total number of people they supported. (See Figure **2**.) Stratum 1 included the 10 largest agencies serving 300 or more people that combined to provide 37% of the DDA-funded support services. Stratum 1 agencies were sampled with certainty and will be included in the survey every year. Half had been included in prior years of Ask Me! and half were new to the project in FY2002. Stratum 2 included the 21 next largest agencies serving 130-299 people each, which combined to provide 27% of the services (other than service coordination) supported by DDA. Stratum 2 agencies are included in the survey every other year, with 11 included in FY2002. Stratum 3 included the next 40 agencies supporting 55 to 129 people each, which provided 25% of the services supported by DDA. They are included in the sample every fourth year with 10 agencies in FY2002. Stratum 4 included 46 agencies serving 10-54 people each that combined to provide 10% of the services supported by DDA. A random sample of 3 of these agencies was included in the FY2002 survey. Stratum 5 included 19 agencies that served fewer than 10 people supported by DDA, which combined to provide 0.5% of all DDA supported services. Three of these agencies provided DDA-supported services to no one who was not also supported by some other agency, and excluding the other 16 agencies from the sample frame excluded only 43 people from the possibility of being included in the survey. Stratum 5 agencies were not sampled.

Person Selection

One sampled agency served 32 people, and the project selected all of the people for interviews. A random sample of 40 person/agency records was selected for the remaining 34 agencies. In nine agencies, more than 10% of the selected people were children, no longer supported by DDA, no longer served by the agency, or they or their guardians refused to participate. From 5 to 26 additional names were randomly selected as replacements, with an expectation of interviewing 30 people from each agency. Seven individuals were selected for interviews through two agencies. While interviewed only once and included in state estimates only once, they were included with the data for each agency through which they were selected. A total of 1, 487 were selected for interviews.

Response

The project collected information for 957 people, including interviews with the selected people and interviews with proxies when the selected people could not answer for themselves. The 88 people at two agencies that served the deaf community were not interviewed during FY2002 due to interviewer difficulties. A comparison of the DDA file from July 2001 with the DDA file from July 2002 identified people who had left services during the year, and these were assumed to have not been truly part of the sample frame. Technically, they should have been replaced by people began DDA services between July 2001 and the time of the interviews at their agency to prevent bias in the sample frame, but it is assumed that this bias was small. The DDA file in July 2002 also included birth dates, so children less than 18 at the start of FY2002 could be identified. These two groups were considered not in the sample and excluded from the denominator in the calculation of response rates. The comparison of these two files also showed officially recorded change of providers during the year that might have affected the ability of the project to track and interview people. These people could have been potentially interviewed at another provider if procedures had been in place to track them. Insight into other reasons for non-response came from re-contacting the first seven agencies for which interviewing had been completed. Frequently they identified people as not longer receiving services from the agency, while the DDA file at the beginning of the next fiscal year still showed them as the provider of record with no other providers. This suggests that the DDA files were updated only after about a six-month lag, or people identified and approved by DDA as eligible for services were not getting the services they needed, or some combination of the two. The follow-up with the agencies also showed other gaps in the project's fieldwork that will be corrected in the next project year.

Data Processing

The project double keyed survey and background forms using a data entry program designed for it in Visual Basic. The project employed a person receiving DDA supports as the primary data entry clerk. The second person independently keyed the forms, compared the two keyings, and identified the correct entry when a disagreement occurred. The log of disagreements and corrections document a primary keying error rate of 1.0% and the second keying error rate of 0.3%. All disagreements in keying were flagged and reconciled. The probability that both keyers erroneously keyed the data the same way, or that the reconciliation accepted the erroneous keying, is infinitesimal. Many of the disagreements involved the handling of nonstandard or incomplete responses. For instances, nothing was to be keyed if a survey question had no answer recorded, or had two answers recorded without any indication of which was the correct or final answer. Keyers also had specific instructions on handling multiple answers on the background forms (staff recorded the person was both employed and participated in a day habilitation program), ranges of answers (e.g., 20-30 hours of residential services per week), and open-ended ranges (e.g., IQ less than 20).

Proxy Respondents

The responses of two proxy respondents were averaged, which required making no assumption of which proxy was more likely to be correct when they disagreed. When an advocate and a staff member answer the survey for a person, the advocate gave significantly lower scores than the staff member in the areas of interpersonal relations (4.9 and 6.3 respectively, p=. 03), social inclusion (2.8 and 4.9, p<.01) and rights (-2.6 and 4.2, p<.01). (See **Figure 36**.) The average quality of life scores provided by two staff proxies also differed significantly in the area of interpersonal relations (5.8 and 2.8, p=.01), suggesting two proxies observe different types of

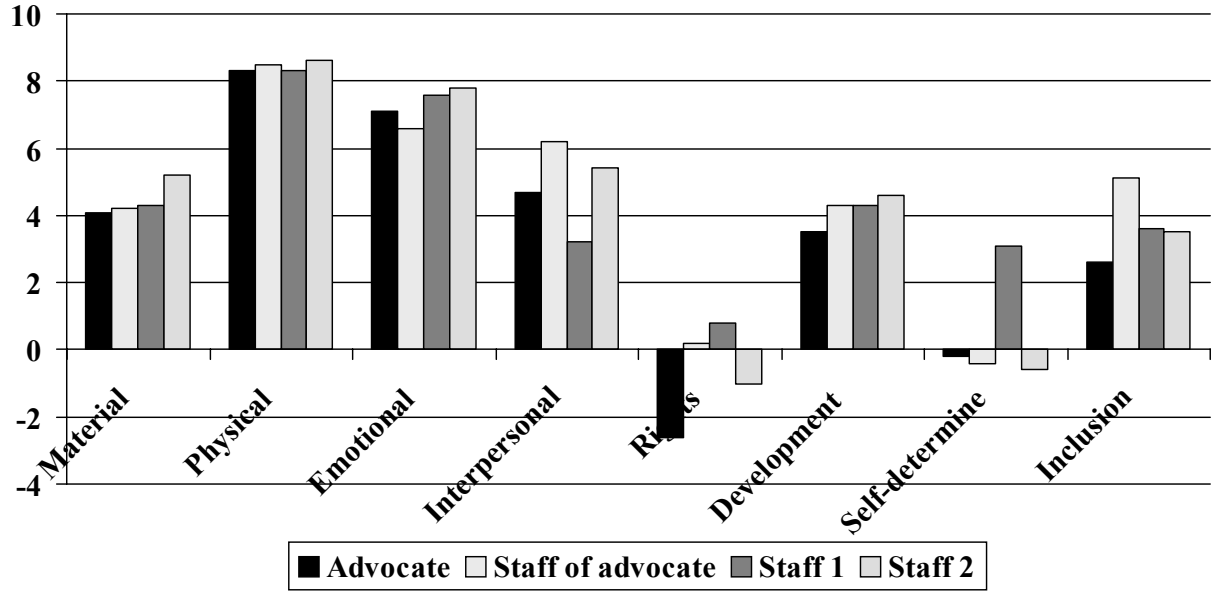


Figure 36. Quality of Life Scores Reported by Pairs of Proxies, by Proxy Type

interpersonal relations, regardless of their relationship with the person unable to respond for her or himself. The two staff proxies also disagreed significantly on the availability of transportation (3.9 and 6.2, p=.03). A further example of the difficulties proxies have in knowing what a person thinks and feels came from the inadvertent interview with a third proxy for one person. Proxy 1 was a vocational/day staff member, while proxies 2 and 3 were residential staff members providing 24 hours per day care. These proxies were not very consistent with themselves, let alone other proxies: Proxy 1 gave different answers in all three pairs of duplicate questions, Proxy 2 gave the same answer in one pair of duplicates and did not answer one pair, and Proxy 3 gave the same answers in two pairs of duplicate questions. All three gave the same answers to 11 out of the 56 questions and gave three different answers to 8 questions. The two residential staff gave the same answers to 60% of the questions. The day staff gave the same answers as one residential staff to 41% of the questions, and the same answers as the other residential staff to 25% of the questions.

Weights

All of the people sampled within an agency had the same probability of selection, and weights were not needed for calculating agency-specific statistics. In calculating agency-specific statistics, it made no difference how many other agencies provided services to their people. For Maryland as a whole or for any analysis that included people served by different agencies, weights were required to adjust for the different probabilities that an agency was selected, the probability of the person being selected within the selected agency, the number of different agencies through which the person could be selected, and the survey response rate within the agency.

A special situation existed for large agencies. A number of people who they served were selected for interviews through another agency. Would it be valuable for the agency to have access to information from them? The project decided to duplicate the records for 109 people served by two sample agencies, but explicitly identify the second record as not part of the random sample of people from the agency. The duplicate record was given a weight of zero (0) so it would not get counted in any weighted analysis. Data from these non-sample agency consumers were provided to the agencies, but not used in calculating any agency-specific statistics for this report.

Weight calculations multiplied the inverse of the probabilities of selection. The largest agency in the sample served 1,176 people. It had a 100% chance to be selected, but only 40 people (3.4%) were selected to represent that agency. The smallest agency served 42 people. It had a 6.5% chance of being selected, but 40 people (95.2%) were selected to represent that agency. In addition, people served by two agencies had twice the chance of selection as people served by one agency, while people served by three agencies had three times the chance. The weights also adjusted for the different response rates from people in the different agencies. (See Table 1.) The final weight was rounded to an integer for analysis purposes. An individual person represents as few as 3 to as many as 39 adults supported by DDA in the community. On the average, each surveyed person represented 12 people. The weights summed to 11,564 people, within rounding error of the 11,539 people identified from the July 2001 DDA data file. Since statistical calculations in SPSS assumes that the weighted number reflects the number of independent data sources, a statistical weight was calculated as 958/11539 times the final person weight.

Measurement

Personal Characteristics

Gender

The analysis primarily used information recorded in the DDA files. Information for 3% of the people with gender missing from the DDA files came from the Background Form. Both sources agreed 98% of the time when both sources contained information.

Age

Age as of July 1, 2002 was calculated from the date of birth recorded on the DDA file. Age for three people with missing information on the DDA file came from their Background Forms. Age from the two sources agreed for 88% of the people, and differed for 4% in a way that could be due to a birthday between the date of interview and July 1, 2002. Age from Background Forms was missing for 4% of the people.

Cognitive Ability

The measurement of cognitive ability was based upon staff reports. The background form requested exact IQ scores when available, and to check the level of retardation when the IQ score was not available: profound, severe, moderate, mild, borderline, low normal or above. Since more checked one of the levels of retardation than provided the IQ score, the level of retardation was used as the measure of cognitive ability. When staff provided an IQ score and did not check a level of retardation, the score was converted to the level of retardation as shown in the first column of **Figure 37**.

Category	*Ask Me*	*ICD-9*	*DSM-IV*
Profound	<15	<20	<20 to <25
Severe	15-31	20-34	20-25 to 35-40
Moderate	32-48	35-49	35-40 to 40-55
Mild	49-65	50-70	50-55 to 70
Borderline	66+	71+	71+

Figure 37. Range of IQ Scores Associated with Categories of Retardation

Disabilities

Different types of disabilities were identified on the DDA file and on the agency-completed Background Forms. The analysis used disabilities identified on the DDA file, supplemented with data from the Background Forms only for the level of retardation. Almost all (98%) of the people identified on the DDA file as having mental retardation were so classified by the agencies, although the agencies also reported mental retardation for 88% of the people not identified with mental retardation on the DDA file. Three-fourths (78%) of the people DDA reported with vision impairments were so reported by agencies. About half (58%) of those identified by DDA with speech and language impairments were so identified by the agencies. About half (58%) of those identified by DDA with epilepsy or seizures were so identified by the agencies. About half (57%) of those identified by DDA with behavior problems were so identified by the agencies. Half (50%) of the people identified by the DDA file with hearing impairments were so identified by the agencies. The DDA file did not identify any person with AIDS or cystic fibrosis, and identified so few people with multiple sclerosis and muscular dystrophy that they were combined with other neurological impairments, and so few people with spina bifida and spinal cord injuries that they were combined with orthopedic impairments.

Years with Agency

The information came primarily from the Background Form completed by the agency. For 5%

of the people with missing Background Form information, the analysis used the earliest date recorded on the July 2002 DDA file for the agency providing service to the person. The DDA date was missing for 16% of the people and indicated shorter lengths of service than the agencies reported for 70% of the people with information from both sources. DDA records indicated that services for 21% of the people started within the last year while agencies reported that only 3% of the people began services with them in the past year. The DDA files have no dates more than 11 years ago, while agencies reported that they began serving 10% of their people 20 or more years ago.

DDA Supported Services

Residential Services

The type of residential setting and services is a combination of information from the DDA file and from the Background Forms completed by agencies. The DDA file provided the major distinction of whether or not DDA supported residential services to the people. Those not receiving residential services were divided into those living with their families and those living in other (or unknown) residential arrangements. Those receiving residential services were divided into those receiving 40 or fewer hours of residential services a week, those receiving more than 40 but less than 24 hours of residential services 7 days a week, and those reported on the Background Forms to receive 24 hours of residential services 7 days a week. The few living in institutions according to the Background Forms were separately identified. The DDA file was used to identify whether the focal agency or some other agency provided the residential services.

Day Services

Day services were classified by whether provided no funding for day services, supported day habilitation services, or supported employment services (including supported employment contracts). People were further classified by whether the agencies reported on Background Forms that the person had employment (13% competitive and 87% supported), in a vocational or pre-vocational program, or in some other type of day program (includes medical day and retirement). The DDA type of day support and agency reported day activities were in agreement 75% of the time.

Support Services

Support services came from the DDA file, and includes one or more of the following services: individual support services, family support services, community supported living services, behavioral services, and foster care services.

Transportation

A scale of perceived transportation availability was constructed from five questions answered by respondents during interviews. The other transportation measures come from information

provided by staff on the background form. Agency transportation was an ordinal scale from no transportation involvement to providing transportation three or more times per week. Since most people had transportation provided by the sample agency three or more times a week, this measure was converted to a dichotomy of three or more times a week or less than three times a week. Family transportation, transit, paratransit, taxi and other agency were dichotomies indicating whether or not the person had used that type of transportation in the past month.

Average Daily Reimbursement Rate

The average daily reimbursement rates for residential services provided by 25 of the 33 were obtained from the Residential Program FY2003 FPS second quarter advance file, *DDA Residential rates.XLS*, based on June 2002 client data (column AV "Fee Payment Rates"). The average daily reimbursement rates for day services provided by 25 of the 33 providers were obtained from the Program-FY03 Rates second quarter advance file, *DDA Day rates.XLS* (column AV "Fee Payment Rates"), based on June 2002 client mix. These rates were based on five categories of client supervision/assistance needs and region of operation.

Acquiescence

Literature mentions a concern about acquiescence among respondents with mental retardation (e.g., Matikka & Vesala, 1997). The pilot years showed little evidence of acquiescence bias, or the opposite nay-saying bias. In FY2002, however, 72% of the people who responded for themselves answered more than half of the questions with the most positive answer. (See **Figure 38**.) Only 46% of the proxies gave the most positive answer to more than half of the questions. Part of this difference may be due to true quality of life differences between people who can and cannot answer for themselves, part of this difference may be due to proxy pessimism, and part of the difference may be due to acquiescence. Project procedures have tried to reduce the

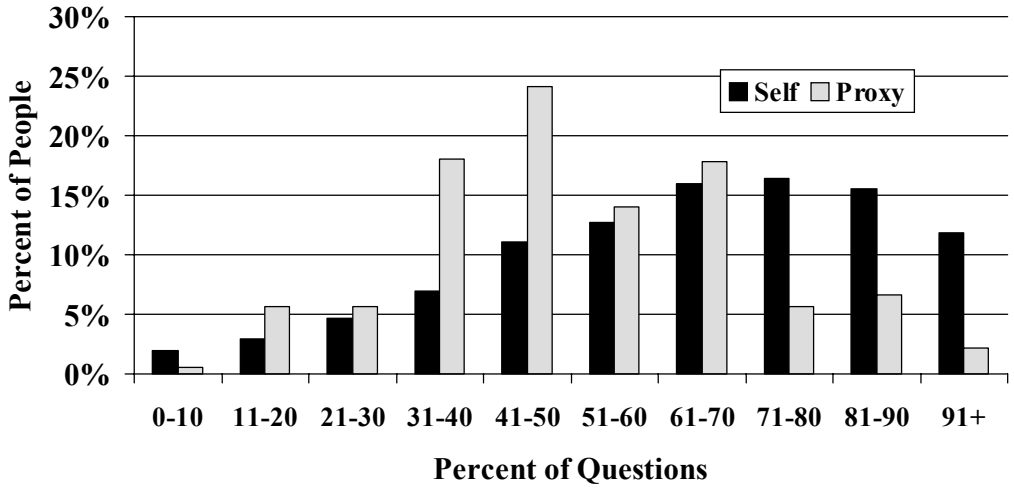


Figure 38. Percent of Respondents by Percent of Questions Answered Most Positively

probability of acquiescence, but it cannot be determined how much remains.

Analysis Methods

All analysis used SPSS (Statistical Package for the Social Sciences), and the 95% level of confidence (p=.05). Statistical calculations assumed a simple random sample of 958 people (less those who did not respond to the item). No adjustment was made for the two-stage sampling process which would decrease the effective size of the sample if people served by a provider were more similar to each other than they were to people served by other providers. However, adjustment was made for the differential probability of selection.

Scale Reliability

The 6 questions for each of the 8 core quality of life domains were combined to produce a single scale score. All eight domains had acceptable scaling properties, with Cronbach's Alphas of 0.66 or higher. (See **Figure 39**.) The reliability among people who responded for themselves was higher than the reliability among proxies for the seven of the eight domains A service-satisfaction scale on transportation availability had less reliability than the eight quality of life scales, but self-respondents still answered more reliably than did proxies.

Scale	*Cronbach's Alphas*		
	Self	*Proxy*	*Total*
Self-determination	0.74	0.70	0.75
Social inclusion	0.73	0.75	0.73
Personal development	0.74	0.59	0.71
Rights	0.66	0.58	0.68
Interpersonal relations	0.75	0.43	0.71
Emotional well-being	0.68	0.58	0.67
Physical well-being	0.74	0.45	0.73
Material well-being	0.71	0.57	0.66
Transportation availability	0.63	0.50	0.61

Figure 39. Scale Reliability by Respondent

ANOVA and T-Test

Statistical tests were used that provided a 95% level of confidence that the findings could not be due to chance. Differences among providers in the average scale scores of the people they served used one-way analysis of variance (ANOVA).

Multiple Regression

Multiple linear regression employed stepwise analysis with p=.05 for entry and p=.10 for removal. The pairwise deletion of missing data option was selected. Variables were tested in the multiple regressions if they had a statistically significant relationship with at least one of the quality of life scales. Variables with n categories (e.g., region) were recoded into a set of n-1 dichotomous variables. Only additive effects were considered and possible interactions were not tested. Standardized multiple regression coefficients (betas) are shown to indicate relative size of the effect. The unadjusted multiple R^2 is shown.

Path Analysis

The path diagrams use the standardized multiple regression coefficients from a series of multiple linear regressions. Path analysis tests the hypothesized relationships among the different measures. Arrows represent statistically significant relationships. The variable on the left at the tail of an arrow is hypothesized to have a direct effect on the variable to its right at the head of the arrow. The numbers on the arrows are standardized multiple regression coefficients (betas) and show the relative strength of relationship. A beta of 1.0 would mean a perfect positive relationship (one unit increase in the independent variable caused a one unit increase in the dependent variable) and -1.0 would mean a perfect negative relationship (one unit increase in the independent variable caused a one unit decrease in the dependent variable). A coefficient of 0.0 would imply no relationship, but also would not appear as an arrow in the path analysis. The path analysis moves from left to right. The leftmost variables are independent to the study, and their causal interrelationships are not hypothesized by the study. As the path moves to the right, variables in the same vertical column are assumed to have no direct causal relationship on each other--any relationship they have is due to their relationships with the variables to their left.

Appendix 2: Agency Quality of Life

PAGE INTENTIONALLY BLANK

General Information

Quality of Life Scales

Social Inclusion: The integration into and participation in one's community, the expression of valued social roles, and the receipt of social supports from community members

Physical Well-Being: The level of health experienced (physical functioning, disease symptoms, pain, fitness, energy, nutrition); the performance of activities of daily living (walking, dressing, self feeding) and leisure activities; and/or the receipt of health care

Interpersonal Relations: The experiencing of social interactions and relationships (with family, friends, peers) and/or receiving support (emotional, physical, financial, feedback) from family, friends, peers or agencies

Material Well-Being: The presence of adequate financial status, employment (a job), and adequate housing

Emotional Well-Being: The condition of being contented (satisfied, happy) having a positive self-concept, and/or being relatively free of stress

Self-Determination: The expression of autonomy and personal control, the pursuit of personal goals and values, and the opportunity to make decisions

Personal Development: The level of education received, personal competence expressed, and/or performance exhibited (includes creativity and personal expression)

Rights: The expression of human rights (respect, dignity, equality) and the guarantee of legal rights (citizenship, access, due process)

Scores and Symbols

Scores can range from -10.0 to 10.0, with a 0.0 score indicating people gave as many positive answers to the component questions as negative answers. Agency scores may differ from each other due only to the random selection of people, but differences between the top 20% and bottom 10% were statistically significant.

● Average score is in the top 20% on this dimension among the agencies surveyed

◒ Average score is in the middle 70% on this dimension among the agencies surveyed

○ Average score is in the bottom 10% on this dimension among the agencies surveyed

Definitions

Survey date:	The average date of interviews
Response rate:	The number of people with completed surveys divided by the number of people selected and eligible for interview
Self response:	The number of people responding for themselves divided by the number of people with completed surveys
Served by other agencies:	The percent of people who receive DDA supported services from other agencies
Number interviewed:	The number of people sampled from this agency with completed surveys
Number residential services:	Of the number interviewed, the number who received DDA funded residential services from this agency
Number employment services:	Of the number interviewed, the number who received DDA-funded employment services from this agency (may also receive residential services)
Number other day services:	The number interviewed who received DDA-funded day services, other than employment services, from this agency (may also receive residential services)
Number support services:	The number interviewed who received DDA-funded support services from this agency (may also receive residential, employment and/or day services)

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Athelas Institute

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.1	3.1	4.7	2.7	0.4	3.2	3.0	1.0
◓	◓	○	○	◓	◓	◓	○

Survey date:	December 2001
Response rate:	70%
Self-response:	82%
Served by other agencies:	54%

Number interviewed:	28
Number residential services:	2
Number employment services:	9
Number other day services:	18
Number support services:	6

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Bayside Community Network

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
3.0	1.9	4.0	1.7	2.4	1.2	1.6	1.1
○	○	○	○	◓	○	○	◓

Survey date:	May 2002
Response rate:	77%
Self-response:	81%
Served by other agencies:	1%

Number interviewed:	31
Number residential:	16
Number employment services:	5
Number other day services:	26
Number support services:	2

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Benedictine Open Community

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
8.3	6.9	7.7	6.9	5.7	7.9	7.0	6.8

Survey date:	October 2001
Response rate:	88%
Self-response:	93%
Served by other agencies:	10%

Number interviewed:	30
Number residential services:	28
Number employment services:	29
Number other day services:	0
Number support services:	5

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

CHI Centers

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
7.5	5.6	6.6	5.4	3.1	4.4	3.2	2.7

Survey date:	February, 2002	Number interviewed:	31
Response rate:	84%	Number residential:	9
Self-response:	87%	Number employment services:	4
Served by other agencies:	38%	Number other day services:	21
		Number support services:	2

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Chimes, Inc.

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.4	3.8	5.7	3.9	1.6	3.3	3.0	2.8

Survey date:	May 2002
Response rate:	73%
Self-response:	64%
Served by other agencies:	28%

Number interviewed:	33
Number residential:	13
Number employment services:	6
Number other day services:	20
Number support services:	2

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Dove Pointe–Wicomico Center

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
7.0	4.8	6.8	4.9	1.7	4.5	4.0	2.9

Survey date:	January 2002
Response rate:	88%
Self-response:	77%
Served by other agencies:	12%

Number interviewed:	30
Number residential:	11
Number employment services:	3
Number other day services:	24
Number support services:	8

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Jubilee Association of Maryland

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
7.4	6.5	6.3	5.8	3.9	4.5	4.9	3.7

Survey date:	February 2002
Response rate:	72%
Self-response:	86%
Served by other agencies:	60%

Number interviewed:	28
Number residential services:	15
Number employment services:	0
Number other day services:	0
Number support services:	13

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Kent Center

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.3	3.6	6.1	4.4	0.9	3.9	4.7	2.9

Survey date:	April, 2002
Response rate:	64%
Self-response:	84%
Served by other agencies:	18%

Number interviewed:	25
Number residential:	11
Number employment services:	12
Number other day services:	11
Number support services:	13

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Mellwood

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.7	5.6	6.7	5.5	2.2	4.3	4.9	3.9
◓	●	◓	◓	◓	◓	◓	◓

Survey date:	May 2002
Response rate:	76%
Self-response:	82%
Served by other agencies:	25%

Number interviewed:	28
Number residential services:	4
Number employment services:	17
Number other day services:	7
Number support services:	5

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

Penn-Mar

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.8	6.3	7.2	6.1	4.0	6.3	5.0	4.4
◓	●	●	●	◓	●	◓	◓

Survey date:	August 2001
Response rate:	72%
Self-response:	69%
Served by other agencies:	14%

Number interviewed:	29
Number residential:	18
Number employment services:	11
Number other day services:	16
Number support services:	10

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Baltimore

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
5.1	3.1	5.3	3.6	2.7	3.3	3.5	1.8

Survey date:	March 2002	Number interviewed:	32
Response rate:	71%	Number residential:	6
Self-response:	63%	Number employment services:	16
Served by other agencies:	28%	Number other day services:	14
Total people served	1,176	Number support services:	5

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Carroll County

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.1	4.1	6.2	4.1	2.1	3.4	4.0	3.6

Survey date:	April 2002
Response rate:	88%
Self-response:	82%
Served by other agencies:	41%

Number interviewed:	38
Number residential:	16
Number employment services:	1
Number other day services:	28
Number support services:	5

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Frederick County

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
7.5	5.3	6.2	6.3	5.1	4.7	5.9	5.7
◓	◓	◓	●	●	◓	●	●

Survey date:	December 2001
Response rate:	63%
Self-response:	97%
Served by other agencies:	46%

Number interviewed:	29
Number residential:	0
Number employment services:	0
Number other day services:	0
Number support services:	24

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Montgomery County

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
8.5	5.5	7.5	4.5	4.1	4.1	4.2	3.9
●	◓	●	◓	●	◓	◓	◓

Survey date:	January 2002
Response rate:	69%
Self-response:	89%
Served by other agencies:	39%

Number interviewed:	27
Number residential services:	13
Number employment services:	5
Number other day services:	12
Number support services:	7

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Northern Chesapeake

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
6.1	5.5	5.8	3.6	4.6	4.3	4.1	4.1
◓	◓	◓	◓	●	◓	◓	◓

Survey date:	March 2002
Response rate:	73%
Self-response:	92%
Served by other agencies:	13%

Number interviewed:	36
Number residential:	16
Number employment services:	14
Number other day services:	15
Number support services:	6

Average Quality of Life Measured by the Ask Me!sm Survey for People Supported by:

The Arc of Prince George's County

Physical Well-being	Material Well-being	Emotional Well-being	Inter-Personal Relations	Rights	Personal Development	Social Inclusion	Self-Determination
9.0	5.8	7.1	5 .7	1.0	5.4	4.5	4.2
●	●	●	●	◓	●	◓	◓

Survey date:	May 2002
Response rate:	76%
Self-response:	56%
Served by other agencies:	41%

Number interviewed:	25
Number residential:	9
Number employment services:	6
Number other day services:	12
Number support services:	5

END OF REPORT