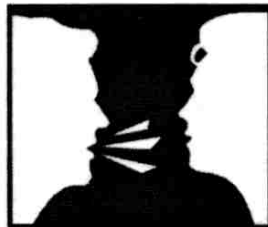


Ask Me!sm FY 2004

The Quality of Life of Marylanders With Developmental Disabilities



Receiving DDA Funded Support

Prepared for the
Maryland Developmental Disabilities Administration

by
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Committed and skilled interviewers, who themselves have received support funded by the DDA, make The Ask Me! Project possible. In FY2004, 35 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. They averaged 4.0 years of Ask Me! experience, with five interviewers having interviewed in all six prior years of the survey and three interviewers having interviewed for five prior years. One interviewer also served as a Regional Supervisor (RS) and two interviewers served as Quality Assurance Consultants (QA). Linda McKinley and Terri Allen worked for Bonham Research as Data Entry Clerks (DE). The Ask Me! FY2004 interviewers, with years interviewing in parentheses (), included:

Amy Grossman (2)	Faith Waugh (2)	Michael Raidt (5)
Anne Bates (1)	Fran Appold (7)	Missy Perrott (3)
Angela Weeda (2)	James Devore (7)	Patty Worff (5)
Angie Lepore (3)	Howard Holland (2)	Robert Haburchak (7)
Barbara Moore (1)	Howard Poteet (1)	Robert Heil (1)
Betsy Partrige (5)	Kenneth Capone (2)	Rose Marie Hancock (5)
Branden Frahm (2)	Kim Witt (5)	Scott Heim (6)
Brian Plater (3)	Kimberly Smith (5)	Terri Allen (1, DE)
Bridgette Pressley (6, QA)	Linda Cooper (3)	Tracy Wright (4, RS)
Carlo Harris (7, QA)	Lori Powell (6)	Vernon DeHaven (5)
Carolina Cano (1)	Michael Danzig (7)	Vicki Mills (4)
Diana Warther (2)		

Ask Me! has available a training manual for organizations interested in conducting the project in other states. The manual provides all necessary materials and information to conduct the survey. It 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. For additional information, contact Sarah Basehart, The Arc of Maryland, 49 Old Solomons Island Rd., Suite 205, 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 FY2004 survey was the third 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 FY2004 survey of 1,540 people from 44 providers, and presents findings from the combined FY2002-FY2004 *Ask Me! Surveys* of 3,692 people served by 88 providers.

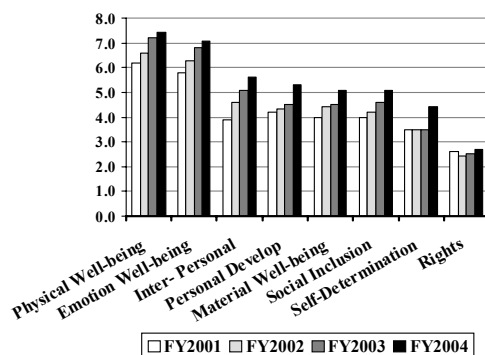
Among people supported by DDA, 57% are men, 71% are 25-54 years of age, and 27% are classified with severe or profound retardation. DDA funded residential support for 38% of the people, employment support for 27%, day habilitation for 47%, individual support services for 17%, community supported living assistance for 10%, and resource coordination services for 47%. People received an average of 1.9 services, with 76% receiving support from a single provider.

This report includes survey responses, information from staff about frequency of transportation, information abstracted from the quality assurance plans providers submitted to DDA in 2000-2003, and information from the DDA files. The findings suggest six conclusions and recommendations on ways community providers, DDA, and the total support system can best contribute to the quality of life of people with developmental disabilities.

1. Most people in Maryland with developmental disabilities reported a good quality of life that has improved over the past four years in most, but not all, of eight domains.
 - a. People reported that their quality of life increased continuously between FY2001 and FY2004 in six of the eight domains;
 - b. 94% reported positive physical and positive emotional well-being;
 - c. Interpersonal relations had the greatest increase;
 - d. Self-determination increased only in FY2004;
 - e. Rights of people did not change over the four years.

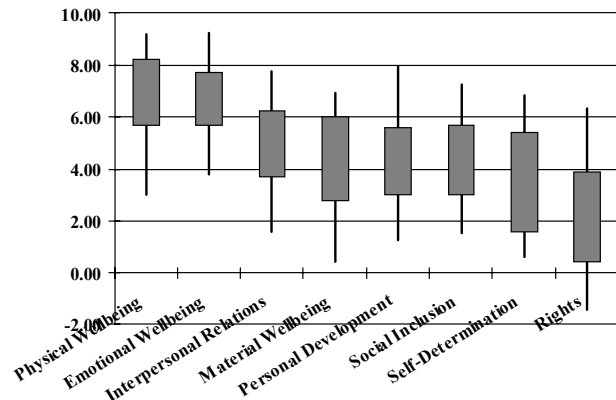
Recommendation 1: Physical and emotional well-being are foundational to a life of quality and should be maintained, but attention should now turn to increasing self-determination and rights.

Average Quality of Life by Year



2. The average quality of life reported by people supported by different providers varied, and only some of the variability could be explained by differences among their consumers.
 - a. People at most providers reported high physical and emotional well-being that varied little among providers;
 - b. The reporting of rights varied most by provider, with people at some providers reporting more negative than positive rights;
 - c. Self-determination varied next most showing that a number of providers were doing very well and others were not;
 - d. The physical, intellectual and behavioral characteristics of people has little relation to the quality of life they report, and explains little of the differences among providers;
 - e. The availability of transportation and employment have the greatest relation to the quality of life people report.

Quality of Life At Providers



Recommendation 2: Providers should recognize that their average quality of life scores are determined neither by the characteristics of the people they support nor the type of services they do or do not provide, and that no matter what types of supports they provide, they have a stake in people's quality of life.

3. The goals providers wrote in their quality assurance plans affected the quality of life of the people they supported in the following years.
 - a. 38% of QA plan goals related to process and organizational outcomes, not quality of life of the people supported;
 - b. 36% of the goals sought to increase people's physical well-being and personal development; 11% sought to increase rights and self-determination;
 - c. The quality of life increased in three domains at providers with rights goals and in two domains for

Number of Changes in Quality of Life by Provider Goals			
<i>Person-Valued Goals</i>	#	<i>Provider-Valued Goals</i>	#
Physical well-being	+4	Organizational	+1
Rights	+3	Other process	+1
Self-determination	+2	Consumer process	0
Personal development	+2	Staff process	0
Interpersonal relations	+1	Consumer satisfaction	-3
Social inclusion	0	Staff satisfaction	-5
Material well-being	0		
Emotional well-being	-5		

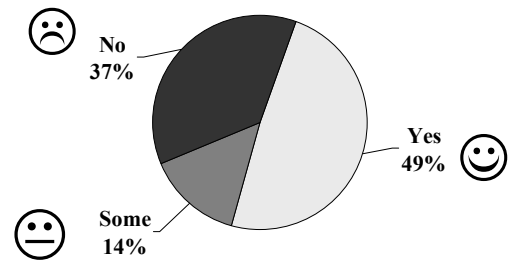
- providers with self-determination goals;
- d. The quality of life of people supported decreased significantly when providers set goals of consumer and staff satisfaction.

Recommendation 3: Providers of services need to keep their focus on the quality of life of the people they support. While it is expected that quality services will enhance quality of life, quality defined by others needs to be validated by quality defined by the people supported.

4. Self-determination and rights are the two domains in which the quality of life can increase most.

- a. 34% of people reported a negative quality of life in their rights to respect, dignity and equality, with no change over the past four years;
- b. 51% of people said they had little or no choice in picking who they lived with, and the overall level of self-determination did not increase until FY2004;
- c. Providers varied most in the rights and self-determination reported by the people they support, and few of the differences can be explained by the characteristics of the people they support or the services they provide;
- d. Quality of life significantly increased among the 12% of the providers who placed goals of rights in their quality assurance plans, and among the 26% who placed goals of self-determination in their plans.

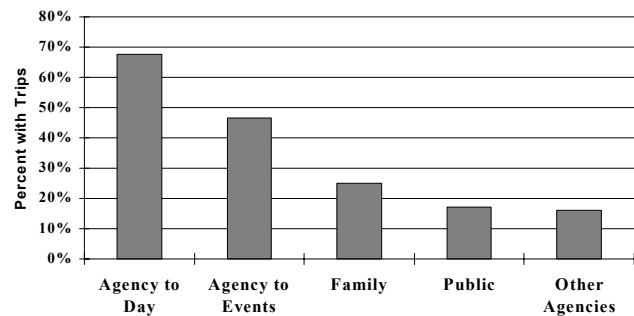
Did you pick who you live with?



Recommendation 4: Providers should set goals to increase rights and self-determination through the supports they provide, develop ways to increase rights and self-determination at the provider and state level, and develop measures to evaluate if these are effective.

- 5. The availability of transportation predicts people’s quality of life better than do their physical, behavioral or intellectual abilities:
 - a. The providers at which people were surveyed transported 68% of the people they

Source of Transportation



- supported to day habilitation or employment, and 47% to other activities and events;
- b. Staff-reported frequency of transportation predicted little of the availability of transportation as perceived by the people supported, and this perceived availability of transportation was the single most important predictor of quality of life in all eight domains;
- c. Perceived availability of transportation changed little from FY2002 to FY2004;
- d. At the provider level, greater use of public transportation by consumers independent of perceived transportation availability predicted higher quality of life in about half of the domains.

Recommendation 5: Providers should seek to help people find transportation that they will identify as available to them, and not rely on others to do so.

- 6. Employment support is the one type of service, other than transportation, that relates to higher quality of life for people.
 - a. People with supported employment authorized by DDA reported higher quality of life in seven of the eight domains than did people with day habilitation authorized;
 - b. Providers offering employment support services had higher quality of life scores in personal development, social inclusion and self-determination than providers not offering employment services;
 - c. DDA-authorized community supported living arrangements, individual support services and service coordination did not predict the quality of life of people in any domain; the percent of people to whom a provider gave these types of support did not predict the average quality of life reported at the provider;
 - d. Neither the number of providers supporting a person, nor the size of providers, had any relation to people's quality of life;
 - e. The Ask Me! Survey did not measure the appropriateness or quality of support services, and there remains a substantial amount of variation in quality of life that may be explained by these and other variables.

Recommendation 6: Providers should promote supported employment within their own organization or from other providers, and work with their consumers to increase the appropriateness and quality of the supports they provide.

The *Ask Me! Survey* collects information directly from the people supported in the community through funding from the Maryland Developmental Disabilities Administration. People report a high quality of life in the domains of physical well-being and emotional well-being, a quality that has increased over the past three years. They report lower quality of life in the domains of self-determination and rights. Rights has not changed at all over the past three years. Providers can make a difference in people's quality of life if they set goals of self-determination and rights. A provider is not constrained by the types of supports it offers in promoting self-determination and rights, nor is a provider constrained by the characteristics of the people it supports. Services that are most likely to enhance quality of life are those that support people to respond for themselves, to see transportation as available, and to move toward employment.

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Project Overview

The *Ask Me! Survey* collects information from people receiving support 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 support services. People's quality of life should be improved by the nature and quality of support they receive, although this support is mediated by people's values, perceptions, and other life experiences. Providers may overlook overall quality of life in a focus to provide quality services in a specific situation. Consumer satisfaction with a particular support may also be mistaken as consumers' satisfaction with their overall life quality. Ideally, the receipt of quality supports results in satisfaction with those supports and overall quality of life. However, different people may view quality of life differently, and the *Ask Me! Survey* allows people with developmental disabilities to define quality of life for themselves. People with developmental disabilities helped develop the survey instrument and procedures, promote the survey, conduct the interviews, and key the data into the computer. People with developmental disabilities have the opportunity to answer questions for themselves and share their experiences with providers who seek to understand how to use the survey information to improve support. The Ask Me! 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 combined data from the FY2002, FY2003 and FY2004 *Ask Me! Survey*. FY2004 is the third year of a four-year cycle during which 99% of the people supported by DDA will be represented, and all community providers supporting ten or more people will participate at least once. DDA's objectives in surveying consumers about satisfaction with their quality of life are to make the system more responsive to their desires, to improve support services funded by the DDA, and to provide Maryland consumers with information to help them make informed choices.

This report includes analysis of the quality assurance (QA) plans that community providers submitted to the DDA in 2000-2003 and their plans' relations with quality of life. These QA plans identify the ways providers intended to enhance the support they provided. Ask Me! data from the final pilot year of FY2001 and from FY2002-FY2004 provide insight into how these plans relate to the quality of life of the people supported, and how pursuing the plans did or did not increase the quality of the life reported by the recipients of support.

The Ask Me! Project began in 1996, and developed through a four-year pilot study (FY1998-FY2001) 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 three pilot years used a survey instrument with five quality of life domains adapted from Schalock and Keith's *Quality of Life Questionnaire* (1993). The FY1998 pilot included interviews for 237 consumers served by ten providers (Bonham, Pisa, Marchand, Harris, White & Schalock, 1998; Schalock, Bonham & Marchand, 2000). The FY1999 Ask Me! pilot included 535 consumers served by 21

providers (Bonham, Pisa, Basehart, Marchand, Harris, Heim and Ingram, 1999). The FY2000 pilot interviewed 735 people served by 28 providers. During this year, the project developed a new version of the *Ask Me! Survey* based on *Signs of Quality* written by People on the Go of Maryland (1996) and reflecting more recent research on the domains of quality of life. The new version included both an English and an American Sign Language version (Bonham, Basehart & Marchand, 2000). The final year of the Ask Me! pilot in FY2001 used the new survey instruments to interview 923 hearing people served by 33 providers and 56 deaf people served by two providers (Bonham, Basehart & Marchand, 2001).

The FY2002 Ask Me! Survey was the first of a four-year cycle that was planned to include people supported by all providers that support 55 or more people, and a sample of smaller providers. The sample expanded part way through the cycle to all providers supporting ten or more people. The FY2002 project interviewed 958 people from 33 providers (Bonham, Basehart & Marchand, 2002). The survey in FY2003 included 1,110 hearing people served by 36 community providers and 52 deaf people served by the two providers (Bonham, Basehart & Marchand, 2003).

The FY2004 Ask Me! Survey collected information for 1,540 people supported by 44 community providers. It also collected information from the quality assurance plans submitted to the Maryland Developmental Disabilities Administration by 109 community providers. Changes in the quality of life were calculated for 43 providers that were included in the survey at least twice during FY2001, FY2002, FY2003 or FY2004.

The Ask Me! Project has generated the following book chapters and journal articles:

- Basehart, S, Marchand, C & Bonham, GS. (2003.) "Ask Me!sm" A survey on quality of life designed by and for people with developmental disabilities. In Bradley, VJ & Kimmich, MH, Ed., *Quality Enhancement in Development Disabilities*. Baltimore MD: Paul H. Bookes Publishing Co., 163-177.
- Bonham, GS, Basehart, S, Schalock, RL, Marchand, CB, Kirchner, N & Rumenap, J. (2004.) Consumer Based Quality of Life Assessment: The Maryland Ask Me! Project. *Mental Retardation*, 42(5):338-355.
- Schalock, RL. & Bonham, GS. (2003). Measuring Outcomes and Managing for Results. *Evaluation and Program Planning*, 26:229-235.
- Schalock, RL, Bonham, GS & Marchand, CB. (2000.) Consumer based quality of life assessment: a path model of perceived satisfaction. *Evaluation and Program Planning*, 23:77-87.

Survey Background

Quality of Life Research

The concept of quality of life (QOL) is affecting program development, service delivery, management strategies, and outcome evaluation in a number of human service areas, including supports for people with developmental disabilities. It has three important aspects: 1) it is multidimensional and includes a number of domains of personal well-being, 2) a number of subjective and objective indicators of each of these core domains can be used for either quantitative or qualitative QOL assessments, and 3) the perception of the individual is the criterion that reflects the quality of life that he or she is experiencing, even though quality of life has both subjective and objective components (Schalock, 2001; Schalock & Verdugo, 2002).

Schalock and Keith (1993) developed a survey instrument with four dimensions of quality of life organized around general satisfaction and the three major support delivery principals of independence, productivity and community integration. Their survey had been widely used, and the Ask Me! Project initially simplified the wording of their survey to make it easier for people with developmental disabilities to administer and answer the survey, and to add a dimension of quality of life not included in that survey, a dimension we labeled dignity. During this time, other researchers had suggested as many as fourteen dimensions of QOL (Hughes & Hwang, 1996). Schalock, who advised the Ask Me! Project, documented eight basic domains to quality of life. He and his co-author found these eight domains in the international literature of

- **Social Inclusion:** The integration into and participation in one's community, the expression of valued social roles, and the receipt of social support 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 the receipt of health care
- **Interpersonal Relations:** The experiencing of social interactions and relationships (with family, friends, peers) and receiving support (emotional, physical, financial and 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 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 performance exhibited (includes creativity and personal expression)
- **Rights:** The expression of human rights (respect, dignity and equality) and the guarantee of legal rights (citizenship, access and due process)

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

intellectual disabilities literature, as well as in the international literature of education, mental health, physical health and aging (Schalock & Verdugo, 2002). They found that the eight domains had been studied in different amounts. Social inclusion had been studied the most and rights had been studied the least. (See **Figure 1.**) The new survey developed for the FY2001 Ask Me! Included these eight domains, measuring them with questions that self-advocates had earlier defined as important to them.

Participatory Action Research

The increased understanding of QOL during the last decade occurred simultaneously with the emergence of participatory action research (PAR). PAR is an approach to research and evaluation that relies on stakeholders to identify the elements of their lives that warrant investigation for potential change, and to participate in the investigation and change process. PAR is appropriate for studying the QOL of individuals with intellectual and developmental disabilities. They can contribute to our understanding of how quality of life should be conceptualized, what QOL looks like to them, and how to improve QOL outcomes (Gardner, 2000; Gettings, 2001; Pennell, 2001; Whitney-Thomas, 1997). The Ask Me! Project involves three QOL and PAR-related premises: (1) people with developmental disabilities can and should identify the specific issues that are important to their quality of life, (2) people with developmental disabilities can and should be asked directly about their own lives, and (3) interviewees with developmental disabilities are in the best position to elicit meaningful responses from their peers. Three-fourths of the questions included in the Ask Me! Survey came from questions that the Maryland self-advocacy group had developed as *Signs of Quality* prior the Ask Me! Project (People on the Go, 1996). The Ask Me! Project involved self-advocates in refining the survey instrument and in planning survey procedures. It used simplified language and response formats to maximize self-response. The project trained people with developmental disabilities to survey their peers, and used experienced interviewers to help train new interviewers and to observe interviews for quality control purposes. It provided job opportunities and career paths for people with developmental disabilities, including promotion to supervisory positions.

Purposes of Ask Me!

The Ask Me! Project reflects the rapidly emerging importance given to consumer outcome measurement and the need for programs to measure outcomes and manage for results (Schalock & Bonham, 2003). Consumer-based quality of life assessment can be useful for quality management on three levels: provider-level continuous program improvement; state-level for establishing goals and monitoring the mental retardation and developmental disabilities system; and advocacy-level choice of supports and self-determination. The most important use of consumer-reported quality of life information is for continuous program enhancement at the provider level (Schalock, 2001). Quality support should help people with developmental disabilities live as independent and satisfying lives as possible. Therefore, the perception of those receiving support is an important component in evaluating services. The Ask Me! Project began as a component of a consent decree to which DDA agreed to survey people receiving

support services. DDA planned for the data to go to the community providers and encouraged them to use their results as measures of achieving goals. DDA used the Ask Me! results to measure achievement of its own goals of personal development, self-determination and social inclusion as required by the state budgetary process. DDA plans to include Ask Me! Survey results in its Guide to Services at the conclusion of each four-year cycle.

Findings from Ask Me! have been presented each year at workshops for Maryland providers. Ask Me! teams have also made presentations and conducted workshops at the national conferences of the U.S. Administration on Developmental Disabilities Commissioner's Forum (2003), the American Association for Mental Retardation (2003), The Arc of the United States (2002), the National Association of State Directors of Developmental Disabilities Services (2001), the Improving Quality Conference (2001), the TASH (2001), and the President's Committee on Mental Retardation (1999, 2000). Most recently, Ask Me! Findings were presented at the International Society for Quality of Life Studies (2004). Four book chapters and journal articles have presented the methods, findings and uses of the data for an even broader examination and use (Basehart, Marchand & Bonham, 2002; Bonham, et al., 2004; Schalock & Bonham, 2003; Schalock, Bonham & Marchand, 2000).

Project Description

Sample

The FY2004 Ask Me! Project collected information between August 2003 and June 2004 for 1,540 people with developmental disabilities served by 44 community providers. The sample represented 11,226 adults (18 years and over) with community supports funded by DDA and represented 114 of the 134 providers that provided them support in the community.¹ The DDA file of about 24,795 person-support-provider records in July 2003 formed the basis for sampling. The first sampling step involved stratifying providers by their size in July 2001, and then assigning them for interviews according to a four-year cycle. (See **Figure 2.**) The second stage involved randomly selecting a primary sample of 40 people and a secondary sample of 10 people from each provider. All the people were selected if the provider served fewer than 50 people. Ask Me! attempted interviews with all the people in the primary sample. When this resulted in fewer than 30 completed interviews for the provider, Ask Me! interviewed some or all of the people in the secondary sample to achieve 30 completed interviews.

<p>Strata 1 (300+ people)</p> <ul style="list-style-type: none">• 10 providers support 37% of people• Sampled every year, 10 in FY2004 <p>Strata 2 (130-299 people)</p> <ul style="list-style-type: none">• 22 providers support 27% of people• Sampled every 2 years, 11 in FY2004 <p>Strata 3 (55-129 people)</p> <ul style="list-style-type: none">• 40 providers support 25% of people• Sampled every 4 years, 10 in FY2004 <p>Strata 4 (10-54 people)</p> <ul style="list-style-type: none">• 42 providers support 10% of people• Sampled every 4 years, 17 in FY2004 <p>Strata 5 (1-9 people)</p> <ul style="list-style-type: none">• 20 providers support 1%• Not included in sample

Figure 2. Provider Sample Frame

Every person served by a provider had the same probability of selection, so no weights were needed for analysis within providers. Weights were needed for analysis that included people from more than one provider in order to reflect the different probabilities of provider selection. Weights were applied to data presented in this report so that they accurately reflect all adults receiving DDA-supported community services as of July 2001 (FY2002), July 2002 (FY2003), or July 2003 (FY2004 and FY2002-FY2004). Some people surveyed at small providers represented only themselves, while others surveyed at largest provider represented 35 people. The combined FY2002-FY2004 data was based upon 3,692 people served by 88 providers

Interviewers

The Arc of Maryland employed interviewers for The Ask Me! Project who themselves had received supports 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-

¹Four of these should probably be considered as programs within parent providers as they did not submit separate quality assurance plans to the state.

advocacy skills. Accommodations were made for interviewers who required augmentative communication strategies and technology.



Figure 3. Interviewer Training Session

The Arc of Maryland and Bonham Research conducted a centralized one-day training at the beginning of the survey period for both new and experienced interviewers. (See **Figure 3.**) Following the centralized training, interviewers in four regional teams met regionally for additional interviewing practice prior to their first actual on-site interview session. Monthly regional training also occurred throughout the interview period for continuous quality improvement. Quality improvement 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! Project employed 34 individuals with developmental disabilities as interviewers in FY2004. They averaged 4.0 years of prior experience. Five interviewers had worked on all six prior years of the project. Interviewers conducted three-fifths 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 recorded 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 a single interviewer to conduct the interview. Interviewers conducted an average of 72 interviews, with five interviewers conducting fewer than ten interviews and ten interviewers conducting 100 or more interviews.

Survey Procedures

Provider staff contacted the selected individuals or their guardians to explain the survey and to secure initial agreement to participate. The providers then made the necessary arrangements to get their people to the interview sites. After the people to be interviewed arrived, the Ask Me! coordinator gave them information about the Ask Me! Survey 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 interviewer teams assigned to the people asked them a series of questions to make sure they understood enough to consent to the interview. (See **Figure 4.**) The teams then asked the person to sign a form giving consent to be interviewed and to have their providers give

information on the frequency of their transportation.

Three-fourths (76%) of the interviews took place at the respondents' day locations. One-eighth (12%) took place at the respondents' homes, one-eight (11%) were conducted by telephone, and the remainder took place in other locations. The interview room included other people for only 16% of the time. The interview team assisted the person by pointing to "happy" (☺), "neutral" (☹), and "sad" (☹) faces as they read the three response choices. As interviews ended, the Ask Me! session coordinator thanked the person 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.



Figure 4. Typical Interview Setting

Response

The *Ask Me! Survey* selected 2,154 person-provider records from 44 providers for the FY2004 primary and secondary samples, with 70 people selected twice. However, 123 of the names in the secondary sample were not needed and the project never contacted the people. (See **Appendix Table 4.**) An additional 40 people turned out to be ineligible for interview because they no longer received DDA-supported services according to DDA files at the end of the year (including those who had died or moved out of Maryland), were less than 18 years of age, or were Ask Me! interviewers. These people did not figure in calculating response rates. Over half (57%) of the people selected for and eligible for interviews responded to the survey for themselves. (See **Figure 5.**) An additional 21% agreed to participate in the survey, but did not have the ability to answer the questions for themselves. Interviewers interviewed two

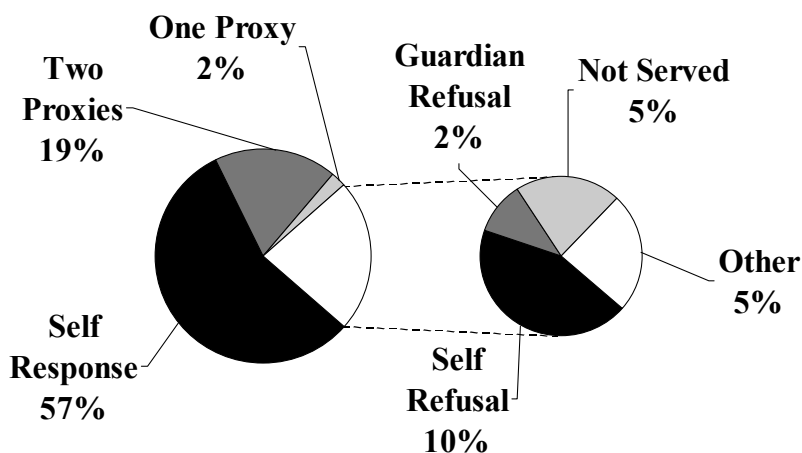


Figure 5. Response of People Eligible and Selected for Interview: FY2004

interviewers interviewed two proxies for most of these people and one for the rest. The *Ask Me! Survey* did not obtain interviews for the remaining 22% of the people. Half of those not interviewed (10% of the total)

refused the interview themselves, and an additional 2% had 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 these people as eligible for support. The remaining 5% 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.

Ask Me! obtained information for 3,690 people over the three years. (See **Appendix Table 6.**) It collected information for as few as 11 people at one small provider and as many as 103 people at a large provider with interviews all three years. Ask Me! collected information for 76% of the people initially identified in the sample. It completed surveys for 90% or more of the sampled people at thirteen of the 88 providers, but completed surveys for fewer than half of the sampled people at three of the providers. Three-fourths (73%) of the information came from people responding for themselves. Almost all of the people classified with none to mild retardation responded for themselves. (See

Figure 6.) About half of those with severe retardation, and one-fifth of the people with profound retardation, responded for themselves. Self-respondents provided the information for 90% or more of the surveys at 21 providers, and for less than half of the surveys at 10 providers.

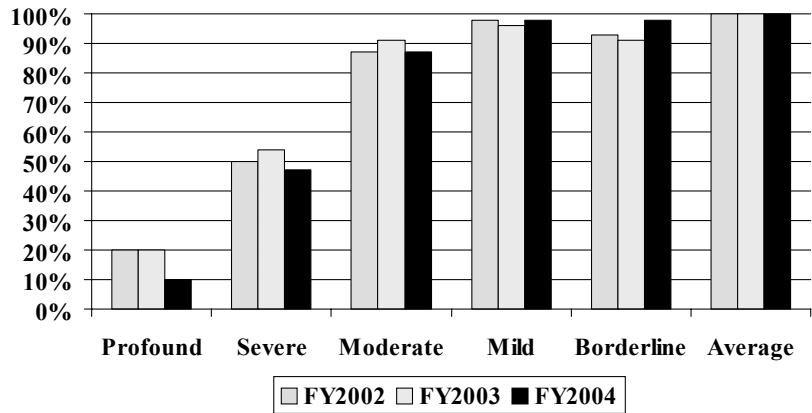


Figure 6. Percent Self-Response: FY2002-FY2004

Quality of Life

Quality of Life in Maryland

The *Ask Me! Survey* includes six indicator questions for each of the eight quality of life domains. The project calculated a quality of life score from the responses to indicator questions if a person answered at least four of them. It calculate emotional well-being scores for 3,664 people (99%), showing almost universal response to questions at the beginning of the interview. (See **Figure 7.**) It calculated material well-being scores for 3,354 people (91%) from questions near the end of the survey. 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 domains of emotional and physical well-being, where 94% of the people had positive scores, with average scores of 6.8 and 7.1. People rated their quality of life lowest in the domains of rights and self-determination. Fewer than four-fifths had positive scale scores and the average scores were under 4.0. People varied the least in their reporting of physical and emotional well-being (standard deviations of about 3.6) . They varied the most in their reporting of rights and self-determination (standard deviations of about 5.0). Fewer than four-fifths of the people had positive scores on the transportation availability scale, a measure that will be discussed in a later section as a major predictor of quality of life.

<i>Domain</i>	<i>% Positive</i>	<i>Avg. Score</i>	<i>Std. Error</i>	<i>Std. Dev.</i>	<i># People</i>
Rights	66	2.6	.087	5.0	3364
Self-determination	79	3.9	.083	4.9	3499
Social inclusion	85	4.7	.073	4.4	3596
Material well-being	85	4.7	.073	4.2	3354
Personal development	86	4.8	.074	4.4	3505
Interpersonal relations	89	5.1	.070	4.2	3573
Emotional well-being	94	6.8	.060	3.6	3664
Physical well-being	94	7.1	.061	3.6	3482
Transportation availability	77	4.1	.078	4.5	3340

Figure 7. Quality of Life Scores: FY2002-2004 Combined

The FY2001 Ask Me! Project piloted the survey used in subsequent years. Although this pilot did not represent a true probability sample of people supported by DDA, it included a representative sample of 979 people served by 35 providers throughout Maryland. Including the results from the FY2001 pilot year shows a continuous improvement in the quality of life of people in Maryland with developmental disabilities in six of the eight domains. The percent of people reporting positive physical well-being steadily increased from 86.7% in FY2001 to 94.0% in FY2004. (See **Figure 8.**) Emotional well-being increased in a similar way from 87.3% in FY2001 to 93.9% in FY2004. Future increases in these two domains will be constrained by the fact that no more than 100% of the people can have positive quality of life. On the other hand, the percent with positive scores on rights changed inconsistently over the four years, with the FY2004 percent only 1.2 points higher than the FY2001 percent. Self-determination increased only 0.7 percentage points between FY2001 and FY2003, and then

increased substantially by 7.2 percentage points between FY2003 and FY2004. The overall four-year increase in self-determination, however, remained less than the change in four other domains, and the inconsistency in reporting over the four years cautions against assuming a trend has begun. The greatest increase between FY2001 and FY2004 occurred in the domain of interpersonal relations (13.4 percentage points), social inclusion (10.3 percentage points), and personal development (9.4 percentage points).

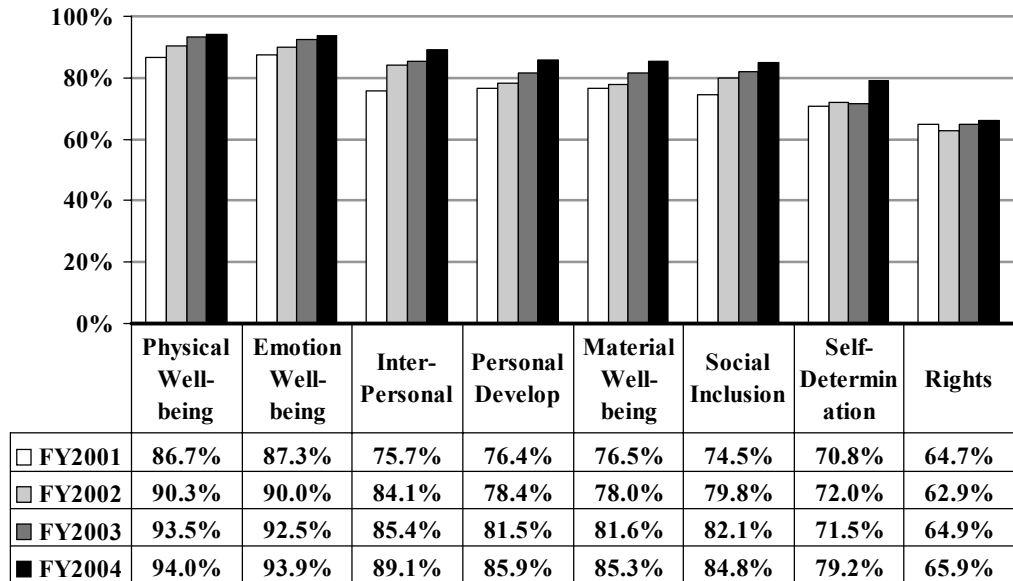


Figure 8. Percent with Positive Quality of Life, by Domain and Year

The average quality of life scores show a similar pattern of change between FY2001 and FY2004, increasing steadily over the four years in six of the eight domains. (See **Figure 9**.) The average reporting of rights barely changed between FY2001 and FY2004, and self-determination increased only between FY2003 and

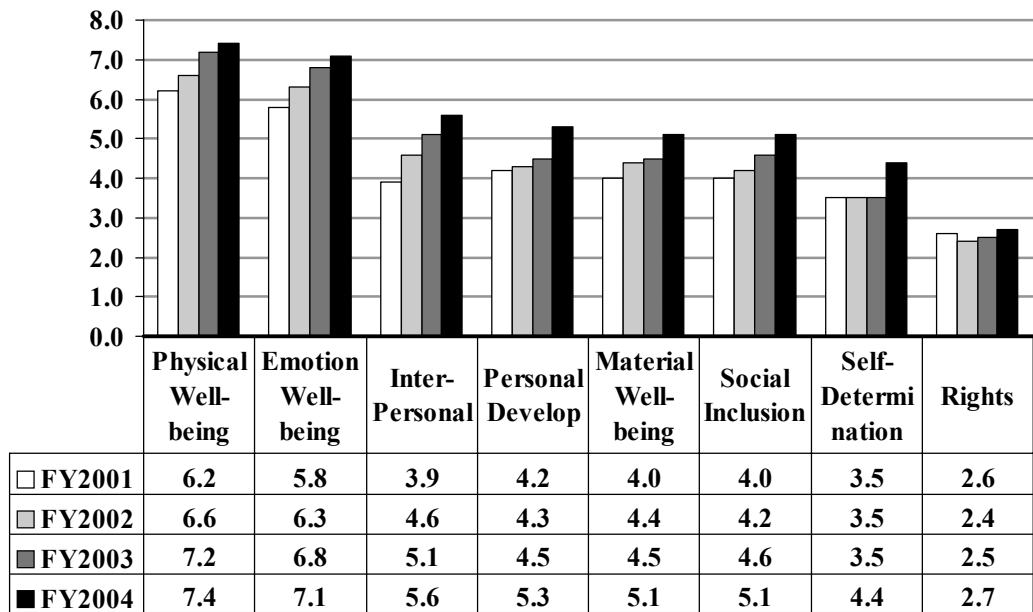


Figure 9. Average Quality of Life Scores, by Domain and Year

FY2004. The four-year change in self-determination was still less than in the other six domains. The greatest change over the four years came in the domain of interpersonal relations (1.7 points). The least change came in the domain of rights (0.1 points).

Eight questions received favorable (☺) answer from over three-fourths of the respondents during the three years combined. (See **Figure 10**.) Three of the questions related to physical well-being: 90% said the people they lived with never hit or hurt them, 80% felt that people had the right level of concern about their

#	Question	% ☺
37.	Do staff or people you live with hit or hurt you? ☺	90%
1.	Would you say that you are a happy person?	80%
32.	On health, are people concerned the right amount? ☺	80%
25.	Do you get the services you need? ☺	78%
35.	Do you have regular check-ups with a dentist?	77%
4.	How safe do you feel in your neighborhood? ☺	77%
5.	Do you like yourself?	77%
23.	Learning things that will make you a better person? ☺	77%

Figure 10. Questions with the Most Favorable Responses: FY2002-2004

health, and 77% had regular checkups with a dentist. Three of the questions related to emotional well-being: 80% said they were a happy person, 77% felt very safe in their neighborhood, and 77% liked themselves. The remaining two questions related to personal development: 78% said they got the services they needed and 77% said they were learning things that would make them a better person. The percent of favorable responses to five of these eight questions increased each year from FY2002 to FY2004 (indicated by ☺ following the questions).

Five questions received a negative (☹) response by 30% or more of the people for the combined FY2002-FY2004 surveys. (See **Figure 11**.) Two of these questions were in the domain of rights: 63% of the people said they never voted in governmental elections, and 32% said they could not lock the bathroom door if they wanted. One of the questions was in the domain of self-determination: 35% said they did not pick with whom they lived. The fourth question was in the domain of personal development: 51% said they did not get the information they needed about sexuality. The fifth question related to

transportation availability, not a domain of quality of life but a strong predictor of it. Two of these five questions progressively received more negative responses each year between FY2002 and FY2004 (indicated by ☹ following the questions).

#	Question	% ☹
49.	How often do you vote in government elections? ☹	63%
24.	Do you get the information you need about sexuality?	51%
26.	Did you pick who you live with?	35%
52.	Have to ask and plan days ahead for transportation? ☹	34%
45.	Can you lock the bathroom door if you want to?	32%

Figure 11. Questions with the Most Negative Responses: FY2002-2004

These findings suggest that the greatest opportunities for improving quality of life can occur in the domains or rights and self-determination. They are the domains where the quality of life

people report is the lowest, where one-third or more report negative responses to at least one question, where the greatest variation among people occurs, and where the least change has take place over the past four years.

Rights and Self-Determination

The summary scale scores for the rights domain showed small and inconsistent change over the four years of *Ask Me! Surveys*. All of the individual questions that make up the scale show similar small or inconsistent changes. (See **Figure 12**.)

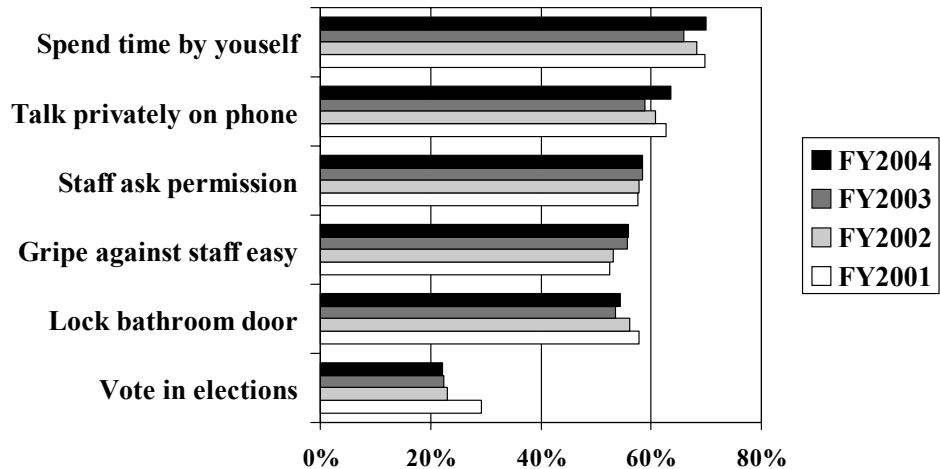


Figure 12. Percent with Favorable Response to Rights Questions, by Year

The decrease in voting participation over the three years may relate to the national election cycle. However, there seems to be no external reason why fewer people felt they could lock their bathroom doors in FY2004 than in FY2001. The previous figure showed only the percent giving the favorable response. **Figure 13** shows the full distribution of responses in FY2004. One-third (34%) of the people said they never could lock the bathroom door if they wanted to, and an additional 12% said they could lock it sometimes, but not always when they wanted to lock it. Thus almost half felt they lacked rights on this indicator of privacy.

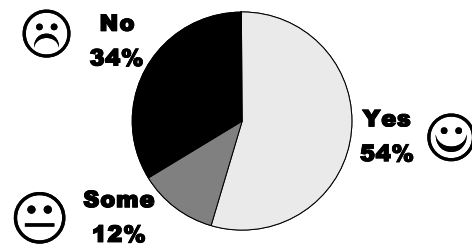


Figure 13. Percent Able to Lock Bathroom Door: FY2004

The average self-determination score did not change from FY2001 to FY2003, but increased greatly in FY2004. All six of the component questions received more positive responses in FY2004 than in FY2003, but they varied greatly in the pattern of change from FY2001 to FY2003. (See **Figure 14**.) Only the question about paying for things with their own money showed a consistent increase from year to year. The least favorable (most negative) change came in response to the question about picking with whom they lived. This declined from 54% in FY2001 to 47% in FY2003, although it increased slightly to 49% in FY2004. Choice in food

had a similar pattern of primarily negative change.

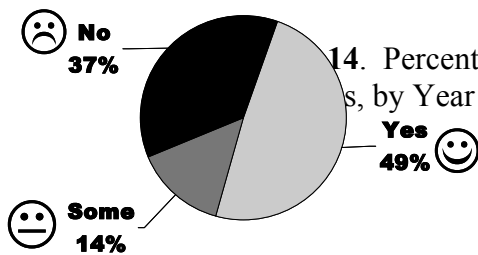
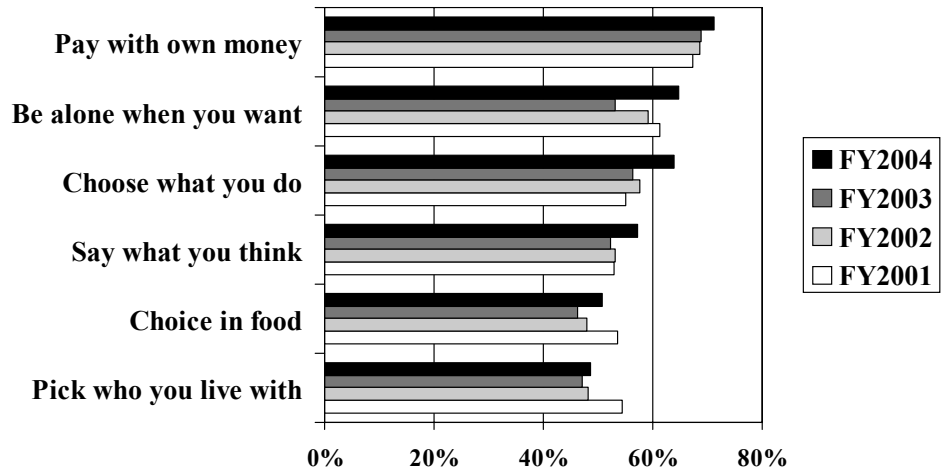


Figure 15. Percent with Choice with Whom They Live: FY2004

A closer look at responses to house-mate choice in FY2004 shows that 37% of the people supported by DDA felt they had no choice at all with whom they lived. (See **Figure 15.**) An additional 14% said they had some choice. Thus half of the people felt they had no or limited

opportunity for self-determination in one of the most important areas of a person's life.

Responses to All Questions

The FY2002-FY2004 combined responses for all the questions on the Ask Me! Survey are shown in **Table 2**. The six questions for each of the eight quality of life domains are grouped in the order in which they were asked. The question that best represents a domain is shown in **bold** type, but eliminating any question would reduce the reliability of the scale scores (except Q24 in Personal Development). The 25 questions to which people gave increasingly positive responses from FY2002 to FY2004 (the three years with statewide statistical sampling) are indicated by a happy face (☺). The two questions to which people gave increasingly negative responses over the three years are indicated by a sad face (☹). The responses to the remaining 26 questions varied from year to year without any noticeable trend.

**Table 1. Percent Giving Each Response to Survey Questions:
Ask Me! FY2002-FY2004**

	1 ☺	2 ☹	3 ☹	Total
<i>Emotional Well-Being</i>				
1. Would you say that you are a happy person?	80	16	04	100
2. How do you feel about your home where you live?☺	67	26	07	100
4. How safe do you feel in your neighborhood?☺	77	14	09	100
5. Do you like yourself?	77	18	05	100
6. Do you feel that others treat you the same as any other person?☺	63	26	11	100
7. In general, how happy are you with your life?☺	70	25	05	100
<i>Social Inclusion Scale</i>				
8. Do people help you to be part of your community?☺	73	18	09	100
9. Do you go to fun things in your community?	65	23	12	100
10. When you go to fun things, are you active?	60	27	13	100
11. Do you think your neighbors like you?☺	67	26	07	100
12. How many friends.....from church, synagogue & comm. orgs.?☺	46	35	19	100
13. How often do you see your friends on weekends?	36	43	21	100
<i>Interpersonal Relations Scale</i>				
14. Do people help you learn how to do things for yourself?	61	30	10	100
15. When you make a mistake, do people help you?☺	71	21	08	100
16. When you set goals, do people help you reach them?☺	74	17	09	100
17. How often do you see or talk with your family?☺	58	28	14	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?☺	66	25	09	100
<i>Personal Development Scale</i>				
20. Does your job or what you do make you feel important?☺	70	21	09	100
21. Are you getting the training that will help you get a job/better job?	55	21	24	100
22. Do others give you a chance to become what you want to be?☺	65	23	11	100
23. Are you learning things that will make you a better person?☺	77	17	06	100
24. Do you get the information you need about sexuality?	37	12	51	100
25. Do you get the services you need?☺	78	14	08	100
<i>Self-Determination Scale</i>				
26. Did you pick who you live with?	49	16	35	100
27. Can you be alone when you want to?	60	20	20	100
28. How much choice do you have in the food you eat?	49	29	22	100
29. Do you get a chance to say what you think?	55	27	18	100
30. Do you pay for things you buy with your own money?☺	69	19	12	100
31. Did you choose your job or what you do most days?☺	61	22	17	100

**Table 1. Percent Giving Each Response to Survey Questions:
Ask Me! FY2002-FY2004 (Continued)**

	1 ☺	2 ☹	3 ☹	Total
<i>Physical Well-Being Scale</i>				
32. On....health, are people concerned, too concerned, not care?☺	80	12	08	100
33. Is your health good, fair or poor?	73	20	08	100
34. Would you say your eating habits are good, fair or poor?☺	73	19	08	100
35. Do you have regular check ups with a dentist?	77	13	10	100
36. Can you get the sleep you need without being disturbed?	75	16	10	100
37. Do staff or people you live with hit or hurt you?☺	90	06	04	100
<i>Material Well-Being Scale</i>				
38. How many things do you own, like furniture, TV, etc.?	52	38	10	100
39. How often do you worry..money pay rent or buy food?	66	19	16	100
40. On money, do you feel you are well off, have problems, are poor?	61	26	13	100
41. Do you have money each week to spend on what you want?☺	68	22	10	100
42. Save money every time you get paid, sometimes, or never?	54	30	15	100
43. Do you have the chance to earn good money?	58	19	24	100
<i>Rights Scale</i>				
44. Do staff ask before they come into your home or room?☺	58	22	20	100
45. Can you lock the bathroom door if you want to?	56	12	32	100
46. Can you talk on the telephone in private?	62	13	25	100
47. Can you spend time by yourself if you want?	68	17	14	100
48. When you have a gripe against staff, is it easy to say something?	56	24	20	100
49. How often do you vote in government elections?☹	23	14	63	100
<i>Transportation Scale</i>				
51. When you want to go somewhere, do you have transportation?	71	19	09	100
52. Can you just....go, have to plan some, or many days ahead?☹	27	39	34	100
53. If you set up a ride, can you depend on it?☺	73	17	10	100
54. Do you miss...have to change plans because of transportation?	51	31	18	100
55. Do transportation problems make you feel separate from others?	59	23	18	100

NOTES:

Bold Indicates question most representative of the domain (whose elimination reduced Alpha the most).

☺ Increase each year in the percent with the favorable response

☹ Decrease each year in the percent with the favorable response

a) The less favorable response was used when proxies differed, e.g., if one proxy gave code 1 and the other gave code 2, the person was included in the percent reporting code 2.

b) Each percent was independently rounded, so the three numbers may not sum to 100 percent.

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

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 others. The Maryland DDA, however, has clearly defined social inclusion, personal development, and self-determination in its mission statement as desired outcomes from supports to 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 16**.) 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. The size of the arrow represents the size of the direct effect of one domain on another. The domain at the tail of a straight arrow is hypothesized to affect or cause the domain at the head of the arrow. When no arrow is shown between two domains, any effect is indirect, operating through an intermediate domain. The double headed curved arrows at the left of the model show that the domains of emotional well-being, physical well-being and material well-being are related but without any hypothesis of which causes which.

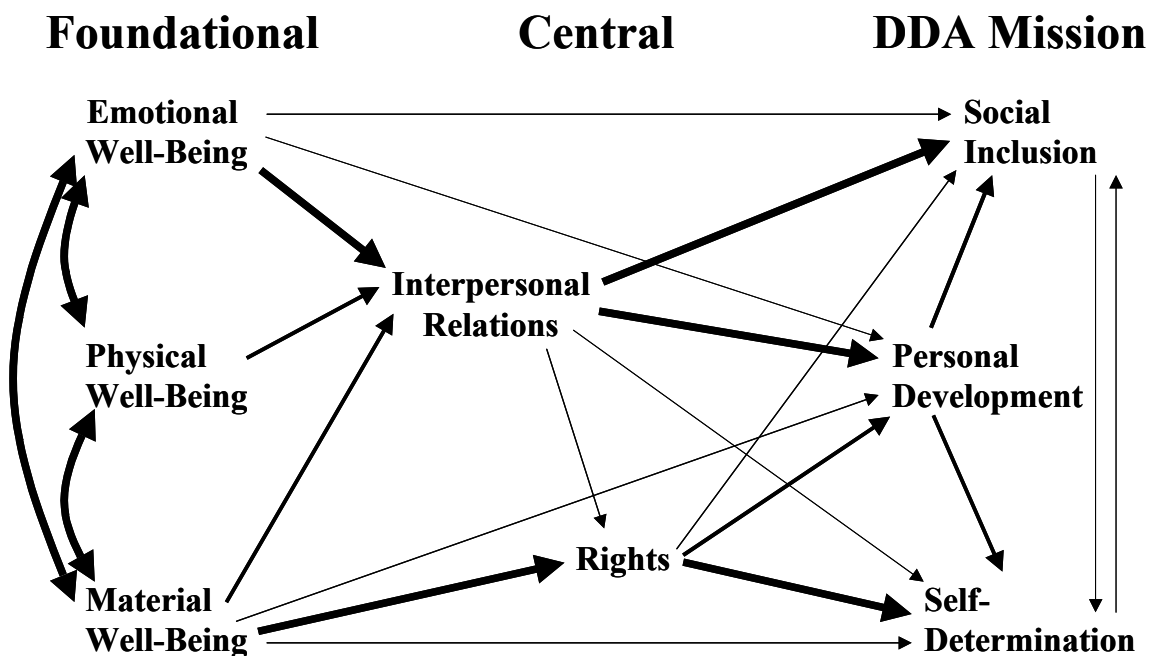


Figure 16. Path Model of Relations Among People's Quality of Life: FY2002-2004

The first analysis of 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 combined data from FY2002-FY2004 did not show as clear a direction of causality between personal development and social inclusion, nor between personal development and self-determination. The three-year 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 FY2001 model which the combined weighted data fit remarkably well. The paths that point to rights suggest the best way to increase the sense of rights is to increase people's sense of material well-being ($\beta = .32$). The best way to increase self-determination would be to increase rights ($\beta = .39$) and personal development ($\beta = .24$). Personal development appears central in quality of life, related to all other domains except physical well-being. Interpersonal relations ($\beta = .38$) and rights ($\beta = .28$) had the strongest effect on personal development.²

The path model suggests that physical well-being, emotional well-being and material well-being were foundational. All three affected interpersonal relations. However, physical well-being did not directly affect rights, personal development, self-determination and social inclusion. Emotional well-being did not directly affect rights and self-determination, and material well-being did not directly affect social inclusion. The path model suggests that interpersonal relations and rights are intermediate between the foundational qualities of life and the long-range outcome qualities of life included in DDA's mission statement.

The path model suggests that a focus on the foundational quality of life domains will have more limited effect than focusing on the other five. In addition, 94% of the people reported positive qualities of life in the domains of physical well-being and emotional well-being and gave the highest average score to these two areas. This limits the amount of increases that can occur. While the interpersonal relations domain was directly related to all the other quality of life domains, 89% 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 the domains of rights, self-determination and personal development would contribute most to people's overall quality of life.

²A β coefficient of 1.0 indicates a perfect direct relationship, -1.0 a perfect inverse relationship, and 0.0 would indicate no relationship.

People Receiving Support

The 3,692 survey respondents in combined FY2002-04 *Ask Me! Surveys* represented a random sample of individuals receiving support from 88 participating providers. These providers supported as few as 10 people funded by DDA, and as many as 1,176 people. The 88 providers represented two-thirds of all community support providers funded by DDA, three-fourths of those supporting ten or more people, and 89% of the people receiving DDA support services.

Demographics

People selected for the Ask Me! Project each year represent a random sample of adults receiving residential, employment, day or other supports from community providers funded by the Maryland

Developmental Disabilities Administration

(DDA). DDA provided support for

12,971 people on July 1, 2003. About 5% of these were children under the age of 18 and excluded from the *Ask Me! Survey*. Among those 18 years and over, 15% were under the age of 25, 25% were 25-34, 26% were 35-44, 20% were 45-54, 10% were 55-64, and 5% were 65 years and over. (See **Figure 17**.) They averaged 39.8 years of age, younger than the general adult population of Maryland. A greater percent of the adults supported by DDA than in the general adult population of Maryland were less than 45 years of age, and a smaller percent than in Maryland as a whole were 45 years of age and over (Maryland State Data Center, 2002). Only 5% of people with developmental disabilities were 65 years and over compared with 15% of the Maryland adult population. Men comprised 57% of the adults supported by DDA and 47% of all Maryland adults.

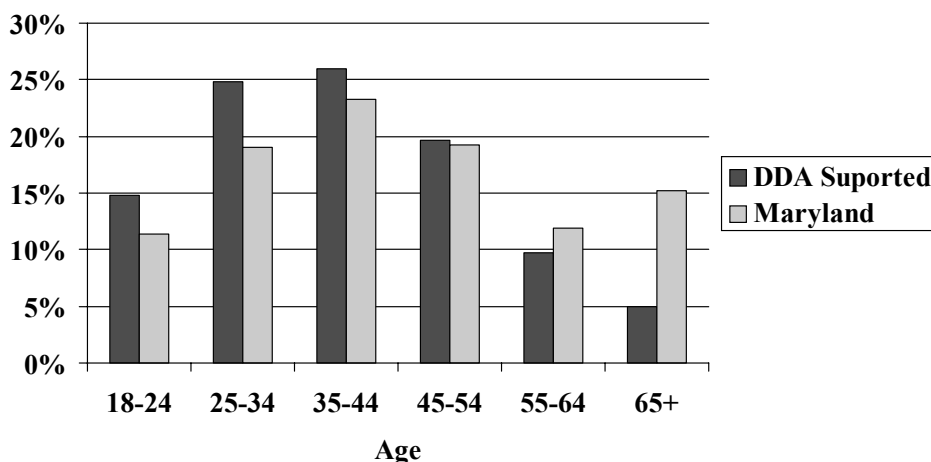


Figure 17. Percent of DDA and Maryland Adults by Age, July 2003

Disabilities

Among the 12,971 people supported by the Maryland DDA, 80% (10,438) had a classification of mental retardation. (See **Figure 18** for disabilities and impairments that affected more than 500 people.) Many people had more than one disability or impairment. Speech and language impairments affected 25% (3,272) of the people. Epilepsy and seizure disorders affected 21%. One person in seven had behavior problems.

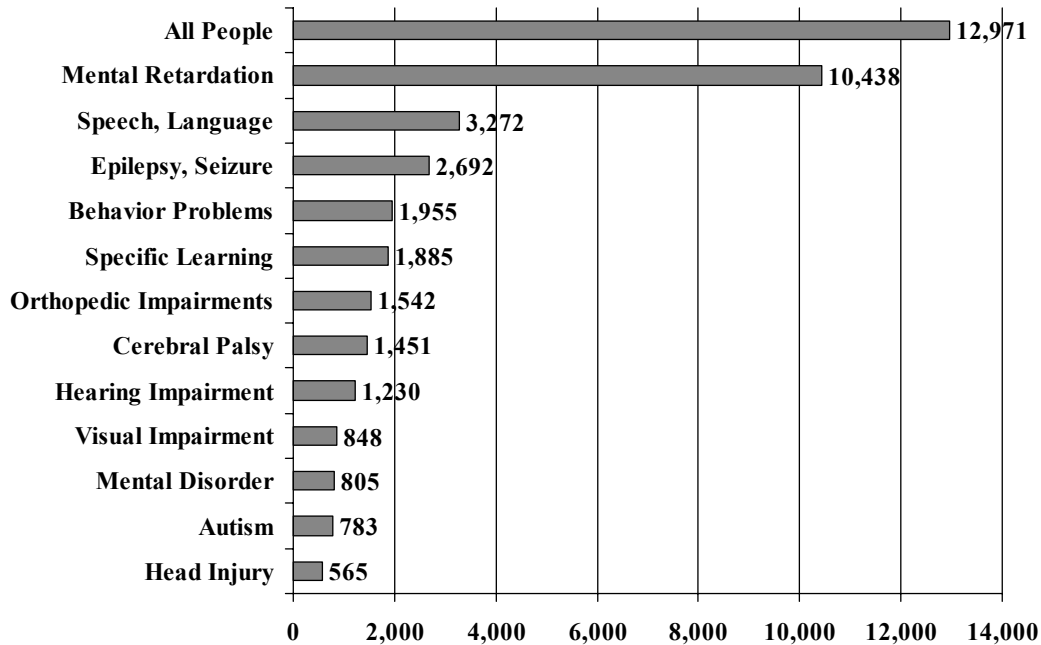


Figure 18. Number of People Supported by DDA by Disability: July 2003

The DDA files did not identify level of retardation, so the Ask Me! Project requested providers to classify people into one of six levels of retardation on the Transportation Form. 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. A few were reported to have normal intelligence (2%) or borderline retardation (4%). One-fourth (28%) had classifications of mild retardation, one-fourth (25%) had moderate retardation, and one-fourth had severe or profound retardation. (See **Figure 19.**) As discussed earlier, some people classified with profound retardation could respond for themselves, and level of retardation is used only as a statistical control. Intellectual ability does not determine a person’s quality of life, even though the ability to understand and respond for oneself has some relationship.

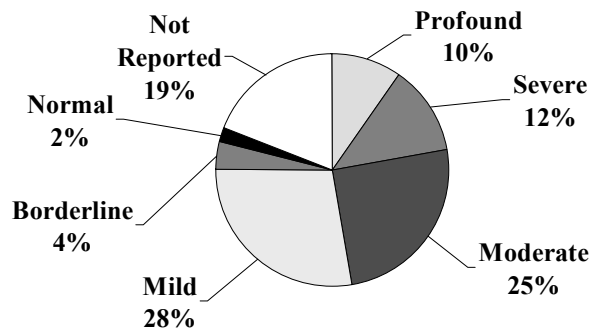


Figure 19. Percent by Level of Retardation: FY2004

Supports

Of the 12,971 people supported by DDA on July 1, 2003, about half (6,133) received resource coordination from a provider who did not provide them other community supports. (See **Figure**

20.) Excluding resource coordination, 76% of the people supported by DDA in the community received all their support from a single provider. Almost all the others (23%) received support from two different providers, with 1% receiving support from three or four different community providers. During the day, two-fifths (5,474) of the people received (or were authorized to receive) day habilitation support and one-fourth (3,454) received employment support.

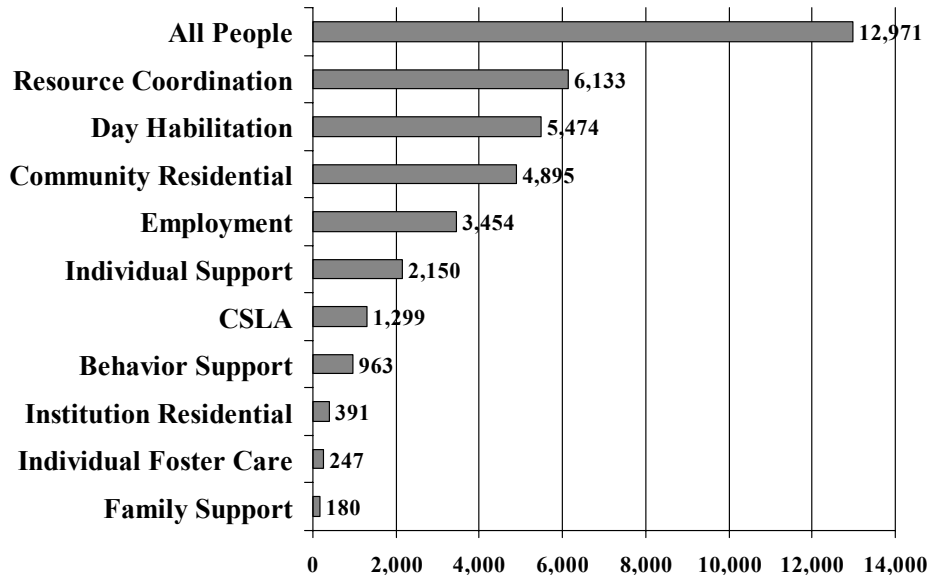


Figure 20. Number of People by Type of DDA Supported Services: July 2003

One-third of the people (4,895) received residential support from community providers. One-tenth received community supported living assistance (CSLA), 3% resided in one of the four state institutions, 2% lived in individual foster care. One person in six received individual support services and 7% received behavior support services.

The providers at which they were selected provided 68% of the people with transportation to their employment or day program with an average of 5.0 round trips per week. (See **Figure 21.**) These providers transported 47% of the people to other types of activities and events with an average of 3.1 round trips per week.

Family and friends transported 25% of the people with an average of 2.7 round trips per week. One-sixth (17%) of the people rode public transportation an average of 4.2 times a week, and 16% received transportation from providers other than the one through which they were

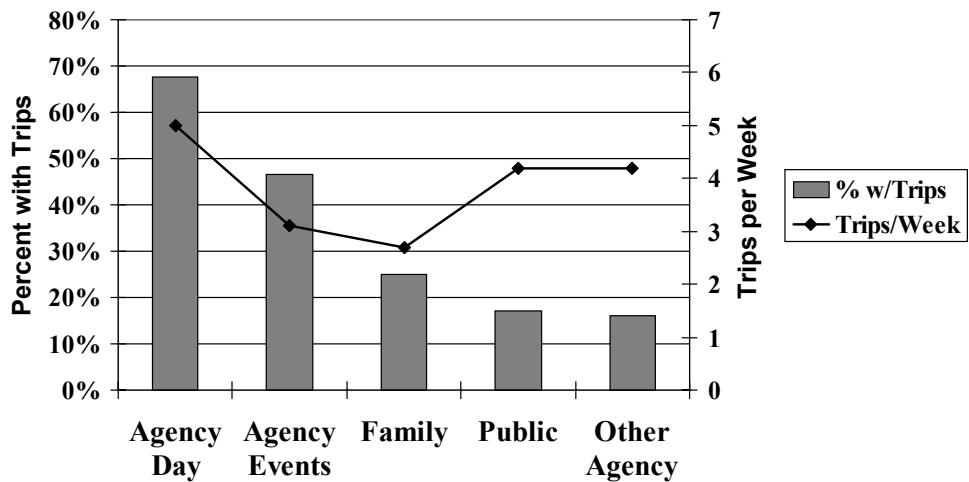


Figure 21. Percent with Transportation and Round Trips per Week by Type: FY2003-2004

selected for the survey, averaging 4.2 round trips per week. Trips by other providers may have been under-reported as staff at one provider may not know what another provider does. These trips by other providers could have been to either employment/day programs or to other activities and events.

Providers transported 87% of the people each week. Half of these people (43%) had transportation from providers for both day activities and other activities. (See **Figure 22**.) Most of the rest (35%) had provider transportation only to their employment or day programs. A few (1%) had transportation only from providers other than the one through they were interviewed, and data were not collected on the destination of this

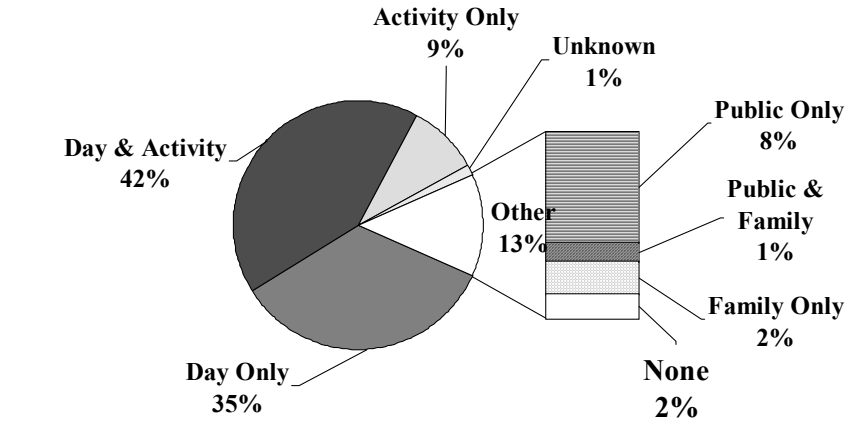


Figure 22. Destination of Transportation by Providers: FY2003-2004

transportation (transportation from other providers was assumed to be for the opposite destination of that from the sample provider.) Neither the sample nor other providers transported 13% of the people, but 8% used public transportation to go where they needed to go, 2% depended on family and friends, and 1% used a combination of public transportation and family/friends. Few (2%) of the people were explicitly reported by providers as having no transportation during a week from any source.³

The last five questions on the survey asked people about how available they thought transportation was for them. The average score on a scale of -10 to +10 of transportation availability did not change consistently over the years. (See **Figure 23**.) One cannot be certain whether FY2004 reflects a change in a trend or whether the three years with statistically weighted representative samples showed about the same availability, and the lower score in FY2001 reflected a lack of statistical representation.

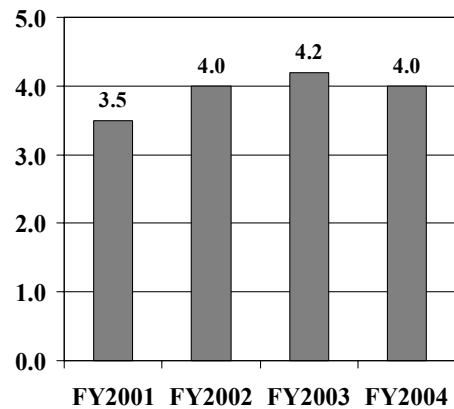


Figure 23. Transportation Availability Score by Year

The differences by year could also reflect some differences in proxy reporting. Proxies reported transportation scores 3.2 points higher than people

³Providers for 6% of the people in FY2003 and 16% of the people in FY2004 did not report transportation for those whom they supported.

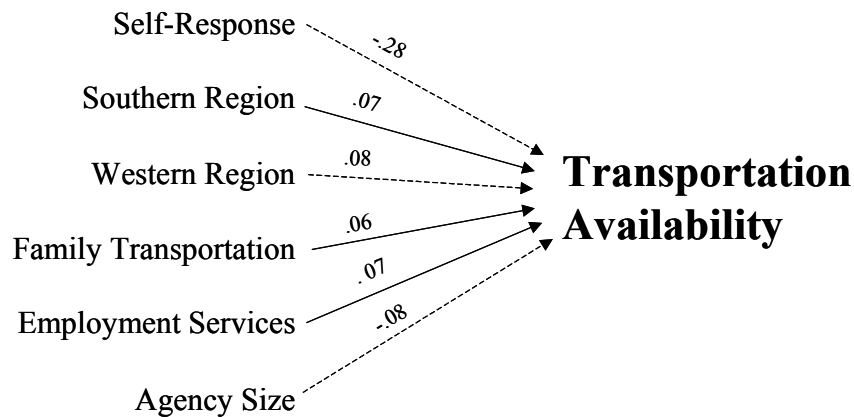


Figure 24. Characteristics Predicting Transportation Availability: FY2002-2004

reported for themselves, and self or proxy reporting explained more of the variation in transportation availability (path coefficient of -.28) than all other characteristics combined. (See **Figure 24.**) The region of the state in which people lived influenced views on transportation availability. People living in the Southern DDA Region that includes the Washington, D.C. Maryland suburbs, and people living in

the Western DDA Region, saw transportation as more available to them than did people living in the Central or Eastern Shore DDA Regions. People who received employment supports also saw transportation as more available than did people who received day habilitation support or neither of these supports. The only objective measure of transportation that predicted perceived availability of transportation was the frequency with which family or friends transported people.⁴ The size of the provider had a relationship, with people supported by larger providers seeing transportation as less available. These six variables explained 13% of the variability among people in their perceptions of the availability of transportation. The number of times a week providers took people to day activities, the number of times they took them to other activities, and the frequency of using public transportation did not affect perceived availability of transportation.

Predictors of Individual’s Quality of Life

Characteristics of people and their supports predicted about 26% of the variation in their reporting of rights and self-determination, 16% of their reporting of personal development, and 12% of their variation in reporting social inclusion. (See **Appendix Table 8** for R^2 .) Transportation and employment were the best predictors of quality of life. People’s perceived availability of transportation was the single most important factor, predicting people’s quality of life in all eight domains. The actual number of times per week the sample or other providers transported people gave additional predictions to people’s quality of life in five domains, including three of the four focal domains of this report. (See first column under each quality of life measure in **Figure 25.**) The more times the sample provider transported people to day

⁴The number of times family and friends transported the person in a week was available for FY2003 and FY2004 only. When dichotomous variables of transported or not transported were used so FY2002 data could be included, provider transportation 3+ times a week predicted transportation availability and family transportation did not.

reported intellectual ability (level of retardation) added additional prediction in the domains of rights and self-determination, and in the domain of personal development when transportation availability was not included. The greater importance of self-reporting than externally judged level of retardation on predicting quality of life may reflect either 1) self-reporting is a better measure of intellectual abilities than standard IQ tests or 2) proxies see things differently than do people themselves. The table shows that people with epilepsy and seizure disorders reported slightly lower levels of rights and personal development than those without this disorder when transportation availability is included, but not when transportation availability is excluded. It shows that older people reported less personal development than did younger people, as well as lower social inclusion when transportation availability is not included. It shows the deaf and hearing-impaired people reported lower social inclusion than those without hearing impairments, but only when transportation availability is included. Most of the support and person characteristics available for analysis did not offer any additional prediction of quality of life either when transportation availability was included or when it was excluded from analysis. (See **Figure 26.**)

<i>Support Characteristics</i>	<i>Person Characteristics</i>
DDA authorized CSLA support	Gender
DDA authorized day habilitation	Autism
DDA authorized individual support	Behavior problems
DDA authorized service coordination	Blindness and visual impairment
Provider trips to non-day activities	Cerebral palsy
Trips by family and friends	Head injury
Trips on public transportation	Mental disorder
	Orthopedic impairment
	Other neurological impairment
	Specific learning disability

Figure 26. Characteristics That Do Not Predict Individuals' Quality of Life

Community Providers of Support

Quality Assurance Goals

Maryland had 114 community providers in July 2003 that supported at least ten people. The Ask Me! Project interviewed at 88 of these providers during FY2001-FY2004: six in all four years, nine in three of the years, 27 in two of the years, and the rest in only one year. The 42 providers with more than one wave of surveys represent 39% of the community providers in Maryland and provide 66% of the support services. DDA had 109 quality assurance (QA) plans submitted to it by these community providers between January 2000 and August 2003.⁷ About half of the first interviews occurred before or during the year the providers submitted their QA plans and about half in subsequent years. The second, third or fourth interviews occurred after the providers had submitted their QA plans. While it is possible that results from the first interviews could have affected QA plans, it is not possible that changes in results between two survey waves could have affected QA plans. Therefore, it is hypothesized that any relationship between QA plans and change between two interview waves reflects a causal effect of the QA plans on changes in quality of life.

DDA staff coded the first four goals that providers included in their QA plans. One-third (38%) of these QA plan goals related to organizational process and organization-level outcomes. While these might be expected to increase the likelihood of good person-level outcomes, they are not the same as person-level outcomes (Schalock and Bonham, 2003). Quality of care is not the same as quality of life. One-third (36%) of the goals in the QA plans related to people's quality of life in the two domains of physical well-being and personal development. The remaining 26% of the QA goals related to the six other quality of life domains. The most frequent type of goal (64) in the QA plans involved the physical well-being of the people supported, generally their safety, health and health care. (See **Figure 27.**) Half of the physical well-being goals were the first-listed goals, and nine plans included two or more physical well-being goals. Half (53) of

<i>Domain</i>	<i>1st</i>	<i>2nd</i>	<i>3rd</i>	<i>4th</i>	<i>Any</i>
QOL Physical well-being	32	22	17	8	64
QOL Personal development	16	25	15	7	53
Staff process	16	1	16	11	44
Consumer satisfaction	13	7	10	5	32
QOL Self-determination	7	10	6	7	28
Other organization process	10	8	7	12	25
QOL Social inclusion	5	3	6	7	21
QOL Material well-being	5	4	5	2	14
QOL Rights	3	4	3	3	13
Consumer process	3	8	4	2	12
QOL Interpersonal relations	0	4	3	2	9
Staff satisfaction	1	1	1	3	6
Other organization outcomes	2	2	2	1	6
QOL Emotional well-being	<u>1</u>	<u>0</u>	<u>0</u>	<u>1</u>	<u>2</u>
Total	109	108	95	71	109

Figure 27. Number of Providers by Type of QA Goals in the order listed

⁷Four of the community providers identified on the July 2003 DDA file were part of the QA plan submission of the parent organization and should not have been listed separately. One organization did not submit a QA plan.

the QA plans included a goal related to the domain of personal development, most frequently as the second listed goal. Ten plans had more than one personal development goal. Two-fifths (44) of the plans included goals related to staff process, such as writing job descriptions, recruiting qualified staff, training staff, and supporting and evaluating staff. Staff process was most often listed as the third goal, and three plans contained two or more staff process goals. One-fourth (32) of the plans included consumer satisfaction with supports as a goal, frequently as the first goal. Consumer satisfaction with support is an organization-valued outcome that is substantially different from consumer satisfaction with life, an individual-valued outcome that was classified under emotional well-being if not further qualified. Plans infrequently included quality of life goals in the domains of emotional well-being, interpersonal relations, rights and material well-being.

The goals that 89 providers⁸ included in their quality assurance plans had almost no relation to the quality of life reported during their first (or only) Ask Me! interviews. Providers that included physical well-being goals in the QA plans, however, did have significantly lower self-determination ($r = -.21, p < .05$) and rights ($r = -.19, p < .10$) scores during the first Ask Me! Survey than did providers without physical well-being goals.

The average quality of life for the 42 providers that had two or more surveys conducted during FY2001 to FY2004 increased in seven of the domains over one, two or three years. (See **Figure 28.**) Most of these increases were statistically different from zero based on t-tests. No statistical change occurred for the domain of rights. In general, the longer the period of time, the greater the increase in the quality of life. However, changes over all three time periods could be calculated for only the six providers surveyed in all four years. Changes over one and two years could be calculated for four other providers interviewed in FY2002, FY2003 and FY2004, and changes over one and three years for five providers. Changes over three years only were calculated for two providers, changes over two years only for 14 providers, and changes over one year for 11 providers. The patterns of increases over different lengths of time suggest that it takes providers longer to affect quality of life in the areas of self-determination and personal development than in most other domains, and they have not paid much attention to increasing their consumers' perceptions of their rights.

<i>Domain</i>	<i>1 year</i>	<i>2 years</i>	<i>3 years</i>
Social inclusion	0.65*	0.90*	1.28*
Self-determination	0.06	0.64*	1.11*
Personal development	0.25	0.65*	1.26*
Rights	-0.07	0.44	0.22
Interpersonal relations	0.66*	0.97*	1.50*
Emotional well-being	0.78*	0.84*	1.22*
Physical well-being	0.75*	0.74*	1.33*
Material well-being	0.88*	0.54*	1.27*
<i>Number of providers</i>	<i>25</i>	<i>31</i>	<i>13</i>

* Different from zero at $p < .05$

Figure 28. Increase in Quality of Life Scores Over One, Two or Three Years

While the quality of life in all eight domains generally increased, the amounts of the increase differed by the goals providers included in their quality assurance plans and by the length of the

⁸One provider interviewed in FY2001 will be next interviewed in FY2005.

time period. Some of these differences were statistically significant, but generally not in the domain of the goal. Physical well-being goals increased the quality of life in four domains: rights over two years, material well-being over two years, self-determination over three years, and personal development over three years. (See **Figure 29**.) QA plan goals in the domain of rights increased the quality of life over two years in three domains: emotional well-being, physical well-being and material well-being. Goals for self-determination increase the quality of life in two domains: interpersonal relations in both one year and two years and material well-being over one year.

<i>QOL Goals</i>	<i>#</i>	<i>Provider Goals</i>	<i>#</i>
Physical well-being	+4	Organizational	+1
Rights	+3	Other process	+1
Self-determination	+2	Consumer process	0
Personal development	-4/+2	Staff process	0
Interpersonal relations	-1/+1	Consumer satisfaction	-3
Social inclusion	0	Staff satisfaction	-5
Material well-being	0		
Emotional well-being	-5		

Figure 29. Number of Quality of Life Domains Affected by Quality Assurance Plan Goals

QA goals that focused on the organization or its staff resulted in little improvement in the quality of life of the people served. Goals to improve organizational process (e.g., annual review of quality manual, develop document control procedures, incident reports and investigations, home inspection) improved interpersonal relations after three years. Goals to improve organizational outcomes (e.g., stakeholder satisfaction, support coordinator satisfaction, compliance with state standards) improved physical well-being in the first year. Goals related to consumer and staff satisfaction had negative consequences. Consumer satisfaction is frequently mistaken as a valued outcome for the people served rather than a valued outcome for the provider of the supports. Community providers that included goals of consumer satisfaction witnessed declines in the average quality of life of the people they served in three domains: interpersonal relations after both one and two years, material well-being during the first year, and physical well-being after three years. A focus on staff satisfaction, however, was even more detrimental after two years with reduced physical well-being, social inclusion, personal development, emotional well-being and material well-being.

Detailed analysis of the 31 providers surveyed two years apart, either during FY2001 and FY2003 (14 providers) or during FY2002 and FY2004 (17 providers), showed that five of these providers had goals in their QA plans that related to people's rights. The quality of life reported by people supported by these providers increased more than among people supported by other providers in all eight domains. The differences reached statistical significance in three domains: material well-being, emotional well-being, and physical well-being. (See **Figure 30**.) Eight providers included goals in the QA plan related to self-determination. The quality of life among people supported by these providers increased over the two years in all eight domains, increased more than at providers without self-determination goals in six domains, and increased statistically more in the domain of interpersonal-relations. The 16 providers that had QA goals of personal development experienced increases in quality of life in all eight domains, higher than average increases in six domains, and statistically higher increases than providers without personal development goals in the domains of personal development and self-determination.

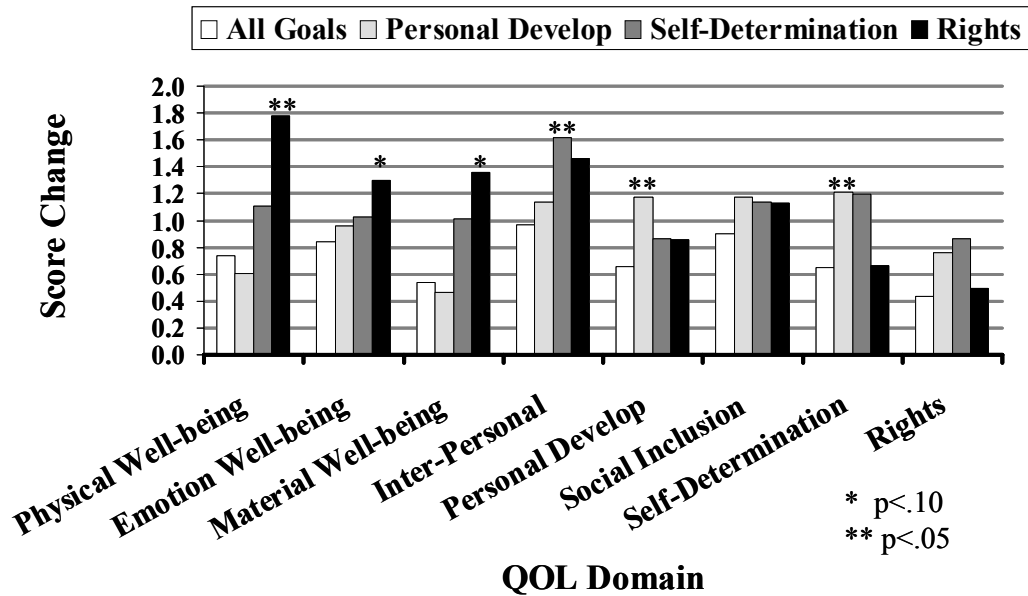


Figure 30. Two-Year Increase in Quality of Life Domain Scores by QA Plan Goal

The emotional well-being goals of two providers resulted in a two-year decrease in self-determination, social inclusion and material well-being, and lower than average increases in three additional domains. (Results not shown.)

Quality of Life Variation

The average quality of life reported by people varied by providers. Only in the domain of rights did any providers have negative quality of life scores, with averages ranging from -1.5 to 6.3. The range was almost as great among providers in the self-determination scores that ranged from 0.6 to 6.8. (See **Figure 31**). The least variation among providers occurred in the domain of emotional well-being with the lowest average score of 3.8 and the highest average score of 9.2. In general, average provider scores within the range shown by the solid boxes were not significantly different from the overall Maryland average, and included 70% of the community providers. One-fifth of the community providers had average scores above than the solid boxes, and one-tenth had average scores below the solid boxes. Thus, 20% of the providers had rights scores of 3.9 or higher and 10% had rights scores of 0.5 or lower. Similarly, 20% had average self-determination scores of 5.4 or higher, while 10% had average self-determination scores of 1.6 or below.

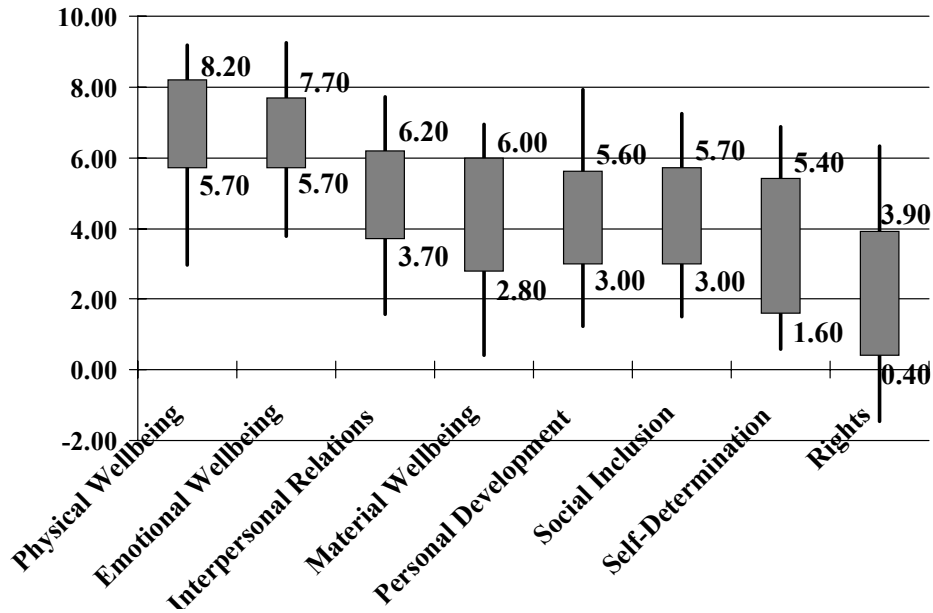


Figure 31. Range of Quality of Life Scores Among Providers: FY2002-2004

The earlier path model in **Figure 16** showed the significant relationships among the quality of life domains reported by individual respondents. A similar path model for the 88 support providers showed the relationships among the average QOL domain scores of the people they supported. The two path models showed many similar relationships. (See **Figure 32.**) At both the provider and individual levels, self-determination was most affected by rights, and rights was most affected by material well-being. At both levels, social inclusion was most affected by interpersonal relations.

Physical well-being had the fewest significant relationships to other quality of life domains, so improvements in the average physical well-being at a provider will do little to enhance people's overall quality of life. The models at the two levels were different in some ways. Self-determination affected social inclusion at the

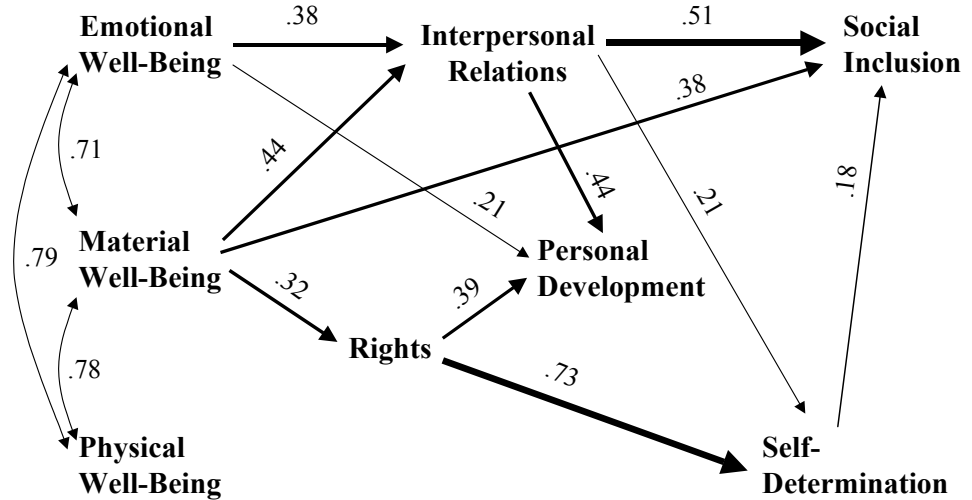


Figure 32. Path Model of Relations Among Provider Quality of Life Scores: FY2002-2004

provider level, and not the reverse as was observed at the individual level. The average level of personal development at the provider level did not have the impact on either social inclusion or self-determination that personal development had at the individual level.

Predictors of Quality of Life at Providers

Some characteristics of the 88 providers included in Ask Me! to date predicted from two-fifths of the variation among providers in average social inclusion ($R^2 = .40$) to two-thirds of the variation in average physical well-being ($R^2 = .67$) when people's perceived transportation availability was included. Objective provider characteristics alone explained about half this amount (R^2 between .15 and .38). (See **Appendix Table 9** for R^2 .) The average provider score on transportation availability best predicted the average provider score in all eight quality of life. In addition, the greater the percent who used public transportation, and the lower the percent whose families or other providers transported them, the higher the quality of life in four domains. When only objective characteristics of the providers were considered (excludes transportation availability), the greater the percent using public transportation, the greater the percent transported by the provider, or the smaller the percent transported by family and friends, the higher the quality of life in five domains.

Providers differed most in average scores in the domains of self-determination and rights, and provider characteristics explained more of the differences in these two domains than in any of the others, with the possible exception of physical well-being. Transportation availability predicted higher quality of life in all four of the focal domains. (See **Figure 33**, first column under each domain.) When

availability was included, the greater the percent of people reported by staff as transported by other providers, the lower the personal development and self-determination scores. With or without transportation availability, the greater the percent of people transported by family and friends, the lower the levels of personal development. The importance of employment shows up at the provider level as well as the

individual level. The greater the percent of the people to whom the provider offered supported employment, the higher the quality of life in the domains of personal development, social inclusion and self-determination. Providers in the western DDA region also had higher scores in self-determination with or without know perceptions of transportation availability, and higher

	Personal Develop	Social Inclusion	Self Determine	Rights
• Transport Available	+ na	+ na	+ na	+ na
• % Other Provider Trips	-		-	
• % Family/Friends Trips	- -			
• % Supported Employment	+	+ +	+ +	
• Western DDA Region		+	+ +	+
• % Self-reporting	+		+ +	+ +
• % Blind Vision Impair	-			-
• % Deaf Hearing Impair		-		
• % Epilepsy & Seizure				-
• % Speech & Language			-	
• Average Age	- -			

Figure 33. Characteristics Predicting Provider Quality of Life: FY2002-2004

levels of rights and social inclusion if only objective measures were included.

Six characteristics of the people supported by providers added some prediction in the focal domains. The greater the percent of people at a provider who responded to the survey for themselves, the higher the level of rights and self-determination (and possibly personal development) they reported. Visual impairments, hearing impairments and speech impairments related to one or two domains, but only when transportation availability was also included in the analysis. Regardless of the inclusion of transportation availability, the higher the average age of consumers, the lower their reporting of personal development.

Other characteristics of their consumers, and the types of supports providers gave them, had no relation to the average reported quality of life. (See **Figure 34.**) The quality of life was equally as good at large and small providers. However, when only objective provider characteristics were considered, providers who helped achieve high responses to the survey (either by self or by proxy) had higher levels of physical, emotional and material well-being than did providers with low levels of participation in the Ask Me! Survey. The percent of the people supported who had mental disorders or behavior disorders did not offer any additional prediction to the average quality of life of the people supported by providers. The average level of retardation had no relationship to quality of life in any domain, except possibly material well-being, once ability to respond for themselves had been taken into account.

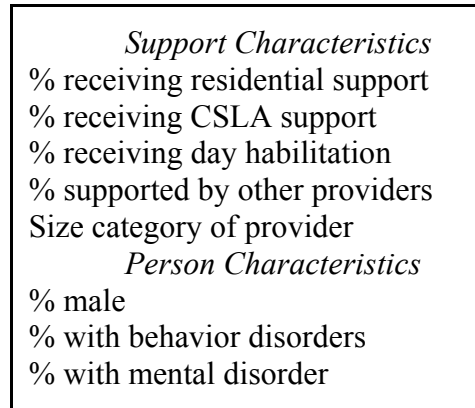


Figure 34. Characteristics Not Predicting Quality of Life at Providers

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 support and employs people who receive support as interviewers. It asks questions that people receiving support say are important to them and involves people receiving support 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, and reduce the error or bias that might creep in at each step of data collection. The procedures ensure that all people respond to the same questions, and this allows information to be compared across groups, providers and time. The analysis can focus on people or providers to predict what contributes to quality of life, while controlling for differences among people and providers.

Most people with disabilities respond for themselves and provide just as consistent responses to questions as do family or staff proxies, regardless of their level of intellectual abilities. Self-respondents and proxies respond differently to many of the questions. Some of this difference may be due to differences between people who can and who cannot respond for themselves, but some of the difference must be due to proxies not knowing what the person truly feels, since two proxies for the same person respond differently. 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 rule 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 reliable, and it is unlikely that other methodological studies would change this overall assessment since any remaining bias is likely to be constant across providers and over time. The value of Ask Me! is in its usefulness for enhancing support based upon the values and perceptions of the people receiving support.

Quality of Life

Most people in Maryland with developmental disabilities report positive qualities of life in all eight domains as identified in the international literature. Their quality of life increased continuously between FY2001 and FY2004 in six of the eight domains. However, self-determination increased for the first time in FY2004, and rights has shown no change over the four years. Much attention of the support delivery system in the past has focused on the physical and emotional well-being of people. This attention was reflected in the very high quality of life reported in these two domains, and the substantial increases that occurred in these domains

between FY2001 and FY2004. The potential for future changes in these domains, however, is limited by the maximum possible scores, and neither of these two domains are explicitly referenced in the mission of DDA. Although physical and emotional well-being are foundational to a life of quality, the focus of supports should switch to other quality of life domains. The mission of DDA explicitly targets social inclusion, personal development and self-determination. These three domains, along with the domain of rights, have more potential for increasing people's quality of life.

Transportation and employment are the supports that offer the greatest potential. The more providers transported people, and the more people felt that this transportation was available to them when they wanted it, the higher they reported their quality of life in all domains. Additionally, people receiving employment support reported higher qualities of life in all domains than did people receiving day habilitation.

Just as quality of life varied among people, the average quality of life varied among providers. The variation was greatest in the domains of rights and self-determination. Some of the differences among providers could be explained by the proportion of people they served who could answer survey questions for themselves, but not by other measures of intellectual abilities. Much of the variation among providers could be explained by the perceptions of transportation availability and by objective measures of transportation. However, almost half of the variation among providers in rights and self-determination remained unexplained by the data available for this analysis. This suggests that providers have substantial ability to enhance the quality of life of the people they support. The types of supports they provide, with the exception of transportation services and employment, do not matter. Their size and whether they are the only provider of supports to people do not limit their ability to enhance people's quality of life.

Enhancing Self-Determination and Rights

Provider goals made a difference. Many providers had goals in their QA plans to improve physical well-being. These did increase quality of life, but have limited potential for future increases since people currently report high levels of physical well-being and physical well-being has limited relationships with other quality of life domains. High physical well-being should be maintained, but more focus should be placed on other domains. The few providers that set goals of self-determination and rights saw quality of life significantly increase in several domains. The relatively low levels of quality of life in these two domains, and the lack of much change between FY2001 and FY2004 suggests that substantial improvements can occur in these two domains. Provider goals of personal development had a positive effect on increasing quality of life and should be a third area for focus. Organizational process goals, as valuable as they may be, resulted in neither increases nor decreases in the quality of life. The findings caution providers that goals of staff and consumer satisfaction do not necessarily translate into better quality of life, and can actually be detrimental. Staff job satisfaction and consumer support satisfaction are values of the organization and not of the people supported. People may like support "with a smile," but what they value are supports that help them achieve the quality of life they want. Quality of life will only be enhanced when providers put people's values ahead of the organization's values. Quality of services does not equal quality of life.

The significantly lower scores in the domains of rights and self determination have motivated both the advocacy community and the state government. The Arc of Maryland and the Maryland Developmental Disabilities Administration will work together on increasing rights and self determination through a variety of efforts over the next few years. A new data dissemination style called *Ask Me! Unleashed!* will drive a move toward self-determination and systems change. Ask Me! Unleashed! will develop key messages from the Ask Me! findings in a user-friendly format. These key messages will be piloted at the quarterly meetings of the DDA Regional Offices and with several additional groups of stakeholders. Once the key messages and their format are solidified, a packaged presentation of the key messages will be prepared with materials for distribution. Presentation will be made at conferences, at meetings and training of provider staff, at meetings of the Boards of Directors of disability organizations, and at self-advocacy meetings.

A Statewide Self-Determination Planning Group is currently being organized. This group has held one meeting to discuss the history of self determination in Maryland, Ask Me! Unleashed! and to brainstorm on the various methods to create a system that is focused on self-determination. Meeting attendees were excited about working on Ask Me! Unleashed!, training staff of providers, providing technical assistance on Ask Me!, and possibly investigating the fiscal aspects surrounding self-determination. These actions should help providers affect the quality of life of their consumers more positively and in more areas.

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Appendix

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Sampling Procedures

The Maryland Developmental Disabilities Administration supported 24,795 person-provider support combinations in July 2003, about the same number as in July 2001 and July 2002.⁹ (See **Appendix Table 2.**) The number of provider designations on the files declined from 171 in 2001 to 147 in 2003, primarily as a result of DDA developing and assigning new provider ID's in 2002 that grouped different regional locations of one agency under a single ID. These designations, however, still included state institutions, different components of the same provider, and organizational entities that provided services periodically to fewer than ten people that were deleted from the sample frame. DDA received quality assurance plans from 110 community-based providers in 2000-2003. Although the number of person-provider records changed little, the number of people supported by DDA increased by 502 between July 2001 and July 2003. About two-fifths of the people had a single provider record, and about one-third had two provider records. Six was the maximum number of providers that any person had.

Appendix Table 2. People Supported by Maryland Developmental Disabilities Administration						
	DDA File			Sample Frame*		
	07/01	07/02	07/03	07/01	07/02	07/03
Number of Provider IDs	171	151	147	136	142	134
Number of Person-Provider Records	24,960	24,557	24,795	13,225	13,519	13,880
Number of Persons Supported	12,469	12,568	12,971	11,539	10,908	11,226
Support by 1 provider	4,721	5,002	5,389	8,739	8,363	8,635
Support by 2 providers	3,881	3,897	3,955	2,747	2,484	2,531
Support by 3 providers	3,122	3,033	3,100	51	56	57
Support by 4 providers	620	523	446	2	5	3
Support by 5 providers	119	108	74	0	0	0
Support by 6 providers	6	5	7	0	0	0
* <i>Sample frame excludes institution and support coordination records</i>						

Sample Frame

The sample frame for the Ask Me! Project included only adults supported in the community through DDA. The first step in creating the Ask Me! sample frame was to exclude children under 18 years of age from the DDA files. During FY2002, this was done at the time the project attempted to set up interviews, since the Project did not realize that the DDA files contained person-records for children. When the sample was developed for FY2003 and FY2004, date of birth in the DDA files was used to select only those records for people 18 years of age and over.

⁹Excel files transmitted by DDA to Bonham Research on July 12, 2001, July 15, 2002 and July 31, 2003 contained a record for each person-provider-support authorized by DDA. Thus a person receiving employment and CSLA supports from one provider, individual support services from another provider, and resource coordination had four records in the file.

This computer selection procedure inadvertently eliminated people missing a date of birth on the DDA files. The project did not identify this problem in FY2003. It came to light in FY2004 when some adults at small providers did not appear on the list for interviews when everyone was supposed to be interviewed. A subsequent check of the July 2003 DDA file identified 44 people with missing dates of birth, with 22 supported by providers selected for interviews in FY2004: six from The Arc of Baltimore, three from Athelas Institute, three from UCP of Prince George's and Montgomery Counties, two from The Arc of Montgomery County, and one each from Alliance, ACCFX Gallagher, The Arc of Prince George's County, CHI, Melwood Horticultural, Rehabilitation Opportunities, Spring Dell, and UCP of Central Maryland. The exclusion of these people had negligible effect for large providers. However, field staff included the three adults at UCP of Prince George's and Montgomery Counties since they represented one-tenth of the people it supported.

The second step in developing the sample frame excluded records associated with the four state institutions (Brandenberg Center, Holly Center, Potomac Center and Rosewood Center) and records for resource coordination services. This excluded about 100 people supported exclusively by institutions and about 1,000 people authorized for resource coordination but not identified as receiving support services from any community provider. Information about resource coordination and institutional services was noted on the records of people receiving community support.

The third step in developing the sample frame involved assigning a single identification number to a provider with multiple DDA identification numbers. The July 2002 DDA made this task easier since it had already made many of these combinations. Ask Me! had mistakenly combined UCP of Central Maryland and UCP of Southern Maryland in FY2002, but separated them for subsequent years. In order to allow easy comparison from year to year, one of the DDA three-digit ID numbers assigned to a provider on the July 2001 files became the unchanging Ask Me! Provider ID. The July 2002 DDA file had seven providers that did not appear on the July 2001 file, and the project assigned them two-digit numbers from 51-57. No new providers appeared on the July 2003 DDA file. Since ID numbers between 500-599 did not appear in the July 2001 DDA file, those numbers were reserved for special Ask Me! Projects.

The fourth step involved combining multiple records with the same person/provider ID combination. Most of these records involved the same provider providing multiple types of supports. Some duplicate records were found for the same person/agency/support combination (25 day, 2 residential, 93 support, and 4 coordination services in July 2002) either due to duplicate entry in the database or to a stop and start of the same type of support for administrative reasons. The record with the most recent start date was retained. Information about residential support, day support and other support was noted in the person's record regardless of whether a single or multiple providers provided these supports.

The fifth step excluded the records associated with 34 Ask Me! interviewers since confidentiality procedures did not allow interviewers to interview people they knew well.

The final sample frame for FY2004 developed from the July 2003 DDA files contained 13,880

person/provider records involving 11,226 people and 134 providers. The primary sampling unit was the provider. The secondary sampling unit was the person within the provider. The identification numbers for the providers providing employment or day support, residential support, other supports, and resource coordination were attached to the 1-4 records for each person to provide assistance in locating them irrespective of the provider through which they might be selected. The number of different community providers that supported a person was included on record as a part of the probability of selection for subsequent use in calculating weights. Three-fourths (77%) of the people received support from a single provider and had a single chance of being selected for the sample. Most of the rest received support from two providers and had a double chance of being selected for the sample. A few (0.5%) had three or four providers and three or four chances of being selected for the sample.

Provider Sample

The final sample frame in July 2003 involved 134 community providers that provided support services in the community, about the same number as in the previous two years. These constituted the primary sampling units for the Ask Me! Survey. The number of person records in the sample frame associated with each provider was counted, and providers were divided into five strata based on the total number of people the provider supported. (See **Appendix Table 3.**) Stratum 1 included the 10 largest providers serving 300 or more people. They provide support to 36% of the people. Stratum 1 providers are all included in the survey every year. Stratum 1 providers did not change between 2001 and 2003, although the number of people served by each varied slightly over the years.

Stratum 2 included providers serving 130-299 people each, providing support to 27% of the people. Stratum 2 providers are included in the survey every other year. In July 2001, 21 providers were initially assigned to Stratum 2. A large number of people listed for The Arc of Frederick County, however, turned out to be children, and the number of adults supported by the provider was less than the threshold for Stratum 2. It was changed from Stratum 2 to Stratum 3 during sample selection in subsequent years, therefore no interviews would occur during the remainder of the four-year cycle. UCP of Southern Maryland was added to Stratum 2 in July 2002 when it was separated from UCP of Central Maryland (which remained in Stratum 1). The Arc of Carroll County had grown above the threshold between Stratum 2 and 3 by July 2002. Since it had been sampled as a Stratum 3 provider for interview in FY2002, it was moved from Stratum 3 to Stratum 2 in FY2004. These changes resulted in 22 providers in Stratum 2 with 11 selected for interview in even number fiscal years and 11 providers selected for interviews in odd number fiscal years.

Appendix Table 3. Number and Percent of Person/Provider Combinations Supported by the Maryland Developmental Disabilities Administration

ID and Provider	Number of People				Year in Sample					
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05	
Stratum 1 (300+ People, Interviews Every Year)										
109 THE ARC OF BALTIMORE	1,176	1,123	1,102	1,050	98-01	x	x	x	x	
112 CHIMES INC (includes 350)	645	633	649	655	98-01	x	x	x	x	
132 UCP CENTRAL MARYLAND (or 615, 810)	549	484	309	300	00-01	x	x	x	x	
811 ARC WASHINGTON CO	508	432	412	408		x	x	x	x	
314 PRINCE GEORGES CO ARC	430	386	402	428		x	x	x	x	
128 PROVIDENCE CENTER	406	407	405	414		x	x	x	x	
311 MELWOOD HORTICULTURAL (or 310)	400	388	386	390	99-01	x	x	x	x	
312 MONTGOMERY COUNTY ARC	348	344	368	385	98-01	x	x	x	x	
104 ATHELAS INSTITUTE	340	350	353	381	00-01	x	x	x	x	
303 CHI	339	349	384	398		x	x	x	x	
Subtotal	5,141	4,896	4,770	4,809		10	10	10	10	
Stratum 2 (130-299 People, Interviews Every Second Year)										
107 ACCFX GALLAGHER	283	288	295	301		x		x		
121 EMERGE	229	231	232	235	99-01	x		x		
135 HOWARD COUNTY ARC (or 113)	225	216	223	213	00-01		x		x	
105 OPPORTUNITY BUILDERS	199	196	213	218	01	x		x		
301 ARDMORE ENTERPRISES	198	188	190	193		x		x		
156 ANNE ARUNDEL CO ARC	197	178	169	169	00-01		x		x	
609 DOVE POINTE, INC (includes 614)	187	183	184	183		x		x		
919 ALLIANCE	186	186	217	199		x		x		
328 REHABILITATION OPPORTUNITIES	184	192	197	205		x		x		
355 ABILITIES NETWORK (or 116)	181	187	232	261	98-01	x		x		
302 ARC OF SOUTHERN MARYLAND	175	165	170	160	99-01		x		x	
915 HUMANIM (DEVELOP SVCS GROUP)	170	184	200	219			x		x	
343 CENTER FOR PROGRESSIVE LRNG (or 158)	167	161	150	137			x		x	
108 BELLO MACHRE	162	170	178	181			x		x	
124 ARC OF NORTHERN CHESAPEAKE	161	168	186	188	98-01	x		x		
827 CHANGE, INC	158	137	147	147			x		x	
319 VOCATIONAL SERVICES INC	156	157	151	146			x		x	
318 CENTER FOR LIFE ENRICHMENT	135	134	159	171			x		x	
933 UCP OF SOUTHERN MARYLAND	156	187	186	190		w/132	x		x	
316 SPRING DELL CENTER	134	131	132	126		x		x		
806 FRIENDS AWARE, INC	134	135	132	132	99-01		x		x	
824 ARC CARROLL COUNTY	111	119	139	148	98-01	x		x		
Subtotal	3,755	3,587	4,082	4,122		11	11	11	11	
Stratum 3 (55-129 People, Interviews Every Fourth Year)										
169 THE ARC OF FREDERICK COUNTY (or 805)	134	81	81	82		x				
325 SOUTHERN MD VOCATIONAL INDUST	124	128	113	133	99-01		x			
817 MED SOURCE COMMUNITY SERVICES (or 320)	116	118	119	123				x		
335 SEEC	113	112	105	105	98-01	x				
149 CREATIVE OPTIONS	111	101	103	100					x	
807 HAGERSTOWN GOODWILL INDUSTRIES	107	94	93	96	01	x				
142 NCIACBAI	106	102	111	121			x			
306 CSAAC	106	111	117	114		x				
812 WASHINGTON CO HDC	106	87	98	95				x		
106 LANGTON GREEN	105	106	105	105	00-01				x	
125 PENN MAR	104	107	112	113	01	x				
611 BAYSIDE COMMUNITY NETWORK, INC	103	105	116	120		x				
610 WORCESTER CO DEVELOPMENTAL CENTER	100	97	94	93	01	x				
322 LT JOSEPH P KENNEDY INSTITUTE	99	99	90	108			x			
819 R & D INSTRUCTIONAL SERVICES (or 164)	98	79	81	107				x		

Appendix Table 3. Number and Percent of Person/Provider Combinations Supported by the Maryland Developmental Disabilities Administration

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
608 SOMERSET COMMUNITY SERVICES INC	97	93	98	96	99-01				x
804 SCOTT KEY CENTER	97	99	108	104	99-01		x		
801 APPALACHIAN PARENT ASSN	90	90	90	84	99-01			x	
802 COMMUNITY LIVING INC	89	86	86	84	01	x			
830 TARGET, INC (or 341)	89	96	97	104					x
602 THE CAROLINE CENTER	86	90	94	94	98-01	x			
606 DELMARVA COMMUNITY SERVICES	86	89	90	91	00-01		x		
308 JEWISH FD FOR GROUP HOMES	81	82	85	86				x	
324 FAMILY SERVICES FD INC (or 160)	80	77	87	82					x
120 LIFE	79	80	78	75			x		
136 WORKFIRST	78	83	107	111				x	
309 JUBILEE ASSOCIATION OF MD	78	74	81	83	98-01	x			
126 PROGRESS UNLIMITED	76	77	78	77					x
129 RICHCROFT	76	80	101	104	99-01		x		
912 CSSD	70	65	64	56	01	x			
616 CHESAPEAKE CARE RESOURCES	69	64	61	61				x	
315 ROCK CREEK FOUNDATION	68	69	61	64					x
140 INTERVALS (or 346, part of 112)	67	67	66	63			x		
809 RAY OF HOPE, INC	63	56	56	54	99-01			x	
951 LOWER SHORE ENTERPRISES	63	75	82	89					x
334 JEWISH SOCIAL SERVICES AGENCY	62	38	41	45			x		
338 CHARLES CO HEALTH DEPT	61	36	46	43				x	
123 NATIONAL MS	58	57	53	48					x
119 JEWISH FAMILY SERVICES	57	59	61	57			x		
352 COMMUNITY SUPPORT SERVICES	57	53	63	66				x	
Subtotal	3,486	3,472	3,472	3,540		11	10	10	9
Stratum 4 (10-54 People, Randomly Sampled in FY2002 and FY2003, Remaining Interviewed in FY2004-FY2005)									
815 JEANNE BUSSARD CENTER	52	45	57	62				x	
351 CALMRA, INC	51	48	50	49					x
601 KENT CENTER INC	51	49	49	47	99-01	x			
101 PROGRESSIVE HORIZONS	50	52	59	58					x
932 TREATMENT & LEARNING CTR, INC	50	51	60	66				x	
624 BAY SHORE SERVICES, INC	50	49	62	66			x		
152 CENTER FOR SOCIAL CHANGE	49	59	77	84					x
607 EPILEPSY ASSOC OF EASTERN SHORE	49	59	59	62					x
818 LYCHER, INC	49	47	45	44					x
139 FORWARD VISIONS	45	53	60	60					x
134 ST PETERS ADULT LEARNING	44	43	39	40					x
931 UCP OF PG & MONTG COUNTY	44	36	27	25				x	
117 HARFORD CENTER	42	41	51	54				x	
605 CHESTERWYE CENTER	42	47	48	53				x	
619 BENEDICTINE SCHOOL	42	44	50	54	01	x			
151 SHURA	40	44	42	42					x
613 CHESAPEAKE DEVELOP UNIT (part of 621)	38	50	55	61				x	
146 AUTUMN HOMES	37	39	36	32					x
323 FULL CITIZENSHIP OF MD	37	37	34	34				x	
165 MID ATLANTIC HUMAN SER CORP	35	30	27	24					x
305 CHARLES CO HARC	35	36	36	35			x		
333 HEAD INJURY REHABILITATION	35	35	35	38					x
828 FLYING COLORS OF SUCCESS (or 143)	34	31	33	33					x
952 DEAF INDEPENDENT LIVING ASSOC	32	26	27	23	99-01	x			
321 MARYLAND NEIGHBORLY NETWORKS	29	29	30	26				x	

Appendix Table 3. Number and Percent of Person/Provider Combinations Supported by the Maryland Developmental Disabilities Administration

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
145 SELFPRIDE	28	28	29	26					x
604 CHESAPEAKE GROUP HOMES (part of 621)	28	25	37	36				x	
803 COUNCIL FOR EC&A	28	28	29	26		x			
147 STARFLIGHT	27	21	23	27		x			
353 SECURECARE SERVICES	26	34	40	63				x	
327 MONT CO GOV DEPT OF FAM RESOUR	24	27	45	46				x	
621 CHESAPEAKE CENTER, INC	21	17	14	12					x
141 CARING HANDS, INC	20	20	19	17					x
808 GOODWILL IND MONOCACY VALLEY	20	17	22	21		x			
330 VOCA CORPORATION	19	19	19	19				x	
836 ANITA LYNNE HOME, INC	16	19	22	25				x	
910 LINWOOD CHILDREN'S CENTER	14	17	18	19				x	
920 VANTAGE PLACE (part of 915)	14	17	19	--					--
163 PACT: HELPING CHILDREN	13	13	13	13				x	
825 CARROLL CO BUREAU OF AGING	11	10	10	8				x	
153 NETCON & EARTHKINS, INC	10	26	36	42				x	
154 KENNEDY KREIGER INST	19	10	8	12					x
313 NATIONAL CHILDRENS CENTER	12	10	9	10					x
166 REM, INC	8	12	13	13					x
354 EBED ENTERPRISES	5	7	9	12					x
52 THE LEAGUE FOR PEOPLE WITH DISAB	--	2	9	23					x
Subtotal	1,425	1,468	1,604	1,618		3	5	17	20
Stratum 5 (<10 People by FY2005, 23 Providers Not Included in Sample)									
950 CHESAPEAKE HEAD INJURY CENTER	12	13	9	1					
304 AMERICAN FOUND AUTISTIC CHILD	11	--	--	--					
623 SHOREHAVEN	10	5	4	4					
617 CROSSROADS COMMUNITY	8	7	7	4					
344 FAIRFAX OPP UNLIMITED	7	--	--	--					
831 MULTIPLE SCLEROSIS SOCIETY	7	7	7	4					
356 RESPITE CARE ASSOCIATES	6	3	--	--					
813 BETHESDA LUTHERAN HOMES*	6	8	7	8					
834 HOPE HOMES OF MD	6	6	1	1					
157 MAXIM HEALTH CARE SERVS	5	5	2	2					
615 UCP EASTERN (with 132 UCP Central)	5	--	--	--					
162 NATIONAL MENTOR HEALTH CARE	3	3	6	3					
167 CTR FOR NEURO REHABILITATION	2	1	1	1					
168 EVERSHERE RESIDENTIAL SERVICES*	2	3	4	5					
337 CALVERT CO HEALTH DEPT	2	3	1	1					
348 GRAFTON SCHOOL, INC	1	1	--	--					
814 ARCHWAY STATION*	1	1	1	1					
822 WASHINGTON CO MENTAL HEALTH	1	1	--	--					
329 COMMUNITY SERVICES OF MD	1	--	--	--					
170 COPE HOMES, INC	1	--	1	4					
56 PSI SERVICES, INC (360)	--	11	--	--					
55 CHRISHARON'S INC	--	7	--	--					
54 CALVERT CO OFFICE OF AGING	--	5	5	3					
51 MARY T MARYLAND (172)	--	3	4	3					
57 SACRED CARE INC	--	2	--	--					
53 INNOVATIVE SERVICES, INC	--	1	5	6					
58 SERVICE SOURCE	--	--	--	5					
63 ESRO HOLDING PROVIDER	--	--	--	3					
59 S & G RESIDENTIAL SERVICES	--	--	--	3					

Appendix Table 3. Number and Percent of Person/Provider Combinations Supported by the Maryland Developmental Disabilities Administration

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
50 LIFELINE, LLC	--	--	--	2					
60 HEBRON ASSOC FOR COMMUNITY SRVC	--	--	--	1					
62 MATTA WAY	--	--	--	1					
61 JOSHUA HOUSE	--	--	--	1					
Subtotal	97	96	65	67	0	0	0	0	
Total Person-Provider Combinations	13,904	13,519	13,993	14,180	35	36	36	36	36

Stratum 3 included 40 providers supporting 55 to 129 people in July 2001, and provided 27% of the people with support. They are included in the sample once every four years. The size of two providers increased sufficiently between 2001 and 2002 to move them into Stratum 3 from Stratum 4, and the size of six additional providers increased sufficiently between 2002 and 2003 to move them into Stratum 3. Three providers decreased in numbers between 2001 and 2002 to drop them from Stratum 3, although one increased between 2002 and 2003 to return it to Stratum 3. One additional provider decreased between 2002 and 2003 to drop it from Stratum 3. The distinction between Stratum 3 and Stratum 4 was important at the time the four-year sampling strategy started, but became unimportant part way into FY2004 when DDA obtained sufficient funds for interviews at all Stratum 4 providers.

Stratum 4 initially included 40 providers serving 10-54 people each, and provided 11% of the people with support. In FY2002 and FY2003, DDA had sufficient funds to sample only 3-6 providers from Stratum 4 each year. These were identified in July 2001 prior to selecting the FY2002 sample. Stratum 4 providers that had not been originally selected for interviews during the four years were sorted by the number of people they supported in July 2003, and then alternately assigned to be interviewed in either FY2004 or FY2005. Five providers serving 10-19 people in July 2001 served fewer than 10 people in July 2003 and were therefore dropped from Stratum 4. None had been selected for either the FY2002 or FY2003 survey, so they had no effect on the sample process. Two of these increased to 10 or more in July 2004 and were returned to Stratum 4 to be interviewed in FY2005. One provider selected for interview in FY2005 had merged with a Stratum 1 before then. Two small providers supported ten or more people in July 2004 and will be included in the FY2005 sample.

Stratum 5 providers support fewer than ten people. There were 19 such providers in July 2001, 21 in July 2002, 20 in July 2003 and 23 in July 2004. Six of the 19 in 2001 supported no one in 2003 and four of the 20 in 2003 supported no one in 2001. An additional three providers supported people only in 2002. Stratum 5 providers were not sampled due to cost, confidentiality and discontinuity of services. Excluding these providers excluded only 0.4% of the people supported by DDA, since some of the people supported by Stratum 5 providers were also supported by providers in other strata.

The providers from each stratum were assigned to survey years as shown in **Appendix Table 3**. The providers included in FY2002 did not constitute a strict probability sample, as provider involvement in earlier years was factored in the selection of providers from Strata 2-4. Subsequent years represent random samples of the remaining providers. The probability of

selecting a provider from Stratum 1 for interviews during a fiscal year was 1/1. The probability of selecting a provider from Stratum 2 was 1/2. The probability of selecting a provider from Stratum 3 was 1/4. The probability of selecting a provider from Stratum 4 was 3/40 in FY2002, 5/47 in FY2003, 17/42 in FY2004 and 17/42 in FY2005.

Person Sample

A primary sample of 40 people and a secondary sample of 10 people was selected from each provider selected for participation in the survey, in order to achieve a goal of 30 completed interviews for each agency. In the FY2002 survey, the field staff received the names of only the 40 people in the primary sample for each agency with the expectation of a 75% response rate. The response rate in FY2002 averaged 68% and supplemental samples had to be selected for 9 of the 35 providers. Even with the supplement, 21 providers did not achieve the desired 30 surveys. In FY2003 and FY2004, the field staff received all 50 names, but were instructed to go into the secondary sample only when the number of completed interviews from the primary sample appeared to be fewer than 27. Once the field staff initiated contact for a person in the secondary sample, they were required to complete an interview or finalize the person as a non-response.

SPSS software was used to randomly select 50 person/provider records for the providers serving 51 or more people. All records were selected for the providers serving 50 or fewer people. This procedure resulted in 2,154 person-provider records being selected, with 70 people selected more than once.¹⁰ (See **Appendix Table 4.**) The people selected twice were interviewed only once, but their survey data were duplicated to appear that they had been interviewed at both providers. A note was placed in the field work control spreadsheet for these people to be interviewed at their employment or day program rather than their residential program, or their residential program rather than their support program, if they were selected in the first 40 people from the preferred program. Otherwise, the note said to interview them with the reverse priority.

Appendix Table 4. Person/Provider Record Selected for Interview: FY2004		
Sample Status	Number	Percent
Initial Sample Only Selection	1,575	73.1
Initial Sample Double Selection for Interview	28	1.3
Initial Sample Double Selection not for Interview	29	1.4
Supplemental Sample Only Selection	461	21.4
Supplemental Sample Double Selection not for Interview	41	1.9
Discovered at Provider with all People Selected	20	.9
Total Selections	2,154	100.0

During the FY2004 field work, some people were discovered at small providers that had not been indicated on the DDA files. When a Stratum 4 provider had fewer than 40 people listed for interviews, Ask Me! interviewed all people 18 years of age and over supported by DDA, and

¹⁰Many of the duplicate selections resulted from two divisions of the same provider being listed in the DDA files as two separate providers. The division was retained to reflect the original sampling scheme.

added their names clearly to their control sheets. Ask Me! still missed new people served by larger providers, but this was expected to have minimal effect on either state estimates or estimates for larger providers.

Past review had shown that some people receive different supports from different providers at the time of interview than had been identified from the DDA files at the beginning of the survey year. This could be due to changes in support since July or due to DDA July files not accurately reflecting supports. The fieldwork procedures attempted to track every sampled person regardless of where they received support.

Two additional problems occurred during fieldwork:

- Ray of Hope had a high non-response among the 50 primary and secondary samples. They served a total of 56 people according to the DDA file, and the interviewers were instructed to interview every person they could at the provider. If the person was not on the DDA list, they were classified as ‘discovered.’
- PACT supported parents with disabilities whose children are under age two. Because they provide support for a short period of time, DDA funds PACT on a direct grant basis rather than a census basis for assigned individuals. PACT supported 29 adults at the time of contact for the interviews. The DDA files had identified three of these as supported by PACT and six as supported by other providers. The other twenty adults did not appear on the DDA file at all. Ask Me! therefore collected from PACT the background information normally available from the DDA file.

Sample Control and Confidentiality

Bonham Research assigned person identification numbers from 1-50 to each person in the order the SPSS program randomly selected them within the provider. The provider ID plus the person ID provided a unique identifier. These two ID numbers plus the name of the agency and the name of the person were sent to The Arc of Maryland in an Excel spreadsheet. After the interview process, The Arc of Maryland added a field status code and returned the spreadsheet to Bonham Research with the completed surveys.

The field status code provided the basis for the non-response adjustment to the weight. An average of 55.5% of the eligible people responded to the survey for themselves, varying little from year to year. (See **Appendix Table 5.**) An additional 20.2% had proxy respondents. The overall percent with proxy respondents did not differ much over the years, but the percent of sampled people with two proxies increased from 5.4% in FY2002 to 18.4% in FY2004 after the project made extra effort to find second proxies. The largest reason for non-response was the refusal of 10.5% of the selected persons to be interviewed, and this varied little from year to year. The percent for whom guardians refused to let participate declined over the three years, as did the percent that could not be found at the sample provider or any other provider, but who DDA still had on their files as eligible for support.

The project matched the DDA files from which the sample was drawn to the DDA files at the beginning of the next year by social security number and name to determine if non-responders

had left DDA supported services. Of the 2,085 names sampled from the DDA July 2003 file for the Ask Me! FY2004 sample, 2,023 or 97% were on the DDA file in July 2004: 98% of those interviewed, 97% of those refusing or having other reasons for non-response, and 75% of those that could not be located at any of the providers.

Appendix Table 5. Final Field Status by Year									
		Number of People				Percent			
		FY 2002	FY 2003	FY 2004	Total	FY 2002	FY 2003	FY 2004	Total
Sample Response	Completed Self	738	780	1,124	2,642	55.7	54.1	56.5	55.5
	Completed 2 Proxies	72	246	367	685	5.4	17.1	18.4	14.4
	Completed 1 Proxy of 2	44	54	30	128	3.3	3.7	1.5	2.7
	Completed 1 Proxy of 1	104	23	19	146	7.8	1.6	1.0	3.1
Sample No Response	Unknown if DDA Funded	84	71	64	219	6.3	4.9	3.2	4.6
	Missed At Other Provider	15	15	9	39	1.1	1.0	0.5	0.8
	Guardian Refused	50	37	48	135	3.8	2.6	2.4	2.8
	Person Refused	131	170	198	499	9.9	11.8	9.9	10.5
	No Contact 6 Tries	22	13	46	81	1.7	0.9	2.3	1.7
	Cannot Schedule	25	3	13	41	1.9	0.2	0.7	0.9
	Provider No Helpful Info	8	1	32	41	0.6	0.1	1.6	0.9
	Language, Health	25	17	31	73	1.9	1.2	1.6	1.5
	Other Non-response	8	11	10	29	0.6	0.8	0.5	0.6
Total Sample		1,326	1,441	1,991	4,758	100.0	100.0	100.0	100.0
Not Sample	5 Died, Moved, Not DDA	27	30	38	95				
	8 Under 18 years, interviewer	41	6	2	48				
	10 Selection Not Needed	93	163	123	379				
Total		161	199	163	523				
Total		1,487	1,640	2,154	5,281				

Ask Me! obtained information for 3,690 people over the three years. (See **Appendix Table 6.**) It collected information for as few as 11 people at one small provider and as many as 103 people at a large provider with interviews all three years. Ask Me! collected information for 76% of the people initially identified in the sample. It completed surveys for 90% or more of the sampled people at thirteen of the 88 providers, but completed surveys for fewer than half of the sampled people at three of the providers. The way providers approached people or their guardians about survey participation may have influenced the percent of the sample with surveys. Providers could have little influence on the percent of surveys with self-response, as the ability to respond for oneself was determined by the Ask Me! interviewers. Three-fourths (73%) of the information came from people responding for themselves, but this varied from a low of 14% to a high of 100%. The percent of the initial sample responding for themselves combines the overall response rate with the rate of self-response. Overall, 56% of the initially selected people responded to the survey for themselves. This varied by provider from a low of 14% to a high of 100%.

Appendix Table 6. Survey Response by Provider: FY2002-FY2004

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2004	FY2002-FY2004
Total		76%	73%	56%	1,540	3,690
Abilities Network	(02 & 04)	64%	98%	63%	31	57
ACCFX Gallagher	(02 to 04)	90%	55%	49%	36	73
Alliance	(02 & 04)	66%	100%	66%	30	56
Anita Lynne Home Inc	(04)	95%	14%	14%	21	21
Appalachian Parent Assn	(04)	88%	77%	68%	44	44
Ardmore Enterprises	(02 & 04)	92%	55%	51%	35	67
Athelas Institute	(02 to 04)	78%	78%	61%	37	101
Bay Shore Services Inc	(03)	44%	90%	40%	0	20
Bayside Community Network	(02)	82%	81%	66%	0	31
Bello Machre	(03)	86%	56%	48%	0	36
Benedictine School	(02)	88%	93%	82%	0	30
Carroll Co Bureau of Aging	(04)	100%	91%	91%	11	11
Center for Life Enrichment	(03)	74%	79%	59%	0	29
Center for Progressive Lrng	(03)	95%	61%	58%	0	41
Change, Inc	(03)	76%	51%	39%	0	37
Charles Co HARC	(03)	94%	32%	31%	0	34
Charles Co Health Dept	(04)	52%	91%	48%	23	23
Chesapeake Care Resources	(04)	90%	41%	37%	44	44
Chesapeake Developmental Unit	(04)	68%	97%	66%	30	30
Chesapeake Group Homes	(04)	78%	83%	65%	29	29
Chesterwye Center	(04)	70%	100%	70%	33	33
CHI Center	(02 to 04)	79%	86%	68%	35	95
Chimes Inc	(02 to 04)	78%	74%	58%	32	92
Community Living Inc	(02)	74%	71%	53%	0	28
Community Support Services	(04)	82%	67%	55%	33	33
Council for EC&A	(03)	68%	26%	18%	0	19
CSAAC	(02)	90%	61%	55%	0	36
CSSD	(02)	55%	94%	52%	0	31
Deaf Independent Living Assoc	(02)	66%	100%	66%	0	21
Delmarva Community Services	(03)	78%	72%	56%	0	32
Dove Pointe Inc	(02 & 04)	74%	67%	50%	28	58
Emerge	(02 to 04)	78%	76%	59%	36	68
Friends Aware, Inc	(03)	85%	74%	63%	0	35
Full Citizenship of MD	(04)	88%	43%	38%	30	30
Goodwill Ind Monocacy Valley	(03)	100%	100%	100%	0	16
Hagerstown Goodwill Industries	(02)	74%	52%	38%	0	25
Harford Center	(04)	88%	37%	32%	35	35
Humanim--Devel. Svcs Group	(03)	83%	84%	70%	0	32
Intervals	(03)	83%	38%	32%	0	34

Appendix Table 6. Survey Response by Provider: FY2002-FY2004

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2004	FY2002-FY2004
Jeanne Bussard Center	(04)	88%	95%	84%	44	44
Jewish Family Services	(03)	79%	88%	70%	0	32
Jewish Fd for Group Homes	(04)	88%	79%	69%	43	43
Jewish Social Services Agency	(03)	65%	70%	45%	0	23
Jubilee Association of MD	(02)	74%	86%	63%	0	28
Kent Center Inc	(02)	64%	80%	51%	0	25
Life	(03)	84%	51%	43%	0	37
Linwood Children's Center	(04)	95%	72%	68%	18	18
Lt Joseph P Kennedy Instit	(03)	69%	74%	51%	0	34
Maryland Neighborly Networks	(04)	97%	89%	86%	29	28
Medsource Community Support	(04)	92%	28%	26%	46	46
Melwood Hort	(02 to 04)	80%	79%	63%	32	90
Mont Co Gov Dept of Fam Resour	(04)	43%	68%	30%	19	19
NCIA CBAI	(03)	84%	79%	66%	0	34
Netcon & Earthkins Inc	(04)	81%	83%	67%	29	29
Opportunity Builders	(02 & 04)	63%	87%	55%	28	53
PACT: Helping Children	(04)	83%	100%	83%	24	24
Penn Mar	(02)	72%	70%	51%	0	30
Providence Center	(02 to 04)	67%	80%	54%	28	85
R & D Instructional Services	(04)	71%	90%	64%	30	30
Ray of Hope Inc	(04)	45%	82%	37%	22	22
Rehabilitation Opportunities	(02 & 04)	79%	96%	76%	37	69
Richcroft	(03)	80%	66%	53%	0	38
Scott Key Center	(03)	82%	78%	64%	0	41
Securecare Services	(04)	87%	69%	60%	34	35
SEEC	(02)	82%	64%	53%	0	28
Southern MD Vocational Indust	(03)	72%	76%	54%	0	29
Spring Dell Center	(02 & 04)	76%	74%	56%	37	66
Starflight	(03)	70%	57%	40%	0	14
The Arc of Anne Arundel Co	(03)	72%	72%	52%	0	29
The Arc of Baltimore	(02 to 04)	82%	68%	56%	31	101
The Arc of Carroll County	(02 & 04)	88%	82%	73%	42	80
The Arc of Frederick County	(02)	64%	96%	62%	0	25
The Arc of Howard Co	(03)	82%	70%	58%	0	33
The Arc of Montgomery Co	(02 to 04)	77%	72%	55%	40	99
The Arc of Northern Chesapeake	(02 & 04)	82%	94%	77%	42	77
The Arc of Prince Georges Co	(02 to 04)	67%	61%	41%	32	87
The Arc of Southern Maryland	(03)	84%	79%	66%	0	43
The Arc of Washington Co	(02 to 04)	73%	64%	47%	40	103
The Caroline Center	(02)	71%	67%	47%	0	27

Appendix Table 6. Survey Response by Provider: FY2002-FY2004

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2004	FY2002-FY2004
Treatment & Learning Ctr Inc	(04)	80%	100%	80%	32	32
UCP Central Maryland	(02 to 04)	74%	67%	49%	34	90
UCP of PG & Montgomery Co	(04)	83%	92%	76%	24	24
UCP of Southern MD	(03)	69%	94%	65%	0	33
Voca Corporation	(04)	89%	24%	21%	17	17
Vocational Services Inc	(03)	77%	70%	54%	0	30
Washington Co HDC	(04)	98%	47%	46%	49	49
Worcester Co Developmental Ctr	(02)	70%	85%	59%	0	26
Workfirst	(04)	51%	100%	51%	24	24

People were identified by name on the spreadsheets used during the field work, but names were not recorded on the survey forms in order to protect confidentiality. A public identification number was assigned to each person on the final files that had no relationship to the person's name or the Ask Me! identification numbers. Files sent to providers for their own analysis contained only the public identification number and the information provided by the person during the interview. Information provided by the providers or taken from the DDA files were not included so no individual could be identified.

Data Processing

Data Entry

The project double keyed survey forms using a data entry program designed in Visual Basic. It keyed transportation data in a QuatroPro spreadsheet. Bonham Research employed a person receiving DDA support as the primary data entry clerk for surveys. Its office manager independently keyed the surveys, ran a Visual Basic program to compare the two keyings, and identified the correct entry when a disagreement occurred. The office manager and research advisor keyed the transportation data and then compared worksheets. The log of disagreements and corrections documented a keying error rate of 0.3% for the data entry clerk, 0.2% for the office manager, and 0.4% for the research advisor. Much of the data entry counted as errors involved different ways of handling nonstandard or missing responses. For instance, one keyer interpreted an interviewer's markings of two answers as equal and keyed nothing while the other keyer saw one marking as heavier than the other and keyed the one they thought the interviewer meant (the interviewer should have put a line through the wrong marking). In other situations, one keyer left an item blank and the other keyed zero. 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, was less than one chance in 100,000. Once data were verified, they were processed using SPSS-10 (Statistical Package for the Social Sciences, version 10.5).

Weights

People selected for interviews at two providers were assigned to be interviewed at only one provider in the priority of 1) residential, 2) day, and 3) support. A note was placed in the spreadsheet of the other provider not to interview the person. However, they were assigned a person number appropriate to their sampled position at the second provider (i.e., 1 through 40). During file processing prior to weighting, the survey responses for a person selected twice were duplicated and included with both providers, with each record during weighting counting as only half a person. The person was counted as responding for both providers in the calculation of provider-specific non-response adjustments. An interviewed person no longer supported by the provider through which they were sampled was not included in analysis for that provider, but was included in statewide estimates. For purposes of weight calculations, however, they were considered as a respondent for the provider through which they were originally selected. The people discovered at small providers were assigned the same probability of selection as all the other people selected from that provider.

Weights were used for all estimates that include more than one provider. The weight for an individual respondent was calculated as:

- (1) $wt_{final} = wt_{strata} * wt_{provider} * wt_{nonresponse} * wt_{person}$
or
(2) $wt_{final} = wt_{strata} * wt_{response} * wt_{person}$

where wt_{final} = final weight for the person
 wt_{strata} = number of providers in the stratum / number of selected providers in the stratum
 $wt_{provider}$ = number of people supported by the provider / number of people in the provider selected for interview
 $wt_{nonresponse}$ = number of people in final provider's sample / number of people interviewed
 wt_{person} = 1 / number of providers serving the person
 $wt_{response}$ = number of people supported by the provider / number of people interviewed.

The difference between using $wt_{provider} * wt_{nonresponse}$ and $wt_{response}$ revolves around the terms "selected for interview" and "in final provider's sample." These are not exactly the same, and the implications need to be tested empirically. An initial sample of 40 people were selected from each provider assuming all were in the sample frame and appropriate for interview. Some turned out to be children, deceased, Ask Me! interviewers, or no longer supported by any Maryland provider at the time of interview. A secondary sample of 10 names had also been drawn which the field staff could use to replace people not in the sample, with "sampled finally for interview" calculated as the number of people initially sampled plus the number of replacement sample people minus the number not in the sample for that provider. The first way of calculating the within provider sample weight will produce final estimates without representation for children (appropriately), deceased people (questionably), interviewers (questionably), and people ending Maryland support (questionably). The second way of

calculating the within provider sample weight will produce final estimates with representation by living nonmoving adults for children (inappropriately), deceased people (questionably), interviewers (appropriately), and those ending support (appropriately). Neither will represent people who started receiving support during the year except for small agencies where all people were selected for interviews. It was expected that either estimating procedure would produce an accurate enough weight for statistical estimation.

The weights for people prior to the post-stratification adjustment summed to 12,435, 10.7% higher than the 11,226 people in the sample frame. The post-stratification adjustment brought the final decimal weight down to the correct number. (See **Appendix Table 7.**) Once rounded to a whole number for each person, the weights summed to 11,160 people, or 1% lower than the actual number but within acceptable tolerance. Each surveyed person in FY2004 represented between 1 and 35 other people. The final statistical weight summed to 1,530.95 people rather than the 1,540 people actually interviewed, but this was within acceptable tolerance.

Components	N	Min.	Max.	Sum	Mean	S.D.
Weight for Probability of Provider Selection	1540	1.00	10.50	4,981.63	3.23	2.67
Weight for Selection Within Provider	1540	1.00	27.55	7,171.00	4.66	4.81
Weight for Person Probability of Multiple Selection	1540	0.25	1.00	1,239.67	0.81	0.25
Revised Selection Probability within Provider	1540	1.00	30.61	7,150.63	4.64	5.52
Weight for Nonresponse of People in Final Sample Frame	1540	1.00	2.32	1,991.00	1.29	0.26
Sum of Weights Before Final Weight Adjustment	1540	12,435	12,435	N.a.	12,435	0.00
Adjustment for Final Weight to Sum to Actual People Eligible	1540	0.90	0.90	1,390.27	0.90	0.00
Person Weight Adjusted for Agency Nonresponse (Decimal)	1540	0.74	34.77	11,226.17	7.29	5.67
Final Population Weight	1540	1.00	35.00	11,160.00	7.25	5.68
Final Statistical Calculation Weight	1540	0.14	4.80	1,530.95	0.99	0.78

Most analysis in this report used the final statistical weight, since this weight was appropriate whether the data were tabulated for a single year, for two years combined, or for three years combined. The use of this weight also made statistical tests between groups appropriate, as each group would have a sum of weights approximately equal to the actual number of people in the group that were interviewed.

Personal Characteristics

The analysis used the information on gender recorded in the DDA files for 99.6% of the people. The project calculated age as of July 1, 2003 from the date of birth recorded on the DDA file. The DDA file did not have dates of birth recorded for four sample people in FY2004. For ease of calculation, the project used age as of July 1, 2003, the midpoint of the four-year cycle, rather than age at the date of the interview.

The DDA files identified 21 different disabilities with which a person may be classified. Less than 0.1% had AIDS or cystic fibrosis, while 83.8% had mental retardation. The infrequent disabilities were not analyzed in this report, and the DDA classification of mental retardation without any gradation was also not used. Instead, the measurement of intellectual ability was based upon staff reports recorded on the Transportation Form. The Transportation Form

requested the person be classified as having profound retardation, severe retardation, moderate retardation, mild retardation, borderline retardation, or no retardation. Provider staff did not report degree of retardation data for 4% in FY2002, 13% in FY2003 and 20% of the people in FY2004.

DDA Authorized Services

This report classified a person as receiving support if the DDA file contained a record for the person with the support. The person was further classified as receiving the support from the primary provider—the provider through which the person was selected. However, the DDA file as of July 1, 2003 may not have reflected the actual cluster of supports a person received at the time of the FY2004 interview, since people may have changed supports or providers in between. The DDA file as of July 2003 may not have even reflected the supports received in July 2003. It takes time for providers to be certain that people don't want a support anymore, it takes time for an agency to notify DDA about the change, and it takes time for DDA to process the information and update its database. Finally, some information may have erroneously gotten into the database, or the person and provider were never notified of an authorized support. However, for purposes of this report, a person was considered to receive a support if it appeared in the DDA file at the beginning of the fiscal year (July 1) during which the person was interviewed.

Transportation

A scale of perceived transportation availability was constructed from five questions answered by respondents during interviews. Provider staff in FY2003 and FY2004 recorded on a Transportation Form the number of round trips per week each interviewed person received transportation from various sources and various purposes: 1) to employment or day activities from the provider through which the person was selected for interview, 2) to other activities from the provider through which the person was selected, 3) from other providers, 4) from family, friends or drove self, and 5) from public sources (bus, train, taxi, paratransit). The project keyed the high end of any recorded range and rounded up any recorded decimal. Therefore, a "1" could represent "occasionally" as well as "1 time per week." The Transportation Form did not as clearly identify "trips" as "round trips" in FY2003 as it did in FY2004. Some providers recorded much greater frequency of transportation than other providers. The project researcher halved all FY2003 frequencies of trips greater than seven (i.e., once a day) on the hypothesis that the providers in these cases had counted each leg of a trip rather than a round trip, and placed an upper limit in FY2004 of 10 trips per week from one source to one type of activity.

Provider staff in FY2002 recorded on a Background Form how frequently the provider through which the person was selected for the interview provided transportation in a week, using an ordinal scale from no transportation involvement to providing transportation three or more times per week. Staff recorded that a person did or did not receive transportation from other providers, family, transit, paratransit and taxis during the past month. Analysis in this report on the relationship of trips per week to perceived availability of transportation and to the quality of life domains exclude FY2002 data.

Analysis Methods

All analysis used SPSS and the 95% level of confidence ($p = .05$). Statistical calculations assumed a weighted random sample equivalent to 1,009 people for FY2002, 1,139 for FY2003, 1,531 for FY2004, and 3,679 people for FY2002-FY2004 combined, approximately the actual number responding. No adjustment was made for the two-stage sampling process, which means this report will overestimated the statistical significance of a finding to the extent people served by a single provider were more similar to each other than they were to people served by other providers.

Scale Reliability

The six questions for each of the eight core quality of life domains in the survey were combined to produce a single scale score. A scale score was not calculated for an individual if more than one-third of the questions in the domain had not been answered. The eight domains had low but acceptable scaling properties overall, with Cronbach's *alpha* of 0.61 to 0.71. (See **Appendix Figure 35**.) The scale reliability for people who responded for themselves was higher than for proxies for the seven of the eight quality of life domains and for transportation availability. Self-respondents saw the set of six questions as all related to physical well-being, whereas proxies did not. Self-respondents saw the set of six questions relating to interpersonal relations as all relating to the underlying concept whereas proxies did not. Only for the six questions that measured social inclusion did proxies as reliably link them together as did self-respondents.

Scale	Cronbach's Alpha		
	Self	Proxy	Total
Self-determination	0.74	0.70	0.69
Social inclusion	0.73	0.75	0.71
Personal development	0.74	0.59	0.66
Rights	0.66	0.58	0.67
Interpersonal relations	0.75	0.43	0.67
Emotional well-being	0.68	0.58	0.67
Physical well-being	0.73	0.44	0.66
Material well-being	0.71	0.57	0.61
Transportation available	0.63	0.50	0.61

Appendix Figure 35. Scale Reliability by Respondent: FY2002-FY2004

The scale of transportation availability with five component questions had slightly less reliability than the eight quality of life domains. Self-respondents showed a greater reliability in answering these questions similarly than did proxies, just as for most of the quality of life domains.

Statistical Significance

The statistical significance of any number is based upon the size of the number and its standard error. The standard error is based upon the standard deviation and the number of observations that generated the number and the standard deviation. This report primarily uses a 95% confidence interval to identify statistical significance which leaves a 5% or less probability of making an error ($p < .05$). The report also identifies when statistics have a 1% or less probability of making an error ($p < .01$). All statements about relationships were tested for statistical significance using the most appropriate method, and assuming sampling with

replacement. **Appendix Figure 36** shows the 95% confidence interval about selected percentages to assist the reader in interpreting statistical significance of a comparison with other percentages. If 20% of all people in Maryland gave a specific answer and 10% of the people interviewed at a provider gave that answer, the response at the provider would not be statistically different from the total response (10% + 11% includes 20%) if interviews had been conducted at the provider in only one year, but would be different if interviews had been conducted at the provider during two years (10% + 8% does not include 20%).

	<i>Number of Surveys</i>				
	<i>30</i>	<i>60</i>	<i>90</i>	<i>1000</i>	<i>3500</i>
10% or 90%	±11%	±8%	±6%	±2%	±1%
20% or 80%	±15%	±10%	±8%	±2%	±1%
30% or 70%	±17%	±12%	±10%	±3%	±2%
50%	±19%	±13%	±11%	±3%	±2%

Appendix Figure 36. 95% Confidence Interval of a Percent, by Number of Surveys

Statistical significance for an average quality of life score cannot be summarized as easily as for a percent. The standard errors (Std. Error) for the state were shown in **Figure 9** (page 11) and the 95% confidence interval is about 2.0 times the standard error. The standard errors for individual providers varied, but were about the amount shown in the “1 Year” column of **Appendix Figure 37** if the provider was included in the sample during only one year (about 30 people interviewed), the “2 Years” column if the provider was included in both years (about 60 people interviewed), or the “3 Years” column if the provider was included in all three years (about 90 people interviewed). The difference between the quality of life means of a provider in two different years, or two providers in the same year, would be statistically significant if it was 1.414 times the confidence interval for the 1-year mean.

<i>Domain</i>	<i>1 Year (n=30)</i>	<i>2 Years (n=60)</i>	<i>3 Years (n=90)</i>
Rights	±1.9	±1.3	±1.1
Self-determination	±1.7	±1.1	±1.0
Personal development	±1.7	±1.1	±0.9
Social inclusion	±1.7	±1.1	±0.9
Interpersonal relations	±1.6	±1.1	±0.9
Material well-being	±1.6	±1.1	±0.9
Emotional well-being	±1.4	±0.9	±0.8
Physical well-being	±1.4	±0.9	±0.8
Transportation available	±1.7	±1.2	±0.9

Appendix Figure 37. 95% Confidence Interval of a Quality of Life Score, by Number of Surveys

The selection of people from the DDA list can be considered selection with replacement, as less than 10% of the people were selected in any single year and less than 20% were selected in the three years combined. The samples from large providers can also be considered as made with replacement. When half or more of the people served are sampled, however, the confidence interval does not need to be as large to determine statistical significance. For providers serving 40 or fewer, all people were selected and zero sampling error occurs (all other error is due to non-response or to errors in responding). For providers serving 45 people, 90% were sampled and the confidence intervals shown in **Appendix Figures 36** and **37** can be multiplied by a factor of 0.3. The factor is 0.5 for providers serving 54 people (75% sampled), 0.7 for providers serving 80 people (50% sampled), and 0.9 for providers serving 200.

ANOVA

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 for people employed stepwise analysis with $p = .01$ for entry and $p = .02$ for removal. The regressions for providers used $p=.05$ 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 (β) indicate the relative size of the relation. Only the β 's that had statistically independent relations to the quality of life scores are shown. The unadjusted multiple R^2 shows the total amount of the variance in the quality of life scores that could be explained by all the significant characteristics and supports combined. The F-statistic and the degrees of freedom identify the significance of the total equation (all $p < .01$). **Appendix Table 8** shows the stepwise multiple regression results for the person as the unit of analysis. **Appendix Table 9** shows the stepwise multiple regression results for the provider as the unit of analysis.

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 (β) and show the relative strength of relationship. A β 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, and 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 Table 8. Standardized Multiple Regression* Coefficients (β) of Quality of Life Domains on Person and Support Characteristics: FY2002-FY2004

Person and Support Characteristics	Trans Available	Physical Well-being		Emotional Well-being		Material Well-being		Interpersonal Relations		Personal Development		Social Inclusion		Self-Determination		Rights	
Transportation availability		.45		.38		.48		.39		.34		.32		.37		.31	
# trips by other providers				-.07						-.06				-.06			
# provider trips to day activity**						.06											
Provider 3+ trips per week**												.08	.07				
# family/friend trips per week	.06																
Employment support	.07		.08	.05	.09		.12	.08	.10	.12	.13	.07	.10	.06	.08	.09	.11
Residential support							.08										
Western DDA region	.08		.05		.06		.06		.07				.06	.08	.10	.05	.06
Southern DDA region	.07																
Size of provider	-.08		-.05														
Number of providers						.05											
Self reporting	-.28	-.09	-.22		-.14	.17			-.07	.21	.10	.16	.08	.36	.25	.40	.31
Intellectual ability							.08				.06			.11	.14	.10	.12
Deaf, hearing impaired												-.05					
Epilepsy and seizure disorder										-.06							-.04
Age								-.07	-.07		-.05						
R^2	.09	.24	.05	.15	.03	.24	.03	.16	.02	.16	.05	.12	.03	.27	.14	.26	.18

* Stepwise regression with p=.01 to enter and p=.05 to delete.

** "# trips by provider to day activity" is not available for FY2002 but is related to the dichotomous "provider 3+ trips per week" which is available.

Characteristics not related: public transportation, family transportation, receives community supported living assistance, receives DDA day habilitation support, receives DDA individual support services, receives DDA support coordination, size of provider, gender, autism, behavior problems, blindness or visual impairment, cerebral palsy, head injury, mental disorder, neurological impairment, orthopedic impairments, specific learning disability, and speech and language impairment.

Appendix Table 9. Standardized Multiple Regression Coefficients* (β) of Average Quality of Life Scores on Provider Characteristics (Dichotomous Transportation): FY2002-FY2004

Provider Characteristics	Trans Available	Physical Well-being	Emotional Well-being	Material Well-being	Inter-personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights								
Average transportation availability		.82	.63	.78	.51	.61	.55	.59	.61								
% Provider transports 3+ times/week				.43													
% Other providers transport			-.29			-.17		-.21									
% Family and friends transport						-.23	-.21										
% Using public transportation	.19	.26	.23	.33	.52	.22	.30										
% Supported employment services						.22	.23	.27	.19								
% Individual support services		-.16		-.28													
Western DDA region	.23	.25		.24			.32	.34	.41								
% of sample with survey data		.20	.24	.26	.21												
% Self reporting	-.45	-.42	-.33		-.22	.21	.34	.64	.41								
Average intellectual abilities				.25													
% Blindness, visual impairments	.19			-.17		-.28			-.30								
% Deafness, hearing impaired	.24	-.24		-.28	-.49	-.36	-.33										
% Epilepsy and seizure disorder			.17						-.26								
% Speech and language impairment								-.19									
Average age						-.34	-.32										
R^2	.38	.69	.36	.57	.26	.54	.27	.48	.28	.48	.22	.40	.15	.62	.38	.57	.38

* Stepwise regression with $p = .05$ for entry and $p = .10$ required for removal
 Characteristics not related: % receiving residential support, % receiving day habilitation support, % receiving community supported living arrangements, Eastern Shore DDA region, southern DDA region, size of provider, % supported by other providers, % male, % autism, % behavioral problems, %cerebral palsy, % head injury, % mental disorder, % neurological impairment, % orthopedic impairments, and % specific learning disability.



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