Ask Me!sm FY 2003

The Quality of Life of Marylanders With Developmental Disabilities
Receiving DDA Funded Supports

Prepared for the
Maryland Developmental Disabilities Administration
by
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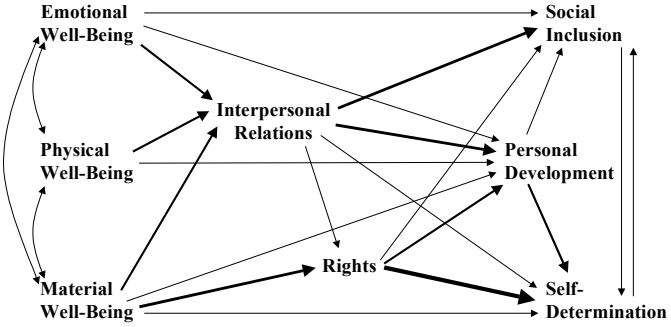
[This online version is a condensed form of the full report that may be obtained from The Arc of Maryland, 49 Old Solomons Island Rd., Suite 105, Annapolis, MD 21401, 888-272-3449, sbasehart@thearcmd.org.]

Executive Summary

The Ask Me! Project puts people first. Interviewers who have disabilities ask other people with disabilities about their long-term quality of life using questions developed by self-advocates. Three-fourths of those surveyed responded for themselves. The FY2003 survey was the second year of a four-year cycle to survey adults in Maryland supported by the Developmental Disabilities Administration (DDA) through community providers serving ten or more people. This report describes the FY2003 survey and presents findings from the combined FY2002 and FY2003 *Ask Me! Surveys* that together included 2,122 people served by 61 providers. This report includes additional information from staff about transportation, information abstracted from providers' quality assurance plans, and information from providers surveyed about their use of Ask Me! data. Seven conclusions and recommendations are supported by the project's findings:

1. A life of quality has eight dimensions that are interrelated, and the goal of all parts of the developmental disabilities system should be to enhance people's quality of life.
   a. Interpersonal relations and personal development are central to a life of quality as they relate to all of the other quality of life domains
   b. Social inclusion and self-determination, along with personal development, are the



Relations of the Eight Quality of Life Domains

three stated missions of DDA, with social inclusion most affected by interpersonal relations, self-determination most affected by rights, and personal development equally affected by interpersonal relations and rights

c. Physical well-being, emotional well-being and material well-being are foundational, relating to each other and directly affecting interpersonal relations, with material well-being also strongly affecting rights.

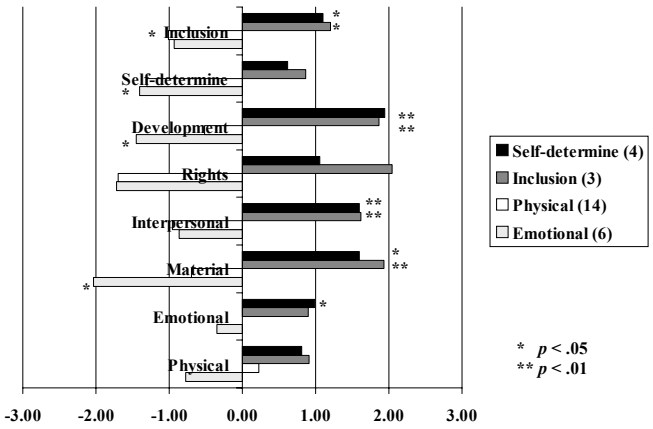
2. People who receive services from the Maryland Developmental Disabilities Administration have very positive views of their physical and emotional well-being that vary little by provider. While these foundational domains should be maintained, greater attention needs to be given to other domains of a life of quality.

a. 94% of the people in FY2003 reported positive scores on physical well-being and 93% reported positive scores on emotional well-being, both higher than in FY2002

b. Both individuals and providers had the least variability in physical and emotional well-being, and the most variability in rights and self-determination

c. Physical well-being did not directly affect DDA's goals of social inclusion and self-determination, and emotional well-being did not directly affect self-determination

d. Personal development was the DDA goal that related to all the other quality of life domains, even when personal and service characteristics were controlled



Quality of Life Change by Quality Assurance Goal

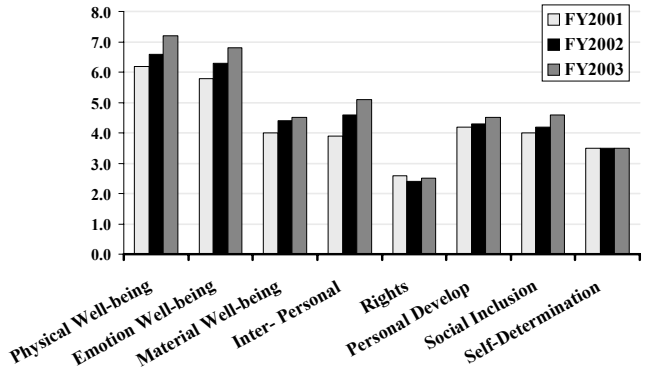
e. 75% of providers had physical well-being goals in their quality assurance plans, and they saw significant declines in social inclusion

f. 31% of providers had emotional well-being goals in their quality assurance plans and they saw significant declines in personal development, self-determination and material well-being.

3. The Maryland developmental disabilities system needs to increase its attention on rights and self-determination.

a. Rights and self-determination received the lowest average rating by people (2.5) and were the only domains that did not increase between FY2002 and FY2003

b. 35% of the people reported zero or negative scores on rights and 28% reported zero or negative scores

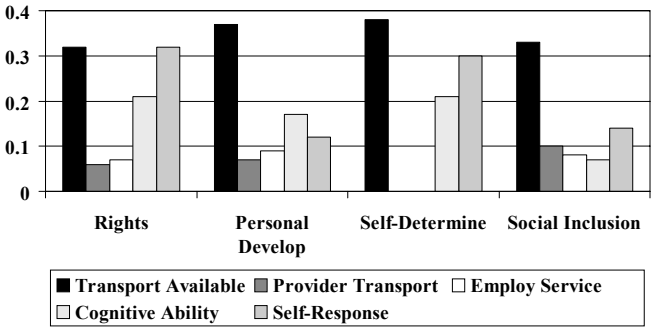


Average Quality of Life by Domain and Year

on self-determination

c. 8% of the providers had negative average scores on rights
d. Providers had the greatest variation in rights and self-determination, and much of the variation in these domains can be explained by provider characteristics
e. Less international research has been done on rights than any other domain, with self-determination being the third least researched domain
f. 25% of the providers had self-determination goals in the quality assurance plans, and their quality of life significantly increased in five of the eight domains.

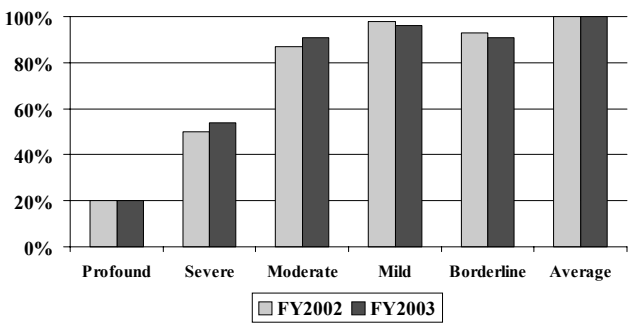
4. Transportation and employment services offer the greatest predictions of people's quality of life, and are therefore prime areas to consider for service enhancements.
   a. People's perceived availability of transportation had significant relations to all quality of life domains at both the individual and provider levels
   b. In addition to people's perceptions, the more frequently providers transported people, the higher their quality of life in half the domains



Size (β) of Relations of Characteristics to Quality of Life

   c. The more providers rely on other providers to transport people they support, the lower their average quality of life in two domains
   d. People with employment services reported higher quality of life in five domains, while people with day habilitation reported lower quality of life in the other three
   e. Providers with larger proportions of people in employment services had higher quality of life in two of the domains.

5. The disabilities people 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 greater degrees of retardation reported lower quality of life in seven of the domains, but the percent with retardation affected only one provider score
   b. People who responded for themselves, independent of cognitive ability, reported higher quality of life in five domains than did proxies; the greater the percent of people at a provider who responded for themselves, the higher the provider's average score in three domains
   c. Cognitive ability always offered less prediction of people's quality of life than did the availability of transportation
   d. Hearing impairments, mental disorders and cerebral palsy had minor effects on people's quality

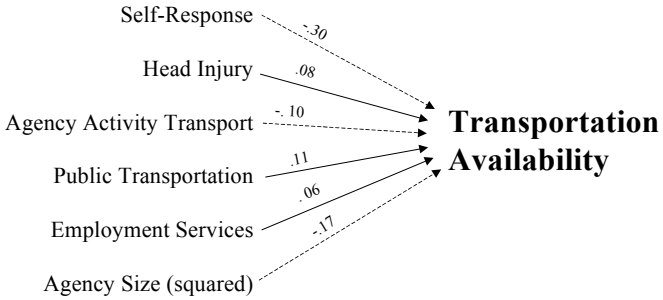


Percent Responding for Self by Cognitive Ability

of life in one or two domains

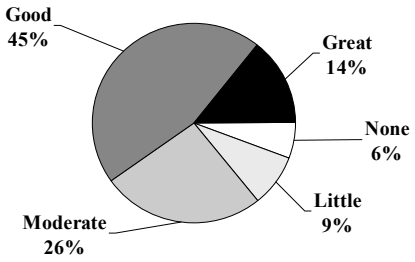
e. Providers with greater proportions of people with vision, language or hearing impairments had lower average quality of life in 3-4 domains, but these were less important than the average availability of transportation
f. Almost all people with moderate or less retardation answered quality of life questions themselves, as did 50% with severe and 20% with profound retardation.

6. The quality of services as judged by the recipients should be the focus, not just the provision of service, since the types of DDA authorized services other than employment had minimal predictions on people's quality of life.
   a. Transportation services affected people's quality of life, but people's perceptions of the availability of transportation had a greater effect on their quality of life
   b. Agency-provided transportation had little direct effect on perceived availability of transportation
   c. DDA authorization of residential services, community supported living assistance, individual support services, and resource coordination offered no prediction of people's quality of life in any domain.



Contributions to Perceived Transportation Availability

7. Service providers can increase the quality of life of the people they support by setting appropriate person-centered goals.
   a. The relationships of average quality of life among providers reflected the relationships of quality of life found among individuals
   b. People supported by some providers reported significantly higher quality of life than people supported by other providers, particularly in rights and self-determination
   c. 59% of the providers said that Ask Me! findings had good or great value to the organization
   d. 90% of providers used Ask Me! results for their quality assurance plans, yet half of their goals had little potential for increasing people's quality of life
   e. Providers with goals of self-determination and social inclusion saw significant increases during the following year in the quality of life of the people they supported
   f. Quality of life declined at providers that set organization-centered goals of service satisfaction
   g. Providers with physical well-being goals saw no change at all
   h. The more provider staff attended training on Ask Me! and analyzed their provider's data, the more valuable they found the Ask Me! information.



Value of Ask Me! to Providers

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 has become 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. Hughes and Hwang (1996) identified fourteen dimensions of the quality of life that had been studied by researchers, and Schalock and Verdugo (2002) documented eight basic domains to quality of life discussed internationally in the developmental disabilities literature and in the literature of education, mental health, physical health and aging. They found that the eight domains had been studied in different amounts, with social inclusion the most discussed and rights the least discussed. (See order in **Figure 1**.) The Ask Me! Project developed a 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). The *Ask Me! Survey* used since FY2001 is part of the copyrighted Ask Me! Project and may be used only with permission of The Arc of Maryland.

- **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 providers
- **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)

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

Sample

The FY2003 Ask Me! Project collected information for 2,152 people with developmental disabilities served by 61 sample providers between August 2001 and June 2003, the first and second year of a four-year cycle. Each year represented an independent sample of the 10,848 people 18 years and over that had services supported by DDA through 118 community providers that supported ten or more adults.

Over half (54%) of the eligible people responded to the FY2003 survey for themselves. (See **Figure 2**.) An additional 22% agreed to participate in the survey, but did not have the ability to answer the questions for themselves. Interviewers interviewed two proxies for most of these people. The *Ask Me! Survey* did not obtain interviews for the remaining 24% of the people. Half of those not interviewed (12% of the total) refused the interview themselves, with an additional 3% having guardians or others refusing to let them participate in the project. Providers reported that they no longer (or never) served 5% of the people. Attempts by the project to locate them through other providers failed. A search of the DDA files in July 2003 after the end of the fieldwork showed that DDA still listed two-fifths of these people as eligible for services from the provider, one-third as receiving services from different providers, and one-fourth no longer receiving DDA supported services. The remaining 4% of the eligible people were not interviewed for a variety of reasons: illness, language problems, repeated failure to keep appointments, and inability to contact the person or a proxy in six or more attempts.

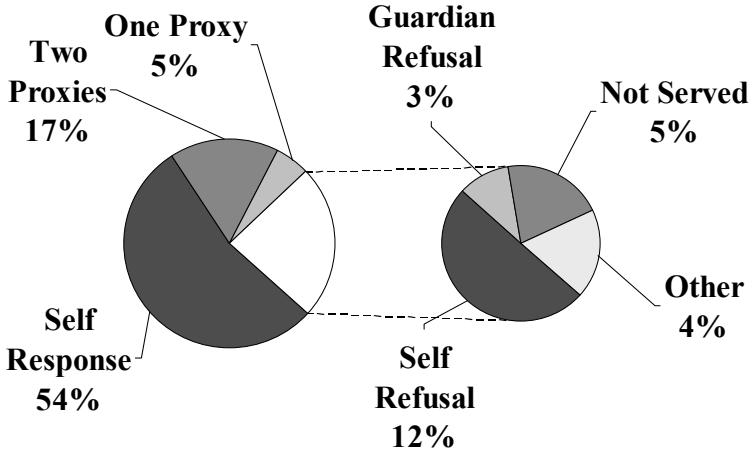


Figure 2. Response of People Selected and Eligible for Interview

Interviewers and Survey Procedures

The Arc of Maryland employed 39 interviewers for the FY2003 Ask Me! Project, all of whom had received services funded 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. Interviewers averaged 2.8 years of prior experience. Five interviewers had worked on all five prior years of the project. Both new and experienced interviewers participated in a centralized one-day training at the beginning of the survey period. They then participated in monthly regional training throughout the interviewing period. Quality assurance measures included additional interviewing practice prior

to the first interview, 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. They conducted three-fourths 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. Interviewers conducted an average of 47 interviews.

Staff at the provider contacted the selected individuals or their guardians to explain the survey, to secure initial agreement to participate, and to make the necessary arrangements to get their people to the interview sites. The Ask Me! Staff gave the people information about the Ask Me! Project and the interview process after they arrived. 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 interviewer teams to whom they were assigned then asked the people a series of questions to make sure they understood enough to consent to being interviewed. The teams asked the people to sign forms saying they consented to be interviewed and to have their providers to provide background information about them to the Ask Me! Project. These signed permission forms were later sent to the provider along with a Transportation Form that listed the names of the interviewed people.

The interviews were conducted in conference rooms and empty offices provided by the participating providers. No staff from the provider was in the room during the interviews unless respondents asked someone to accompany them. Ask Me! staff was available in a central area to answer specific questions, problem-solve, or offer suggestions if interviewers needed assistance or respondents needed additional accommodation to complete the interview. Interviews generally took 15-45 minutes, with an average of 30 minutes. Interviews with proxies took about as long as interviews with self-respondents.

Self and Proxy Responses

Peer interviewers, the survey instrument, the flash card with 'happy,' 'neutral,' and 'sad' faces, and survey procedures enabled 76% of the selected people to respond for themselves. One-fifth of the people classified with profound retardation responded for themselves in both years, and about half of those classified with severe retardation responded for themselves. (See **Figure 3**.) Almost all of those classified with moderate, mild, borderline or no retardation responded for themselves.

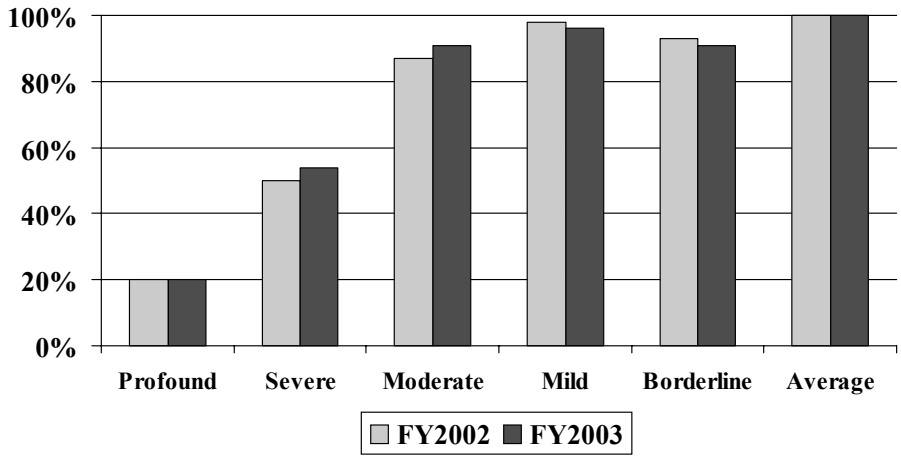


Figure 3. Percent Responding for Themselves: FY2002 and FY2003

When the Ask Me! interviewers and supervisor determined that a person could respond for himself or herself, they asked the provider to identify two proxies for the person. Preferably, one of the proxies was a family member, friend, or service coordinator, with provider staff as the other proxy. Interviewers frequently conducted face-to-face proxy interviews with staff who brought people to the interview location, since those staff generally knew the person well, and 69% of proxy interviews occurred at the place of employment or day program. Interviewers conducted face-to-face interviews with 13% of the proxy respondents at the people's residences or other location, and telephoned 18% of the proxies. Interviewers asked proxies to answer the question as if they were the person. The project averaged the responses from two proxies, 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).

Quality of Data

The survey repeated a question on earnings 13 questions later to check upon internal consistency of responses. About three-fourths of both self and proxy respondents answered both questions the same way, irrespective of the cognitive level of the person. (See **Figure 4**.) A generalized least square test of the degree of consistency showed a small significant effect of proxies (p=.02) and no effect of cognitive ability.

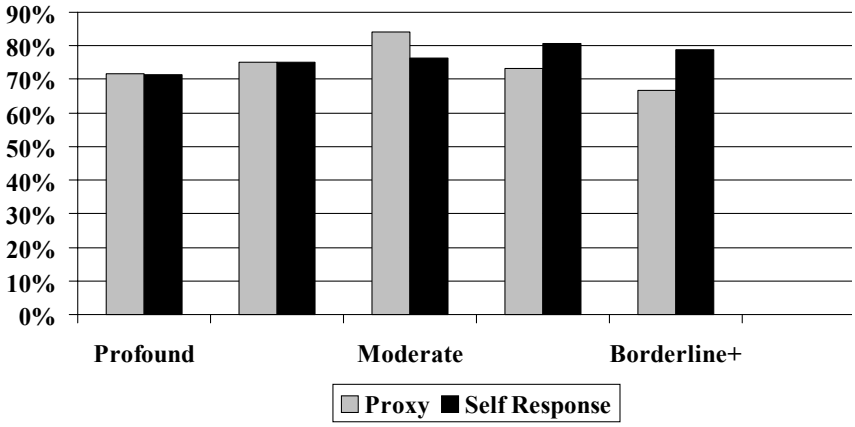


Figure 4. Percent of People and Proxies Answering Consistently

Background Characteristics

People selected for the Ask Me! Project in FY2002-03 represented a random sample of adults receiving services from community providers supported by DDA. They averaged 39.8 years of age, with 15% being 18-25, 25% being 25-34, 26% being 35-44, 20% being 45-54, 10% being 55-64, and 5% being 65 years and over. Providers did not report the level of retardation for one-eighth of the people, the majority of whom had autism, cerebral palsy, head injury or other neurological disorders. Among those with reports, a few had normal intelligence (2%) or borderline

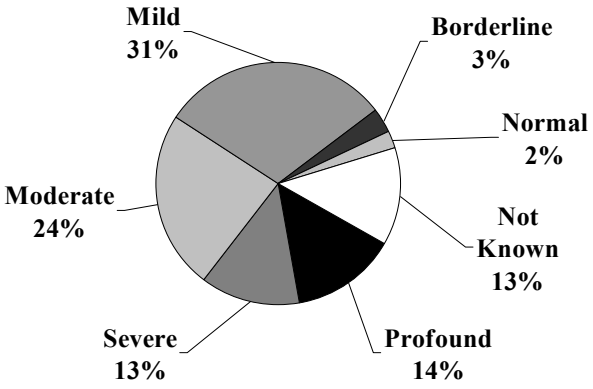


Figure 5. Percent by Level of Retardation

retardation (3%), 31% had mild retardation, 24% had moderate retardation, 13% had severe retardation and 14% had profound retardation. (See **Figure 5**.) As discussed earlier, some people classified with profound retardation could respond for themselves, and level of retardation is used only as a statistical control. Cognitive ability does not to determine a person's quality of life even though it may have some effect.

Services

Of the people supported by DDA, 47% received resource coordination from a provider who did not provide them other community services. (See **Figure 6**.) Excluding resource coordination, 76% of the people supported by DDA in the community received all their services from a single provider. Almost all the others (23%) received services from two different providers, with 1% receiving services from three or four different community providers. During the day, 42% of the people received (or were authorized to receive) day habilitation services and 26% received employment services. One-third (35%) of the people received residential services from community providers, 10% received community supported living assistance (CSLA), and 2% lived in individual foster care. Additionally, 16% received individual support services and 7% received behavior support services.

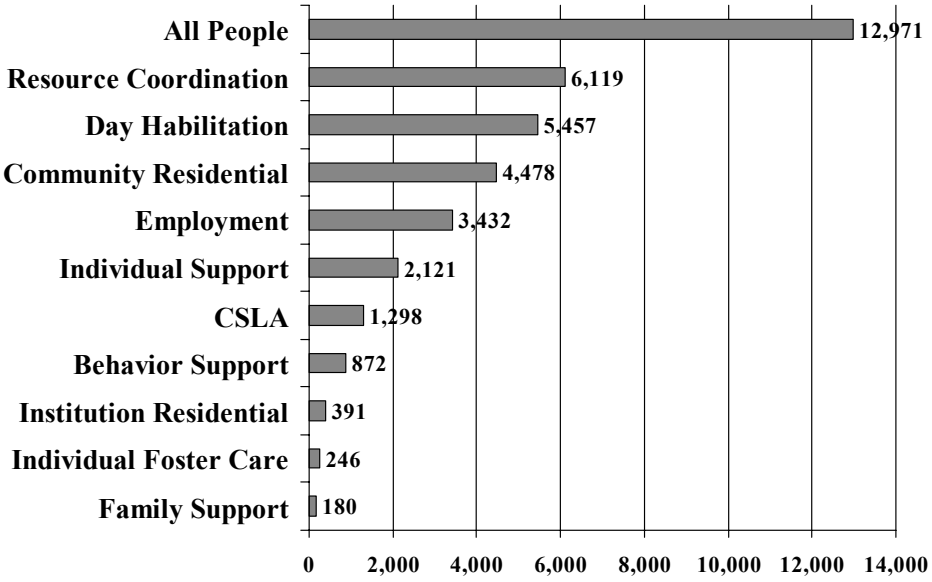


Figure 6. Number of People by Type of DDA Supported Services

The providers at which they were selected provided 64% of the people with transportation to their employment or day program, averaging 4.9 round trips per week. The providers also transported 53% of the people to other activities, averaging 3.4 round trips per week. Other providers transported 23% of the people an average of 4.3 times per week. Family and friends transported 31% of the people an average of 2.7 round trips per week. Only 12% of the people used public transportation (bus, train, taxi or paratransit van), but those that did used public transportation an average of 4.3 times per week.

Quality of Life

Question Responses

The survey instrument included six questions to indicate each of the eight quality of life domains. While dropping any question would reduce the reliability of the scale score, the single question that best represented each domain is shown below:

Social Inclusion: 9. Do you go to fun things in your community?

63%	☺1	Yes
24%	😑2	Sometimes
13%	☹3	No

Self-Determination: 31. Did you choose your job or what you do most days?

59%	☺1	Yes
22%	😑2	Some
19%	☹3	No

Personal Development: 23. Are you learning things that will make you a better person?

74%	☺1	Yes
18%	😑2	Sometimes
08%	☹3	No

Rights: 46. Can you talk on the telephone in private?

61%	☺1	Yes
14%	😑2	Sometimes
25%	☹3	No

Interpersonal Relations: 19. Does what you do most days let you look good to others?

64%	☺1	Yes
26%	😑2	Sometimes
10%	☹3	No

Material Well-Being: 41. Do you have money each week to spend on what you want?

67%	☺1	Yes
22%	😑2	Sometimes
12%	☹3	No

Emotional Well-Being: 7. In general, how happy are you with your life?

68%	☺1	Very happy
26%	😑2	OK
6%	☹3	Not happy

Physical Well-Being: 34. Would you say your eating habits are good, fair or poor?

72%	☺1	Good
21%	😑2	Fair
7%	☹3	Poor

At least three-fourths of the respondents gave the most positive (☺)answer to seven of the questions on the survey. Four questions related to emotional well-being: 80% said they were a happy person, 76% liked themselves, 76% felt very safe in their neighborhood, and 75% felt they got the services they needed. Three questions concerned physical well-being: 87% said the people they lived with never hit or hurt them, 77% had regular checkups with a dentist, and 77%

felt that people had the right level of concern about their health.

Six questions received a negative (☹) response by 30% or more of the people: 63% said they never voted in governmental elections, 52% said they did not get the information they needed about sexuality, 35% said that they did not pick with whom they lived, 30% could not lock the bathroom door, 30% did not have any close friends, and 33% had to make a lot of advance preparation if they wanted to go somewhere.

Sixty deaf people responded to the survey during the two years. Many of the *Ask Me! Survey* questions could not be translated into American Sign Language because the concepts had little meaning to deaf people. An advisory group consisting of deaf people, providers of services to the deaf and the Ask Me! staff developed an American Sign Language (ASL) version of the primary *Ask Me! Survey*. The deaf survey contained 69 questions, with 30 questions the same as in the hearing survey, 22 new questions related to the eight quality of life domains, and 17 new questions related to communication.

Three-fourths or more of the deaf respondents gave the positive (☺) response to seven of the questions unique to the deaf survey: 94% said they had access to TDD, TTY or Maryland Relay, 87% said they could access the people and services they wanted through these communication mediums, 86% felt they got the physical health services they needed, 83% had interpreters when they went to their doctors, 79% said their community activities made them happy, 78% said their job coach was helping them get the job they wanted, and 77% felt happy about the money they made.

Five of the eight questions that 30% or more of the deaf people answered negatively (☹) related to communication: 73% often felt they were left out because they did not have an interpreter, 63% said their choices were limited by lack of interpreters, and 44% said their work supervisors did not understand them when they tried to communicate. Although 66% said they did not understand their doctor or therapist and 57% said their doctor or therapist did not understand them, most had interpreters available when they went to the doctor or therapist. While 86% said they got the physical health services they needed, 46% said they did not get the social services they needed. Additionally, 46% were not involved in deaf events and 30% did not get the government benefits they felt they needed.

Quality of Life in Maryland

The *Ask Me! Survey* calculated a quality of life score for a domain if a person had answered at least four of the six questions. It calculated emotional well-being scores for 2,139 people from questions at the beginning of the survey. It calculated material well-being scores for 1,921 people from questions near the end of the survey. (See **Figure 7**.) Scores ranged from -10.0 to +10.0, with zero being the neutral value (neutral responses to all questions in the scale or as many positive responses and negative responses). The most positive responses occurred in the domain of physical well-being, where 92.2% of the people had positive scores, with an average score of 6.9. Emotional well-being scores varied the least, as measured by the standard deviation, and self-determination scores varied the most. For the deaf survey, the number of indicator questions for a domain varied from three to thirteen. For purposes of this analysis, no

distinction was made between the scores of hearing and deaf people, even though they were based on different questions and different numbers of questions.

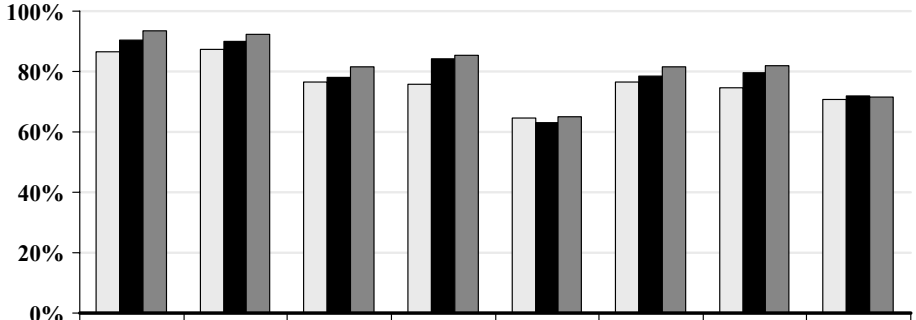
Domain	*% Positive*	*Average Score*	*Std. Error*	*Std. Dev.*	*Alpha*	*# People*
Social inclusion	81.1	4.402	.098	4.469	0.72	2098
Self-determination	71.8	3.580	.114	5.141	0.71	2035
Personal development	80.2	4.381	.100	4.515	0.67	2032
Rights	64.5	2.533	.116	5.109	0.67	1937
Interpersonal relations	84.1	4.806	.093	4.240	0.67	2084
Material well-being	79.9	4.411	.098	4.302	0.67	1921
Emotional well-being	91.5	6.548	.079	3.668	0.68	2139
Physical well-being	92.2	6.924	.083	3.733	0.61	2014
Transportation availability	78.1	4.120	.104	4.571	0.63	1918
Deaf communication	65.7	1.752	.433	3.107	n.a.	52

Figure 7. Quality of Life Scores: FY2002-2003 Combined

The Maryland State Legislature requires each state government agency to set measurable goals for a process called "Managing for Results." The quality of life domains of Ask Me! related well to DDA's mission of fostering "personal growth, independence, and productivity," and DDA chose to use them as measures for Managing for Results. DDA defined two objectives in its FY2003 plan:

- Objective 1.1 – *By the end of FY 2003, the percentage of respondents on the Ask Me! Survey expressing satisfaction in the following [eight] domains will remain the same or improve.*
- Objective 1.2 – *By the end of FY 2003, the average score on the domain of "personal development" will increase by 5% and the average score on the other seven domains will remain the same or improve.*

The FY2001 pilot provided the baseline for establishing targets even though the pilot did not represent a true probability sample of people supported by DDA. The percent of people in FY2003 that expressed positive quality of life exceeded the Objective 1.1 target (the FY2001 percent) in all eight domains. (See **Figure 8**.) In

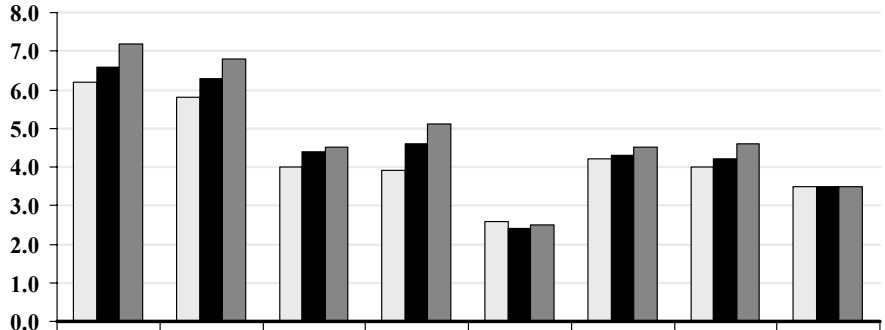


	Physical Well-being	Emotion Well-being	Material Well-being	Inter-Personal	Rights	Personal Develop	Social Inclusion	Self-Determination
FY2001	86.7%	87.3%	76.5%	75.7%	64.7%	76.4%	74.5%	70.8%
FY2002	90.3%	90.0%	78.0%	84.1%	62.9%	78.4%	79.8%	72.0%
FY2003	93.5%	92.5%	81.6%	85.4%	64.9%	81.5%	82.1%	71.5%

Figure 8. Percent with Positive Quality of Life, by Domain and Year

six of the eight domains, the percent that expressed positive quality of life increased each year between FY2001 and FY2003, with FY2003 8% higher on average than FY2001. The greatest increases occurred in the domains of interpersonal relations and social inclusion. Although the domains of self-determination and rights met the goal of not declining below the FY2001 percent, they showed neither a significant increase nor a pattern of consistent increases from year to year.

In objective 1.2, DDA specifically targeted a 5% improvement in the personal development domain score, as the FY2001 Ask Me! findings had shown this domain statistically related to all other quality of life domains. An increase in personal development would either require or cause an increased quality of life in the other seven domains. The personal development average score increased each year from 4.2 in FY2001 to 4.5 in FY2003, a 7% increase that was higher than the targeted 5% increase. (See **Figure 9**.) The quality of life in five other domains also increased each year although they had not been specifically targeted for an increase. The FY2003 scores in those five domains were 18% above their targets on average, with the greatest increase in interpersonal relations. DDA barely achieved its goal of maintaining the baseline average level of self-determination, and did not achieve its goal of maintaining the baseline level of rights.



	Physical Well-being	Emotion Well-being	Material Well-being	Inter-Personal	Rights	Personal Develop	Social Inclusion	Self-Determination
FY2001	6.2	5.8	4.0	3.9	2.6	4.2	4.0	3.5
FY2002	6.6	6.3	4.4	4.6	2.4	4.3	4.2	3.5
FY2003	7.2	6.8	4.5	5.1	2.5	4.5	4.6	3.5

Figure 9. Average Quality of Life Score, by Domain and Year

Relationships of Domains

Some domains have received more attention in the literature than have others, but that does not necessarily mean that they are more important than the others. The Maryland DDA, however, has clearly defined social inclusion, personal development, and self-determination in its mission statement as desired outcomes from services and supports for persons with mental retardation and other developmental disabilities. The project used these three desired outcomes as the start for developing a path model of cause and effect. (See **Figure 10**.) The domains on the right side of a path model are assumed to be the final desired quality of life outcomes. These are predicted or caused by the domains further to the left. A change in the domain at the tail of the arrow is hypothesized to affect or cause a change in the domain at the head of the arrow. When no arrow is shown between two domains, any effect is indirect, operating through intermediate domains. The numbers shown on the arrows are path coefficients (standardized multiple regression

coefficients or β) and indicate the strengths of the relationships.

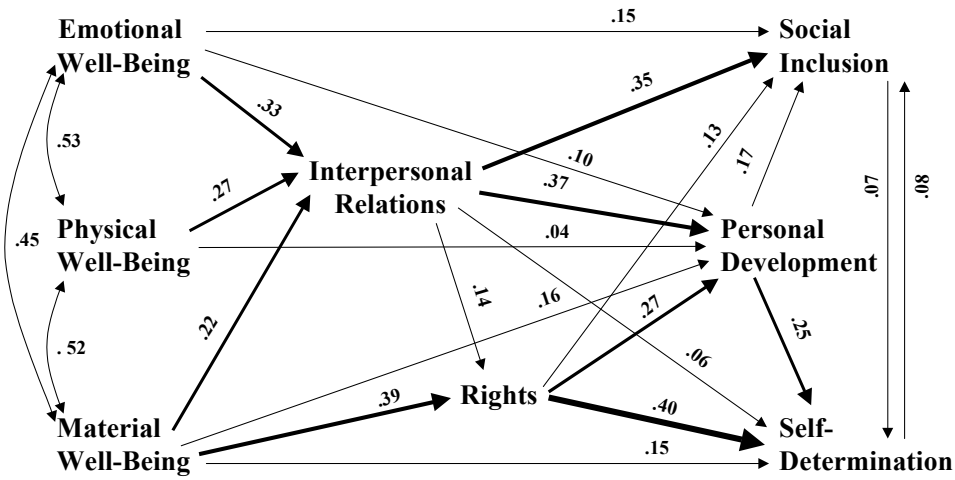


Figure 10. Path Model of the Relationships Among Quality of Life Domains

The model was developed with unweighted data from FY2001. The weighted combined data from FY2002 and FY2003 fit the model remarkably well. The paths with their coefficients that point to social inclusion suggest that the best way to increase social inclusion would be to increase interpersonal relations (β = .35). The next best way to increase social inclusion would be to increase personal development (β = .17) followed closely by emotional well-being (β = .15) and then rights (β = .13). Changes in self-determination would have minor effect on social inclusion (β = .08), while material and physical well-being would have no direct effect on social inclusion. The best way to increase self-determination would be to increase rights and personal development. While personal development appears central in quality of life and relates to all other seven domains, the effect of physical well-being on personal development was barely significant (β = .04, p = .04). Interpersonal relations and rights had the strongest effect on personal development.

The path model suggests that a focus on one of the foundational quality of life domains--physical well-being, emotional well-being and material well-being--will affect overall quality of life less than a focus on the other five. Most (93%) of the people reported positive qualities of life in the domains of physical and emotional well-being, and these two domains had the highest average scores. This limits the amount they can increase. While interpersonal relations directly related to all the other quality of life domains, 85% of the people had positive scores on this domain and gave an average score not far below their scores on physical and emotional well-being. A focus on enhancing rights, personal development, self-determination or social inclusion would therefore contribute most to people's overall quality of life.

Person Characteristics, Services and Quality of Life

Characteristics of people and their services predicted about 30% of the variation in their reporting of rights and self-determination, 19% of their variation in personal development, and 13% of their variation in social inclusion. The availability of transportation was the single most important factor in predicting people's quality of life in all eight domains, particularly for the four domains that could most enhance over all quality of life. (See **Figure 11**.) The more available people reported transportation, the higher they reported their quality of life. In addition, people whose provider provided them transportation three or more times a week reported higher levels of rights, personal development and social inclusion than those who

reported less provider transportation each week. People authorized by DDA to receive supported employment services reported higher levels of rights, personal development and social inclusion than did those without employment services. People authorized to receive day habilitation services reported lower levels of self-determination than those without day habilitation. People with two or more providers reported higher levels of social inclusion than did those with one provider. People with higher cognitive ability, and those who reported for themselves, expressed higher levels of rights, personal development, self-determination and social inclusion than people with less cognitive ability or proxy reporting. For half of the quality of life domains, the ability to respond to the survey for themselves was a more important predictor of their quality of life than was the level of retardation with which they were classified.

	Rights	Personal Develop	Self Determine	Social Inclusion
• Transport Available	+	+	+	+
• Agency Transport	+	+		+
• Employment Services	+	+		+
• Day Habilitation			--	
• Western Maryland			+	
• Southern Maryland	--		--	
• Number of providers				+
• Cognitive Ability	+	+	+	+
• Self Report	+	+	+	+
• Cerebral Palsy	--			
• Deaf				--

Figure 11. Services and Characteristics that Predicted Quality of Life

Transportation Availability

People's perceived availability of transportation had a strong relation to their reporting of quality of life in all eight domains. In the FY2002 survey, only 4% of the perceived transportation availability variability could be explained by the Background Form information collected from providers or by the data on the DDA files. In FY2003, the Ask Me! Project replaced the Background Form with a Transportation Form that collected more detailed information on the frequency of transportation provided by different sources. This new data explained 13% of the variability in transportation availability. The more frequently providers provided transportation to activities other than employment or day programs, the less available people reported transportation (β = -.10). (See **Figure 12**.) This reversal of what might be expected could be due to perceptions that provider

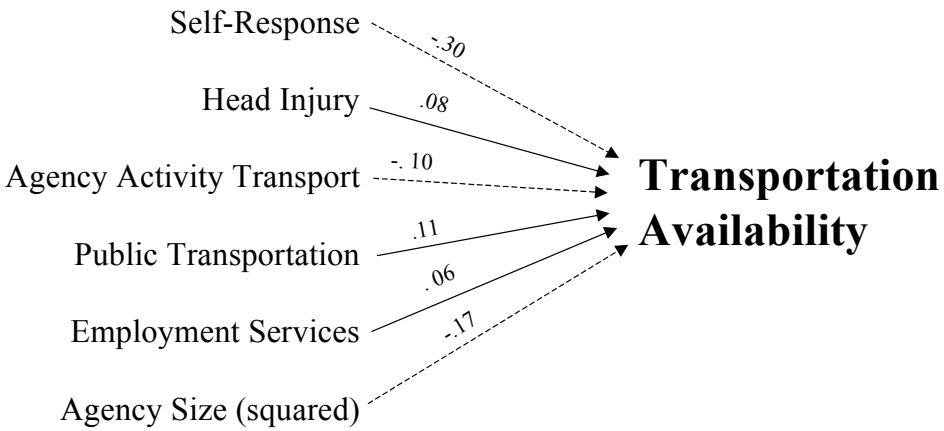


Figure 12. Characteristics Predicting Transportation Availability: FY2003

transportation was available on the provider's time schedule, and not when the person wanted to go somewhere. In contrast, the more frequently people used public transportation, the more available they reported transportation (β = .11). As seen in previous years, self or proxy response had the greatest predictive value, with self-respondents reporting transportation as substantially less available than did proxy respondents (β = -.30 in FY2003, β = -.17 in FY2002, and β = -.23 in both years combined). In both years combined or separate, people receiving employment services reported greater transportation availability than did people not receiving employment services (β = .06 in FY2003, and β = .09 in FY2002 and both years combined). People with head injuries reported slightly greater transportation availability than did those with other types of disabilities in FY2003 (β = .08) or in the two years combined (β = .05). People with deafness or hearing impairments also appeared to report slightly greater availability of transportation (β = .06 in both years combined).

Provider size had an effect on perceived availability of transportation, but the effect was curvilinear (identified in **Figure 12** as the square of the size for individuals, and in **Figure 13** as the logarithm of provider averages), with the greater reductions in transportation availability with increased size among smaller providers than among larger providers.

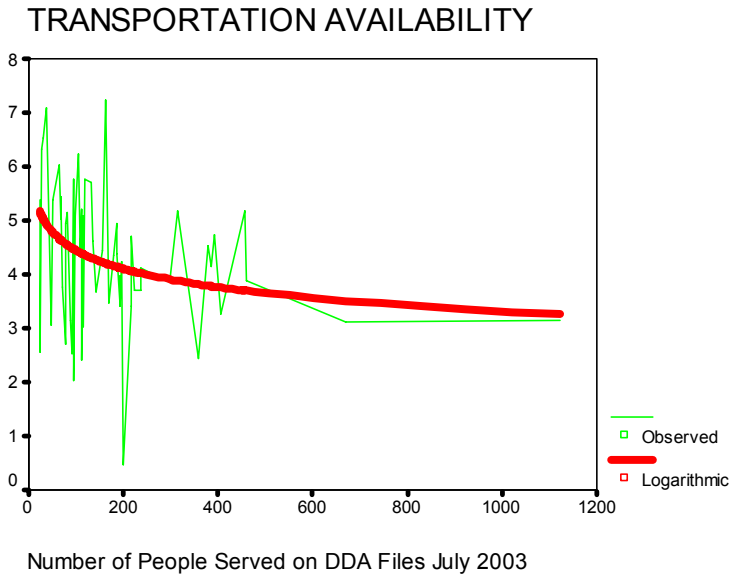


Figure 13. Transportation Availability by Provider Size

Deaf Communication

A previous section showed that 60 deaf people interviewed on the *Ask Me! Deaf Survey* reported lower levels of social inclusion and interpersonal relations than did those interviewed on the regular survey. The deaf survey included seventeen questions about people's ability to communicate with others and others ability to communicate with them. These were combined into a single scale, with an average value of 1.752 on a potential range from -10.0 to +10.0. The greater the communication deaf people reported, the higher their scores on personal development (β = .31), independent of other characteristics like receiving residential services in the community. In addition, the greater the communication, the greater the interpersonal relations (β = .31). None of the personal or service characteristics available from the DDA files predicted the degree of communication that people reported.

Proxies

Earlier discussion showed that self-respondents reported higher levels of rights, personal development, self-determination and social inclusion than did proxies. The measure "proxy

response" may represent the different perspectives of outside people who are asked to guess what individuals who cannot respond for themselves are thinking and feeling. However, since proxies responded for 80% of people classified as having profound retardation and 50% of those with severe retardation, the measure "proxy response" may represent a special characteristic or disability of a person that is not completely captured by classification into levels of retardation.

People who needed proxies to report for them primarily were those classified with profound or severe retardation. The higher the cognitive ability of the person, the less likely they were to need proxies (β = -.60). (See **Figure 14**.) Nine other characteristics provided some small additional, but statistically significant, prediction on who needed proxy respondents. Controlling for cognitive ability, people receiving services in the community while residing in the state institutions were more likely than those residing in the community to need proxies. People with specific learning disabilities were less likely to need proxies, while people with autism, epilepsy/seizure disorders or orthopedic impairments were more likely to need proxy respondents than those without these types of disabilities. Older people needed proxies slightly more than younger people, and men slightly more than women. People living in the Western Maryland needed proxies less often than people living in other parts of the state. People receiving transportation three or more times a week from the provider through which they were sampled also need proxies slightly less than those with less transportation service. Together, these characteristics explain two-fifths of the need for proxies (R^2 = .39).

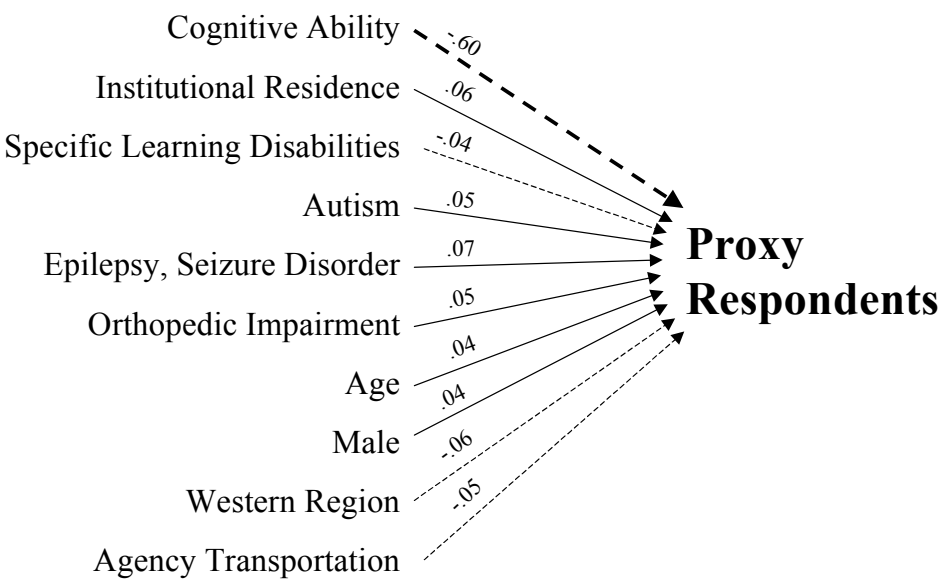


Figure 14. Characteristics of People Who Need Proxies

Provider Variation

The average quality of life reported by people varied by providers. People served by one provider had an average score of 6.9 on self-determination while people served by another provider had an average score of 0.1. The average scores for 70% of the providers fell in the range of 1.1 to 5.2. (See **Figure 15**.) This range was almost as great as the range in rights, with provider averages ranging from 5.9 to -1.0. The least variation among providers occurred in the domain of emotional well-being with the highest provider average of 8.2 and the lowest provider average of 4.0. The Ask Me! Project generally interviewed a sample of the people served by a provider. Provider scores within the range shown by the solid boxes were not significantly different from the overall Maryland average, and include 70% of the community providers.

Average scores above the solid box for 20% of the community providers were significantly higher than the Maryland average, and average scores below the solid box reported by people served by 10% of community providers were significantly lower than the Maryland average.

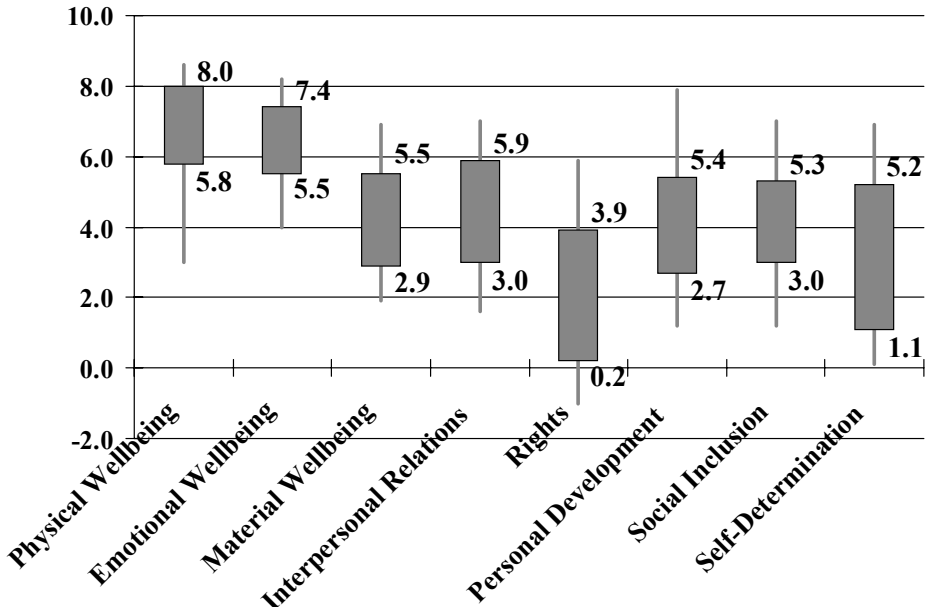


Figure 15. Range of Quality of Life Scores Among Providers

The earlier path model showed the significant relationships among the quality of life domains reported by individual respondents. A similar path model for the 61 service providers showed the relationships among the average scores of the people they serve. The two path models were basically similar. However, self-determination affected social inclusion at the provider level without the reverse effect observed at the individual level. (See **Figure 16**.) At both the provider and individual level, social inclusion was most affected by interpersonal relations. At the provider level, personal development did not have the impact on social inclusion or self-determination as it did at the individual level. At both the provider and individual levels, self-determination was most affected by rights, and physical well-being had the fewest significant relationships to other quality of life domains. Both path analyses suggest that improvements in physical well-being will do little to enhance their quality of life.

Provider characteristics related to the average provider quality of life in ways similar to how person characteristics related to individuals' quality of life. Provider characteristics predicted from one-third of the variation among providers in the level of social inclusion (R^2 = .37) to two-thirds of the variation in the level of self-determination (R^2 =

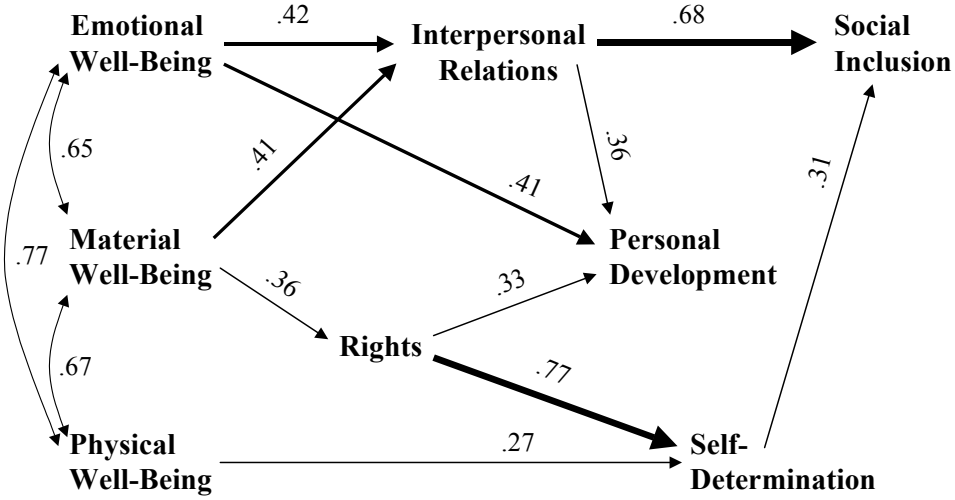


Figure 16. Path Model of Relations Among Provider Quality of Life Scores

.67). The average provider score on transportation availability related significantly to the average provider score on quality of life in all eight domains and was the single strongest predictor in five domains. Independent of perceived availability, the greater the percent of the people who received transportation from other providers, the lower the average levels of personal development. (See **Figure 17**.) The greater the percent of the people at the provider who received employment services, the greater the average levels of social inclusion. Providers in the southern DDA region had lower levels of self-determination than those living elsewhere, the same relationship observed at the individual level. Providers with higher percents of people reporting for themselves had higher average levels of rights and self-determination, as might be expected given the same relations observed at the individual level, but other measures of cognitive abilities were unrelated to provider average quality of life in domains except material well-being. Providers serving a greater percent of people with deafness and hearing impairments had lower reporting of social inclusion than providers serving smaller percents of people with deafness and hearing impairments. Not observed at the individual level, however, were the relations that vision impairments and speech impairments had with rights, personal development, and self-determination. The greater the percent of the people the provider served that had either of these types of impairments, the lower the average reported quality of life in all three domains. Behavior and mental disorders did not predict quality of life at the individual level, but did at the provider level. The greater the percent of people with behavior disorders served by a provider, the higher the average level of rights and self-determination that people reported. The greater the percent with mental disorders, the higher the average levels of personal development reported. The size of the provider and the degree to which it provided residential or support services did not have predictive value at the provider level.

	Rights	Personal Develop	Self Determine	Social Inclusion
• Transport Available	+	+	+	+
• Transport Other Agency		--		
• % Employment Services				+
• Southern DDA Region			--	
• % Self-reporting	+		+	
• Average Age		--		
• % Blind Vision Impair	--	--	--	
• % Deaf Hearing Impair				--
• % Speech Impair	--	--	--	
• % Behavior Disorder	+		+	
• % Mental Disorder		+		

Figure 17. Characteristics Predicting Provider Quality of Life

Use of Information

Ask Me! provides information that is intended to be used for enhancing programs. A discussion occurred earlier on the use of Ask Me! information by DDA in its "Managing for Results" report to the Maryland Legislature. This section discusses additional analysis of the data by Bonham Research to assist DDA and service providers in how to enhance support for people with developmental disabilities.

Maryland Developmental Disabilities Administration

Stability and Change in Quality of Life

DDA established objectives in its Managing for Results Plan to maintain or improve the quality of life for people in Maryland measured by the eight quality of life domains. Findings presented earlier in this report suggested that DDA substantially achieved its FY2003 objectives. However, it is possible that the observed increases were due only to different community providers being involved in each survey year. A detailed analysis of 20 providers that participated in both the FY2001 and the FY2002 *Ask Me! Surveys* showed that the average quality of life scores for the people served by these providers increased significantly in four of the eight domains and possibly increased slightly in three others. These changes almost exactly reflect those observed in **Figure 9**.

While some variations in provider scores from one year to the next could be due to the random selection of people each year, other variation cannot. One hypothesis is that average scores cannot improve indefinitely. The highest possible provider score of +10.0 could only be achieved if every person surveyed gave the positive response to all six questions in a domain. Therefore, the higher the initial score, the less it can increase or the more it can decrease. Changes in provider scores between FY2001 and FY2002 supported this hypothesis. The higher the FY2001 scores were in seven of the eight domains, the less the increase in the scores during the following year: social inclusion ($r = -.60$, $p < .01$), personal development ($r = -.51$, $p < .05$), rights ($r = -.47$, $p < .05$), interpersonal relations ($r = -.62$, $p < .01$), physical well-being ($r = -.73$, $p < .01$), material well-being ($r = -.63$, $p < .01$) and emotional well-being ($r = -.74$, $p < .01$). Only for self-determination was the change unrelated to the size of the initial score.

Service Growth and Quality of Life

DDA supported 10,813 people through 140 providers in March 2000. People received services from 1.4 providers on average. The number of people increased 20% by July 2003, the number of providers increased 6%, and the number of person-provider combinations increased 38%. By July 2003, people received services from 1.6 providers on average. DDA had wondered if the large increases in the number of people served during FY2001 would reduce the quality of life of people. The majority of the providers increased the number of people they served during FY2001: one-fifth by 26% or more, one-fifth by 11-25%, one-fourth by 2-10%, one-sixth stayed about the same size, and one-fifth had a net loss of 2% or more. Changes during FY2001 in the number of people served by providers had no relation to the quality of life expressed simultaneously by people during the FY2001 *Ask Me! Survey*, but did have a significant relation with the quality of life expressed by people during the following year's (FY2002) *Ask Me! Survey*.

In general, the greater the percent the provider grew during FY2001, the higher the quality of life people reported during the following year's Ask Me! (See **Figure 18**.) People at the two providers that had grown by 26% or more during the previous year had an average social inclusion score of 5.0 in FY2002. The ten providers that had grown 11-25% had an average score of 4.8. The nineteen providers that had grown 2-10% had an average score of 4.1. The

two providers that had stayed about the same size or had declined in the number of people served had an average score of 2.3 on social inclusion. This pattern of difference was statistically significant using an analysis of variance (ANOVA). Similar statistically significant patterns were found for the domains of physical well-being and material well-being, although providers gaining 11-25% during FY2001 had about the same or slightly higher average quality of life scores in these two areas than did providers that grew more. Thus, the initial quality of life of people served by providers did not predict which providers grew, but provider growth predicted a subsequently higher quality of life for the people served.

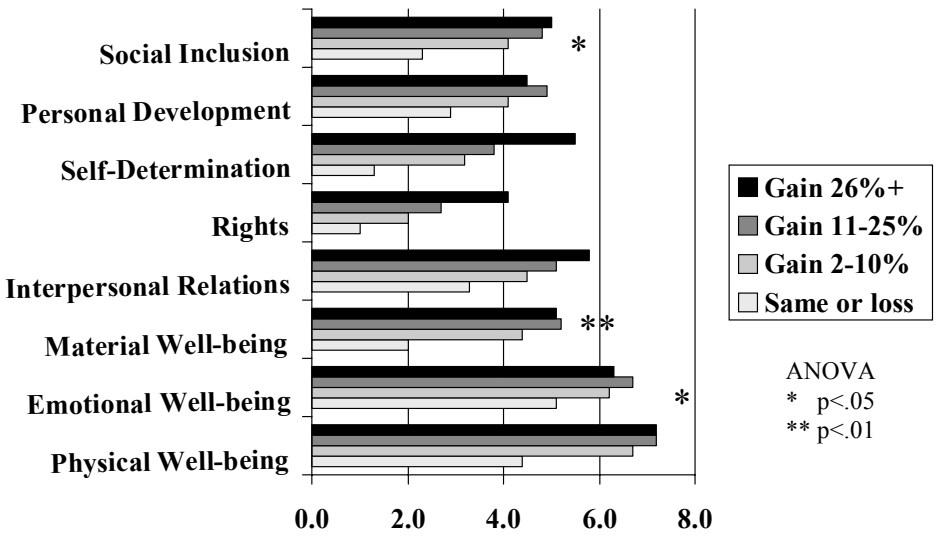


Figure 18. FY2002 Quality of Life by FY2001 Change in Number of People Served

Quality Assurance Plans

DDA requires service providers to submit Quality Assurance (QA) Plans to the State for review and approval. In November 2002, DDA staff abstracted the first four goals from the QA Plans of 32 providers. These providers had participated in both the FY2001 and FY2002 *Ask Me! Surveys*. Although only half of the providers had formally submitted their plans to DDA prior to the start of interviewing on the FY2002 *Ask Me! Survey*, the following analysis assumed that all the providers were operating on the basis of their QA goals between the time their people were interviewed in FY2001 and the time they were interviewed in FY2002.

Three-fourths of the providers (24 of 32) included physical well-being as one of their goals, and most of these (15) made it their primary goal. (See **Figure 19**.) Physical well-being was primarily specified as health, safety or incidence reduction. One-fifth of the providers identified

Domain	*Any*	*Goal1*	*Goal2*	*Goal3*	*Goal4*
Physical well-being	24	15	7	7	6
Personal development	16	7	7	4	4
Emotional well-being	10	1	4	4	1
Self-determination	8	1	4	2	2
Material well-being	8	1	2	2	4
Rights	8	2	2	3	1
Social integration	6	2	1	3	0
Interpersonal relations	4	0	1	0	3
Provider process goal	13	3	3	6	7
No goal	0	0	1	1	4

Figure 19. Number of Providers by Domain of Goals

physical well-being as their second, third or fourth goal. Overall, 28% of all the providers' goals involved physical well-being. Half of the providers identified personal development as one of their goals, 22% said it was their primary goal, and 18% of all the goals involved personal development. Personal development goals revolved around behavior plans (BP) and individual plans (IP). A third of the providers included goals that were classified in the domain of emotional well-being, although most of these were ambiguous as "individual satisfaction." Consumer satisfaction with their quality of life represents a person-centered goal, but consumer satisfaction with services represents an organizational goal. Nevertheless, any expression of consumer satisfaction was classified for this analysis as an emotional well-being goal. Four providers included interpersonal relationships among their goals to make it the least frequent goal, and none included it as a primary goal.

Two-fifths (13) of the providers included goals related to their process rather than to outcomes of the people served. Most of these goals related to the training, support, retention and satisfaction of staff. Staff are central to the provision of services, and good staff outcomes are important to quality services. However, good staff outcomes are not directly related to the quality of life of the people served. Staff could be satisfied with drawing a paycheck as well as being satisfied that they were making valuable contributions to other people's lives. Other goals related to good procedures, which would be expected to contribute to the quality of life of people served, but like any other process measures do not ensure quality outcomes.

Multiple regressions of the change in a domain score on the initial score in that domain, and the presence of a domain goal (entered one at a time), identified the value of social inclusion and self-determination goals in the QA plans. (See **Figure 20**.) The four providers that included self-determination goals in their FY2001 quality assurance plans did not significantly increase their self-determination scores, but had greater increases between the FY2001 and FY2002 surveys in their average quality of life scores in the five domains of social inclusion, personal development, interpersonal relations, emotional well-being and material well-being than did the fifteen providers without self-determination goals. The three providers that included social inclusion goals had not only greater increases in their average social inclusion scores, but

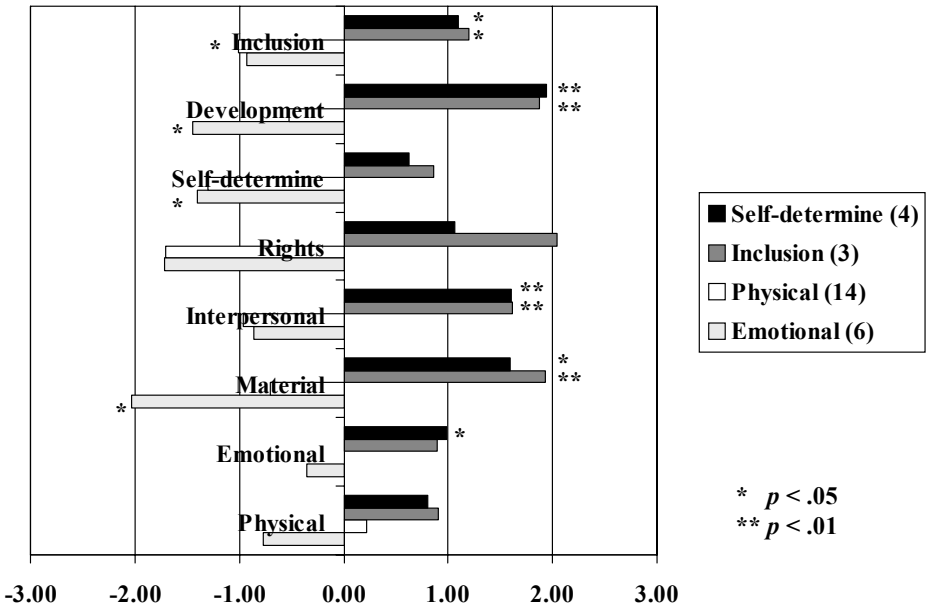


Figure 20. FY2001-FY2002 Change in Quality of Life by Quality Assurance Plan Goals

also greater increases in the three other domains of personal development, interpersonal relations, and material well-being compared with the sixteen providers without social inclusion goals. In contrast, the six providers that included emotional well-being goals in the FY2001 plans not only failed to improve emotional well-being, but had significant decreases in personal development, self-determination and material well-being compared with the thirteen providers without emotional well-being goals. The fourteen providers with physical well-being goals did not improve their physical well-being scores and had significantly lower social inclusion scores the following year than did the five providers without physical well-being goals. Goals in the other four domains did not result in statistically significant changes in quality of life in any domain over one year, controlling for the initial level.

Could providers have chosen goals for their QA Plans that related to their strengths? Four additional providers, making a total of 24, were included in an analysis that compared QA plans with FY2002 quality of life without regard to change in the quality of life. Providers may have submitted QA goals that related to their strengths only in the area of social inclusion. The six providers with QA goals of social inclusion had significantly higher qualities of life in the domain of social inclusion than did providers that did not have social inclusion goals. Providers that submitted social inclusion goals also had significantly higher quality of life in the domains of personal development, rights and interpersonal relations. Providers that submitted self-determination goals had significantly higher qualities of life in the domains of social inclusion, personal development and interpersonal relations than did providers that did not submit self-determination goals, and appear to have set this goal to overcome an area of weakness. Providers submitting interpersonal relation goals had higher level of rights reported in the survey than did providers without interpersonal relations goals, while providers submitting physical well-being goals in their QA Plans had significantly lower levels of rights reported by the people they served.

Community Providers

Bonham Research mailed a survey with twelve questions in March 2003 to 46 Maryland providers who had participated in the Ask Me! Project at least once during its first five years. Thirty-six administrators returned the survey for a response rate of 78%. Executive directors for eight providers completed the provider survey, line administrators (e.g., directors of residential, day, vocational or employment services) completed the survey for eleven providers, quality assurance directors completed the surveys for six providers, staff administrators (e.g., deputy director, chief operating officer, information and referral director) completed the surveys for ten providers, and one respondent did not report his or her position. They were about evenly distributed on the number of times they had participated in the *Ask Me! Survey*, with seven participating a single time and eight participating in all five years. The number of years of Ask Me! participation did not significantly affect administrators' responses to the survey.

Knowledge of Ask Me! Data

Three-fourths (75%) of the administrators said they had extensive knowledge of the Ask Me! results, and the rest said they had some knowledge. One-third (36%) of the administrators reported that they had summarized the data for others in text, chart or table format. An

additional half (50%) said they had personally analyzed the Ask Me! data, but had not summarized it for others. The remainder (14%) had not personally analyzed the data. The Ask Me! Project generally had two opportunities each year for providers to learn about survey results and understand their data. The administrators had attended an average of 2.4 sessions. A few (12%) had not attended any training or presentation, and a few (9%) had attended at least six and had stopped counting.

Most (61%) of the administrators said that the training had some value to them, while one-fourth (28%) said it had great value. The remainder had not attended any training and the question was not applicable. One-fourth (28%) of the administrators said they would definitely attend future training on Ask Me!, and another one-fourth (28%) said there was a strong likelihood that they would attend. The rest said there was some likelihood of attending. No one ruled out future attendance.

Use of Ask Me! Data

The Ask Me! Project included 10 providers in FY1998, 21 in FY1999, 28 in FY2000, 35 in FY2001 and 33 providers in FY2002. Participation in the Ask Me! Project was voluntary during the first four years. Except for one FY1998 provider, all the providers participating in one of the voluntary years participated in the remaining voluntary years. Beginning in FY2002, DDA required that providers participate, and the Ask Me! Project selected the sample of providers to be included each year. The amount that the administrators used Ask Me! results generally increased from one fiscal year to the next, with 73% reporting some or extensive use of their FY1998 data and 100% reporting some or extensive use of their FY2001 data. (See **Figure 21**.) This increased use might reflect the greater usefulness of the eight domains measured in FY2001 and FY2002 over the five domains measured in earlier years. The increased use might reflect a diffusion of knowledge among providers on how to understand and use Ask Me! results and its value for program enhancement. The increased use might also reflect that administrators considered recent information more relevant than earlier information, or it might reflect turnover or reassignment of staff with resulting lack of knowledge about earlier information use.

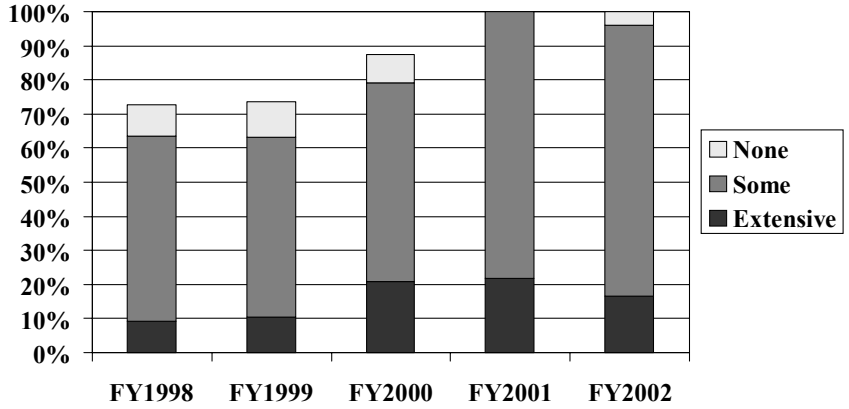


Figure 21. Amount Providers Used Their Ask Me! Results

Almost all (97%) of the administrators had shared Ask Me! information with the providers' top management, and 83% had shared Ask Me! information with mid-level supervisors. Three-fourths (75%) of the administrators had shared the information with their boards of directors, and half (53%) had shared the information with their direct care staff.

Most (89%) of the administrators reported using Ask Me! in their quality assurance planning. Much of this use may have been due to the encouragement of DDA which required quality assurance plan goals to have measurable outcomes. DDA had paid for the *Ask Me! Survey* to be conducted and indicated that Ask Me! data were preferred ways to measure outcomes. Half (49%) of the administrators reported that their organization had used the survey results to make changes in their programs. Almost as many providers used the survey information to train staff on quality of life concepts and what affects quality of life for the people they serve. About one-third (37%) of the administrators reported that their organizations had used the information to develop individual plans for the people they served.

One-third (34%) of the administrators reported seeing specific results from using the Ask Me! Information. One-fifth (22%) reported no specific results, and the rest were uncertain about whether any specific results had occurred.

Value of Ask Me! Data

The provider survey asked administrators how valuable the *Ask Me! Survey* had been to them personally, and how valuable it had been to their organization. They answered the two questions almost the same way ($r = .86$, $p < .01$). On a scale of 1 (no value) to 5 (great value), administrators gave an average value of 3.5 to the data, with 46% circling code 4, interpreted as having "good" value. (See **Figure 22**.) One in seven of the administrators said the survey had little or no value to their organization, and one respondent wrote a note, "It is only no value as of yet because of the time involved evaluating data. . . . We now have a QA chair who will begin to analyze data."

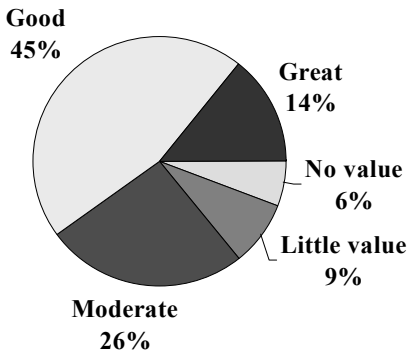


Figure 22. Value of the *Ask Me! Survey* to the Provider

A path model consistent with data from the *Ask Me! Survey*, the provider survey, and QA plans showed that an increase in people's reports of social inclusion between FY2001 and FY2002 predicted a higher reported value of Ask Me! data to the organization, independent of the personal value to the administrator. (See **Figure 23**.) Value to the administrators was higher when they had seen results from using the data. While personal analysis of the Ask Me! data was the strongest predictor of when the administrator had seen

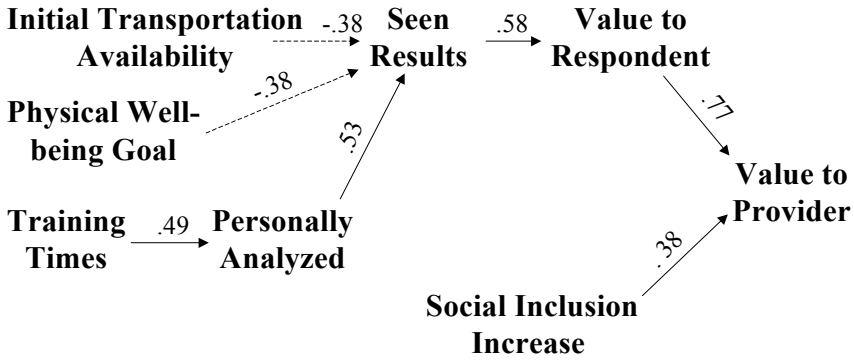


Figure 23. Value of Ask Me! to Provider by Quality of Life and Quality Assurance Goals

results, administrators in providers that had submitted physical well-being goals in the QA plans saw fewer results from using survey data than those that had not set physical well-being goals. The strong relation between transportation availability and quality of life discussed earlier in this report showed up in this model as well. The higher the initial score on the availability of transportation (and therefore the less it could increase), the less frequently administrators saw results from using the Ask Me! information. The number of times the administrator had attended training on the *Ask Me! Survey*, the more likely they were to have personally analyzed their Ask Me! data.

Advocacy

The Arc of Maryland, contractor to the Developmental Disabilities Administration for the Ask Me! Project, is a statewide organization advocating for people with developmental disabilities. The Arc of Maryland is committed to the core value of self determination in its advocacy efforts, and the survey data demonstrated the major impact that *choice* and *control* have on increasing quality lives.

The *Ask Me! Survey* results assist The Arc of Maryland in its advocacy for public policy change and system enhancement. It used Ask Me! data to develop its recent legislative testimony before the Maryland General Assembly on supported living. The testimony documented that individuals who receive support to live, work and participate in the community gave positive survey responses about their quality of life. The Arc of Maryland also used survey findings to craft recommendations and positions for state task forces and committees dealing with transportation, employment and self determination. The survey allowed it to keep the viewpoints of people with disabilities visible during major policy discussions about services in these areas.

In a time of significant changes in the service delivery system for people with developmental disabilities, Ask Me! data make available important information from the people most affected by changes in the system. The Ask Me! Project provides training and technical assistance for service providers in addition to collecting data. What people report in the survey sets the agenda and direction for this training. For example, the low scores in the domains of *self determination*, *social inclusion* and *rights* led project staff to focus on the significance of community connections and self determination during its FY 2003 training. The training provided information to those who support people with developmental disabilities on how to encourage more personal connections and self-determined lives. The Arc of Maryland has used the *Ask Me! Survey* results in applications for training grants to further reduce gaps in knowledge.

The Arc of Maryland has included survey data in its newsletters distributed to 5,000 members, public officials, service providers and sister advocacy organizations. A recent newsletter included an article on community connections and the important role these relationships play in the quality of the lives of people with developmental disabilities. Staff frequently makes presentations on employment, earnings, job choice, career advancement and other topics. The data collected through the *Ask Me! Survey* underscore the importance of these areas and give insight as to how they affect quality of life.

People on the Go of Maryland, the statewide self advocacy group, contributed to all aspects of the Ask Me! Project. It uses the data to assist with setting its priorities and agenda for statewide self advocacy. It noted the highly negative answers to the question on voting. As a result, People on the Go invited speakers to its meetings to discuss the importance of voting, and increased its efforts to help members understand how and where to register to vote. Individual self advocates influenced by Ask Me! have had impact. Two self advocates, both Ask Me! interviewers, had the opportunity to talk with the new Maryland governor during his election campaign about the importance of support services in the community. The governor referred to them in his justification for minimal budget cuts in developmental disabilities services during a time of severe cuts in most other state budget areas.

Discussion

Quality of Data

The Ask Me! Project collects important information in a consistent way from people with developmental disabilities that accurately reflects their quality of life. Ask Me! is people centered. It collects information on quality of life directly from people receiving services. It employs people who have received services to collect this information through personal interviews. It asks questions that people receiving services said were important to them. It involves people receiving services in discussions and presentations of the findings. Its procedures allow everyone with the ability to consent to answer for themselves, even when deaf, nonverbal or with profound retardation. The procedures guarantee privacy and confidentiality in relaxed settings. They ensure that all people respond to the same questions. They reduce error or bias that might occur at each step of collection, processing and analysis. They allow information to be compared across groups and time and focus on specific aspects while controlling for other differences between people and the services provided to them. The Ask Me! has well-established procedures for training interviewers to administer the survey to people who can hear and understand English.

Analysis has shown that people with disabilities show no inclination to respond negatively to questions about their quality of life (nay-saying) or to select the last response read by the interviewer (recency effect). The data collected to date cannot ruled out the possibility that people are giving more positive answers than they should, either because they think they are supposed to give positive answers (acquiescence), or they are selecting the first answer category they hear (order bias). However, the Ask Me! procedures included many of the recommendations Finlay and Lyons (2002) recommend to reduce acquiescence. All of the Ask Me! methodological studies to date suggested that the data are valid and reliably, and it is unlikely that other methodological studies would change this overall assessment. The value of Ask Me!, though, goes far beyond its validity and reliability.

Quality of Life

Most people in Maryland with developmental disabilities report positive qualities of life in all eight domains identified in the international literature. Their quality of life increased between

FY2001 and FY2003 in six of the eight domains. Much attention of the service delivery system in the past has focused on the physical and emotional well-being of people. This attention is reflected in the very high quality of life reported in these two domains, and the substantial increases that occurred in these domains. The potential for future change decreases as the measures of these two domains approach their highest values. Neither of these domains is explicitly referred to in the mission of DDA. The greatest potentials for measurable increases in quality of life are in the domains of rights and self-determination. These two domains received the lowest average quality of life scores in FY2001, with little change over the next two years. Self-determination, along with personal development and social inclusion, is specifically mentioned in the mission of DDA. Neither physical well-being nor emotional well-being directly contributes to people's rights and self-determination. Although physical and emotional well-being are foundational to a life of quality, the focus of services should switch to rights and self-determination, or to material well-being, interpersonal relations and personal development which are related to rights and self-determination.

The information people have provided through Ask Me! goes further to show how to improve people's quality of life. Transportation offers the greatest potential. The more transportation is provided, and the more people feel that this transportation is available to them when they want to go somewhere, the higher they report their quality of life in all domains. The next greatest potential is employment. People receiving employment services report higher qualities of life in all domains than do people receiving day habilitation services, controlling for their disabilities and location.

People served by some providers report much higher quality of life than people served by other providers. This is particularly true in the domains of rights and self-determination. Some of the differences among providers can be explained by vision, hearing and speech abilities of the people they serve, but not by their cognitive abilities. The greatest difference can be explained by the availability of transportation that they foster. However, one-third of the variability among providers in rights and two-thirds of the variability in self-determination remain unexplained. This suggests that providers have substantial ability to enhance the quality of life of the people they serve. The types of services provided, with the exception of employment services, do not matter. Nor does it matter if it is the sole provider or if it is one among several providing support. It does not matter in what part of the state the provider is located, nor its size.

Enhancing Services

Provider goals make a difference. The few providers that set goals of self-determination and social inclusion saw the quality of life increase in all domains among the people they served, and some of the increases could not be due to chance. In contrast, the three-fourths of the providers that set goals of physical well-being and the one-third that set goals of emotional well-being saw only decreases in the quality of life among the people they served, and some of these decreases had statistical significance. Goals in the other four domains, as well as goals to improve procedures, had no significant impact on people's quality of life. Perhaps most of the goals described in the quality assurance plans providers submitted to DDA reflected the values of the providers and not the values of the people they served. Most provider goals that could be classified as emotional well-being related to satisfaction with services. People may like services

"with a smile," but what they value are services that help them achieve the quality of life they want. When organizations can look beyond their values (e.g., satisfied consumers that keep attending so they can keep receiving DDA funds) and understand their consumers' values (e.g., quality of life), they can begin to enhance quality of life.

The majority of providers that participated in Ask Me! reported that the information it provided had value for them. The extent of that value, however, depended on the extent to which the providers had taken the time to understand, analyze and summarize what the people they support said. The training the Ask Me! Project provided helped them. The more they attended Ask Me! training, the more they analyzed the data. The more they analyzed the data, the more likely they saw results. The more they saw results, the more they valued Ask Me! information. Providers that had not included physical well-being goals in the quality assurance plans saw more results from using Ask Me! than those focused on physical well-being. Providers also rated the value of Ask Me! higher when they had experienced increases in social inclusion.

Enhancing services and managing for results, whether at the DDA system level or the individual provider level, requires that goals be established and monitored based on data. Ask Me! provides data directly from people with disabilities on their quality of life, and quality of life is or should be the goal of all parts of the disabilities services system. Data will not enhance quality of life unless they are used to guide the provision of services. DDA may need to promote and reward processes that enhance life quality. It may need to assist and monitor providers that have a hard time helping their consumers achieve higher qualities of life. Providers, however, should not wait for external changes. They have the ability to make changes immediately. They can share with other providers what seems to be working for the people they serve. They can ask for assistance from other providers when what they do does not seem to have the desired effect. In all cases they should involve the people they serve and ask them how they can better contribute to life quality. Without doing so, providers may focus on the wrong areas and not provide the services the consumer would choose.

Consumer Choice and Self-Determination

The developmental disabilities service system in the United States is moving in the direction of greater consumer choice and self-determination. A number of states have started publishing information collected from consumers to provide help in making informed choices. The DDA plans to publish results from the *Ask Me! Survey* in its *Guide to Services* following the FY2005 survey. People seeking services and their families will then have information on quality of life from people served to supplement the information on services from providers. During the four-year cycle from FY2002 to FY2005, the Ask Me! Project will have interviewed at least once at every provider serving ten or more people. Large providers will have had interviews in two or four of the years and their data will be averaged. By then, providers will have had time to try different ways to enhance their people's quality of life.

The magnitude of the Ask Me! database can support many additional or focused analysis. About two-fifths of the people supported by DDA will have been interviewed during the four-year period, with about 5% of them interviewed twice. Does continuity or change in the type of services best serve to enhance quality of life? Does continuity or change in providers enhance

quality? Does the level of DDA support for an individual make a difference in that person's life? Do the policies and procedures of DDA assist providers to enhance services? These and other questions may be possible to answer as additional information is linked to what people report in their Ask Me! interviews.

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