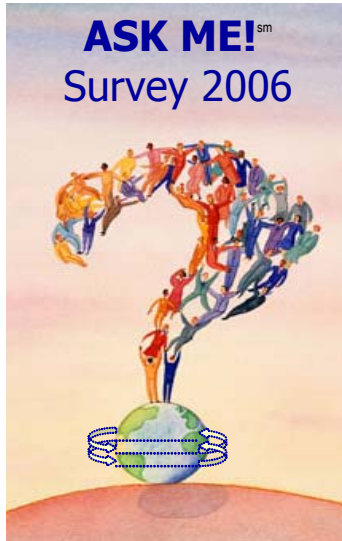


# Ask Me!<sup>sm</sup> FY 2006



## 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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December 2006

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Judy Volkman at the Arc of Maryland managed the Ask Me! Project, supported by Suzanne Carley, Nolie Rife, Tracy Wright and Suzy Fletcher as regional coordinators. Jessica Yaeger scheduled interviews and arranged transportation. Donna Bailey served as the Quality Assurance Consultant. Tonja Trap conducted American Sign Language interviews with deaf respondents.

Committed and skilled interviewers, who themselves have received support funded by the DDA, make The Ask Me! Project possible. In FY2006, 34 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 4.3 years of Ask Me! experience: 3 with 9 years, 4 with 8 years and 4 with 7 years experience. Michael Raidt worked for Bonham Research as Data Entry Clerk (DE). The Ask Me! FY2006 interviewers, with years interviewing in parentheses ( ), included:

Aileen Riley (1)	Greg Gray (2)	Natalie Turner (2)
Amanda Zittle (2)	James Devore (9)	Patrick Rhinehart (2)
Amy Grossman (4)	Howard Holland (4)	Patty Worff (7)
Anne Bates (3)	Kathleen Hagerty (2)	Paula Suter (2)
Barbara Moore (3)	Kenneth Capone (4)	Robert Haburchak (9)
Bernadette Quinn (1)	Kim Vander Weyden (2)	Robert Heil (3)
Brad Kram (2)	Kimberly Smith (7)	Scott Heim (8)
Brian Plater (5)	Linda Cooper (5)	Sean Taylor (1)
Bridgette Pressley (8)	Lori Powell (8)	Valerie Smith (1)
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Fran Appold (9)		

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](mailto:sbasehart@thearcmd.org).

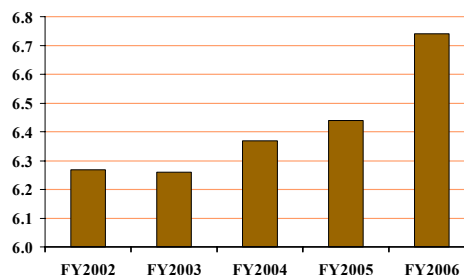
## Ask Me!<sup>sm</sup> FY 2006 Executive Summary

The FY2006 Ask Me! Project collected information between August 2005 and July 2006 for 1,225 adults with developmental disabilities served by 41 community provider agencies. Half of the people received day habilitation services and three-tenths received employment support. One-fourth lived in community residences staffed by agencies. Three-fourths (72%) of the survey responses came from the individuals, generally face-to-face with the person at their weekday program or employment site.

### Quality of Life Change in Maryland

The rights expressed by Maryland adults with developmental disabilities increased significantly between 2005 and 2006, from a scale score of 6.43 to 6.73 (see chart), or from 66.9% to 71.9% who expressed positive feelings about their rights. This increase was large enough to overcome no or insignificant increases in previous years, resulting in a 1.9% per year average increase over the years between FY2002 and FY2006. Self-determination increased next most over the period, at 1.6% per year on average. The quality of life increased in the other six domains increased an average of 0.8% to 1.2% per year.

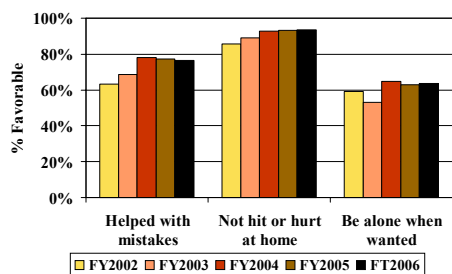
Rights increased significantly between FY2005 and FY2006



*Recommendation 1: Continually recognize that quality of life is multi-dimensional.*

*Recommendation 2: Continue to focus rights, self-determination and personal development, the three domains that still show the lowest quality of life.*

### Questions with most positive 5-year changes

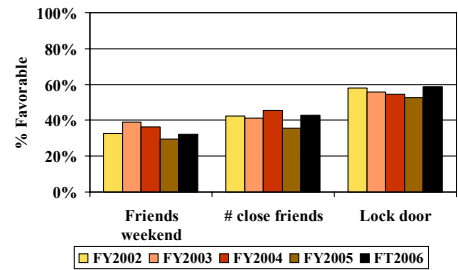


The three questions that increased most in favorable responses between FY2002 and FY2006 suggest specific ways community agencies are enhancing the quality of life of the people they support. The percent who said people helped them when they made a mistake increased from 63% to 77%. The percent who reported never being hit or hurt by people where they lived increased from 86% to 94%. Over 60% say they can now be alone when they want to be by themselves, although there is opportunity for this percent to increase further.

*Recommendation 3: Believe that system-wide and agency-specific efforts can enhance people's quality of life, while recognizing that they do not determine them.*

In FY2002, 58% reported being able to lock their bathroom door if they wanted. This percent steadily declined to 53% in FY2005, the only quality of life indicator question (out of 48) that had a significant decrease in favorable responses. The jump in favorable responses to 59% in FY2006 may indicate the downward trend has ended or even reversed. Two questions about friends also had an overall significant decline over the five years, although fluctuating from year to year. A declining percent say they see friends every weekend, probably because a declining percent say they have lots of friends from places other than work or home.

Questions with most negative 5-year changes



*Recommendation 4: Helping people develop friendships outside of weekday activities will contribute to quality of life.*

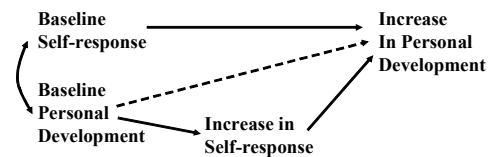
*Recommendation 5: Involve individuals in the decisions that affect their lives, including how an agency interprets and uses Ask Me! results.*

#### Four Year Change in Agency QOL

With FY2006 being the start of the second four-year cycle of interviewing, 38 agencies have been surveyed at least twice four years apart. The quality of life did not increase at all agencies. Interpersonal relations scores increased at double the average rate at six agencies and decreased at four agencies. The rights scores increased at least 0.20 scale points at 17 agencies while they decreased at 14 agencies.

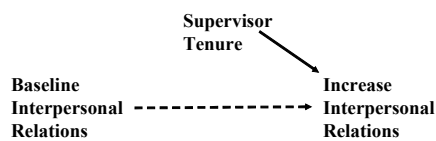
Agencies that supported a large percent of people who responded for themselves at the first (baseline) survey also had higher levels of rights, self-determination and personal development (see chart) reported at the first survey than agencies where fewer people could respond for themselves. What caused this could not be determined with just one survey, so a curved arrow is shown on the chart to indicate the unexplained relationship. With the most recent survey, it is clear that self-response affects rights, self-determination and personal development. The solid straight arrow shows that the higher the percent of people who responded for themselves during the first survey, the greater the increase in reported personal development. The chart for rights and self-determination would be the same. In addition, the greater the increase (or the less the decrease) in the percent of people responding for themselves, the greater the average annual increase in personal development, rights and self-

Personal Development and self-response contribute to each other



determination. (The dashed-arrow indicates a negative relationship, reflecting that agencies with high levels of personal development, rights and self-determination at the first survey had less potential for subsequent increases in personal development, rights and self-determination than agencies with low levels at the first survey.) In only the domain of personal development, however, did the baseline quality of life affect change in self-response. The greater the level of personal development reported at the first survey, the greater the increase is self-response over the following 4-5 year period (or less the decrease, since self-response tended to decline over the

### Supervisor tenure contributes to interpersonal relations



period). This suggests that agencies that promote personal development also promote the ability of individuals to understand questions and respond for themselves, while agencies that do not promote the personal development of the people they support cause individuals to lose their ability to express themselves.

The repeated surveys showed that agencies that retained their first line supervisors had significantly greater increases in interpersonal relations (see chart), material well-being and emotional well-being over the time period, controlling for the quality of life reported in these domains in the first survey.

*Recommendations 6: Place importance on stable staff, while remembering that staff have secondary importance to the people they support.*

### Proxy Knowledge

The *Ask Me! Survey* seeks to interview two proxies for each person who cannot respond for himself or herself. Direct care day program staff provided 49% of the proxy responses, direct care residential staff provided 29%, other agency staff provided 6%, and family and friends provided 16% of the proxy responses. Almost all proxies had known the person for two or more years and three-fourths saw the person daily, but these measures of interaction had little relation to how they answered survey questions. The individuals had expressed their feelings a lot to 58% of family proxies, 54% of residential staff proxies, and 36% of direct care day staff. Proxies answered three more questions on average when they reported the person had expressed their feelings a lot than when the person had not expressed feelings to them.

People responding for themselves reported lower levels of physical and emotional well-being than proxies reported. Both reported about the same level of material well-being and interpersonal relationships. People responding for themselves reported higher levels of personal development, social inclusion, self-determination and rights than proxies reported. People responding to the survey with the help of family or staff they wanted to be in the room with them reported quality of life generally in between self-respondents interviewed alone and proxies. In all eight domains, residential and day staff proxies reported higher quality of life than did family members. Residential staff reported higher quality of life than day staff in the domains of

emotional well-being, material well-being, interpersonal relations and rights. Two proxies for the same person disagreed on two-thirds of the questions. Proxies disagreed least in the domain of physical well-being and disagreed most in the domain of rights.

Proxies have a difficult time knowing how someone who cannot respond directly to survey questions would answer those questions. Proxies are more likely to answer based upon the context they share with the individuals than upon specific knowledge of the individuals' thoughts and feelings, although the amount the individuals express their feelings to their proxies makes some difference. Agreement between two proxies for the same person is also most likely due to a shared context than to specific knowledge. The type of proxy explained more variation in their reporting of people's quality of life than did characteristics of the individual or their support.

Although family and staff cannot know exactly what individuals think and feel when they cannot respond for themselves, decisions must be made on the supports that would best enhance quality of life. The findings from the *Ask Me! Survey* provide suggestions about whose impressions might be best for each quality of life domain:

- Physical Well-being: all family and staff appear to be overly optimistic with none likely to reflect the viewpoint of the person.
- Emotional Well-being: family members and non-direct care staff provide more reasonable perspectives than direct care staff.
- Material Well-being: direct care day staff are best relative to earning money, but direct care residential staff are best on the use of use of earnings and feeling well-off.
- Interpersonal Relations: all impressions appear to be useful as each sees the person in different settings.
- Social Inclusion: day staff see the inclusion offered through employment and residential staff see inclusion offered in the home and neighborhood.
- Personal Development: day staff appear to have the best insight in this domain, but are still influenced by their goals for the individuals rather than the individuals' goals.
- Self-determination: the family or staff to whom individuals most express their feelings will have the best insight, not the type of family or staff.
- Rights: this domain is the most difficult to determine for others, and Ask Me! data provided little evidence to determine who might have the best impressions.

*Recommendation 7: Involve people with various relationships and from various settings when making decisions for individuals who cannot communicate their own needs and desires.*

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## Background

The *Ask Me! Survey* has been used annually since FY2002 to collect information from people receiving support from all Maryland community providers through funds from the Maryland Developmental Disabilities Administration (DDA). A pilot study in FY2001 collected the same information from people supported by providers who had volunteered to participate during that year. The *Ask Me! Survey* measures people's perceptions of the quality of their lives. People's quality of life should be improved by the nature and quality of support they receive, but this support is mediated by the individual's values, perceptions, and other life experiences. It is possible for provider agencies to overlook overall quality of life as they focus on providing quality services in specific situations. 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. The Ask Me! Project has demonstrated that people with developmental disabilities elicit and provide data on quality of life that are valid, reliable, and useful for program enhancement.

The Maryland DDA conducts the *Ask Me! Survey* on a four-year cycle. Each year consists of a random sample of adults throughout the state, about thirty adults from each of about 41 agencies. Large agencies participate every year, middle sized agencies participate every other year, and small agencies participate once in the four-year cycle. Small agencies and micro-boards supporting fewer than ten adults are not included in the survey. This report presents and analyzes data from the FY2006 *Ask Me! Survey*, the first year of the second cycle of interviews. It also analyzes change in the average quality of life at providers interviewed 4-5 years earlier. The FY2005 report was more comprehensive, summarizing the information from the first four-year cycle in greater detail and presenting the average quality of life reported for each of 116 Maryland community provider agency. Other information on the *Ask Me! Survey* can be found in the publications listed on the back cover.

Quality of life has become an important concept in program development, service delivery, management strategies, and outcome evaluation in a number of human service areas, including supports for people with developmental disabilities (Schalock, 2001; Schalock & Verdugo, 2002). Although some researchers had suggested as many as fourteen dimensions (Hughes & Hwang, 1996), Schalock and Verdugo (2002) documented eight domains found in the international literature of intellectual disabilities, education, mental health, physical health and aging. They found that social inclusion had been studied the most and rights had been studied the least. The Ask Me! Survey, developed in consultation with Robert Schalock, includes these eight domains and measures them with questions that Maryland self-advocates had earlier defined as important to them (People on the Go, 1996).

The Ask Me! Survey involves three premises of participatory action research: (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) interviewers with developmental disabilities are in the best position to elicit meaningful responses from their peers. The Ask Me! Survey involved self-advocates in refining the survey instrument and in planning survey procedures. It trains people with developmental disabilities to survey their peers. It provides paid job opportunities and career paths for people with developmental disabilities. It indirectly has contributed to individual and group self-advocacy.

The Ask Me! Survey is 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 agencies participating in the Ask Me! Survey receive the aggregate responses of the people they support. This information is designed to help them enhance their programs, and can be used to measure achievement of outcomes included in the quality assurance plans they submit to the DDA. DDA uses the Ask Me! results to develop and measure achievement of its goals of personal development, self-determination and social inclusion as required by the state budgetary process. Individuals and families have Ask Me! quality of life findings available as a resource in seeking the most appropriate agency for providing support services. The Arc of Maryland uses Ask Me! results to guide its advocacy and training program.

# Project Description

## Sample

The FY2006 Ask Me! Project collected information between August 2005 and July 2006 for 1,225 people with developmental disabilities served by 41 community provider agencies. The agencies were sampled according to their size strata, and people were randomly selected within these agencies. (See **Figure 1.**) This two-stage sample represent approximately 12,000 people 18 years and over with community supports funded by the Maryland DDA. One-fourth of the adults receive services from two or more agencies, and the sample included 28 people who were sampled through two of the 41 agencies. During a four-year period, interviews will be conducted with people supported by an expected 111 community provider agencies serving ten or more people. The DDA files of about 25,000 person-support-provider records in July 2005 were used to select the sample. (See **Appendix Table 1.**) Entities serving fewer than ten adults were not included in the sample. These included micro-boards, health departments or other organizations with only fiscal responsibility for purchasing services; nursing homes, rehabilitation centers or other organizations providing specialized services to the general for limited periods; and start-up agencies that frequently have a short life-span. Additionally, about 1,800 persons included in the DDA files were not included in the Ask Me! sample selection because they were under 18 years of age, received only service coordination, received all services within the four state institutions, or were Ask Me! interviewers.

- |  |
|--|
| <p><b>Strata 1</b> (300+ people)</p> <ul style="list-style-type: none"><li>• 11 agencies support 37% of people</li><li>• 11 sampled every year</li></ul> <p><b>Strata 2</b> (130-299 people)</p> <ul style="list-style-type: none"><li>• 21 agencies support 27% of people</li><li>• 10 sampled in FY2006</li></ul> <p><b>Strata 3</b> (50-129 people)</p> <ul style="list-style-type: none"><li>• 48 agencies support 29% of people</li><li>• 14 sampled in FY2006</li></ul> <p><b>Strata 4</b> (10-49 people)</p> <ul style="list-style-type: none"><li>• 31 agencies support 6% of people</li><li>• 6 sampled in FY2006</li></ul> <p><b>Strata 5</b> (1-9 people)</p> <ul style="list-style-type: none"><li>• 24 entities support 0.5% of people</li><li>• Not included in sample</li></ul> |
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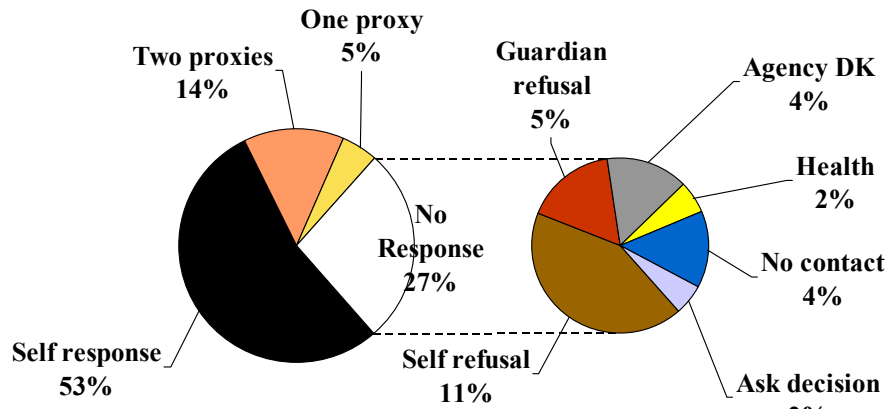
**Figure 1.** Provider Sample Frame

The survey collected information for three-fourths of the selected adults: 54% responded for themselves, 14% had responses from two proxies that were averaged, and 5% had information from a single proxy. (See **Figure 2.**) Most of the nonresponse came from refusals: 5% of their guardians refused to give permission for the interview and 11% of the individuals declined for themselves. Agencies no longer (or never) supported 4% of the people that the DDA files indicated they were authorized to support, and these people could not be located through another agency or service coordinator.<sup>1</sup> Ask Me! interviewers could not make contact with 4% of the

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<sup>1</sup>The DDA files represent authorization to provide support, not the billing for support services. Some people had not started receiving support at the time of the interview, some had left the agency between the time the sample was drawn and interviewing began, some had left the agency earlier and the DDA file had not been updated prior to sampling, and some were totally unknown to the agencies. Those who had died or moved out of Maryland were treated as if they were never eligible to be selected for the sample.

people, frequently those who were fairly independent, could not be interviewed at work, and could not be reached by telephone at home. A few (2%) could not be interviewed during the survey period because of their health or because they understood only a language for which a translator was not available (a deaf interviewer conducted



**Figure 2.** Response of People Selected for Interview

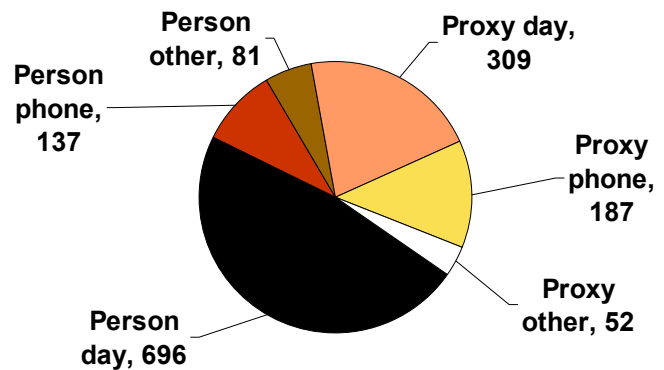
The Ask Me! director made the decision to not pursue interviews with 1% of the people because of time, distance or cost limitations.

Three-fourths (72%) of the survey responses came from the people themselves, although 6% did have someone in the room to help them understand. The percent who responded for themselves increased from 10% of those classified with profound retardation, 46% of those with severe, 84% of those with moderate, 96% of those with mild, 98% with borderline, and 100% of those with no retardation.

Weights adjust for the probability that some people could have been selected through more than one provider agency, to adjust for the different probabilities of an agency being selected for the FY2006 survey, the different probabilities of being selected within different size agencies, and the different rates of nonresponse at different agencies. All the data presented in this report, except for response rates, were weighted to accurately reflect all adults receiving DDA-supported community services as of the start of FY2006 (July 2005).

### Survey Procedures

The Arc of Maryland employed 34 peer interviewers who had an average of 4.3 years experience interviewing on The Ask Me! Project. (See inside front cover.) Most work in pairs and conduct interviews face-to-face with the selected person or the person's proxy. A few interviewers only conduct telephone interviews. About half of the interviews (696 of 1462) were conducted face-to-face with the person at their weekday program or employment site. (See **Figure 3.**) Some people (81) were



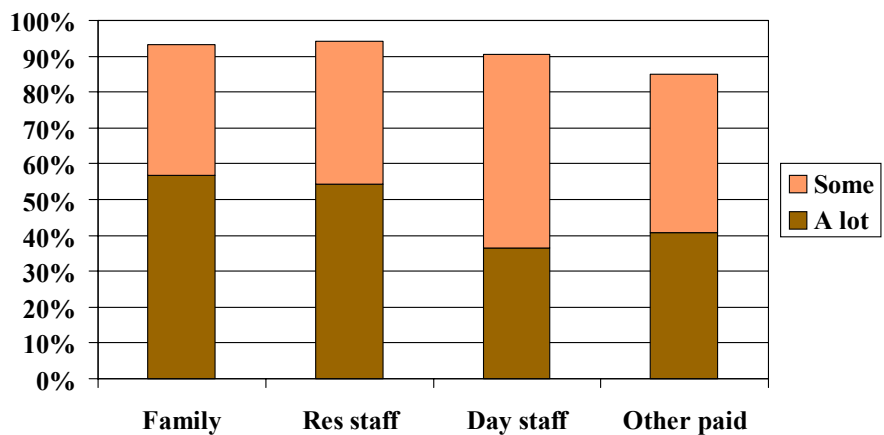
**Figure 3.** Respondent by Location of Interview

interviewed face-to-face at their home or other location. However, a number (137) were interviewed over the telephone, especially when they were employed at scattered sites with minimal agency support. When the interviewers determined that the selected individuals were not able to understand the survey and give informed consent, they interviewed proxies. The interviewers conducted face-to-face interviews with the majority of proxies (309 or 56%) while they were at the day program site, as survey protocol included staff as one proxy. Survey protocol indicated that the second proxy should be a family member or friend when possible, with next preference being a direct care staff at the person’s residence. Interviewers conducted 187 telephone interviews with proxies, and 52 face-to-face interviews with proxies at the consumer’s residence or some other location.

## Proxies

Proxies had a variety of relationships with those who could not respond for themselves. Direct care day program staff provided 49% of the 548 proxy responses and direct care residential staff provided 29%. Supervisors, trainers, nurses, other agency staff and service coordination staff provided 6% of the proxy responses. Parents provided 12%, siblings provided 1%, and other relatives and friends provided 3% of the proxy responses. Three-fourths of the proxies saw the person daily, including 90% of day staff, 80% of residential staff, 46% of other staff, and 68% of family or friends. An additional 12% saw the person at least once a week. Almost all family and friends had known the person for ten or more years. Half of staff proxies had known the person two or three years, one-fourth of staff had known the person four to nine years, and one-fourth of staff had known the person for ten or more years. Few proxies had known the person less than two years: 2% of residential staff and 7% of day staff.

Over half of family and residential staff proxies (58% and 54% respectively) said that the people for whom they were responding expressed their feelings a lot to them. (See **Figure 4**.) Only 36% of direct care day staff said the person expressed their feelings a lot; most of the rest said the person expressed their feelings some.



**Figure 4.** How Much People Express Their Feelings to Proxies

Proxies answered 49.7 questions on average when they reported the person had expressed their feelings a lot, but answered only 46.8 questions when the person had expressed their feelings some, and 46.7 questions when the person had not expressed feelings to them. In addition,

proxies who had known the person for four or more years answered 48.9 questions compared to 47.0 questions when they had known the person two and three years, and 43.9 questions when they had known the person less than two years. Residential staff answered 2.5 more questions on average than other proxies, after accounting for the length of time they had known the person and the degree the person had expressed his or her feelings. The frequency proxies saw the person had no relation to the number of questions proxies answered.

## Demographic Characteristics

Of the people represented in the survey, 16% were 18-24 years of age, 26% were 25-34, 26% were 35-44, 21% were 45-54, and 12% were over 55 years of age. (See **Figure 5.**) Men outnumbered women 56% to 44%. The majority had mild or moderate retardation, although agencies did not report intellectual ability for one-fourth of the people. In addition to various levels of intellectual abilities, 15% had specific learning disabilities. Speech and language difficulties affected 27% of the people, indicating the importance of allowing them to respond during the interview by pointing to facial representations associated with their answers (☺, ☹ or ☹).

Some peer interviewers also had speech difficulties and conducted interviews by activating the pre-recorded questions on their computer. About one in ten persons had hearing impairments, and two percent of the interviews were conducted in American Sign Language by a deaf interviewer.

## Support Services

Almost half (49%) of the people lived in the Central DDA Region that primarily includes the Baltimore metropolitan area. An additional 23% lived in the Southern DDA Region that includes Montgomery, Prince George's, Calvert, Charles and St. Mary's Counties. The Western DDA Region included 15% of the people, and the Eastern DDA Region included 13% of the people.

<i>Characteristic</i>	<i>Percent</i>	<i>Characteristic</i>	<i>Percent</i>
Total	100	<i>Gender</i>	
<i>Age</i>		Female	44
18-24	16	Male	56
25-34	26	<i>Other Disabilities</i>	
35-44	26	<i>(may have multiple)</i>	
45-54	21	Speech and language	27
55-64	9	Epilepsy and seizures	21
65 and over	3	Behavior problems	16
<i>Intellectual Ability</i>		Specific learning	15
Profound retardation	9	Cerebral Palsy	10
Severe retardation	11	Orthopedic impairment	9
Moderate retardation	21	Deaf, hearing impairment	9
Mild retardation	26	Autism	7
Borderline retardation	4	Mental disorder	7
No retardation	3	Blind, vision impairment	5
Not reported	27		

**Figure 5.** Percent by Characteristics

Half of the people receive day habilitation services, with 27% living in community residences staffed by agencies and 26% either living with their families or living independently with individual support services (ISS) or community supported living assistance (CSLA). (See **Figure 6.**) Three-tenths of the people receive supported employment services, with 9% living in community residences operated by agencies and 20% living with their families or independently with ISS or CSLA support. The remainder receive neither day habilitation or supported employment services, although 6% lived in staffed community residences. More than half of the people in staffed community residences also have service coordination compared to one-eighth of the people receiving only supported employment services.

<i>Type of Support</i>	<i>Percent</i>
All	100
Day habilitation and residential	27
Day habilitation (includes ISS/CSLA)	26
Employment (includes ISS/CSLA)	20
Employment and residential	9
Residential (includes ISS)	6
ISS and/or CSLA only	12

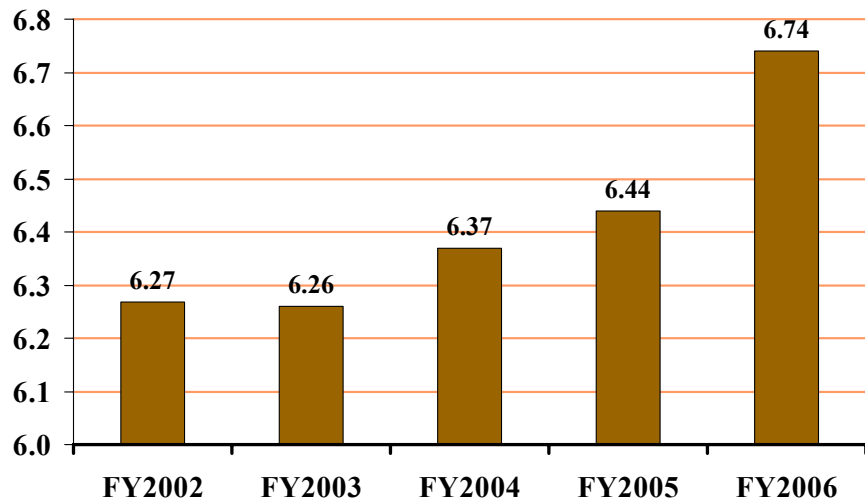
**Figure 6.** Percent of Persons by Type of Support

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# Quality of Life

## Maryland FY2002-FY2006

The rights expressed by Maryland adults with developmental disabilities increased significantly between 2005 and 2006, from 6.43 in 2005 to 6.73 in 2006, continuing, and perhaps accelerating, the increase that began after 2003. (See **Figure 7**.) The percent who expressed positive feelings about their rights also increased from 66.9% in 2005 to 71.9% in 2006. Both of these increases were much too large to be attributed to chance alone. The quality of life scale would be 0 if the person gave negative responses to all the questions in the scale, 10 if the person gave positive responses to all questions, and 5 if the person gave a neutral responses to all questions or an equal number of positive and negative responses.



**Figure 7.** Average Quality of Life in the Domain of Rights

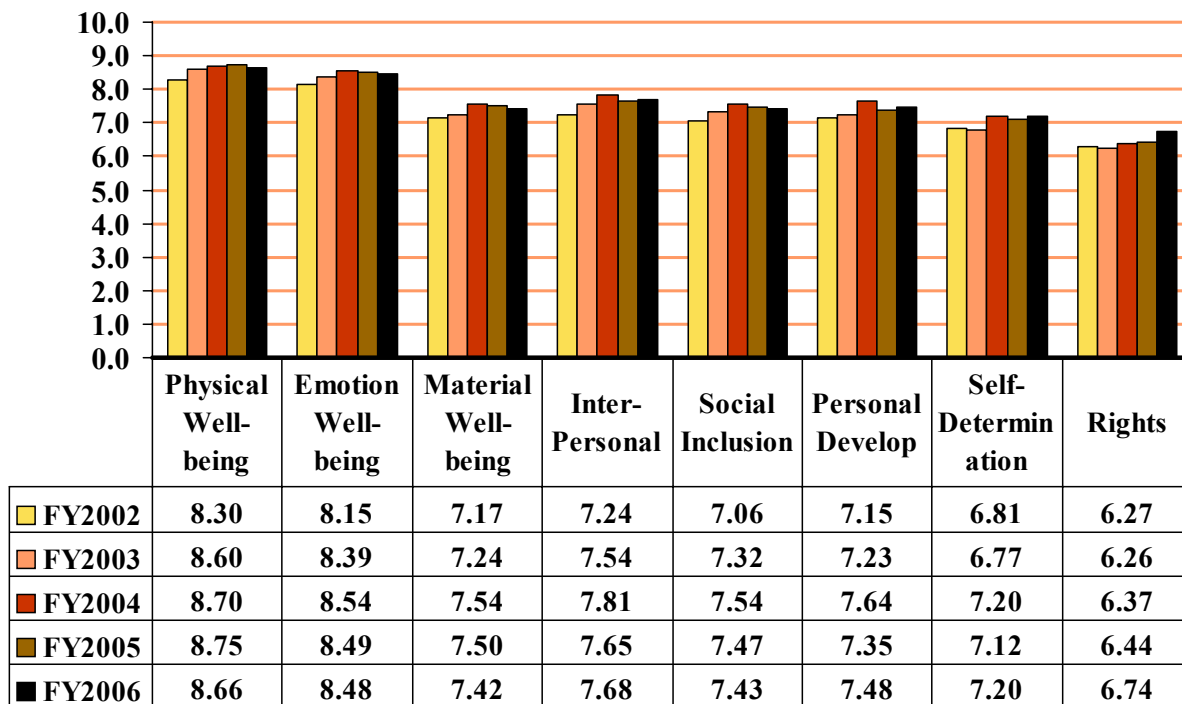
Over the period between FY2002 and FY2006, the quality of life increased in all eight domains. Linear regression showed that physical well-being average increased 0.08 scale points per year, or 0.32 points over the four years. (See **Figure 8**.) Since the average physical well-being over the time frame was 8.6 on the 10-point scale, the 0.08 points represents an average increase of 0.9%. Five other domains increased 0.07 to 0.09 points per year, or an average of 0.8% to 1.2% per year: emotional well-being, material well-being, interpersonal relations, social inclusion, and personal development. Rights increased 1.9% per year (0.12 scale points) due to the large increase in FY2006, and self-determination increased 1.6% per year (0.11 scale points) due to the large increase between FY2003 and FY2004. All of the increases were statistically significant at a 99.9% level of certainty ( $p < .001$ ), although they were based on only five data points for each domain. Linear

Domain	Scale	%
Physical well-being	0.08	0.9
Emotional well-being	0.07	0.8
Material well-being	0.07	0.9
Interpersonal relations	0.09	1.2
Social inclusion	0.08	1.1
Personal development	0.07	0.9
Self-determination	0.11	1.6
Rights	0.12	1.9

**Figure 8.** Average Annual Increase in Quality of Life

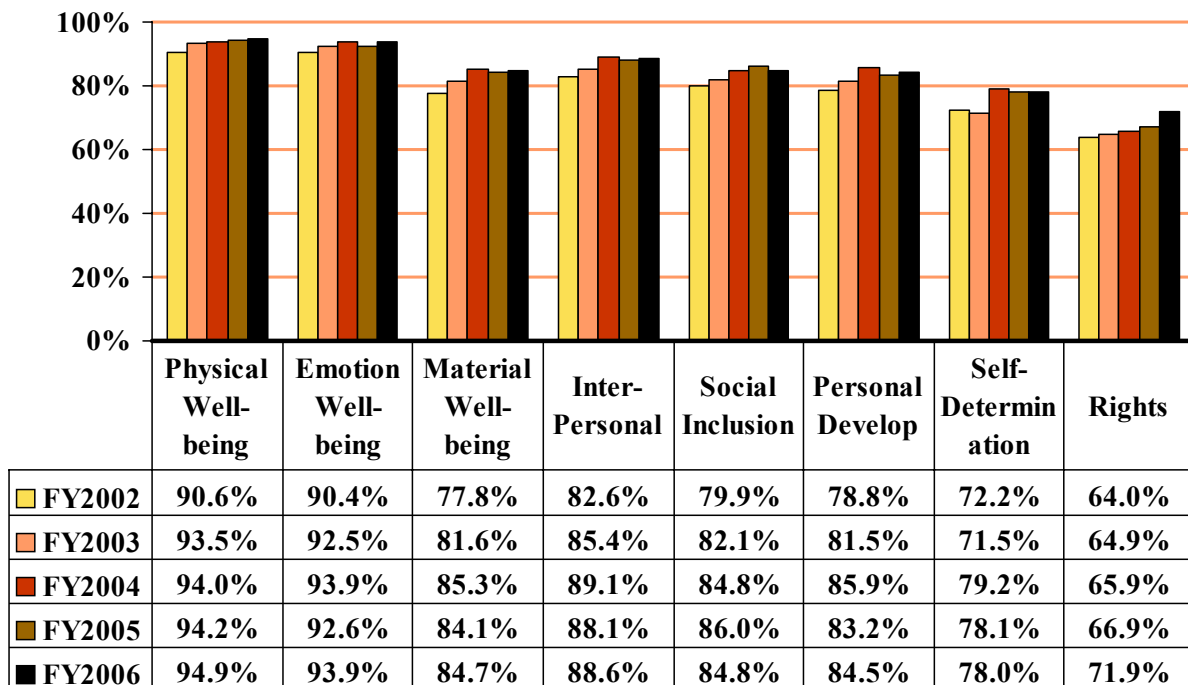
regression ignores any variation around a straight trend line, assuming the variations are due only to sampling error.

The average quality of life for each domain for each year is shown in **Figure 9**. The average physical well-being was 8.30 in FY2002, 8.60 in FY2003, 8.70 in FY2004, 8.75 in FY2005 and 8.67 in FY2006. While a linear regression fits the data well, it assumed an equal increase each year that would be expected to continue. The greatest increase in physical well-being, however, was between FY2002 and FY2003, with a slight decrease between FY2005 and FY2006. This may suggest that physical well-being may have reached a plateau, and little increase may be expected in the future. For all domains except rights, and possibly personal development, the changes between FY2005 and FY2006 were not statistically different from no change. The change in rights was discussed earlier. Personal development increased from 7.35 to 7.51 between FY2005 and FY2006, with a 94% chance of certainty rather than the generally accepted 95% chance of certainty.



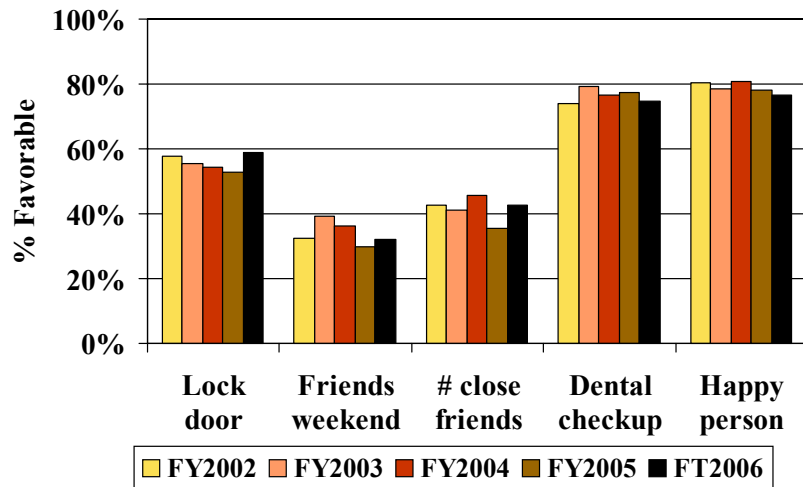
**Figure 9.** Average Quality of Life, by Domain and Year

Almost all Maryland adults with developmental disabilities reported a positive quality of life during 2006 in the domains of physical well-being (94.9%) and emotional well-being (93.9%). (See **Figure 10.**) More than 84% also reported positive qualities of life in material well-being, interpersonal relations, social inclusion and personal development. About three-fourths (76.2%) reported positive self-determination and rights (71.9%). A significant increase occurred between 2005 and 2006 in the percent expressing positive rights. All other increases or decreases between 2005 and 2006 could have been due to chance alone.



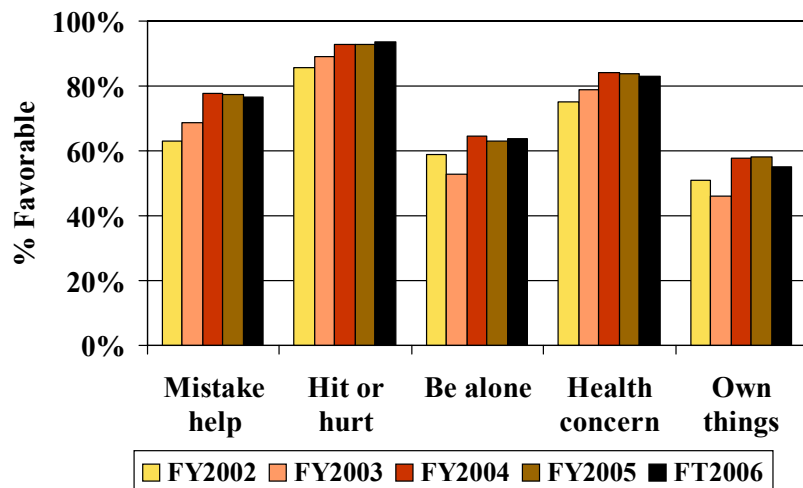
**Figure 10.** Percent Reporting Positive Quality of Life, by Domain and Year

Between FY2002 and FY2005, only one of the 48 quality of life questions had a significant decrease in favorable responses. Fewer people in FY2005 (53%) than in FY2002 (58%) reported being able to lock their bathroom door if they wanted. (See **Figure 11**.) The favorable response to this question increased in FY2006 to 59%, possibly stopping the downward trend or even starting an upward trend. The responses to four other questions gave no indication of an overall increase in favorable responses. The lack of increase for two questions may have been the high favorable response in the first year: 80% in FY2002 saw themselves as a happy person and 74% reported regular dental check-ups. In FY2006, 77% saw themselves as a happy person and 75% reported regular dental check-ups. Friendships, however, had a great potential for improvement from FY2002, but did not. In FY2002, 33% of the respondents reported seeing friends on weekends, declining to 32% in FY2006 (no statistical change). In both FY2002 and FY2006, 43% of the respondents said they had a lot of close friends.



**Figure 11.** Questions with No Four-year Statistical Increase

The five questions with the greatest overall increases in favorable responses between FY2002 and FY2006 are shown in **Figure 12** ( $r = .07$  to  $.09$ ,  $p < .001$ ). The percent who said people helped them when they made a mistake increased from 63% to 77%. The percent who reported never being hit or hurt by people where they lived increased from 86% to 94%. The percent who said they could be alone when they wanted increased from 59% to 64%. The percent who said people were concerned the right amount about their health increased from 75% to 83%. The percent who owned a lot of things, like furniture, TVs, stereos or bikes, increased from 51% to 55%.



**Figure 12.** Questions with Greatest Four-year Favorable Increase

The percent who responded to the questions in a positive manner (☺ 1) during each of the years from FY2002 to FY2006 are shown in **Table 1**. The questions are grouped in the order they appeared on the questionnaire and are identified by the quality of life domains that they measure. The overall correlations (*r*) of favorable responses with year are shown in the last column.

Question	Fiscal Year					<i>r</i> with year
	2002	2003	2004	2005	2006	
<i>Emotional Well-Being</i>						
Q1 Would you say that you are a happy person?	80.4%	78.6%	80.9%	78.3%	76.7%	.00
Q2 How do you feel about your home where you live?	64.7%	66.5%	69.1%	70.3%	69.2%	.03
Q4 How safe do you feel in your neighborhood?	73.3%	77.4%	79.7%	78.2%	76.8%	.03
Q5 Do you like yourself?	73.1%	78.9%	77.9%	78.0%	79.8%	.05*
Q6 Feel others treat you the same as any other person?	58.2%	61.9%	67.5%	63.2%	62.5%	.04
Q7 In general, how happy are you with your life?	67.8%	67.7%	72.9%	71.4%	71.1%	.05*
<i>Social Inclusion</i>						
Q8 Do people help you to be part of your community?	68.5%	72.6%	76.5%	76.7%	73.7%	.05*
Q9 Do you go to fun things in your community?	63.7%	62.2%	67.4%	67.2%	66.2%	.04
Q10 When you do to fun things, are you active?	62.1%	58.7%	59.7%	61.5%	62.6%	.04
Q11 Do you think your neighbors like you?	64.0%	65.6%	70.6%	69.0%	68.0%	.05*
Q12 Friends from places other than work or home?	43.4%	44.2%	47.8%	43.3%	46.8%	.06*
Q13 How often do you see these friends on weekends?	32.6%	39.2%	36.2%	29.7%	32.2%	-.02
<i>Interpersonal Relations</i>						
Q14 People help you learn to do things for yourself?	57.1%	64.0%	60.3%	59.6%	57.3%	.01
Q15 When you make a mistake, do people help you?	63.1%	68.7%	77.9%	77.3%	76.5%	.09*
Q16 Do people help you reach your goals?	70.4%	72.9%	77.7%	76.6%	76.2%	.04
Q17 How often do you see or talk with your family?	53.3%	58.1%	59.9%	60.0%	58.1%	.05*
Q18 How many close friends do you have?	42.6%	41.1%	45.6%	35.5%	42.8%	-.01
Q19 Does what you do let you look good to others?	62.6%	64.9%	70.1%	68.6%	66.8%	.05*
<i>Personal Development</i>						
Q20 Does what you make you feel important?	68.3%	69.3%	71.4%	70.2%	68.8%	.03
Q21 Are you getting training to help you get a job?	56.4%	51.7%	57.3%	51.9%	55.5%	.00
Q22 Others give you a chance to be what you want?	60.0%	63.8%	69.6%	66.0%	65.7%	.05*
Q23 Learning things to make you a better person?	71.1%	77.0%	80.4%	76.7%	75.2%	.03
Q24 Get the information you need about sexuality?	36.2%	34.4%	39.6%	37.3%	41.8%	.04
Q25 Do you get the services you need?	72.7%	77.0%	81.9%	79.4%	76.5%	.03

\* statistically significant ( $p < .001$ )

<b>Table 1. Percent Giving the Favorable Response by Question and Year</b>						
Question	Fiscal Year					r with year
	2002	2003	2004	2005	2006	
<i>Self-Determination</i>						
Q26 Did you pick who you live with?	49.5%	48.9%	48.7%	53.0%	57.8%	.06*
Q27 Can you be alone when you want to?	59.0%	53.0%	64.7%	62.9%	63.7%	.08*
Q28 How much choice do you have in your food?	49.9%	47.1%	50.8%	49.2%	49.7%	.02
Q29 Do you get a chance to say what you think?	53.5%	52.4%	57.4%	56.0%	54.7%	.03
Q30 Do you pay for things with your own money?	66.3%	68.6%	71.1%	70.9%	71.1%	.06*
Q31 Choose your job or what you do most days?	58.2%	59.2%	63.8%	59.7%	59.4%	.01
<i>Physical Well-Being</i>						
Q32 On your health are people concerned?	75.1%	78.8%	84.1%	83.6%	82.9%	.07*
Q33 Is your health good?	71.6%	69.2%	76.2%	74.3%	75.6%	.04
Q34 Would you say your eating habits are good?	70.7%	73.5%	74.9%	75.0%	73.2%	.02
Q35 Do you have regular check ups with a dentist?	74.1%	79.1%	76.6%	77.5%	74.6%	-.00
Q36 Get the sleep you need without being disturbed?	69.1%	76.8%	76.6%	80.7%	77.1%	.05*
Q37 Do staff or people you live with hit or hurt you?	85.7%	89.0%	92.8%	93.0%	93.5%	.09*
<i>Material Well-Being</i>						
Q38 How many things do you own?	51.0%	46.2%	57.6%	58.0%	55.2%	.07*
Q39 How often do you worry about money?	61.0%	69.4%	65.9%	68.5%	67.0%	.02
Q40 On money, do you feel that you are well off?	56.5%	63.1%	61.8%	64.9%	62.6%	.04
Q41 Do you have money each week to spend?	66.2%	67.4%	69.1%	72.2%	69.2%	.04
Q42 Do you save money?	52.3%	51.6%	57.5%	50.2%	50.9%	.00
Q43 Do you have the chance to earn good money?	59.0%	54.0%	59.2%	55.6%	58.1%	.01
<i>Rights</i>						
Q44 Staff ask permission before entering your home?	57.3%	58.4%	58.5%	61.4%	60.9%	.03
Q45 Can you lock the bathroom door if you want to?	57.9%	55.6%	54.4%	52.7%	58.7%	-.00
Q46 Can you talk on the telephone in private?	62.0%	60.3%	63.5%	63.5%	65.7%	.04
Q47 Can you spend time by yourself if you want?	67.4%	66.6%	69.9%	71.0%	72.4%	.07*
Q48 When problem with staff, easy to say something?	54.0%	56.3%	55.9%	58.0%	61.0%	.05*
Q49 How often do you vote in government elections?	23.9%	23.8%	22.2%	24.7%	27.9%	.04
<i>Transportation Availability</i>						
Q51 Transportation when you want to go somewhere?	67.5%	74.2%	71.8%	73.2%	72.6%	.03
Q52 How much planning to go somewhere	30.8%	28.6%	23.9%	26.2%	25.1%	-.04
Q53 If you set up a ride, can you depend on it?	70.3%	72.6%	75.2%	76.9%	71.9%	.03
Q54 Do you miss things because of transportation?	50.3%	52.4%	50.6%	51.3%	51.2%	-.00
Q55 Transportation problems make you feel separated?	58.5%	60.8%	58.6%	60.1%	60.7%	.00

\* statistically significant ( $p < .001$ )

## Change in Quality of Life at Provider Agencies

The FY2006 Ask Me! Survey began the second cycle of interviews at all Maryland provider agencies. The first cycle covered the years FY2002 to FY2005. Some agencies volunteered to participate in the earlier FY2001 pilot survey, and their data are included in the following discussion as they are comparable. The Ask Me! survey includes the largest agencies every year. Six of these volunteered for the FY2001 pilot with five years between their first and last survey. The other five began in FY2002 with four years between their first and most recent survey. (See **Figure Figure 12.**) Ask Me! includes the next largest agencies every second year. Six of these interviewed in FY2006 volunteered for the FY2001 pilot and have five years between their first and most recent surveys. Four were interviewed in FY2001 and FY2005 and four were interviewed in FY2002 and FY2006, with four years between their first and most recent survey. The other agencies currently in this size category were interviewed in FY2003 and FY2005, and will surveyed again in FY2007. Among agencies supporting 80-193 people in FY2006, eight were surveyed in FY2001 and FY2006 with five years between their first and last surveys. Two were surveyed in FY2001 and FY2005 and one surveyed in FY2002 and FY2006 with four years between surveys. Ten agencies have been surveyed twice, but with less than four years between surveys, and 27 agencies have been surveyed only once. Among the smallest agencies, only two had been surveyed four or five years apart. Most of the rest had been surveyed a single time.

Agency Size	Total	Number of Years From First to Most Recent Survey					
		5	4	3	2	1	0
All	111	22	16	3	15	3	52
425 to 1,277	11	6	5	-	-	-	-
194 to 424	21	6	8	-	7	-	-
80 to 193	48	8	3	2	5	3	27
10 to 79	31	2	0	1	3	-	25

**Figure 13.** Number of Agencies by Size and Years Between First and Most Recent Survey

By the end of the second four-year cycle in FY2009, three-fourths of the agencies will have been surveyed at four or more years apart, the expected time period over which change will be analyzed. One-eighth of strata three and four agencies will have been surveyed only two years apart and one-eight will have been surveyed three years apart in order to distribute interviewing evenly over the second four

QOL Domain	Average All Increase	Average Yearly Increase					Loss
		.30+	.29	.19	.09	.00-	
Rights	38	.09	4	13	2	5	14
Self-determination*	36	.11	4	7	10	7	8
Personal development	38	.09	2	9	9	9	9
Social inclusion	38	.13	5	7	14	5	7
Interpersonal relations	38	.14	6	8	11	9	4
Material well-being	38	.10	4	8	9	7	10
Emotional well-being	38	.13	3	10	10	9	6
Physical well-being	38	.10	4	6	10	12	6

\* Score could not be calculated for two agencies as most interviews were conducted with the American Sign Language survey form that does not measure this domain.

**Figure 14.** Number of Agencies by Average Yearly Increase in Quality of Life in Each Domain

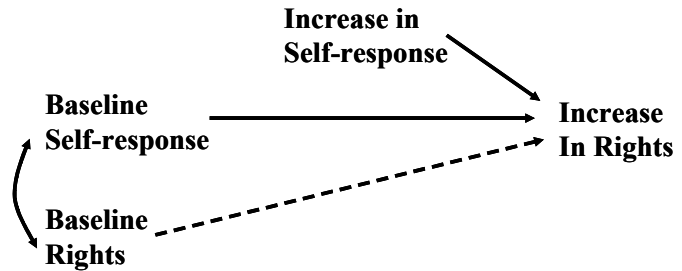
year cycle. As a first investigation of change over four years, the following section analyzes the change in the average quality of life of people supported by 38 agencies that have been surveyed at least four years apart through FY2006. These agencies have four or five years between the first and most recent interviews: 31 most recently interviewed in FY2006 and 7 most recently interviewed in FY2005. These 38 agencies had increases in quality of life that average 0.09 points per year in rights and personal development, and 0.14 points in interpersonal relations. (See **Figure 13.**) The quality of life did not increase at all agencies. The rights scores at 14 agencies declined over the four or five years, as much as 0.27 points per year. It increased more than 0.30 points a year for four agencies. In contrast, the interpersonal relations score decreased for only four agencies during the period, and increase more than 0.30 points at six agencies.

The FY2005 report identified several characteristics of all Maryland agencies that related to the average quality of life among the people they support as measured at the same point in time. It could not be determined, if these characteristics directly affected, or caused, the quality of life or if they were merely correlated. Having at least two quality of life measurements for agencies four or more years apart can begin to address cause and effect, although limited at this time to one-third of Maryland agencies that over represents large agencies. In the following analysis, the average annual change in quality of life was measured by a regression coefficient rather than the arithmetic mean and the baseline was the FY2001 regression intercept, projected backward for those agencies first surveyed in FY2002. The use of the regression statistics allows all the data to be used, rather than only the first and last years for large agencies interviewed every or every second year. The also permits the same starting year of FY2001 for all agencies so that comparisons are unaffected by the interaction of when interviews occurred and any overall change in quality of life over time.

First of all, does the quality of life in FY2001 for these 38 agencies show the same relation to the 21 characteristics of agencies and people found for all 116 Maryland agencies shown in the FY2005 report? The 21 characteristics explained none of the variation in physical and emotional well-being among the 38 agencies at the first survey, whereas they explained 52% and 15% of the variation among all Maryland agencies. One or two of the characteristics explained 11% to 25% of the variation in the other six domains of quality of life, compared with 3-7 characteristics explaining 38% to 51% of the variation among all agencies. It therefore appears that findings from these 38 agencies will be conservative and identify only the major cause-and-effects, not all cause-and-effects. Most quality of life scores are positive and they cannot go beyond 10. Therefore, it was expected that the higher the baseline (FY2001) score, the less it could and would increase in the following four or five years, or alternative, the more it could and might decrease. This was observed for all eight domains, with correlations between the baseline quality of life level and the annual increase in the score ranging from -.58 in interpersonal relations to -.75 in physical well-being.

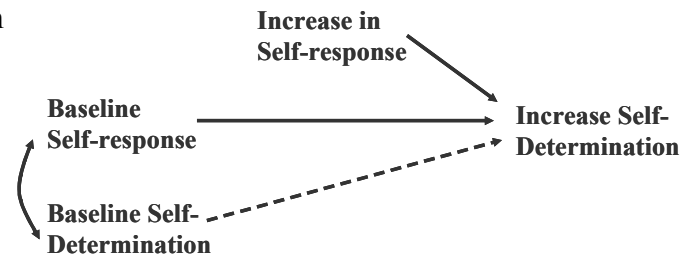
Agencies that supported a large percent of people who could respond for themselves in the FY2001 or FY2002 Ask Me! Survey (baseline) also had higher levels of rights reported in those years than agencies where fewer people could respond for themselves. (See **Figure 15**, a curved arrow does not assume causation.) The figure also shows that agencies with high baseline self-response had greater increases in rights over the following 4-5 years than did agencies with low

baseline self-response, controlling for the baseline level of rights (negative affect shown by the dashed-arrow). This suggests that the ability to respond for oneself (which is determined by the Ask Me! interviewers) is a causal factor in the reporting of rights--self-respondents report higher levels of rights than do proxy respondents. However, the ability to respond for oneself was not static. The rate of self-response decreased from 80% at the baseline to 77% four to five years later. If the percent of the people responding for themselves increased above the baseline, the reported level of rights increased irrespective of the baseline situation, and if the percent responding for themselves decreases, the level of rights decreased.



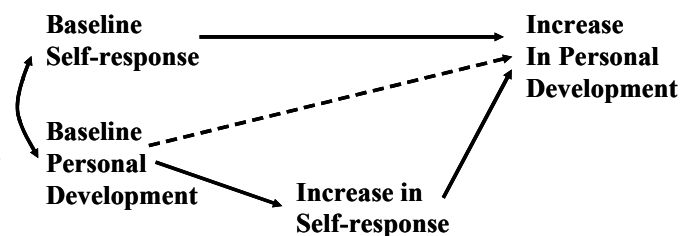
**Figure 15.** Predictors of Increase in Rights over 4-5 years: 38 Agencies

The same thing was observed in the domain of self-determination. Agencies with a large number of people who could respond for themselves at the first survey also had higher levels of self-determination reported at the first survey than did agencies with fewer people who could respond for themselves. (See **Figure 16.**) Controlling for the fact that high baseline levels of self-determination allow less increase in self-determination than low baseline levels (indicated with the dashed-arrow), agencies with high levels of self-response on the first Ask Me! survey in FY2001 or FY2002 had greater increases in their self-determination scores over the next four or five years than did agencies with lower levels of self-response reported in the baseline survey. In addition, agencies that had a greater increase (less decrease) in self-response over the four or five years had greater increases (less decreases) in their levels of reported self-determination.



**Figure 16.** Predictors of Increase Self-Determination in 4-5 Years: 38 Agencies

The level of personal development reported at baseline for agencies also related to the percent of self-response at the baseline. (See **Figure 17.**) As with rights and self-determination, agencies with higher levels of self-response at the baseline also had greater increases in personal development during the following years than agencies with lower levels of self-response, controlling for the baseline level of personal development.

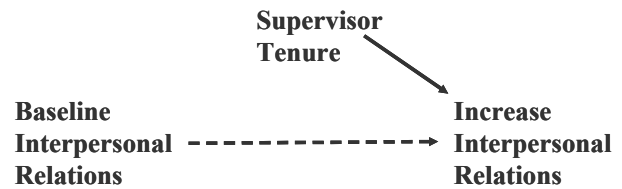


**Figure 17.** Predictors of Increased Personal Development over 4-5 years: 38 Agencies

Increases in self-response were also related to increases in personal development. While rights and self-determination did not affect self-response, agencies with higher levels of personal

development reported at baseline had greater increases in self-response over the following 4-5 years than agencies with lower levels of personal development.

The tenure of first line supervisors with agencies affected changes over the four to five year period in interpersonal relations, material well-being and emotional well-being. (See **Figure 18** for interpersonal relations.) The longer first line supervisors had been with the agencies in 2003, the greater the annual increase in interpersonal relations, material well-being and emotional well-being over the next four to five years, controlling for the quality of life reported in these three domains in the baseline survey. Supervisor tenure was unrelated to the baseline quality of life scores.

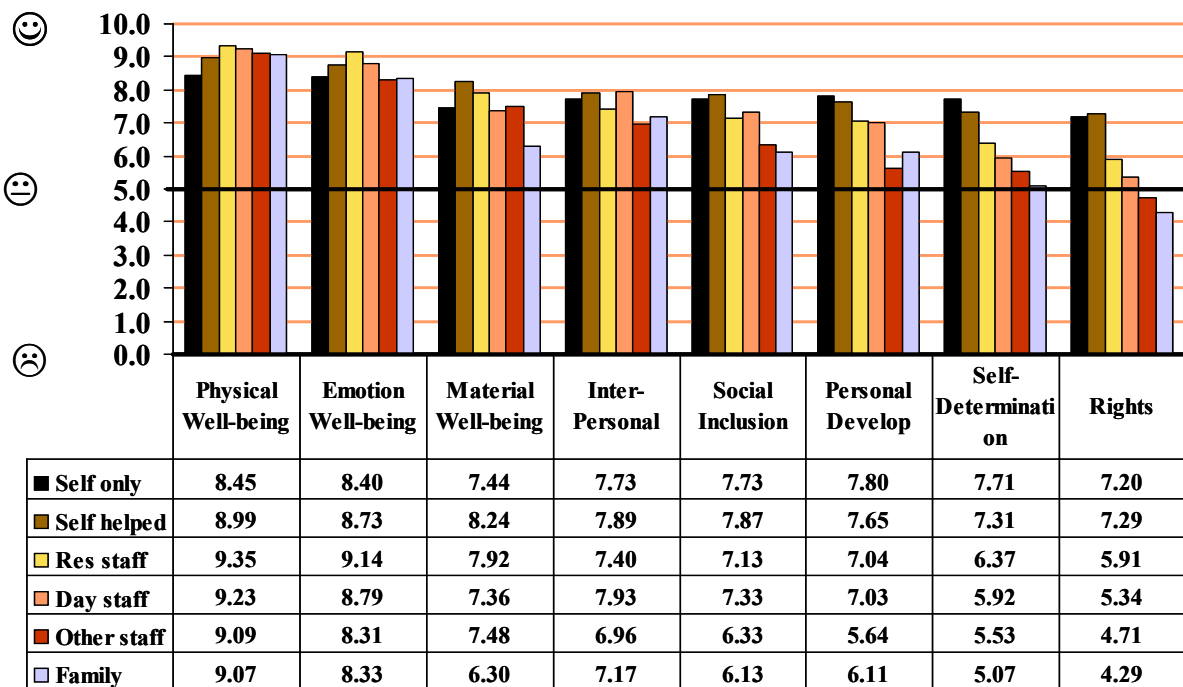


**Figure 18.** Predictors of Increase Interpersonal Relations over 4-5 Years: 38 Agencies

No baseline agency characteristic predicted increases in either social inclusion or physical well-being over the next four or five years, after the baseline score had been controlled. Neither did any change in characteristics predict changes in quality of life in these two domains.

### Self and Proxy Differences

Interviewers identified the Ask Me! Survey respondent as self, self helped by others, family (includes non-staff friends), residential direct care staff, day program or supported employment

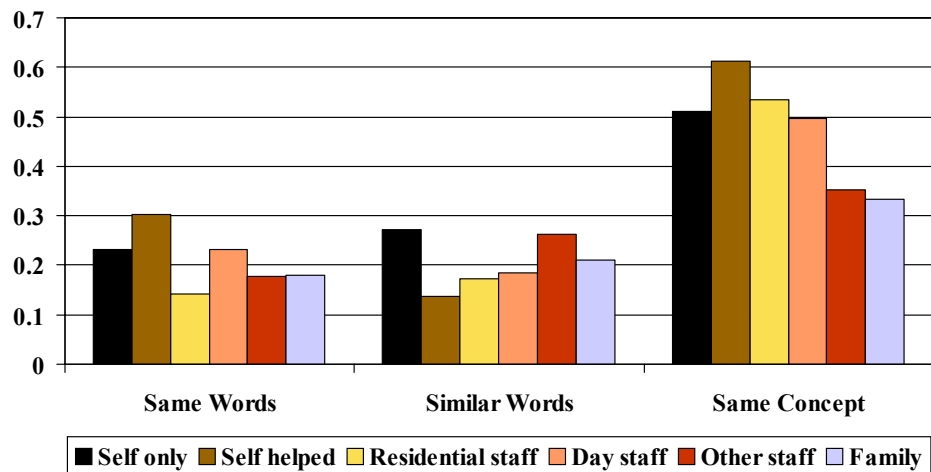


**Figure 19.** Quality of Life by Type of Respondent

Interviewers identified the Ask Me! Survey respondent as self, self helped by others, family direct care staff, and other staff. Responses from self helped by others probably represent a mixture of self-response and proxy response. People responding completely for themselves reported lower levels of physical and emotional well-being than did proxies in general, and self-respondents helped by others reported intermediate levels in both domains. (See **Figure 19**.) Self-respondents and proxies reported about the same level of material well-being, but self-respondents helped by others reported significantly higher material well-being. All three groups reported about the same level of interpersonal relationships. In the domains of personal development, social inclusion, self-determination and rights, self-respondents reported higher quality of life than did proxies. Self-respondents helped by others reported intermediate levels of personal development and self-determination, but the same as did un-helped self-respondents in the domains of social inclusion and rights. In all eight domains, residential staff and day staff proxies tended to report higher quality of life than did family members, and the differences were statistically significant for all domains except physical well-being, and interpersonal relations for residential and family proxies. Day proxies reported significantly lower quality of life than residential staff in the domains of emotional well-being, material well-being, interpersonal relations and rights.

One measure of the validity of survey responses is the degree to which the same answer is given to the same or similar question when it is asked again. The Ask Me! Survey included three repeated questions: 1) same words and order (*Do you have a chance to earn good money?*), 2) similar words and different order (*In general, how happy are you with your life?* and *How happy are you with your life overall?*), and 3) different words for the same concept (*Did you pick who you live with?* and *How much choice did you have in whom you live with?*). The absolute difference between the numeric scores of the answers became a self-disagreement score that was zero if the respondent gave the favorable, neutral or unfavorable response to both questions, one if the respondent gave the neutral response to one question and either the favorable or unfavorable response to the other, and two if the respondent gave the favorable response to one and the unfavorable response to the other or failed to answer one or both questions. Self-respondents had a disagreement score of 0.23 when the words were identical or were similar, meaning that they

gave different answers about one-fourth of the time to identical questions. They had a disagreement score of 0.51 when the concept was the same but the words were different, giving different answers about half the time. (See **Figure 20**.) Self-respondents helped by others had significantly lower

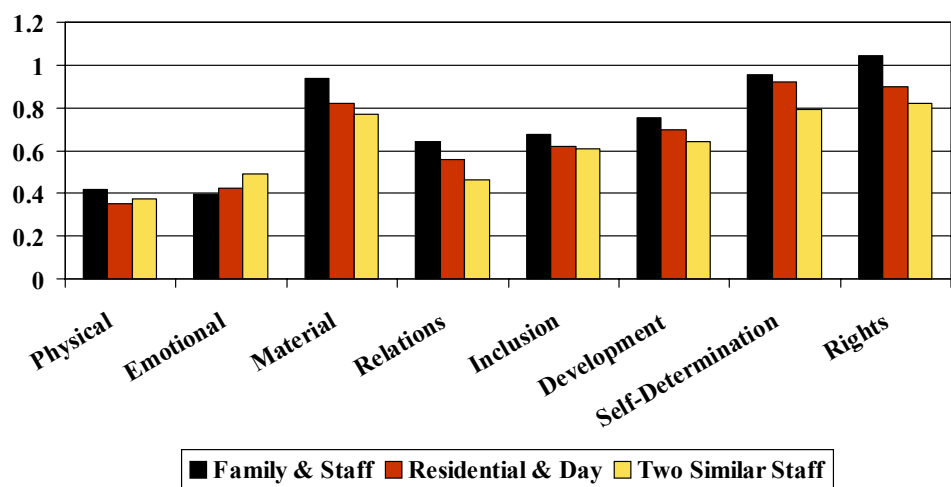


**Figure 20.** Disagreement with Self on Three Question Pairs

disagreement with themselves on one of the three sets of duplicate questions than did self-respondents interviewed alone. Similarly, direct care residential and day staff proxies had significantly less disagreement with themselves than did self-respondents only on the same set of duplicate questions with similar words. Family members were more consistent than self-respondents only on the same concept with different words. Among proxies, the only significant difference was between residential staff and family on the same concept of house mate choice. Overall, staff and families did not answer questions any more consistently than self-respondents, and no type of proxy was uniformly more consistent than another type of proxy.

Proxies for the same person disagreed with each other as well as with themselves. Overall, two proxies for the same person had a disagreement score of 0.67, suggesting they disagreed on two-thirds of the questions. Proxies disagreed least in the domain of physical well-being (0.38) and disagreed most in the domain of rights

(0.91). (See **Figure 21**.) However, different proxy combinations had different levels of disagreement. In general, family and staff disagreed most, two similar staff disagreed least, and residential and day staff disagreed at an intermediate level.



**Figure 21.** Disagreement Between Proxy Combinations on Quality of Life

Proxies can report different levels of quality of life than self-respondents report for three reasons: 1) individuals who cannot respond for themselves are different than individuals who can respond for themselves, and experience a truly different quality of life; 2) proxies do not have specific knowledge about what the individuals for whom they are reporting think or feel, particularly because the individuals have difficulty in understanding and communicating; and 3) proxies have a different perspective on quality of life that is shaped their own experiences and their roles in the lives of the individuals for whom they are reporting. Studies comparing the quality of life reported by individuals with mild retardation to the quality of life reported by others for them have provided suggestions for testing and improving the accuracy of self-reporting (Sigelman, et al, 1982; Heal and Siegelman, 1996; Perry and Felce, 2002), but have also identified the presences of the second and third reasons for differences (Gaudet, Pulos, Crethar and Burger, 2002; Lunsky and Benson, 1997; Stancliffe, 1999; Umb-Carlsson, 2005). Stancliffe (2000) cautions about projecting findings on the validity of proxy reporting from people who can respond for themselves to those who cannot, and Cummins (2002) argues that proxy responses are least valid for people who cannot respond for themselves and should not be used to make decisions concerning a person's life. The Ask Me! data does not solve these

problems nor clearly separate the three sources of differences between self and proxy report. It does, however, provide some evidence on the relative importance of the three sources of differences, and provides suggestions for evaluating staff and family perspectives of an individual's quality of life and what supports will most enhance it.

The Ask Me! Survey is linked to a number of individual characteristics available from the DDA files. To the extent that self and proxy differences are due to differences between those who can and those who cannot respond for themselves, variation among individual characteristics should explain a large amount of the variation in responses of proxies. It would also be expected that characteristics associated with self-respondent differences would be reflected in differences in proxy reporting. If self-proxy differences are due to proxy knowledge of the individual, a substantial amount of variability among proxies should be explained by the amount and nature of contact between the proxy and the individual for whom they proxy is reporting. Further, proxies that have more and closer contact with the individuals better should report more similarly to self-respondents than proxies who less and more distant contact. Finally, if proxies are largely responding based on shared experiences, much of the variation among proxies should be due to the context they share with the individuals or with other cognition they share with other proxies have the same relation to the individuals.

Quality of life was regressed separately for self- and for proxy-reports on fifteen characteristics of individuals: their intellectual ability as measured by level of retardation, age in ten-year groups, gender, and the presence of a number of conditions or impairments. These individual characteristics explained none of the variation in self-reported quality of life in five domains, 1% of the variation in interpersonal relations and rights, and 2% of the variation in social inclusion. (See multiple regression adjusted  $R^2$  in **Table 2**.) Self-respondents with higher intellectual ability, and self-respondents with head injuries, reported lower levels of social inclusion than people with lower intellectual ability and without head injury. Self-respondents with epilepsy and seizure disorders reported higher levels of social inclusion. Self-respondents with epilepsy and seizure disorders also reported higher levels of interpersonal relations than self-respondents without seizures. The fifteen characteristics of individuals had no relation to the proxy-reported quality of life in three domains. They did explain 6% of the variation among proxies in their reporting of interpersonal relations: proxies for older individuals and individuals with vision impairments reported lower levels of interpersonal relations, and proxies for individuals with cerebral palsy reported higher levels of interpersonal relations than proxies for other people reported. The characteristics that affected proxy reports were different than the characteristics that affected self reports except in the domain of rights. Self-reported and proxy-reported level of rights both increased with greater intellectual ability of the person, so this is the only domain where differences between those who could and could not respond for themselves (highly related to intellectual ability) clearly explained some of the differences in self and proxy reporting.

Proxies might be able to provide reliable reports for individuals if they share contextual factors that influence both of them the same way, even though proxy reports might not be highly sensitive to the specific individuals. These shared contextual factors include the region of the state, the size of the agency through which the individual was selected, and the types of supports that DDA has authorized for the individual. Among self-respondents, these contextual factors

<b>Table 2.</b> Factors Affecting Quality of Life Reporting by Self-respondents and Proxies [explained variance ( <i>adj.R<sup>2</sup></i> ), significant factors ( <i>p</i> >.05) and direction of relationship]						
Quality of Life Domain	Self-respondents		Proxies			
	Individual	Context	Individual	Context	Contact	Cognition
Physical well-being	.00 none	.02 west +	.03 age - male +	.01 none	.01 none	.02 none
Emotional well-being	.00 none	.01 west +	.01 none	.01 none	.01 feelings +	.06 family - res staff + other staff -
Material well-being	.00 none	.03 west +	.00 none	.11 west + employ + coordinate +	.15 feelings +	.20 family -
Interpersonal relations	.01 seizure +	.03 west +	.06 age - visual - CP +	.09 west + east +	.09 none	.15 family - res staff - other staff -
Social inclusion	.02 intellect - head injury - seizure +	.03 west +	.02 male + autism - CP +	.04 employ +	.06 feelings +	.14 family - other staff -
Personal development	.00 none	.00 employ +	.02 intellect + male +	.06 employ + south +	.08 feelings +	.13 family - other staff -
Self-determination	.00 none	.00 west +	.00 none	.06 west + employ +	.10 feelings +	.13 family -
Rights	.01 intellect + mental dis -	.02 west +	.02 intellect +	.08 south + west + employ +	.11 feelings +	.18 family - other staff -
<p><b>Individual:</b> Intellect (level of retardation), age, gender, and the presence of autism, behavior problems, cerebral palsy, head injury, hearing impairment, mental disorder, neurological impairment, orthopedic impairment, seizure disorder, speech impairment and visual impairment.</p> <p><b>Context:</b> DDA region (east, south and west with central as omitted category), agency size (natural log) and DDA authorized supports (residential, CSLA, day habilitation day employment, individual support services and resource coordination).</p> <p><b>Contact:</b> Daily contact, and extent person express feelings.</p> <p><b>Cognition:</b> Proxy type (family, residential staff and other staff with day staff as the omitted category).</p> <p>+ Quality of life increases with increase or presence of the variable</p> <p>- Quality of life decreases with increase or presence of the variable</p>						

may increase the explained variance by 3%. Self-respondents in the western part of Maryland reported higher quality of life than self-respondents in the other parts of Maryland in seven of the eight domains. In the eighth domain, personal development, those with employment support report a higher quality of life than people without employment support. Proxies in the western region similarly reported higher quality of life in four of the domains, suggesting that self-respondents and proxies in the western region shared similar perspectives. In some domains, however, proxies in southern Maryland and the Eastern Shore reported higher quality of life than those in central Maryland that was not reflected in self-reports. If anything, self-respondents on the Eastern Shore tend towards reporting lower quality of life than self-respondents in other regions. Similarly, while both self-respondents and proxies report higher personal development when supported employment is authorized, proxy reporting four additional domains was affected by supported employment. It is not immediately obvious why supported employment should affect the material well-being, the social inclusion, the self-determination and the rights of people who cannot respond for themselves and not similarly affect these quality of life domains for individuals who can respond for themselves. Much of the shared context therefore appears to be what proxies share with other proxies, and not what they share with the individuals for whom they report.

The amount and nature of contact proxies had with the individuals for whom they reported did not affect proxy reporting of physical well-being and only slightly affected proxy reporting of emotional well-being. Adding the amount the proxies felt that the individuals expressed their feelings to them increased the explained variance among proxy reports from by 2% to 4% in five domains. In four of these domains, social inclusion, personal development, self-determination and rights, the quality of life reported by proxies for people who expressed their feelings a lot was intermediate between proxy reports for people who did not express their feelings and self-respondents. This suggests that the quality of life in these domains is related to the ability to express oneself, and the lower quality of life reported by proxies reflects both this relationship and the inability to know the subjective thoughts of people who cannot express them.

Adding the type of proxy to the regression equation increases the explained variance in seven of the eight quality of life domains, and caused the greatest increase in six of them. Family proxies reported significantly lower qualities of life than did staff proxies in seven of the domains, and staff other than direct care staff reported significantly lower qualities of life than did direct care staff in five domains. Direct care residential staff reported higher emotional well-being than did direct care day staff, but lower interpersonal relations. These findings suggest that proxy-reported quality of life is most influenced by the proxy's role in the individual's life and the shared experiences they have with others in the same role. Proxy-reported quality of life is next most influenced by the geographic and support service context that proxies share with the individuals for whom they respond. Neither of these influences relate to the specific individual for whom the proxy is responding. Only after these two influences does information relative to the specific individual come into importance, and that is the extent to which the individual shares his or her feelings with the proxy. This sharing is very important as directly observable characteristics of people and their disabilities explain little variation in the quality of life reported by either proxies or self-respondents.

In summary, what do the findings suggest about who might best report for a person who cannot respond for themselves, and what type of caution should be exercised in accepting that report?

- Physical Well-being: All proxies reported almost perfect quality of life in this domain regardless of the roles they had or the intellectual abilities of the individuals for whom they reported. Self-reported levels of physical well-being increased with intellectual ability, but never reached the level reported by proxies. These findings suggest reports of physical well-being by any support giver be viewed as unlikely to reflect the viewpoint of the support receiver.
- Emotional Well-being: direct care staff appear to overestimate the quality of life in this domain, with family members and non-direct care staff providing more reasonable perspectives. Proxies on the Eastern Shore were less reliable and reported higher well-being than proxies in other parts of the state, just the opposite of self-respondents.
- Material Well-being: employment and earning money is an important component of material well-being and direct care day staff (includes those supporting employment) have the best information in this area, but direct care residential staff have better information on the use of earnings and whether the use meets the desires.
- Interpersonal Relations: all sources of information appear to be useful, as each proxy sees the individual in different settings with different opportunities for interpersonal relations.
- Social Inclusion: employment appears to be the most important component of social inclusion, and day staff can provide the most information on quality of life in this domain. Home, however, is also important and residential staff can provide information in this area. Which can provide more accurate assessment depends on the staff to whom the individuals express their feeling most.
- Personal Development: day staff appear to have the best insight in this domain, as employment is again the most important factor. However, even day staff tend to underestimate how individuals feel about their personal development, probably comparing progress toward their goals for the individuals rather than comparing progress toward the individuals' goals that are difficult to know. The higher proxy ratings on personal development in southern Maryland could be due to staff defining personal development more similar to how individuals define personal development than staff in other regions.
- Self-determination: residential staff report the highest levels and families report the lowest levels, but the data do not suggest whose viewpoint has greater validity. Employment is an observable factor with a strong relation to self-determination, but the individuals' expressions of their feelings is key to understanding their feelings and is more important than the role of the proxy in the individual's life.
- Rights: quality of life in this domain is clearly affected by intellectual ability and is the most difficult to determine for those who cannot report for themselves. Proxies disagree more in this than in any other domain, and the data provide little evidence to determine which type of proxy may be most knowledgeable. Employment is an important contributor to rights, and this suggests day staff might have better understanding of the individuals' viewpoints, but probably only if the individuals express their feelings to day staff. The findings suggest that proxies in southern Maryland maybe too optimistic on their assessment of rights.

## Discussion

The Maryland Developmental Disabilities Administration (DDA) collects information through the *Ask Me! Survey* about the quality of life of people with developmental disabilities that it supports through community provider agencies. The survey asks questions that people with developmental disabilities said were important to them, and that indicate their quality of life in eight domains identified through international research. The survey includes 1,200-1,300 adults each year, randomly selected from a sample of about 41 providers each year. The individuals selected represent a probability sample each year of all people supported by DDA, and annual assessment of the quality of life in Maryland is an important part of the report following each year's data collection. FY2006 represents the fifth year of the state-wide implementation of the *Ask Me! Survey*, and changes over five years are included in this report. All community provider agencies supporting ten or more adults are included at least once in a four-year cycle, with the largest agencies participating every year and the next largest agencies participating every other year. The quality of life supported by agencies can be compared only after a four-year cycle is complete, and this comparison was the focus of the *Ask Me! FY 2005* report. With the start of the second cycle in FY2006, four-year changes in the quality of life supported by agencies can begin to be analyzed, and analysis of four-year change in quality of life begins in this report. The FY2006 survey collected supplemental information about proxies when the selected individuals could not respond to the survey for themselves. This supplemental information is included in this report to better understand the value of information reported by proxies.

### Maryland Quality of Life

Most people in Maryland with developmental disabilities, or their proxies, report positive qualities of life in all eight domains that have been identified in the international literature. Their quality of life increased between FY2002 and FY2006 in all eight domains, whether measured by the percentages who report positive quality of life or the average quality of life scores. The *Ask Me! FY2002* report recommended that while the high levels of physical well-being and emotional well-being should be maintained, DDA and agencies should give greater attention to other domains. DDA and The Arc of Maryland became concerned that the quality of life in the domain of rights had changed little through FY2005, and that self-determination had not shown a consistent pattern of increase. They focused much of their communication and training activities to strengthen these two domains, and the FY2006 data suggest these efforts had success. The average quality of life in the domain of rights increased so much between FY2005 and FY2006, that the 1.9% average yearly increase between FY2002 and FY2006 surpassed the increases in the other seven domains. Self-determination followed with a 1.6% average annual increase in quality of life. These increases did not come at the expense of emotional and physical well-being which increased an average of 0.8% and 0.9% per year.

### Quality of Life at Agencies

With the FY2006 *Ask Me!* Surveys completed, 38 of 109 agencies had surveys four years apart, and many of these had also been surveyed during the FY2001 pilot year five years earlier. The

38 agencies include 100% of the eleven largest agencies, 70% of the twenty-one next largest agencies, 30% of moderate size agencies, and 10% of agencies supporting fewer than 80 people. This permits some analysis of change in the average quality of life at agencies over time, although it will be skewed toward change at the larger agencies. The average agency increase was slightly less than the average Maryland increase in the domain of rights (.09 versus .12 score points per year), the same in the domain of self-determination (.11) and slightly higher in the other six domains (.09-.14 versus .07-.09). The similarities suggest the reasonableness of analyzing agency change at this time, with the small differences reflecting either the limited number of agencies with four years between surveys or the use of the agency as the unit of analysis rather than the person--agency level analysis counts a large agency the same as a small agency whereas an individual from a large agency counts more than an individual from a small agency at the person level of analysis.

While the average agency quality of life increased in all domains, the quality of life did not increase at all agencies in any quality of life domain. Rights increased as much 0.27 points per year at 24 agencies and declined at 15 agencies. Self-determination increased at 29 agencies and declined at 8. The most widespread increase occurred in the domain of interpersonal relations where only 4 agencies experienced a decline. Dividing the change between FY2002 and FY2006 by four to find the average annual increase uses all the data for agencies with surveys in only the two years. For the larger agencies surveyed every year or every other year, however, the regression coefficient is a better measure because it takes into account the intervening surveys and represents the slope of the line that averages the change over all the years with data. In addition, data from surveys in FY2001 could be used if the regression line began with, or was extended back to, FY2001 as the intercept. Use of the regression intercept and slope for additional analysis also meant that agencies with data from FY2001 and FY2005, but not FY2006 could be included.

Can anything explain why the average reported quality of life in a domain increased or decreased for different agencies? The FY2005 report, with cross-sectional data for all Maryland agencies, showed that reporting of rights and self-determination was higher at agencies with greater percentages of people responding for themselves. It also showed that the quality of life in five of the eight domains was related to staff turnover. Surveys at 38 agencies 4-5 years apart gave opportunity to explore these relationships--what caused what? The longitudinal data show that the higher levels of self-response at the first survey, and greater increases (or less decrease) in self-response over the 4-5 years, the higher the levels of rights, self-determination and personal development reported in the most recent survey, statistically controlling for the level of rights, self-determination and personal development reported in the first survey. Self-response produces higher levels or reported quality of life in these three domains. It might seem that agencies could do nothing to maintain or increase the percent of people who could respond for themselves since Ask Me! peer interviewers, use standardized procedures, make this determination. However, agencies with low levels of personal development reported during the first survey experienced declines in the ability of people they support to respond for themselves over the following years, while agencies with high levels of personal development reported during the first survey had the same or higher level of self-response four years later. Thus lower levels of personal development at the baseline survey resulted in people losing their ability to

respond for themselves, which resulted in even lower levels of personal development 4-5 years later. This finding adjusted for the statistical fact that scores could increase more when they were low to begin with than when they were high (e.g., a student with a D-average has much more room for improvement than a student with a B-average).

The FY2005 report showed that characteristics of agency staffing related to quality of life in seven of the eight domains during the first cycle of surveys. The cross-sectional relationships were not big enough in the first survey of the 38 agencies with 4-5 years of longitudinal data by FY2006 to be statistically significant. However, the tenure of first line supervisors during 2003 had statistically significant relationships to changes in the quality of life at the 38 agencies in three of the eight domains. Agencies whose first line supervisors had been with them for longer periods of time experienced greater increases in the reporting of interpersonal relations, material well-being and emotional well-being over the 4-5 year period than agencies whose first line supervisors had been with them for shorter lengths of time. While staff turnover may be found to affect other domains once more agencies can be included in the analysis, these three domains appear to be particularly sensitive to stable staffing. These findings also suggest that the key to stable staffing is the stability of first line supervisors.

## **Proxy Reporting**

Proxies report higher levels of physical and emotional well-being than do people responding for themselves. It is not immediately obvious why people with the least intellectual abilities and unable to respond for themselves should be much better off physically and emotionally than those with greater intellectual abilities and able to express their own opinions. It seems more reasonable that family and staff proxies see quality of life differently than do people with developmental disabilities. Proxies and self-respondents report about the same level of material well-being and interpersonal relationships, and there is no *a priori* reason to question this finding. Proxies report lower levels of personal development, social inclusion, self-determination and rights than do self-respondents. It is reasonable to accept that people who can understand questions and express themselves would have higher quality of life in these domains than those who cannot understand questions and respond to them. Those able to respond, if someone they knew helped them understand the questions, reported quality of life levels between those reported by people responding all by themselves and those reported by proxies.

Although the reporting of proxies in a number of domains may appear reasonable on average, reports by two proxies for the same person seldom agreed. In all eight domains, residential staff and day staff proxies tended to report higher quality of life than did family members, and the differences were statistically significant for all domains except physical well-being, where proxies had little variation in reporting almost maximal quality of life regardless of the type of proxy or for whom they were reporting. Day proxies reported significantly lower quality of life than did residential staff in half of the eight domains. Proxy reporting was not affected by how many years they had known the person for whom they reported, nor by the frequency that they see the person. It did make a difference in proxy reporting when proxies believed the people shared a lot of their feelings with them.

People cannot be ignored just because they cannot respond for themselves, and the only alternative is to have those who know the person represent the person. However, what others say about a person should be always heard skeptically. No one can totally know another person's thoughts and feeling, even if that person communicates them very well. How much less can one know a person's thoughts and feelings when the person has difficulty communicating. In the absence of specific knowledge, a proxy is likely to project their own perspective of quality of life to the person for whom they are reporting, a perspective shaped by their own experiences and their roles in the lives of the individuals for whom they are reporting. This suggests that who provides ideas or makes decisions about services and supports should be considered in how much weight to give to suggestions. Residential caregivers are less likely to see safety problems in the home than are staff involved in people's lives outside the home. Service providers are less likely to see problems with services than are family members or advocates.

These findings strongly support involving people with developmental disabilities as much as possible in decisions that affect their lives. The less able a person is to participate in making decisions, the more important it is that a number of people with different perspectives be involved. While a group average or consensus may not accurately reflect the person's thoughts and feelings, it at least avoids the bias of a single perspective.

## **Recommendations**

The findings of the FY2006 *Ask Me! Survey* in Maryland suggests a number of recommendations for the Developmental Disabilities Administration, community provider agencies and advocates:

1. Continually recognize that quality of life is multi-dimensional. While rights, self-determination, personal development, social inclusion, interpersonal relations, material well-being, emotional well-being and physical well-being are inter-related, they are not the same.
2. Focus enhancement efforts on the quality of life domains that have the greatest opportunity and need for enhancement, while recognizing that the others are still important and their quality of life should be maintained. The focal domains generally should be rights, self-determination and personal development, but may be different for different agencies.
3. Believe that system-wide and agency-specific efforts can enhance people's quality of life, while recognizing that the state and community providers do not, and should not, completely determine a person's quality of life.
4. Place importance on an appropriate and stable staff, but remember that the quality of life of staff is secondary to the quality of life of the people they support.
5. Provide bridges of support to help individuals be part of their communities through employment and developing friendships in the community. These are important components of a life of quality.

6. Involve individuals every way possible in the decisions that affect their lives, including identifying areas that are already strong and areas where improved support could help.
7. Do not accept ideas or suggestions from any single family or staff as exactly reflecting those of the individual. The more difficult it is for an individual to understand and communicate his or her own needs, the more important for a number of people, who have different relationships with the individual and sees him or her in different settings, to be involved in discussions and decisions.

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## Appendix. Survey Methods

### Sample

The Maryland Developmental Disabilities Administration (DDA) authorized 24,795 person-provider support combinations in July 2005, the beginning of Fiscal Year 2006.<sup>2</sup> (See **Appendix Table 1.**) These supports involved 154 provider agencies and 13,665 individuals. The Ask Me! Survey sample frame included 139 agencies and 12,067 individuals. It excluded state institutions and agencies that only coordinated services, and combined component units or multiple designations of agencies. The Ask Me! Survey sample frame therefore excluded individuals who received all their services with state institutions or who received only service coordination. It also excluded individuals under 18 years of age. About three-fourths of the individuals received all their support (excluding service coordination) from a single agency and had one record in the sample frame. Most of the remainder received support from two agencies and had two records in the sample frame. The few that received support from three or four provider agencies had three or four records in the sample frame. The Ask Me! sample frame also excluded the 34 Ask Me! interviewers. The equivalent numbers from the DDA July files or other years are provided for comparison.

**Appendix Table 1. People Supported by Maryland Developmental Disabilities Administration**

	DDA File						Sample Frame*					
	07/01	07/02	07/03	07/04	07/05	07/06	07/01	07/02	07/03	07/04	07/05	07/06
Provider IDs	171	151	147	149	154	162	136	142	134	138	139	114
Person-provider records	24,960	24,557	24,795	25,130	25,201	25,343	13,225	13,519	13,880	14,151	14,991	15,025
Persons supported	12,469	12,568	12,971	13,272	13,665	13,863	11,539	10,908	11,226	11,377	12,067	12,112
1 provider	4,721	5,002	5,389	7,008	7,305	5,990	8,739	8,363	8,635	8,661	9,203	9,244
2 providers	3,881	3,897	3,955	4,426	4,564	4,515	2,747	2,484	2,531	2,661	2,807	2,826
3 providers	3,122	3,033	3,100	1,794	1,756	3,142	51	56	57	52	54	39
4 providers	620	523	446	42	38	193	2	5	3	3	3	3
5 providers	119	108	74	2	2	23	0	0	0	0	0	0
6 providers	6	5	7	0	0		0	0	0	0	0	

\* Sample frame excludes records for children, institutions and support coordination.

The agency sample frame for the Ask Me! Project in the four-year cycle beginning July 2005 (FY2006) contained 111 community providers based upon service data from DDA as of July 2004. Stratum 1 consisted of the eleven largest community providers, supporting at least 290 adults, at which interviews will be conducted every year. (See **Appendix Table 2.**) Stratum 1 included 8% of the providers (11 of 141) and 37% of provider-person supports (5,172 of 14,077), which would include 43% of the individuals if no one was served by more than one

<sup>2</sup>Excel files transmitted by DDA to Bonham Research in July of each year contain 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.

agency in this stratum. Stratum 2 consisted of 21 community providers supporting 130 to 289 people, with interviews scheduled every other year. Stratum 2 includes 15% of the providers, 27% of provider-person supports, and as many as 32% of the individuals. Stratum 3 consisted of 48 community providers supporting 51 to 129 people from which a sample people will be randomly selected for interviews once every four years. Stratum 4 consisted of 31 providers supporting 10-50 people at which all people will be selected for interviews once during the four-year cycle. Stratum 5 consisted of 31 providers that supported fewer than ten people and will not be included in the sample as long as they continue to support fewer than ten adults. While Stratum 5 contained 21% of the providers, it provided only 0.5% of provider-person supports, and many of the people supported by these agencies are also supported by larger community providers as well.

The eleven Stratum 1 providers were assigned for interviews in each of the years FY2006, FY2007, FY2008 and FY2009. Eleven of the Stratum 2 providers were initially randomly assigned by SPSS to be included in FY2006 and FY2008, and the remaining ten were assigned to be interviewed in FY2007 and FY2009. This was overridden when necessary to keep a two-year interval for interviews that started in FY2002/2003. Twenty Strata 3 and 4 providers were randomly assigned by SPSS to be interviewed in FY2006, twenty of the remaining were randomly assigned to be interviewed in FY2007, nineteen of the remaining were randomly assigned to be interviewed in FY2008, and the final twenty were assigned for interviews in FY2009. This was subsequently modified for six pairs of providers where one would have been interviewed one year after a FY2004 interview and the other seven years after a FY2002 interview. The modification resulted in both being interviewed four years after the previous interview. One additional provider was changed from interviews in FY2009 to FY2008 to even out the number of interviews each year and to yield a four-year cycle rather than five-year cycle for that provider. The 79 Strata 3 and 4 providers are nominally interviewed every four years, but the expansion of interviewing in the third and fourth years of the first four-year cycle required a redistribution of years for interview during the second cycle. The result of the modified random assignment was that 13 providers will be interviewed in the second round two years after their first round interviews, 16 will be interviewed three years after their first interview, 35 interviewed four years after their initial interview, and 15 will be interviewed five years after their first interview. By the end of the second cycle of interviewing, change for the 111 community providers in strata 1-4 can be analyzed over the following time periods: eight years (11 providers), seven years (11 providers), six years (31 providers), five years (28 providers), four years (66 providers), three years (18 providers), two years (46 providers), and one year (10 providers).

SPSS software was used to randomly select 40 individuals for a primary sample and 10 records for a secondary sample for providers in strata 1-3. All individuals were selected for the providers in stratum 4, with any over 40 placed in the secondary sample. A total of 1,970 person-provider records were selected that included 1,878 people selected once and 46 people selected twice.

**Appendix Table 2. Community Providers by Year Selected for Interviews**  
(selection for sample in a fiscal year indicated by "1")

Ask Me Provider ID	People 7/1/05	Sample Strata	FY06 Sample	FY07 Sample	FY08 Sample	FY09 Sample
<b>Strata 1 Subtotal (290+ People)</b>	<b>5,172</b>	<b>11</b>	<b>11</b>	<b>11</b>	<b>11</b>	<b>11</b>
109 The Arc of Baltimore	1050	1	1	1	1	1
112 Chimes Inc, includes Intervals	718	1	1	1	1	1
314 Prince George's Co Arc	428	1	1	1	1	1
128 Providence Center	414	1	1	1	1	1
811 The Arc of Washington Co	408	1	1	1	1	1
303 CHI Center	397	1	1	1	1	1
311 Melwood Hort	390	1	1	1	1	1
312 The Arc of Montgomery Co	385	1	1	1	1	1
104 Athelas Institute	382	1	1	1	1	1
107 ACCFX Gallagher	301	1	1	1	1	1
132 UCP Central Maryland	299	1	1	1	1	1
<b>Strata 2 Subtotal (130-289 People)</b>	<b>3,826</b>	<b>21</b>	<b>10</b>	<b>11</b>	<b>10</b>	<b>11</b>
355 Abilities Network	262	2	1	0	1	0
121 Emerge	235	2	1	0	1	0
915 Humanim (add Workfirst 7/05)	219	2	0	1	0	1
105 Opportunity Builders	218	2	1	0	1	0
135 The Arc of Howard Co	213	2	0	1	0	1
328 Rehabilitation Opportunities	204	2	1	0	1	0
919 Alliance	199	2	1	0	1	0
301 Ardmore Enterprises	193	2	1	0	1	0
933 UCP of Southern MD	190	2	0	1	0	1
124 The Arc of Northern Chesapeake	186	2	1	0	1	0
614 Dove Pointe Inc	183	2	1	0	1	0
108 Bello Machre	181	2	0	1	0	1
318 Center for Life Enrichment	171	2	0	1	0	1
156 The Arc of Anne Arundel Co	169	2	0	1	0	1
302 The Arc of Southern Maryland	160	2	0	1	0	1
824 The Arc of Carroll Co	148	2	1	0	1	0
827 Change, Inc	147	2	0	1	0	1
319 Vocational Services Inc	146	2	0	1	0	1
158 Center for Progressive Learning	137	2	0	1	0	1
325 Southern MD Vocational Industries	133	2	1	0	1	0
806 Friends Aware, Inc	132	2	0	1	0	1
<b>Strata 3 Subtotal (50-129 People)</b>	<b>4,098</b>	<b>48</b>	<b>14</b>	<b>10</b>	<b>15</b>	<b>9</b>
316 Spring Dell Center	126	3	0	1	0	0
817 Medsource Community Services	123	3	1	0	0	0
142 NCIA CBAI	121	3	1	0	0	0
611 Bayside Community Network	120	3	0	1	0	0
306 CSAAC	114	3	0	1	0	0
125 Penn Mar	113	3	1	0	0	0
136 Workfirst (merged with Humanim 7/05)	111	3	0	0	0	1
830 Target, Inc	109	3	0	0	0	1
322 Lt Joseph P Kennedy Institute	109	3	0	1	0	0
819 Spectrum Support (was R & D Instr)	107	3	1	0	0	0
106 Langton Green	105	3	0	0	0	1

Ask Me Provider ID	People 7/1/05	Sample Strata	FY06 Sample	FY07 Sample	FY08 Sample	FY09 Sample
335 SEEC	105	3	1	0	0	0
129 Richcroft	104	3	1	0	0	0
804 Scott Key Center	104	3	0	0	1	0
149 Creative Options	100	3	0	0	1	0
608 Somerset Community Services Inc	96	3	0	0	0	1
807 Hagerstown Goodwill Industries	96	3	1	0	0	0
812 Washington Co HDC	95	3	0	0	1	0
602 The Caroline Center	94	3	1	0	0	0
610 Worcester Co Developmental Center	93	3	1	0	0	0
606 Delmarva Community Services	91	3	0	0	1	0
951 Lower Shore Enterprises	89	3	0	0	0	1
308 Jewish Foundation for Group Homes	86	3	0	0	1	0
802 Community Living Inc	84	3	0	1	0	0
801 Appalachian Parent Assn	84	3	0	0	0	1
152 Center for Social Change	84	3	0	0	1	0
309 Jubilee Association of MD	83	3	0	1	0	0
324 Family Service Foundation Inc	82	3	0	0	0	1
805 The Arc of Frederick County	82	3	1	0	0	0
621 Chesapeake Center Inc	78	3	0	0	1	0
126 Progress Unlimited	77	3	0	0	1	0
120 Life	76	3	0	0	1	0
352 Community Support Services	66	3	0	1	0	0
624 Bay Shore Services Inc	66	3	1	0	0	0
932 Treatment & Learning Ctr Inc	66	3	0	0	0	1
315 Rock Creek Foundation	64	3	0	1	0	0
353 Securecare Services	63	3	0	0	1	0
815 Jeanne Bussard Center	62	3	1	0	0	0
607 Epilepsy Assoc of Eastern Shore	62	3	0	0	1	0
616 Chesapeake Care Resources	61	3	0	0	1	0
139 Forward Visions	60	3	0	0	1	0
101 Progressive Horizons	58	3	0	1	0	0
119 Jewish Family Services	57	3	0	1	0	0
912 CSSD	56	3	1	0	0	0
619 Benedictine School	55	3	1	0	0	0
809 Ray of Hope Inc	54	3	0	0	1	0
117 Harford Center	54	3	0	0	1	0
605 Chesterwye Center	53	3	0	0	0	1
<b>Strata 4 Subtotal (10-49 People)</b>	<b>907</b>	<b>31</b>	<b>6</b>	<b>10</b>	<b>5</b>	<b>10</b>
351 Calmra Inc	49	4	0	0	0	1
123 National MS	48	4	0	0	0	1
601 Kent Center Inc	47	4	1	0	0	0
327 Montgomery Co Dept of Fam Resour	46	4	1	0	0	0
334 Jewish Social Services Agency	45	4	1	0	0	0
818 Lycher Inc	44	4	0	1	0	0
338 Charles Co Health Dept	43	4	0	0	0	1
151 Shura	42	4	0	1	0	0
134 St. Peters Adult Learning	40	4	0	0	1	0
333 Head Injury Rehabilitation	38	4	0	0	0	1
305 Charles Co HARC	35	4	0	0	1	0

Ask Me Provider ID	People 7/1/05	Sample Strata	FY06 Sample	FY07 Sample	FY08 Sample	FY09 Sample
323 Full Citizenship of Maryland	34	4	0	0	1	0
828 Flying Colors of Success	33	4	0	0	0	1
931 UCP of PG & Montgomery Co	27	4	0	1	0	0
147 Starflight	27	4	0	1	0	0
803 Council for EC&A	26	4	0	1	0	0
145 Selfpride	26	4	0	0	0	1
321 Maryland Neighborly Networks	26	4	0	0	0	1
836 Anita Lynne Home Inc	25	4	1	0	0	0
165 Mid Atlantic Human Services Corp	24	4	0	1	0	0
952 Deaf Independent Living Association	23	4	1	0	0	0
052 The League for People with Disabilities	23	4	0	0	1	0
808 Goodwill Industries Monocacy Valley	21	4	0	1	0	0
910 Linwood Children's Center	19	4	0	1	0	0
330 VOCA Corporation	19	4	0	0	0	1
141 Caring Hands Inc	17	4	0	1	0	0
163 PACT: Helping Children	13	4	1	0	0	0
166 REM Inc	13	4	0	1	0	0
154 Kennedy Kreiger Inst	12	4	0	0	1	0
354 Ebed Enterprises	12	4	0	0	0	1
313 National Children's Center	10	4	0	0	0	1
Strata 5 Subtotal	74	24	0	0	0	0
825 Carroll Co Bureau of Aging	8	5	0	0	0	0
813 Bethesda Lutheran Homes	8	5	0	0	0	0
053 Innovative Services, Inc	6	5	0	0	0	0
058 Service Source	5	5	0	0	0	0
168 Evershine Residential Services	5	5	0	0	0	0
617 Crossroads Community	4	5	0	0	0	0
623 Shorehaven	4	5	0	0	0	0
170 Cope Homes Inc	4	5	0	0	0	0
831 Multiple Sclerosis Society	4	5	0	0	0	0
051 Mary T Maryland	3	5	0	0	0	0
054 Calvert Co Office on Aging	3	5	0	0	0	0
063 Esro Holding Provider	3	5	0	0	0	0
162 National Mentor Health Care	3	5	0	0	0	0
050 Lifeline LLC	2	5	0	0	0	0
059 S & G Residential Services, Inc	2	5	0	0	0	0
157 Maxim Health Care Services	2	5	0	0	0	0
337 Calvert Co Health Dept	1	5	0	0	0	0
060 Hebron Assoc for Community Services	1	5	0	0	0	0
061 Joshua House	1	5	0	0	0	0
062 Matts Way	1	5	0	0	0	0
167 Center for Neuro Rehabilitation	1	5	0	0	0	0
814 Archway Station	1	5	0	0	0	0
834 Hope Homes of MD	1	5	0	0	0	0
950 Chesapeake Head Injury Center	1	5	0	0	0	0
TOTAL	14,077	135	41	42	41	41

## Response

Interviews were conducted with 15 people selected twice, and with proxies for 13 people selected twice, and the survey responses were duplicated for inclusion with both agencies. Interviews were not completed for 14 people selected twice, and 4 people were in the secondary sample that was not needed. Of the total 1,970 person-provider records included in the sample frame, 45 people had died, moved out of state or dropped DDA funding by the time interviewing began two to ten months after the sample had been selected. (See **Appendix Table 3.**) Three individuals were not eligible for interview because they were under 18 years of age or had joined the Ask Me! interviewing staff by the time interviews were scheduled at their agencies. An additional 206 person-provider records in the secondary sample were not needed at agencies with average or better response rates.

<b>Appendix Table 3. Final Field Status</b>				
Final Field Status of Case		Frequency	Percent	
			Sample	Respondents
Response	1 Completed Self (15 duplicated)	929	54.1%	74.1%
	2 Completed 2 Proxies (6 duplicated)	237	13.8%	18.9%
	3 Completed 1 of 2 Proxies (7 duplicated)	84	4.9%	6.7%
	4 Completed Only Proxy Identified	3	0.2%	0.2%
	<b>Total Response</b>	<b>1,253</b>	<b>73.0%</b>	<b>100.0%</b>
Non-response	12 Guardian Refused	78	4.5%	
	13 Person Refused	196	11.4%	
	6 Agency doesn't know but on DDA files	69	4.0%	
	15 No Contact 6 Tries	45	2.6%	
	16 Cannot Schedule	20	1.2%	
	19 Language, Health	29	1.7%	
	20 Other Non-response	26	1.5%	
	<b>Total Non-response</b>	<b>463</b>	<b>27.0%</b>	
<b>Total Sample</b>		<b>1,716</b>	<b>100.0%</b>	
Not in Sample	5 Died, Moved, Not DDA	45		
	8 Under 18 years	1		
	9 Ask Me Interviewer	2		
	10 Secondary Sample Not Needed	206		
	<b>Total Not in Sample</b>	<b>254</b>		
<b>Total</b>		<b>1,970</b>		

Interviews were attempted for 1,716 people, and 54.1% of these responded to the survey for themselves, little different from the 54.3% average during the first four-year cycle. An additional 18.9% had proxy respondents. The largest reason for non-response was the refusal by 11.4% of the selected persons to be interviewed, and the refusal by 4.5% of guardians to allow

the person or their proxies to participate. The self-refusal rate did not differ significantly from the average in the first four-year cycle, but the guardian refusal rate increased significantly from 2.9% in the first cycle. Agencies for 4.0% of the selected people said they no longer supported the individuals, or they never supported the individuals, but the DDA files used to draw the sample for the next fiscal year still indicated that these people were authorized for support at that agency with DDA funds. Agencies generally scheduled the sampled individuals for interview at the agencies' offices or program sites. For some fairly independent people requiring only periodic support, the agencies provided telephone numbers for the Ask Me! team to make direct arrangements. The Ask Me! team was unable to make contact with 45 individuals because all available phone numbers were out of service or because no one answered the phone on six attempts at different times of the day and different days of the week and did not return calls when messages were left. Twenty individuals failed keep one or more scheduled appointments for interview and another interview time could not be scheduled during the interviewing period for the agency. Twenty-nine individuals could not be interviewed because they did not understand English or American Sign Language and no translator was available, they were too ill during the survey period to respond for themselves and no proxy was available, or they were out of state during the interview period and could not consent to the interview. A final 26 individuals were not interviewed due to decisions by the Ask Me! team that an interview was not practical due to location, schedule or other special situations.

## **Confidentiality**

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 provider agencies for their own analysis contained only the public identification number and the information provided by the person during the interview. Information provided by the provider agencies or taken from the DDA files were not included so no individual could be identified.

## **Data Entry**

The project double keyed survey forms using a data entry program designed in Visual Basic. It keyed transportation data in Access. Bonham Research employed a person receiving DDA support as the primary data entry clerk for surveys. All surveys were independently keyed, compared, and differences were adjudicated. The keying error rate was less than 0.5%, with much of "error" involving how to handle 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. 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 provider agencies had their survey responses duplicated and included with both provider agencies prior to weighting. The person was counted as responding for both provider agencies in the calculation of provider-specific response adjustments. An adjustment was then made during the weighting process. 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 additional people discovered at small provider agencies were assigned the same probability of selection as all the other people selected from that provider.

Weights were used for all analysis included in this report. The weight for an individual respondent was calculated as:

$$(1) \quad w_{\text{final}} = w_{\text{strata}} * w_{\text{provider}} * w_{\text{nonresponse}} * w_{\text{person}}$$

or

$$(2) \quad w_{\text{final}} = w_{\text{strata}} * w_{\text{response}} * w_{\text{person}}$$

where  $w_{\text{final}}$  = final weight for the person

$w_{\text{strata}}$  = number of provider agencies in the stratum / number of selected provider agencies in the stratum

$w_{\text{provider}}$  = number of people supported by the provider / number of people in the provider selected for interview

$w_{\text{nonresponse}}$  = number of people in final provider's sample / number of people interviewed

$w_{\text{person}} = 1 /$  number of provider agencies serving the person

$w_{\text{response}}$  = number of people supported by the provider / number of people interviewed.

The difference between using  $w_{\text{provider}} * w_{\text{nonresponse}}$  and  $w_{\text{response}}$  revolves around the terms “selected for interview” and “in final provider's sample.” An initial sample of 40 people was selected from each provider assuming all were in the sample frame and appropriate for interviews. 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 resident 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.

Two weights were calculated for each person with survey responses. The population weight was an integer to show how many people that individual represented. Depending upon the year, an individual could represent just themselves or they could represent 39 people. (See **Appendix Table 4.**) The sum of the population weights each year approximated the true number of people in the sample frame for that year. A final statistical weight was calculated that summed to the total number of people with survey data and averaged 1.00. This weight was used in this report to combine information across years.

<b>Appendix Table 4. Weight Characteristics</b>					
<b>Type of Weight and Year</b>	<b>True Number</b>	<b>Sum of Weights</b>	<b>Minimum Weight</b>	<b>Maximum Weight</b>	<b>Average Weight</b>
Final Population Weight	12,067	12,032	2.00	32.00	9.60
Final Statistical Weight	1,253	1,253	0.25	3.30	1.00

## **Personal Characteristics**

The analysis used the information on gender as recorded for 99.6% of the people in the DDA files. The project calculated age as of July 1 of the beginning of each fiscal year from the date of birth as recorded on the DDA file. 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 21% of the people in FY2006, higher than in any previous year.

## **DDA Authorized Services**

This report classified a person as receiving support if the DDA file at the time the person was selected for interview contained a record for the person with the support. It did not matter for the person-level analysis whether the person received the support from the agency through which he or she was selected or from some other agency. However, the DDA file as of July 1 may not have reflected the actual cluster of supports a person received at the time of the interview, since people may have changed supports or provider agencies in between. The DDA file as of July 1 may not have even reflected the supports received in July. It takes time for provider agencies 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 during which the person was interviewed.

## **Agency Staff and Wages**

Agencies report wages, vacancies and tenure of direct support staff and first line supervisors to DDA on an annual basis. The analysis for this report used data reported for 2003 (January through December), half way through the six-year period of FY2001-FY2006 (July 2001 through June 2006). When an agency had not reported data for 2003, the analysis used data for 2004. Direct staff wages, direct staff turnover, first line supervisor tenure and direct staff to supervisor ration were available for 100 agencies, while direct staff turnover was available for 98 agencies. Agencies reported data separately for residential live-in staff, residential non-live-in staff, CSLA staff, day staff and individual support staff. These were combined to provide agency averages across all the types of services provided.

## **Transportation**

The scale of perceived transportation availability was constructed from five questions answered by respondents during interviews. Frequency of transportation use was constructed from information provider staff recorded on a Transportation Form about the number of round trips per week to an interviewed person: 1) to employment or day activities by the provider through which the person was selected for interview, 2) to other activities by the provider through which the person was selected, 3) from other provider agencies, 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." Transportation was considered zero (0) if provider staff either recorded a zero or recorded nothing. It was assumed to be 10 round trips per week if a number greater than 10 was recorded from one source to one type of activity.

## **Scale Construction**

The Ask Me! Survey contained six indicator questions for each of the eight quality of life domains, and five questions for the area of transportation availability. Respondents could give one of three answers to each question. The first answer was favorable ("yes", "a lot", "very happy", "most times", etc.) and keyed as 1. The second answer was neutral ("sometimes", "a little", "OK", etc.) and keyed as 2.. The third answer was negative ("no", "none", "not happy", "no times", etc.) and keyed as 3. When a person answered four or more questions for a quality of life domain, a scale score was calculated as  $15 - (5 * \text{average keyed value})$ . Thus the scale score would be 0 if the person gave negative responses (3) to all the questions in the scale, 10 if the person gave positive responses (1) to all questions, and 5 if the person gave neutral responses (2) to all questions, or an equal number of positive and negative responses.

The eight domains had low but acceptable scaling properties overall, with Cronbach's *alpha* of 0.57 to 0.66 (See **Appendix Figure 22.**) These were lower than the 0.66 to 0.75 alphas in FY2002, 0.61 to 0.71 in FY2003 and FY2004, and 0.61 to 0.70 for the four years in the first cycle combined. The scale of transportation availability with five component questions had about the same reliability as the eight quality of life domains, but has not changed over the years.

Rights	0.64
Self-determination	0.65
Personal development	0.63
Social inclusion	0.66
Interpersonal relations	0.59
Material well-being	0.58
Emotional well-being	0.65
Physical well-being	0.57
Transportation available	0.62

### Statistical Significance

All analysis used SPSS 11.5 software (Statistical Package for the Social Sciences). Analysis using person-level data used a 95% level of confidence ( $p < .05$ ). Analysis using agency-level data used a 90% level of confidence ( $p < .10$ ). No specific adjustment was made for the two-stage sampling process, which means this report might overestimate the statistical significance of a finding to the extent that people served by a single provider were more similar to each other than they were to people served by other provider agencies.

**Appendix Figure 22.** Cronbach Alpha of Scale Reliability

### Regression

Simple linear regression was used to measure the average increase in the quality of life of people in Maryland each year, and whether this could be due only to the different samples used each year. Test of curvilinear models were not appropriate with only five observations over the four-years between FY2002 and FY2006. Data from the pilot year FY2001 did not represent a scientific sample of agencies and was not used for state estimates. FY2001 data was used in regressions for agencies, since individuals had been randomly selected within agencies during this pilot year. Regressing the average quality of life reported at an agency over the five-year period produced two statistics for use in further analysis. The constant term (*a*) estimated the quality of life in FY2001, and the slope of the regression line (*b*) estimated the average annual change in the quality of life score. The statistical significance of these estimates was unimportant since some agencies only had two observations, and for those with three or more observations, *a* was always statistically different from zero and *b* was never statistically different from zero.

Multiple linear regression used the pairwise deletion of missing data option. All variables that the FY2005 report had found associated with quality of life were included in a stepwise process. All other variables found to have statistically significant zero-order correlations with any quality of life, or its change measure, were also included. Only additive effects were tested. Separate regressions were computed when interactions might have substantive importance. The criteria for entry and removal from the stepwise regressions were  $p = .05$  and  $.10$  when an individual person was the unit of analysis and  $p = .10$  and  $.20$  when the agency was the unit of analysis.

## **Path Analysis**

The path diagrams were based upon a series of stepwise multiple linear regressions. Path analysis tests hypothesized relationships among different measures. Arrows represent those relationships that were found to be statistically significant different from zero. The variable on the left, or 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 leftmost variables were measured in FY2001 or FY2002, prior to any variables to their right and can be a cause but not an effect of variables to their right. Curved arrows are shown when these initial variables were correlated and imply no hypothesized cause or effect. As the path moves to the right, the variables represent more recent measurements. Variables in the same vertical column were assumed to have no direct causal relationship on each other--any relationship they had was caused by their relationships with the variables to their left.

## **Ask Me!<sup>sm</sup> Book Chapters and Journal Articles**

- Keith, K. D., & Bonham, G. S. (2005.) The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research*, 49(10):799-805.
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## **Ask Me!<sup>sm</sup> Annual Reports**

- Bonham, G. S., Basehart, S., and Marchand, C. B. (2005.) *Ask Me!<sup>sm</sup> Year FY2005: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
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