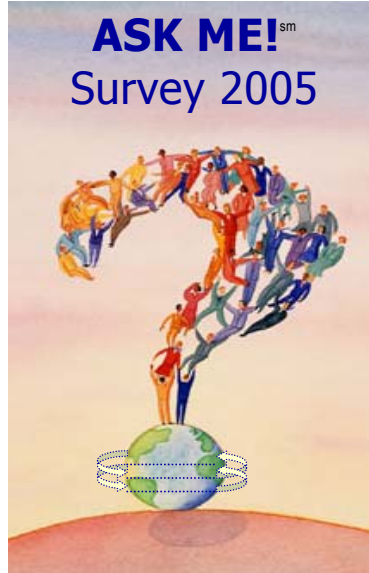


# Ask Me!<sup>sm</sup> FY 2005



## The Quality of Life of Marylanders With Developmental Disabilities Receiving DDA-FUNDED Support

Prepared for the  
Maryland Developmental Disabilities Administration

by  
Gordon Scott Bonham, Ph.D.  
Bonham Research

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

Draft  
December 9, 2005

## Authors

*Gordon Scott Bonham* has been the project's researcher from the initial development of the questions to the present. He is President of Bonham Research, a private human services research and evaluation company. His 34 years of developing and analyzing surveys have included research at Towson University, the University of Louisville, and the National Center for Health Statistics. Dr. Bonham earned his Ph.D. in sociology from the University of Michigan (Ann Arbor) and has a wide range of experience in surveys, social research, and program evaluation. The social health and well being of the individual in society has been the primary subject of his research, including a number of studies involving supports to people with intellectual and other developmental disabilities. Dr. Bonham serves on the Board of The Arc of Baltimore and chairs its Quality Assurance Committee.

*Sarah Basehart* is Assistant Director of The Arc of Maryland. Ms. Basehart holds a Master's Degree in Policy Sciences from the University of Maryland Baltimore County. In addition to coordinating the Ask Me! Project, she facilitates the statewide self-advocacy group, People On the Go, and works on policy issues of concern to persons with developmental disabilities and their families.

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

Suzanne Carley, Nolie Rife, Judy Volkman and Tracy Wright served as regional coordinators for The Arc of Maryland. Jessica Yaeger scheduled interviews and arranged transportation. Donna Bailey served as the Quality Assurance Consultant. Tonja Trappiel 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 FY2005, 35 consumer interviewers worked for The Arc of Maryland. They demonstrated that people with developmental disabilities can learn and use professional interviewing skills to collect quality information. They averaged 3.7 years of Ask Me! experience: 3 with 8 years, 4 with 7 years and 6 with 6 years experience. Terri Allen and Michael Raidt worked for Bonham Research as Data Entry Clerks (DE). The Ask Me! FY2005 interviewers, with years interviewing in parentheses (), included:

Amanda Zittle (1)	Greg Gray (1)	Patrick Rhinehart (1)
Amy Grossman (3)	James Devore (8)	Patty Worff (6)
Anne Bates (2)	Howard Holland (3)	Paula Suter (1)
Barbara Moore (2)	Kathleen Hagerty (1)	Robert Haburchak (8)
Brad Dram (1)	Kenneth Capone (3)	Robert Heil (2)
Branden Frahm (3)	Kim Vander Weyden (1)	Rose Marie Hancock (6)
Brian Plater (4)	Kim Witt (6)	Scott Heim (7)
Bridgette Pressley (7)	Kimberly Smith (6)	Tara Festermann (1)
Bruce Cramer (1)	Linda Cooper (4)	Terri Allen (2, DE)
Carolina Cano (2)	Lori Powell (7)	Vernon DeHaven (6)
Diana Warther (3)	Michael Raidt (6, DE)	Vicki Mills (7)
Fran Appold (8)	Natalie Turner (1)	

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).

## Executive Summary

The Ask Me! Project puts people first. Interviewers who have disabilities ask other people with disabilities about their quality of life using questions developed by self-advocates. Three-fourths of those surveyed responded for themselves. During each state fiscal year, interviews are conducted for a random sample of adults in Maryland supported by the Developmental Disabilities Administration (DDA) through a sample of community provider agencies. The FY2005 survey included 1,433 people from 49 agencies. During the four-year period of FY2002-FY2005, The *Ask Me! Survey* included 5,125 people supported by all 116 agencies providing community services to ten or more adults.

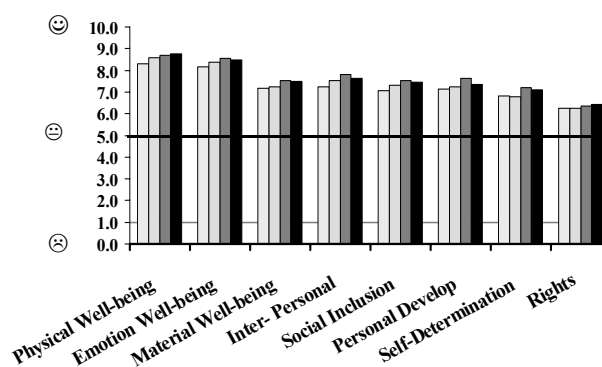
Among the adults supported by DDA, 57% are men, 71% are 25-54 years of age, and 27% are classified with severe or profound retardation. DDA funded residential support for 38% of the people, employment support for 27%, day habilitation for 47%, individual support services for 17%, community supported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

This report combines survey responses for FY2002-FY2005 to analyze trends in quality of life, identify the factors associated with quality of life to guide enhancement plans, and investigates the differences among agencies in the quality of life reported by the people they support. The appendix displays the average quality of life reported for all 116 Maryland agencies providing supports in the community, the body of the report analyzes the differences among these agencies, the difference among the people supported, and the changes over time. The following are key findings:

1. Most people in Maryland with developmental disabilities reported a good quality of life that has generally improved over the past four years in seven of eight domains.
  - a. Continuous increases in physical well-being with 94% reporting positive physical well-being;
  - b. No change in the level of rights with 67% reporting positive rights;
  - c. Less change in self-determination and personal development than in social inclusion and interpersonal relations.

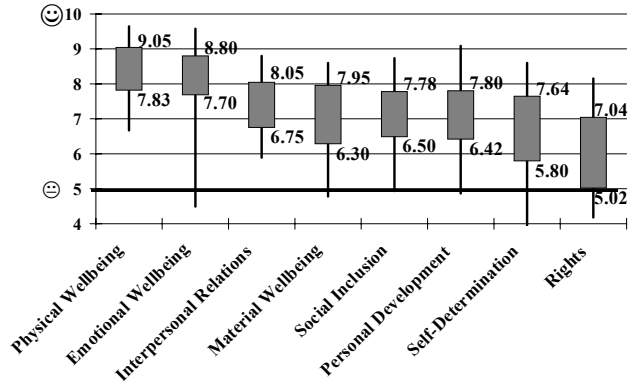
*Recommendation 1: Physical and emotional well-being are foundational to a life of quality and should be maintained, but increased attention should be focused on personal development, self-determination and rights.*

Quality of life in Maryland generally increased between FY2002 and FY2005



2. The average quality of life varies among agencies, and only some variability can be explained by consumer differences:
  - a. Physical well-being and interpersonal relations are positive at all provider agencies;
  - b. People report negative rights at almost one in ten agencies;
  - c. Agencies vary least in physical and emotional well-being, and most in self-determination and rights;
  - d. No provider in the top 20% in four domains was in the bottom 10% in any domain:
  - e. High response rates to the Ask Me! Survey are associated with high emotional well-being, material well-being, social inclusion and personal development.

Quality of life differs among agencies, very positive at some but negative at others



*Recommendation 2: Providers should recognize that their average quality of life scores reflect something about them, seek to understand their scores, and use the information to enhance quality of life.*

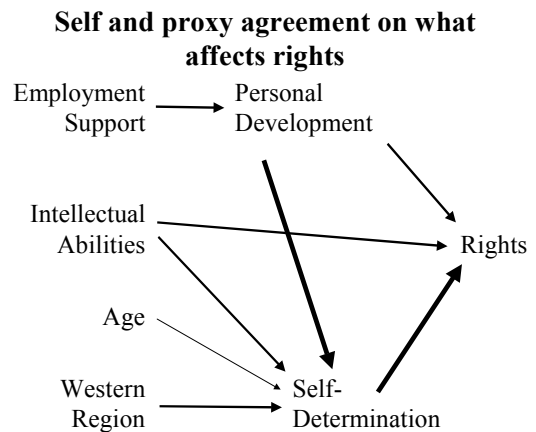
3. People who can respond for themselves report different quality of life than proxies report for the people who cannot respond for themselves, and different proxies for the same person report differently:
  - a. People who cannot respond for themselves have higher levels of physical and emotional well-being, according to proxies, than people who can respond for themselves;
  - b. Self and proxy respondents see the availability of transportation in very different ways;
  - c. Two day staff proxies frequently disagree on a person's quality of life, a day and residential staff disagree more, but family and staff disagree most;
  - d. Self and proxy respondents agree that personal development is key to self-determination, and self-determination is key to rights;
  - e. Self and proxy respondents agree that supported employment is one of the best predictors of high levels of personal development and rights.

Some proxy pairs disagree more than others



*Recommendation 3: Staff should recognize that their perceptions of a person's quality of life will differ from that of other staff and from the person themselves. Therefore, individuals should be involved as much as possible in decisions affecting them, and multiple staff and family perspectives can help reduce unwarranted assumptions.*

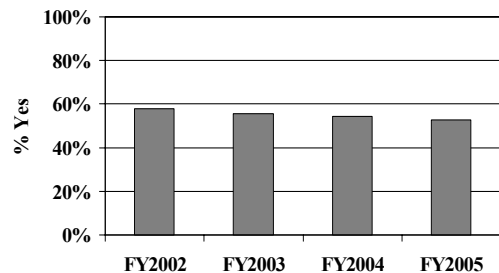
4. Quality of life in the domain of rights has not changed during the past four years. The primary contributors to rights are self-determination and personal development.
- Rights changed insignificantly from 6.3 in FY2002 to 6.4 in FY2005;
  - Self-determination changed slightly more from 6.8 to 7.1, and personal development changed from 7.2 to 7.4;
  - Self-determination and personal development had the strongest relation to rights in both self and proxy reporting;
  - Both self and proxy respondents reported greater personal development for adults in supported employment;
  - Individuals and proxies in the Western DDA region had reported higher self-determination than those in other regions.



*Recommendation 4: Providers should focus on enhancing rights through enhancing self-determination and personal development. Focusing on supported employment is a primary way to enhance personal development, and lessons may be learned from the Western DDA region on how to help adults, with the same level of intellectual ability and personal development, have a greater sense of self-determination.*

5. Responses to specific questions provide indicators of areas to target enhancement efforts:
- Staff asking permission before coming into the room increased steadily from 57% in FY2002 to 61% in FY2005;
  - Being able to lock the bathroom door was the only question that received more negative responses in each successive year;
  - 50% the adults had no, or only some, choice with whom they lived, and this changed little in four years;
  - Only half said they received the training they needed for employment, increasing to two-thirds for those with moderate or less retardation;
  - 52% said they received no information about their sexuality, or did not even know what the word meant.

Locking the bathroom door is the only question with significant decline

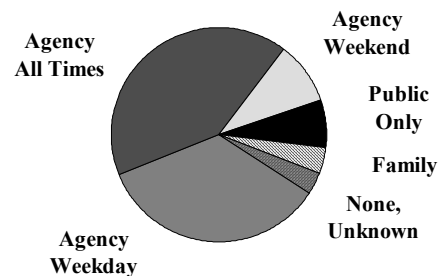


*Recommendation 5: The progress that has been made in respecting people's rights before entering their rooms needs to be extended to giving them choice of house mates, privacy in the bathroom, and helping them understand their sexuality. Adults also need to have training that will help them get a job of their choice and one that will make them feel important.*

6. The availability of transportation relates strongly to quality of life in every domain, yet predicting perceptions of transportation availability remains elusive and self-responders and proxies see things very differently.

- a. 42% of adults had transportation both to employment or day programs, and to other activities;
- b. Proxies saw an increase in transportation availability between FY2002 and FY2005, but self-respondents saw no change;
- c. Proxies reported transportation was highly availability for people with profound and severe retardation, while self-responders reported much less availability, particularly those with profound and severe retardation;
- d. Staff thought trips provided by their agency to weekday activities meant transportation was available, but self-respondents associated supported employment with available transportation;

Transportation is provided but not seen as available when wanted



*Recommendation 6: Provider agencies should recognize that available transportation is important to quality of life and that individuals define availability differently from how staff define it. Unfortunately, Ask Me! data collected to date provide little concrete guidance in this area.*

The *Ask Me! Survey* collects information directly from the people supported in the community through funding from the Maryland Developmental Disabilities Administration. People report a high quality of life in the domains of physical well-being and emotional well-being, a quality that has increased over time. They report much lower quality of life in the domains of self-determination and rights. Rights has not changed at all over the past four years, and it is not clear if self-determination has started to increase. Ask Me! results show that provider agencies can make a difference in people’s quality of life if they set goals of self-determination and rights. A provider can promote self-determination and rights regardless of the characteristics of the people it supports and the types of supports it offers. Supports most likely to enhance quality of life are those that respect people’s rights, help people to respond for themselves and make choices, and help them develop in ways that they see move them closer to desired employment.

## Table of Contents

Executive Summary .....	i
Table of Contents .....	v
List of Figures .....	ix
List of Tables .....	x
Project Overview .....	1
Survey Background .....	3
Quality of Life Research .....	3
Measuring Quality of Life .....	4
Purposes of Ask Me! .....	5
Project Description .....	7
Sample .....	7
Interviewers .....	8
Survey Procedures .....	9
Response .....	9
Characteristics of Adults and Their Supports .....	13
Demographics .....	13
Disabilities .....	13
Support Services .....	15
Transportation .....	15
Transportation Availability .....	16
Quality of Life .....	19
Maryland FY2002-FY2005 .....	19
Maryland Strengths .....	24
Physical Well-Being .....	24
Emotional Well-Being .....	25
Social Inclusion .....	25
Domains for Enhancement .....	26
Rights .....	26
Self-Determination .....	27
Personal Development .....	28
Self and Proxy Differences .....	29
Differences Among Proxies .....	32
Enhancing Individual Quality of Life .....	35
Self-Respondents .....	35
People with Proxy Reporting .....	37

Quality of Life at Provider Agencies .....	39
Quality of Life Variation .....	39
Relationship of Domains .....	40
Understanding Agency Scores .....	41
Discussion .....	43
Quality of Data .....	43
Individual Quality of Life .....	44
Quality of Life at Agencies .....	46
Enhancing Quality of Life .....	47
References .....	50
Appendix .....	53
Appendix A. Sampling Procedures .....	55
Sample Frame .....	55
Provider Sample .....	57
Person Sample .....	62
Sample Control and Confidentiality .....	63
Appendix B. Data Processing .....	70
Data Entry .....	70
Weights .....	70
Personal Characteristics .....	72
DDA Authorized Services .....	72
Transportation .....	72
Appendix C. Analysis Methods .....	74
Scale Reliability .....	74
Statistical Significance .....	74
Multiple Regression .....	75
Path Analysis .....	76
Quality of Life Score Adjustment .....	76
Appendix D. Quality of Life at Maryland Provider Agencies .....	80
General Information .....	80
Definitions and Symbols .....	81
Abilities Network .....	82
ACCFX Gallagher .....	82
Alliance .....	83
Anita Lynne Home Inc .....	83
Appalachian Parent Association .....	84
Arc of Anne Arundel County .....	84
Arc of Baltimore .....	85
Arc of Carroll County .....	85
Arc of Frederick County .....	86
Arc of Howard County .....	86
Arc of Montgomery County .....	87
Arc of Northern Chesapeake .....	87

Arc of Prince George's County .....	88
Arc of Southern Maryland .....	88
Arc of Washington County .....	89
Ardmore Enterprises .....	89
Athelas Institute .....	90
Autumn Homes .....	90
Bay Shore Services Inc .....	91
Bayside Community Network .....	91
Bello Machre .....	92
Benedictine School .....	92
Calmra Inc .....	93
Caring Hands Inc .....	93
Caroline Center .....	94
Carroll County Bureau of Aging .....	94
Center for Life Enrichment .....	95
Center for Progressive Learning .....	95
Center for Social Change .....	96
Change, Inc .....	96
Charles County HARC .....	97
Charles County Health Dept .....	97
Chesapeake Care Resources .....	98
Chesapeake Developmental Unit .....	98
Chesapeake Group Homes .....	99
Chesterwye Center .....	99
CHI Centers .....	100
Chimes Inc .....	100
Community Living Inc .....	101
Community Support Services .....	101
Community Support Services for the Deaf (CSSD) .....	102
Council for EC&A .....	102
Creative Options .....	103
CSAAC .....	103
Deaf Independent Living Association .....	104
Delmarva Community Services .....	104
Dove Pointe Inc .....	105
Ebed Enterprises .....	105
Emerge .....	106
Epilepsy Association of Eastern Shore .....	106
Family Service Foundation Inc .....	107
Flying Colors of Success .....	107
Forward Visions .....	108
Friends Aware, Inc .....	108
Full Citizenship of Maryland .....	109
Goodwill Industries of Monocacy Valley .....	109
Harford Center .....	110
Head Injury Rehabilitation .....	110

Horizon Goodwill Industries .....	111
Humanim .....	111
Intervals .....	112
Jeanne Bussard Center .....	112
Jewish Family Services .....	113
Jewish Fd for Group Homes .....	113
Jewish Social Services Agency .....	114
Jubilee Association of Maryland .....	114
Kennedy Kreiger Institute .....	115
Kent Center Inc .....	115
Langton Green .....	116
League for People with Disabilities .....	116
Life .....	117
Linwood Children's Center .....	117
Lower Shore Enterprises .....	118
Lt Joseph P Kennedy Institute .....	118
Lycher Inc .....	119
Maryland Neighborly Networks .....	119
Medsource Community .....	120
Melwood Horticultural Training Center .....	120
Mid Atlantic Human Services Corp .....	121
Montgomery County Department of Family Resources .....	121
National Children's Center .....	122
National MS .....	122
NCIA CBAI .....	123
Netcon & Earthkins Inc .....	123
Opportunity Builders .....	124
PACT: Helping Children with Special Needs .....	124
Penn Mar .....	125
Progress Unlimited .....	125
Progressive Horizons .....	126
Providence Center .....	126
R & D Instructional Services .....	127
Ray of Hope Inc .....	127
Rehabilitation Opportunities .....	128
REM Inc .....	128
Richcroft .....	129
Rock Creek Foundation .....	129
Scott Key Center .....	130
Securecare Services .....	130
SEEC .....	131
Selfpride .....	131
Shura .....	132
Somerset Community Services Inc .....	132
Southern Maryland Vocational Industries .....	133
Spring Dell Center .....	133

St. Peters Adult Learning .....	134
Starflight .....	134
Target, Inc .....	135
Treatment & Learning Center Inc .....	135
UCP of Central Maryland .....	136
UCP of Prince George's & Montgomery Counties .....	136
UCP of Southern Maryland .....	137
Voca Corporation .....	137
Vocational Services Inc .....	138
Washington Co HDC .....	138
Worcester County Developmental Center .....	139
Workfirst .....	139

### List of Figures

<b>Figure 1.</b> Dimensions of Quality of Life by Frequency of Discussion .....	3
<b>Figure 2.</b> Provider Sample Frame .....	7
<b>Figure 3.</b> Interviewer Training Session .....	8
<b>Figure 4.</b> Typical Interview Setting .....	9
<b>Figure 5.</b> Responses of People Eligible and Selected for Interview .....	10
<b>Figure 6.</b> Percent of Self-Response by Level of Retardation .....	11
<b>Figure 7.</b> Percent of DDA and All Maryland Adults by Age, July 2003 .....	13
<b>Figure 8.</b> Number of People Supported by DDA by Disability: July 2003 .....	14
<b>Figure 9.</b> Level of Retardation .....	14
<b>Figure 10.</b> Number of People by Type of DDA Supported Services: July 2003 .....	15
<b>Figure 11.</b> Percent with Trips and Average Number of Round Trips per Week by Source of Transportation .....	15
<b>Figure 12.</b> Destination of Transportation by Provider .....	16
<b>Figure 13.</b> Transportation Availability Score by Year .....	16
<b>Figure 14.</b> Predictors of Transportation Availability (standardized regression coefficients), by Respondent .....	17
<b>Figure 15.</b> Quality of Life by Domain .....	19
<b>Figure 16.</b> Percent Reporting Positive Quality of Life, by Domain and Year .....	20
<b>Figure 17.</b> Regressions of Quality of Life Scores on Year of Interview, by Domain .....	20
<b>Figure 18.</b> Average Quality of Life Scores, by Domain and Year .....	21
<b>Figure 19.</b> Questions with the Most Favorable Responses .....	24
<b>Figure 20.</b> Percent with Favorable Response to Physical Well-being Questions, by Year .....	25
<b>Figure 21.</b> Questions with the Most Negative Responses: FY2002-2005 .....	26
<b>Figure 22.</b> Percent with Favorable Response to Rights Questions, by Year .....	27
<b>Figure 23.</b> Percent with Favorable Response to Self-Determination Questions, by Year .....	28
<b>Figure 24.</b> Percent Having Choice with Whom to Live .....	28
<b>Figure 25.</b> Percent with Favorable Response to Personal Development Questions, by Year ..	29
<b>Figure 26.</b> Average Quality of Life Reported by Self and Proxies .....	30
<b>Figure 27.</b> Path Model of Self-Reported Quality of Life Domains .....	31
<b>Figure 28.</b> Path Model of Proxy-Reported Quality of Life Domains .....	31
<b>Figure 29.</b> Disagreement Between Proxy Combinations on Quality of Life .....	33

<b>Figure 30.</b> Predictors of Quality of Life Reported by Self-Respondents .....	35
<b>Figure 31.</b> Predictors of Quality of Life Reported by Proxies .....	37
<b>Figure 32.</b> Range of Quality of Life Scores Among Provider Agencies .....	39
<b>Figure 33.</b> Path Model of Relations Among Average Quality of Life of Provider agencies ...	40
<b>Figure 34.</b> Predictors of Average Quality of Life at Agencies .....	41
<b>Figure 35.</b> Self and Proxy Agreement on What Affects Rights .....	47
<b>Figure 36.</b> Percent with Supported Employment, by Region and Level of Retardation .....	49
<b>Appendix Figure 37.</b> Scale Reliability by Respondent .....	74
<b>Appendix Figure 38.</b> 95% Confidence Interval of a Percent, by Number of Surveys .....	75

### List of Tables

Table 1. Percent Giving Each Response to Survey Questions: .....	22
Appendix Table 2. People Supported by Maryland Developmental Disabilities Administration .....	55
Appendix Table 3. Maryland Provider Agencies by Number of People Supported and Year Included in the Sample .....	58
Appendix Table 4. Final Field Status by Year .....	64
Appendix Table 5. Survey Response by Provider .....	65
Appendix Table 6. Weight Characteristics, by Year .....	71
Appendix Table 7. Standardized Multiple Regression* Coefficients ( $\beta$ ) of Quality of Life Domains on Person and Support Characteristics .....	77
Appendix Table 8. Standardized Multiple Regression Coefficients* ( $\beta$ ) of Provider Quality of Life Scores .....	79

## Project Overview

The *Ask Me! Survey* collects information from people receiving support funded by the Maryland Developmental Disabilities Administration (DDA) to determine their satisfaction with the quality of their lives. Quality of life is the ultimate goal of support services. People's quality of life should be improved by the nature and quality of support they receive, although this support is mediated by 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. People with developmental disabilities have the opportunity to answer questions for themselves and share their experiences with providers who seek to understand how to use the survey information to improve support. The Ask Me! Project demonstrates that people with developmental disabilities elicit and provide data on quality of life that are valid, reliable, and useful for program enhancement.

This report presents and analyzes combined data from the FY2002, FY2003, FY2004 and FY2005 *Ask Me! Survey*. FY2005 was the final year of the first four-year cycle during which 99.7% of the people supported by DDA had a chance to be included, and all community providers supporting ten or more people participated at least once. DDA's objectives in surveying consumers about satisfaction with their quality of life are to make the system more responsive to their desires, to improve support services funded by the DDA, and to provide Maryland consumers with information to help them make informed choices. To assist with this third objective, this report presents the average quality of life reported by people supported by each Maryland community provider agency. Quality of life scores and rankings are shown for eight domains along with survey response rates and characteristics of survey responders.

The Ask Me! Project began in 1996, and developed through a four-year pilot study (FY1998-FY2001) with funding through cooperation between DDA and the Maryland Developmental Disabilities Council. The Arc of Maryland, People on the Go, and Bonham Research developed the interview instruments and procedures, hired and trained consumer interviewers, conducted the interviews, processed the data, and produced the reports. The first three pilot years used a survey instrument with five quality of life domains adapted from Schalock and Keith's *Quality of Life Questionnaire* (1993). The FY1998 pilot included interviews for 237 consumers served by ten providers (Bonham, Pisa, Marchand, Harris, White & Schalock, 1998; Schalock, Bonham & Marchand, 2000). The FY1999 Ask Me! pilot included 535 consumers served by 21 providers (Bonham, Pisa, Basehart, Marchand, Harris, Heim and Ingram, 1999). The FY2000 pilot interviewed 735 people served by 28 providers. During this year, the project developed a new version of the *Ask Me! Survey*, based on *Signs of Quality* written by People on the Go of Maryland (1996), that reflected more recent research on the domains of quality of life. The new

version included both an English and an American Sign Language version (Bonham, Basehart & Marchand, 2000). The final year of the Ask Me! pilot in FY2001 used the new survey instruments to interview 923 hearing people served by 33 providers and 56 deaf people served by two providers (Bonham, Basehart & Marchand, 2001).

The FY2002 Ask Me! Survey was the first of a four-year cycle that was planned to include people supported by all community agencies that support 55 or more people, and a sample of smaller agencies. The sample expanded part way through the cycle to all agencies supporting ten or more people. The FY2002 project interviewed 958 people from 33 provider agencies (Bonham, Basehart & Marchand, 2002). The survey in FY2003 included 1,110 hearing people served by 36 community provider agencies and 52 deaf people served by the two provider agencies (Bonham, Basehart & Marchand, 2003). The FY2004 Ask Me! Survey collected information for 1,540 people supported by 44 community provider agencies (Bonham, Basehart & Marchand, 2004). The FY2005 Ask Me! Survey collected information for 1,433 people supported by 49 provider agencies. The four-year cycle included 5,125 Marylanders supported by 116 community provider agencies.

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

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

# Survey Background

## Quality of Life Research

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

Schalock and Keith (1993) developed a survey instrument with four dimensions of quality of life organized around general satisfaction and the three major support delivery principals of independence, productivity and community integration. Their survey had been widely used, and the Ask Me! Project initially simplified the wording of their survey to make it easier for people with developmental disabilities to administer and answer, and to add a dimension on “dignity” absent in that survey. During this time, other researchers had suggested as many as fourteen dimensions of QOL (Hughes & Hwang, 1996). Schalock and Verdugo (2002) documented eight domains found in the international literature of intellectual disabilities literature, as well as in the international literature of education, mental health, physical health and aging. They found that

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

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

social inclusion had been studied the most and rights had been studied the least. (See **Figure 1**.) The new Ask Me! Survey, developed in consultation with Schalock, was centered around these eight domains, measuring them with questions that self-advocates had earlier defined as important to them.

## **Measuring Quality of Life**

Research since the late 1980's has asked people with intellectual disabilities to express their own views (Cummins, 2002; Stancliffe, 2000). Their increased participation, however, has raised four basic issues: 1) who determines the capability of people to respond for themselves, 2) can self-respondents provide valid information, 3) can proxies provide valid information, and 4) how should those who cannot respond for themselves be represented? Cummins (2002) found that the more subjective the measure, the lower the correlation between self and proxy respondents (see also Perry & Felce, 2002; Dudley, 2001). Since people cannot escape the projection of their own prejudices, staff and caregivers may be the least valid proxies in the areas that reflect upon their responsibilities, and peers may provide more reliable reports than non-peers (Cummins, 2002). Lunsy and Benson (1997) found that staff members tended to agree more with each other than with consumers. Gaudet, Pulos, Crethar and Burger (2002) found low correlations between family members and provider staff, similar to the low correlations between self-responses and proxy-responses. Cummins (2002) suggested that proxy correlations reflect general response reliability rather than specific response validity. Stancliffe (2000) cautioned against projecting findings on the validity of proxy reporting for people who can respond for themselves to the validity of proxy reporting for people who cannot respond for themselves.

As a result, some researchers question whether proxy responses are preferable to a total absence of information about those who cannot respond for themselves. Some even suggest that using proxies to estimate subjective well-being to guide decisions for an individual's life may even be unethical (Cummins, 2002; Perry and Felce, 2002). Other researchers consider the use of proxy respondents to be preferable to complete non-response, especially when the selected person is willing to participate (Parsons, Baum & Johnson, 2000). Cummins (2002) concedes that proxy responses may be acceptable when the primary objective is to reflect shared views, but suggests that obtaining two proxies only doubles the response effort without increasing validity. The Ask Me! Survey took the position that proxy responses were preferable to complete non-response, that two proxies were better than one, and that analysis should identify differences between self, and proxy responses as a caution to provider agencies.

The increased involvement of people with intellectual disabilities to express their own views was part of the emergence of participatory action research. Participatory action research relies on stakeholders to identify the elements of their lives that warrant investigation for potential change, and to participate in the investigation and subsequent change process. The use of participatory research contributes to our understanding of how quality of life should be conceptualized, what quality of life looks like to people with intellectual disabilities, and how to improve quality of life outcomes (Gardner, 2000; Gettings, 2001; Pennell, 2001; Whitney-Thomas, 1997). The Ask Me! Project involves three quality of life and participatory action research premises: (1) people with developmental disabilities can and should identify the

specific issues that are important to their quality of life, (2) people with developmental disabilities can and should be asked directly about their own lives, and (3) interviewers with developmental disabilities are in the best position to elicit meaningful responses from their peers. Three-fourths of the questions included in the Ask Me! Survey came from questions that the Maryland self-advocacy group had developed prior the Ask Me! Project (People on the Go, 1996). The Ask Me! Project then involved self-advocates in refining the survey instrument and in planning survey procedures. It used simplified language and response formats to maximize self-response. The project trained people with developmental disabilities to survey their peers, and used experienced interviewers to help train and observe new interviews for quality control purposes. It provided job opportunities and career paths for people with developmental disabilities that included promotion to supervisory positions. It indirectly contributed to individual and group self-advocacy.

## **Purposes of Ask Me!**

The Ask Me! Project reflects the rapidly emerging importance given to consumer outcome measurement and the need for programs to measure outcomes and manage for results (Schallock & Bonham, 2003). Consumer-based quality of life assessment can be useful for quality management on three levels: provider-level continuous program improvement; state-level for establishing goals and monitoring the mental retardation and developmental disabilities' system; and advocacy-level choice of supports and self-determination. The most important use of consumer-reported quality of life information is for continuous program enhancement at the provider level (Schallock, 2001). Quality supports should help people with developmental disabilities live as independent and satisfying lives as possible. Therefore, the perception of those receiving support is an important component for evaluating services. The Ask Me! Project began as a component of a consent decree to which DDA agreed to survey people receiving support services. DDA planned for the data to go immediately to the community provider agencies, and encouraged them to use their results as measures of achieving agency goals. DDA also used the Ask Me! results to measure achievement of its own goals of personal development, self-determination and social inclusion as required by the state budgetary process. Now that all community provider agencies have been included in the Ask Me! Survey, DDA will publish agency-level results in its next *Guide to Services*.

The Arc of Maryland launched an Ask Me! Unleashed initiative in 2005 to assist provider agencies and DDA with ongoing assistance on how to use Ask Me! Data as part of their quality enhancement process. This initiative provided each provider agency with a communication toolkit to help them communicate their Ask Me! results with employees, board members, current and potential consumers, self-advocacy groups, volunteers, and other important audiences. An Ask Me! Unleashed workshop in September 2005 also included discussions on how to focus Ask Me! information for larger system change.

[This page is intentionally blank.]

# Project Description

## Sample

The FY2005 Ask Me! Project collected information between August 2004 and July 2005 for 1,433 people with developmental disabilities served by 49 community provider agencies. The FY2005 sample, like those in FY2002 through FY2004, represented about 11,000 people 18 years and over with community supports funded by the Maryland DDA. During the four-year period, interviews were conducted with people supported by all 116 community provider agencies serving ten or more people. (About 18 agencies or incorporated entities serve fewer than ten people.)<sup>1</sup> The DDA files of about 25,000 person-support-provider records in July were used to select the sample for that year. (See **Appendix Table 2**.) The first sampling step involved stratifying provider agencies by their size as of July 2001, and assigning them for interviews during the four-year cycle. (See **Figure 2** and **Appendix Table 3**.) The second stage involved randomly selecting a primary sample of 40 people, and a secondary sample of 10 people, from each selected agency. All the people were selected if the agency served fewer than 50 people. Ask Me! Survey attempted to interview all the people in the primary sample. When this resulted in interviews for fewer than 30 people, attempts were made to interview some or all of the people in the secondary sample to achieve interviews for at least 30 people.

- |   |
|---|
| <p><b>Strata 1</b> (300+ people)</p> <ul style="list-style-type: none"><li>• 10 provider agencies support 37% of people</li><li>• 10 sampled every year</li></ul> <p><b>Strata 2</b> (130-299 people)</p> <ul style="list-style-type: none"><li>• 22 provider agencies support 27% of people</li><li>• 11 sampled in FY2002 and FY2004</li><li>• 11 sampled in FY2003 and FY2005</li></ul> <p><b>Strata 3</b> (55-129 people)</p> <ul style="list-style-type: none"><li>• 40 provider agencies support 25% of people</li><li>• 11 sampled in FY2002</li><li>• 10 sampled in FY2003</li><li>• 10 sampled in FY2004</li><li>• 9 sampled in FY2005</li></ul> <p><b>Strata 4</b> (10-54 people)</p> <ul style="list-style-type: none"><li>• 44 provider agencies support 10% of people</li><li>• 3 sampled in FY2002</li><li>• 5 sampled in FY2003</li><li>• 17 sampled in FY2004</li><li>• 19 sampled in FY2005</li></ul> <p><b>Strata 5</b> (1-9 people)</p> <ul style="list-style-type: none"><li>• Support &lt;1% of people</li><li>• Not included in sample</li><li>• 20 in FY2002, 22 in FY2005 (13 common to both years)</li></ul> |
|---|

**Figure 2.** Provider Sample Frame

Every person served by the same agency had the same probability of selection, so no weights were needed for analysis within provider agencies. Weights were needed for analysis that included people from more than one provider in order to reflect the different probabilities of provider selection and of selection within different size agencies. All the data presented in this

---

<sup>1</sup>The number of provider agencies changed every year as some provider agencies start serving people with funding from DDA, some provider agencies stop serving these people, some provider agencies merge, and the discovery that provider agencies originally identified independent of one another should be considered as programs within parent provider agencies as they did not submit separate quality assurance plans to the state.

report, except for response rates, were weighted to accurately reflect all adults receiving DDA-supported community services as of the start of the fiscal year (July). People surveyed at small provider agencies with high response rates represented only themselves, while others surveyed at the largest provider represented 39 people. The combined FY2002-FY2005 data were based upon 5,125 people served by 116 community provider agencies. All data shown in this report are for the four years combined, unless specifically noted.

## Interviewers

The Arc of Maryland employed interviewers for The Ask Me! Project who themselves have received supports funded by DDA. Interviewers were selected on the basis of listening skills, understanding of the project's goals and expectations, ability to conduct objective interviews and follow protocols, interest in traveling, sensitivity, self-motivation, dependability, and self-advocacy skills. Accommodations were made for interviewers who required augmentative communication strategies and technology.



**Figure 3.** Interviewer Training Session

The Arc of Maryland and Bonham Research conducted centralized one-day training at the beginning of the each fiscal year for both new and experienced interviewers. (See **Figure 3.**) Following the centralized training, interviewers in four regional teams met regionally for additional interviewing practice prior to their first actual on-site interview session. Monthly regional training also occurred throughout the interview period for continuous quality improvement. Quality improvement measures included videotaping of

actual interviews for self and peer evaluation, observation and standardized feedback from quality assurance consultants, and monitoring by project staff.

The Ask Me! Project employed about 35 individuals with developmental disabilities each year, with 72 individuals conducting interviews during the four-year cycle. The 35 FY2005 interviewers averaged 3.7 years of prior experience during the four-year cycle and the prior four pilot years. Three interviewers worked during all eight years of the project. Interviewers conducted three-fifths of the interviews in teams of two, with a lead interviewer reading the questions and the other team member pointing to the response categories on the flash card and helping the lead interviewer with any problems. Either of the interviewers recorded the answers. The team approach allowed a number of consumers who could not read to be involved as interviewers. The team functions, however, could be redistributed among the team members to compensate for any difficulty one of the members might have. Sometimes scheduling problems required a single interviewer to conduct the face-to-face interviews. Interviewers in FY2005

conducted an average of 65 interviews, with two interviewers conducting fewer than ten interviews and six interviewers conducting 100 or more interviews.

## Survey Procedures

Agency staff contacted the selected individuals, or their guardians, to explain the survey and to secure initial agreement to participate. The provider agencies then made the necessary arrangements to get their people to the interview sites. After the people to be interviewed arrived, the Ask Me! coordinator gave them information about the Ask Me! Survey and the interview process. They were told about the role self-advocates had in developing the survey, given assurances of confidentiality, and told about their right to not answer any or all questions if they did not want to answer them. The interviewer team assigned to the person then asked them a series of questions to make sure they understood enough to consent to the interview. (See **Figure 4**.) The team then asked the person to sign a form giving consent to be interviewed and to have their provider agency give information on the frequency of their transportation.



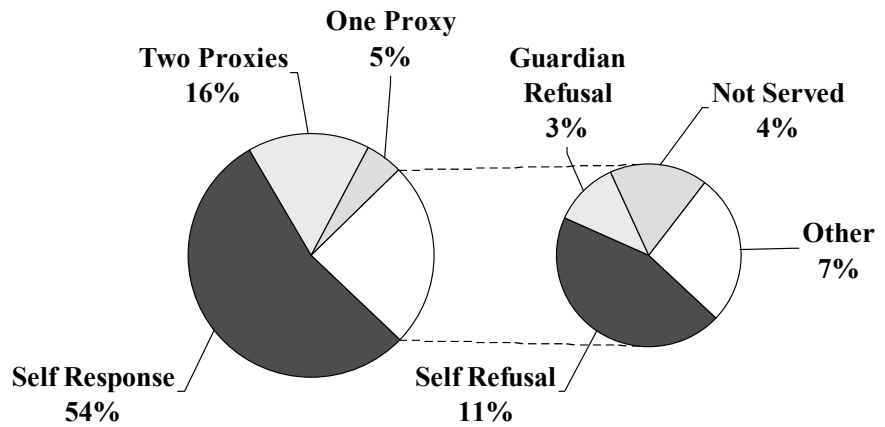
**Figure 4.** Typical Interview Setting

Two-thirds (66%) of the FY2005 interviews took place at the respondents' day locations: 73% of self-respondent interviews, 87% of first proxy interviews and 25% of second proxy interviews. Six percent of the interviews for each group took place at the respondents' homes. One-fourth (22%) of interviews were conducted by telephone: 13% of self-respondents, 3% of first proxies, and 68% of second proxies. The remainder took place in other locations. The interview room included people not involved in the interview 11% of the time. In an additional 8% the consumer-respondents wanted someone else with them to help or support them. The interview team assisted the person during face-to-face interviews by pointing to "happy" (☺), "neutral" (☹), and "sad" (☹) faces as they read the three response choices. At the interview end, the Ask Me! session coordinator thanked the person for his or her time and asked for feedback about the interview process and specific questions. Interviews generally took 15-45 minutes, with an average of 30 minutes. Interviews with proxies took about as long as interviews with self-respondents.

## Response

The *Ask Me! Survey* during the four years selected 7,375 person-provider records from 116 provider agencies for the primary and secondary samples. However, 550 of the names in the secondary sample were not needed and the project never contacted the people. An additional 175 people turned out to be ineligible to be interviewed because they no longer received DDA-

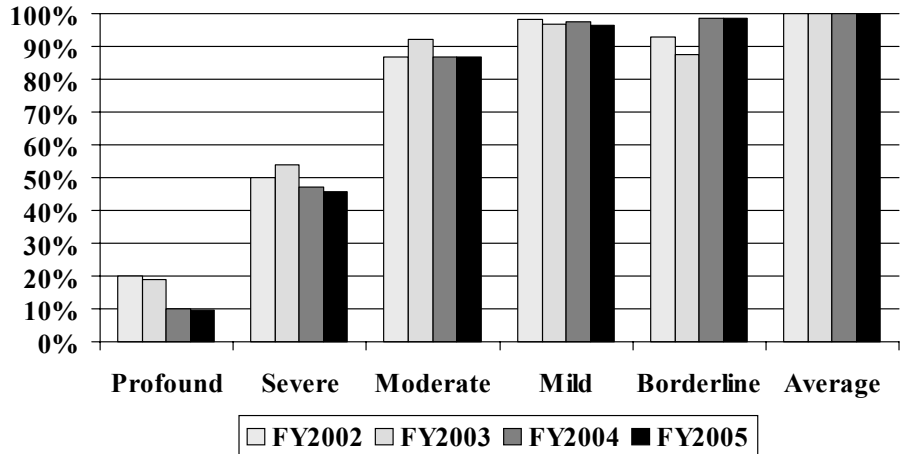
supported services according to DDA files at the end of the year (primarily died or moved out of Maryland), and 50 were less than 18 years of age or were Ask Me! interviewers. These people were not included when response rates were calculated. (See **Appendix Table 4** for individual survey years.) Half (54%) of the people selected for and eligible for interviews responded to the survey for themselves. (See **Figure 5**.)



An additional 21% agreed to participate in the survey, but did not have the ability to answer the questions for themselves. Interviewers interviewed two proxies for most of these people and one for the rest. The *Ask Me! Survey* did not obtain interviews for the remaining 25% of the people. About half of those not interviewed refused the interview themselves (11% of the total) or their guardian refused (3% of the total) to let them participate in the project. Provider agencies reported that they no longer (or never) served 4% of the people. Attempts by the project to locate them through other provider agencies failed. A search of the DDA files at the beginning of the subsequent year showed that DDA still listed these people as eligible for support. The remaining 7% were not interviewed for a variety of reasons: illness, language problems, repeated failure to keep appointments, and inability to contact the person or a proxy in six or more attempts.

About one-fourth of the people were supported by two or more agencies. Since people were randomly selected within each agency, and about one-third of the agencies were included each year, some people were selected at two different agencies. People selected twice were interviewed only once, and their data duplicated. As a result, Ask Me! obtained information for an equivalent of 5,125 people over the four years. (See **Appendix Table 5**.) It collected information for as few as 6 people at one small agency included in Ask Me! in only one year, and as many as 142 people at a large agency with interviews in all four years. Ask Me! collected information for an average of 76% of the people initially identified in the sample. It completed surveys for 90% or more of the sampled people at 22 of the 116 provider agencies, but completed surveys for fewer than half of the sampled people at five provider agencies. Self-respondents provided the information 72% of the time, but self-respondents completed 90% or more of the surveys at 28 provider agencies and less than 50% of the surveys at 19 agencies. When weights are applied, the data represent 5,113 adults.

Three-fourths (75%) of the weighted information came from people responding for themselves. Almost all of the people classified with none to mild retardation responded for themselves. (See **Figure 6.**) About half of those with severe retardation, and one-tenth to two-tenths of the people with profound retardation, responded for themselves.



**Figure 6.** Percent of Self-Response by Level of Retardation

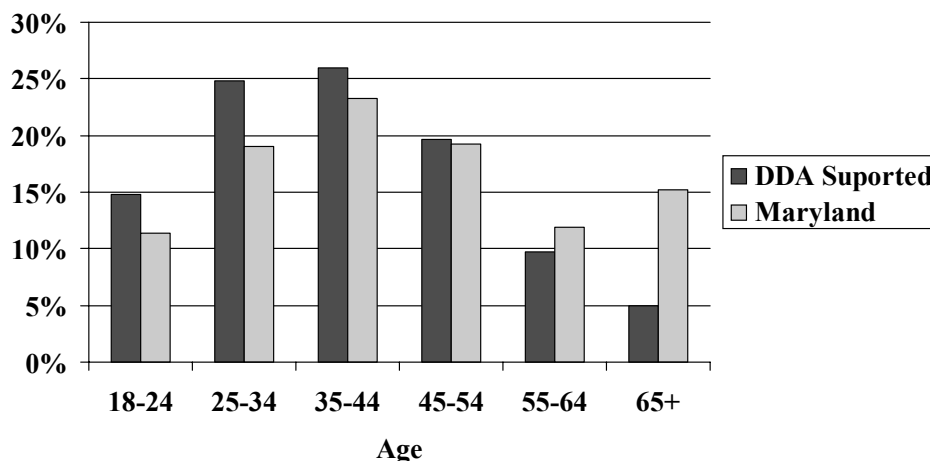
[This page is intentionally blank.]

## Characteristics of Adults and Their Supports

The *Ask Me! Survey* respondents represented a random sample each year of the approximately 11,000 adults receiving DDA support through community provider agencies serving ten or more adults. The excluded adults were supported only by very small agencies (some might be micro-boards for specific individuals), received all their services in institutions, or received no support services at the time.<sup>2</sup> The sample of individuals for each year was selected independent of prior year samples.

### Demographics

DDA provided support for 12,971 people on July 1, 2003, the midpoint of the four-year cycle. About 5% of these were children under the age of 18 and excluded from the *Ask Me! Survey*. Among those 18 years and over, 15% were under the age of 25, 25% were 25-34, 26% were 35-44, 20% were 45-54, 10% were 55-64, and 5% were 65 years and over. (See **Figure 7**.) They averaged 39.8 years of age. A greater percent of the adults supported by DDA than in the general adult population of Maryland were less than 45 years of age, and thus a smaller percent than in Maryland as a whole was 45 years of age and over (Maryland State Data Center, 2002). Only 5% of people with developmental disabilities were 65 years and over compared with 15% of the Maryland adult population. Men comprised 57% of the adults supported by DDA and 47% of all Maryland adults.



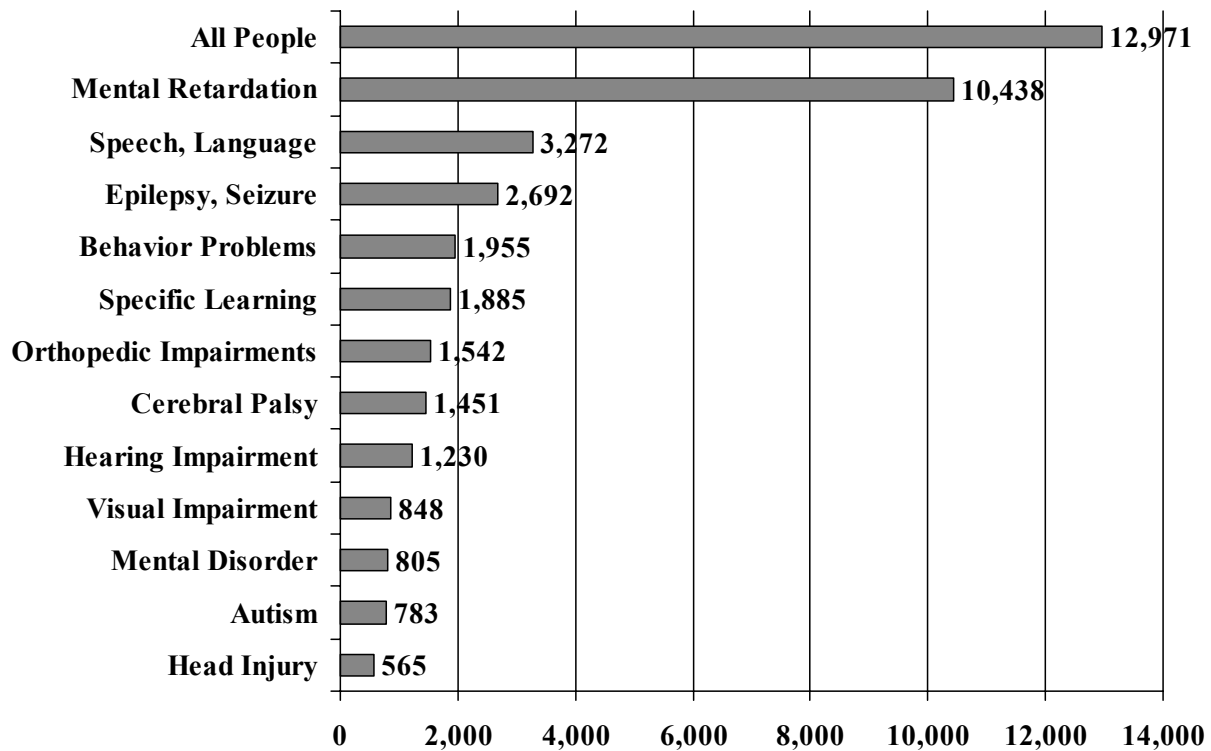
**Figure 7.** Percent of DDA and All Maryland Adults by Age, July 2003

### Disabilities

Among the 12,971 people supported by the Maryland DDA, 80% (10,438) had a classification of mental retardation. (See **Figure 8** for disabilities and impairments that affected more than 500 people.) Speech and language impairments affected 25% (3,272) of the people. Epilepsy and seizure disorders affected 21% (2,692). One person in seven had behavior problems. Two-thirds of the adults had more than one disability or impairment.

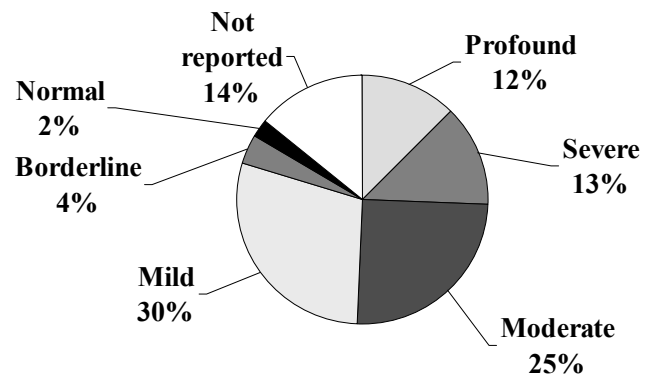
---

<sup>2</sup>Some people had only service coordination indicated in the DDA files at the time the sample was drawn. DDA also has a waiting list for people needing services and who will receive them as funding becomes available, and none of these people were included in the sample.



**Figure 8.** Number of People Supported by DDA by Disability: July 2003

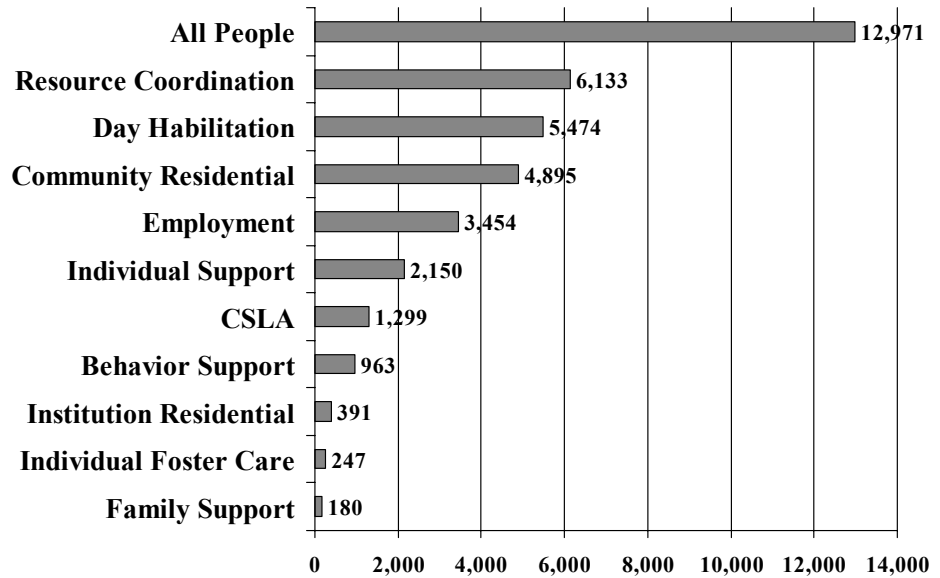
The DDA files did not identify level of retardation, so the Ask Me! Project requested provider agencies to classify people into one of six levels of retardation on the Background Form or Transportation Form. Provider agencies did not report the level of retardation for one-eighth (14%) of the people, the majority of whom had autism, cerebral palsy, head injury or other neurological disorders. (See **Figure 9**.) A few were reported to have normal intelligence (2%) or borderline retardation (4%). About one-fourth had classifications of mild (30%) or moderate (25%) retardation, and one-fourth had severe or profound retardation (13% and 12% respectively). As discussed earlier, some people classified with profound retardation could respond for themselves, and level of retardation is used only as a statistical control. Intellectual ability does not determine a person's quality of life, even though the ability to understand and respond for oneself has some relationship.



**Figure 9.** Level of Retardation

## Support Services

Of the 12,971 people supported by DDA on July 1, 2003, about half (6,133) received resource coordination from a provider who did not provide them other community supports. (See **Figure 10**.) Two-fifths (5,474) of the people received (or were authorized to receive) day habilitation support and one-fourth (3,454) received employment support. One-third of the people (4,895) received residential support from community provider agencies. One-tenth received community supported living assistance (CSLA), 3% resided in one of the four state institutions, 2% lived in individual foster care. One person in six received individual support services and 7% received behavior support services. Excluding resource coordination, 76% of the people received all their support from a single agency. Almost all the others (23%) received support from two different provider agencies, with 1% receiving support from three or four agencies.

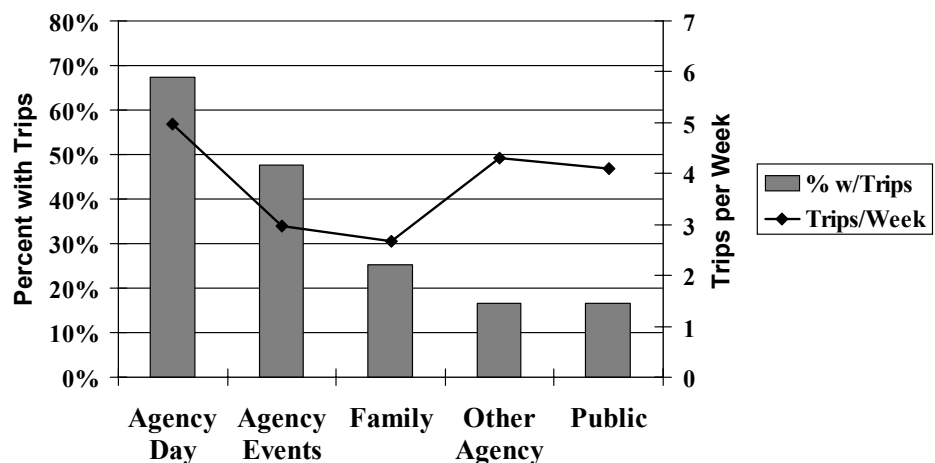


**Figure 10.** Number of People by Type of DDA Supported Services: July 2003

## Transportation

Agencies at which people were selected provided 68% of them with transportation to their employment or day program. Those provided weekday transportation received an average of 5.0 round trips per week. (See **Figure 11**.)

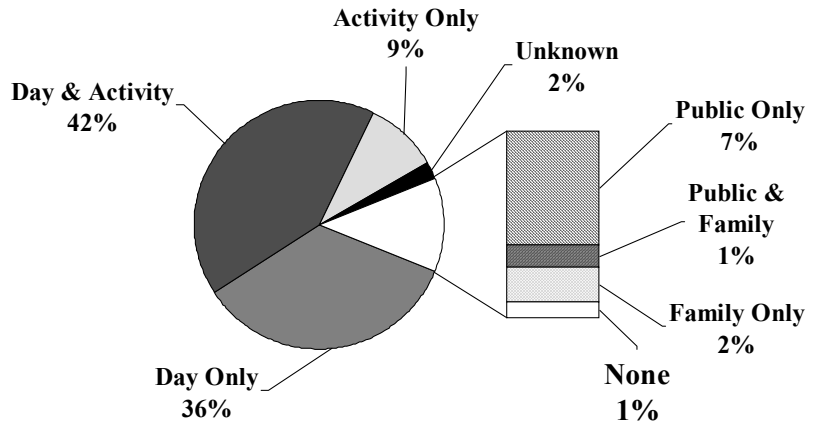
These agencies transported 48% of the people to other types of activities and events



**Figure 11.** Percent with Trips and Average Number of Round Trips per Week by Source of Transportation

round trips per week. Family and friends transported 25% of the people with an average of 2.7 round trips per week. One-sixth (17%) of the people rode public transportation an average of 4.1 times a week. One-sixth (17%) received transportation from agencies other than the one through which they were selected for the survey, averaging 4.3 round trips per week. These trips by other provider agencies could have been to either employment/day programs or to other activities, and may be under-reported.

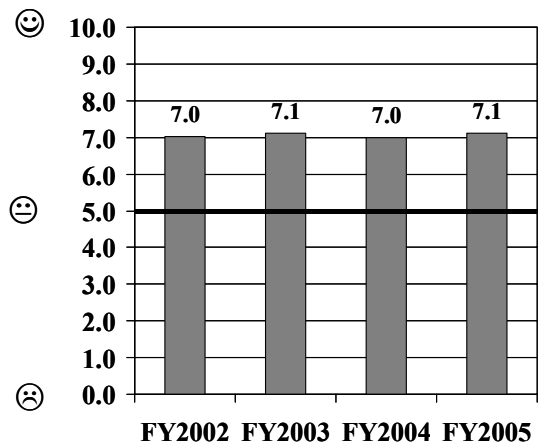
Provider agencies transported 88% of the people each week. Half of these people (42%) had transportation from provider agencies for both day activities and other activities. (See **Figure 12.**) Most of the rest (36%) had provider transportation only to their employment or day programs. A few (2%) had transportation only from provider agencies other than the one through they were interviewed, and data were not collected on the destination of this transportation (transportation from other provider agencies was assumed to be for the opposite destination of that from the sample provider.) Twelve percent of the people were not transported by any agency, but 7% used public transportation to go where they needed to go, 2% depended on family and friends, and 1% used a combination of public transportation and family/friends. A few (1%) of the people were reported by provider agencies as having no transportation during a week from any source.<sup>3</sup>



**Figure 12.** Destination of Transportation by Provider

### Transportation Availability

The last five questions on the survey asked people about how available they thought transportation was for them. The average score on a scale of 0 to 10 of transportation availability barely changed over the four years. (See **Figure 13.**) This lack of overall change was due to different trends in the indicator questions. In FY2002, 70% of the people said that they could count on rides that they set up. The percent increased each year until it reach 77% in FY2005. In contrast, 31% in FY2002 and 26% in FY2005 said they could just decide to go somewhere



**Figure 13.** Transportation Availability Score by Year

<sup>3</sup>Provider agencies for 6% of the people in FY2003, 16% of the people in FY2004, and 7% of the people in FY2005 did not report transportation for those whom they supported.

and had transportation available. In FY2002, 17% said transportation problems made them feel separate from others, and this steadily increased to 19% in FY2005.

Self-respondents reported transportation availability scores (6.7) substantially lower than those reported by proxies (8.1). When transportation availability scores were regressed on factors that might explain or predict them, the most important single factor was who responded to the survey. (See **Figure 14**, total column,  $\beta = -.31$ .) Among self-respondents but not proxies, the higher the intellectual ability of people responding for themselves ( $\beta = .08$ ), the more available they reported transportation. This suggests that the high reporting of transportation availability for those who could not respond for themselves represents a difference in perspective between consumers and staff (the majority of proxies were staff) rather than greater transportation availability for those with the most limited intellectual abilities. No characteristics predicted the transportation availability reported by both self-respondents and by proxies. Self-responders in the Southern and Western DDA regions of Maryland viewed transportation as more available than did self-respondents in the Central DDA region or on the Eastern Shore, but proxies reported no differences by region. Self-respondents with employment support reported greater transportation availability than those without employment support, while proxies thought it was the number of weekday trips that were important rather than where they went. Self-respondents with hearing impairments viewed transportation as more available than did self-respondents without hearing impairments, but proxies thought transportation was less available for those with hearing impairments. Self-respondents saw no change in the availability of transportation over the four years, but proxies saw a great improvement ( $\beta = .18$ ).

	<i>Self</i>	<i>Proxy</i>	<i>Total</i>
Southern region	.12	ns	.11
Western region	.11	ns	.11
Intellectual ability	.08	ns	.06
Supported employment	.06	ns	.05
Deaf, hearing impaired	.06	-.12	ns
Year of survey	ns	.18	ns
Agency day trips	ns	.17	ns
Eastern Shore region	ns	ns	.05
Self reporting	--	--	-.31
$R^2$	.03	.07	.09

**Figure 14.** Predictors of Transportation Availability (standardized regression coefficients), by Respondent

[This page is intentionally blank.]

## Quality of Life

### Maryland FY2002-FY2005

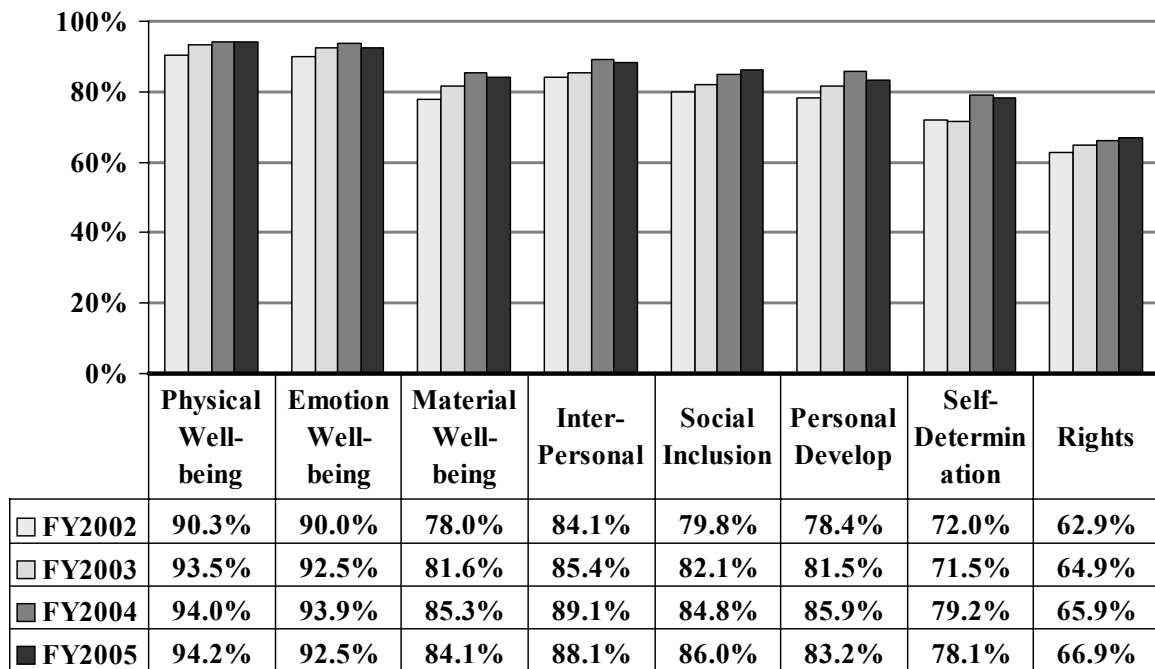
The *Ask Me! Survey* included six indicator questions for each of the eight quality of life domains. A summary quality of life score was calculated if a person answered at least four of the indicator questions. A score could be calculated for emotional well-being for 5,097 people (more than 99%), showing almost universal response to questions at the beginning of the interview. (See **Figure 15**.) Response declined steadily until near the end of the survey, so material well-being scores could be calculated only for 4,691 people (92%). Scores ranged from 0.0 to 10.0, with 5.0 being the neutral value (neutral responses to all questions in the scale or as many positive responses and negative responses). The most positive responses occurred in the domains of emotional and physical well-being, where 93% of the people had positive scores, with average scores of 8.4 and 8.6 respectively.

People rated their quality of life lowest in the domains of rights and self-determination. Only 66% had positive scale scores on rights with an average score of 6.3. People varied the least in their reporting of physical and emotional well-being (standard deviations of 1.76 and 1.79). They varied the most in their reporting of rights, self-determination and personal development (standard deviations of 2.50, 2.44 and 2.20). These, and other data in this report, were based on all four years combined, unless specifically noted otherwise.

<i>Domain</i>	<i>% Positive</i>	<i>Avg. Score</i>	<i>Std. Dev.</i>	<i># People</i>
Physical well-being	93.3	8.61	1.76	4856
Emotional well-being	92.5	8.42	1.79	5097
Material well-being	82.7	7.39	2.09	4691
Interpersonal relations	86.7	7.59	2.05	4976
Social inclusion	83.6	7.38	2.14	5008
Personal development	82.8	7.37	2.20	4887
Self-determination	75.8	7.01	2.44	4884
Rights	65.6	6.35	2.50	4709

**Figure 15.** Quality of Life by Domain

The percent of people supported by the Maryland DDA who reported positive quality of life increased steadily throughout the four years in three domains: physical well-being, social inclusion and rights. In the other five domains, the percent who reported a positive quality of life was higher in FY2005 than in FY2002, but not higher than in FY2004. The percent of people who reported positive physical well-being increased from 90.3% in FY2002 to 94.2% in FY2005. (See **Figure 16**.) Reports of positive emotional well-being increased from 90.0% in FY2000 to 93.9% in FY2004, but then dropped a statistically insignificant amount to 92.5% in FY2005. The percentage point increase was less in physical well-being (2.9) and emotional well-being (2.5) than in the other six domains, and future increases are constrained by the fact that no more than 100% of the people can report a positive quality of life. The greatest percentage point increases between FY2002 and FY2005 were reported in the domains of material well-being, self-determination and social inclusion (6.1, 6.1 and 6.2 points respectively). The slight drops between FY2004 and FY2005 in material well-being and self-determination were statistically insignificant. The greatest opportunity for future increases is in



**Figure 16.** Percent Reporting Positive Quality of Life, by Domain and Year

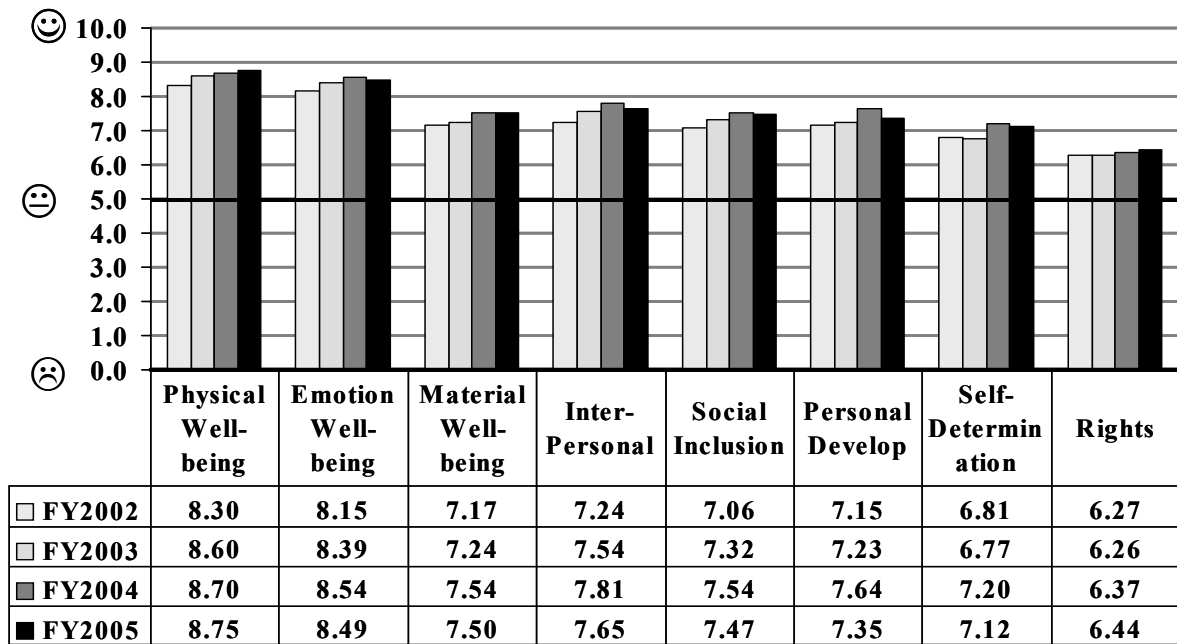
the area of rights where one-third of the people did not report a positive quality of life, even though there was a steady improvement in the quality of life in the rights domain over the four years.

The average quality of life score is a different measure than the percent with a positive quality of life. Linear regression indicates that the average reported quality of life increased significantly between FY2002 and FY2005 in seven of the eight domains. (See **Figure 17.**) The greatest average annual increases were in the domains of interpersonal relations and social inclusion, which increased an average of 0.142 and 0.141 points per year. The time trends in five additional domains were also statistically significant. Only the area of rights showed no statistical change in the average quality of life, even through an increased percent of people each year reported positive rights scores.

<i>Domain</i>	<i>B</i>	<i>Std. error</i>	<i>t</i>	<i>Sig.</i>
Physical well-being	.123	.024	5.20	.000
Emotional well-being	.110	.024	4.49	.000
Material well-being	.123	.028	4.32	.000
Interpersonal relations	.142	.027	5.20	.000
Social inclusion	.141	.029	4.91	.000
Personal development	.078	.030	2.62	.009
Self-determination	.115	.032	3.56	.000
Rights	.046	.034	1.36	.173

**Figure 17.** Regressions of Quality of Life Scores on Year of Interview, by Domain

A linear time trend assumed by the regression analysis fits well the yearly pattern of change in the average physical well-being of people. (See **Figure 18.**) Change in the average quality of life between FY2002 and FY2004 fit a linear time trend model for five additional domains, but it will take additional years of data to determine if the declines between FY2004 and FY2005 represented insignificant departures from linear increases, or represented an end to the increases. The declines between FY2004 and FY2005 in interpersonal relations (from 7.81 to 7.65) and personal development (7.64 to 7.35) were statistically significant.



**Figure 18.** Average Quality of Life Scores, by Domain and Year

The FY2002-FY2004 combined responses for all the question on the Ask Me! Survey are shown in **Table 1**. The six questions for each of the eight quality of life domains are grouped in the order in which they were asked. The question that best represents a domain is shown in **bold** type, but eliminating any question would reduce the reliability of the scale scores (except Q24 in Personal Development). The eight questions with increasingly positive responses from FY2002 to FY2005 are indicated by a happy face (☺). The three questions with increasingly negative responses over the three years are indicated by a sad face (☹). When proxies disagreed, the person is classified by the less favorable response.

**Table 1. Percent Giving Each Response to Survey Questions:**

	1 ☺	2 ☹	3 ☹	Total
<i>Emotional Well-Being</i>				
1. Would you say that you are a happy person?	80	17	04	100
<b>2. How do you feel about your home where you live? ☺</b>	<b>68</b>	<b>25</b>	<b>07</b>	<b>100</b>
4. How safe do you feel in your neighborhood?	78	13	09	100
5. Do you like yourself?	77	18	05	100
6. Do you feel that others treat you the same as any other person? ☺	63	26	11	100
7. In general, how happy are you with your life?	70	25	05	100
<i>Social Inclusion Scale</i>				
8. Do people help you to be part of your community? ☺	74	17	08	100
<b>9. Do you go to fun things in your community?</b>	<b>65</b>	<b>22</b>	<b>12</b>	<b>100</b>
10. When you go to fun things, are you active?	60	28	12	100
11. Do you think your neighbors like you?	68	26	07	100
12. How many friends...from church, synagogue and community?	45	38	17	100
13. How often do you see your friends on weekends?	34	44	21	100
<i>Interpersonal Relations Scale</i>				
14. Do people help you learn how to do things for yourself?	60	30	10	100
15. When you make a mistake, do people help you?	73	19	08	100
<b>16. When you set goals, do people help you reach them?</b>	<b>75</b>	<b>17</b>	<b>09</b>	<b>100</b>
17. How often do you see or talk with your family? ☺	58	28	14	100
18. How many close friends do you have?	41	30	29	100
19. Does what you do most days let you look good to others?	67	24	09	100
<i>Personal Development Scale</i>				
20. Does your job or what you do make you feel important?	70	21	09	100
21. Are you getting the training that will help you get a job/better job?	54	21	25	100
<b>22. Do others give you a chance to become what you want to be?</b>	<b>66</b>	<b>23</b>	<b>11</b>	<b>100</b>
23. Are you learning things that will make you a better person?	77	17	07	100
24. Do you get the information you need about sexuality?	37	11	52	100
25. Do you get the services you need?	78	13	08	100
<i>Self-Determination Scale</i>				
26. Did you pick who you live with?	50	15	35	100
27. Can you be alone when you want to?	61	21	19	100
28. How much choice do you have in the food you eat?	49	30	21	100
29. Do you get a chance to say what you think?	55	28	17	100
30. Do you pay for things you buy with your own money?	70	19	11	100
<b>31. Did you choose your job or what you do most days?</b>	<b>61</b>	<b>22</b>	<b>18</b>	<b>100</b>

**Table 1. Percent Giving Each Response to Survey Questions (continued)**

	1 ☺	2 ☹	3 ☹	Total
<i>Physical Well-Being Scale</i>				
32. On....health, are people concerned, too concerned, not care?	81	12	07	100
33. Is your health good, fair or poor?	73	19	08	100
<b>34. Would you say your eating habits are good, fair or poor? ☺</b>	<b>74</b>	<b>19</b>	<b>08</b>	<b>100</b>
35. Do you have regular check ups with a dentist?	77	13	10	100
36. Can you get the sleep you need without being disturbed?	76	14	09	100
37. Do staff or people you live with hit or hurt you? ☺	91	06	04	100
<i>Material Well-Being Scale</i>				
38. How many things do you own, like furniture, TV, etc.?	54	37	09	100
39. How often do you worry..money pay rent or buy food?	67	18	16	100
<b>40. On money, do you feel you well off, have problems, are poor? ☺</b>	<b>62</b>	<b>25</b>	<b>13</b>	<b>100</b>
41. Do you have money each week to spend on what you want? ☺	69	21	10	100
42. Save money every time you get paid, sometimes, or never?	53	31	16	100
43. Do you have the chance to earn good money?	57	19	24	100
<i>Rights Scale</i>				
44. Do staff ask before they come into your home or room? ☺	59	22	19	100
45. Can you lock the bathroom door if you want to? ☹	55	12	33	100
<b>46. Can you talk on the telephone in private?</b>	<b>63</b>	<b>13</b>	<b>24</b>	<b>100</b>
47. Can you spend time by yourself if you want?	69	17	14	100
48. When you have a gripe against staff, is it easy to say something?	56	24	20	100
49. How often do you vote in government elections?	24	14	62	100
<i>Transportation Scale</i>				
51. When you want to go somewhere, do you have transportation?	72	19	09	100
52. Can you just....go, have to plan some, or many days ahead? ☹	27	39	34	100
53. If you set up a ride, can you depend on it? ☺	74	16	10	100
<b>54. Do you miss...have to change plans because of transportation? ☺</b>	<b>51</b>	<b>31</b>	<b>18</b>	<b>100</b>
55. Do transportation problems make you feel separate from others? ☹	60	22	18	100

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

☺ Increase each year in the percent with the favorable response

☹ Increase each year in the percent with the unfavorable response

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

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

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

## Maryland Strengths

Nine questions received favorable (☺) answers from over three-fourths of the respondents during the four-year period. (See **Figure 19**.) Four of the questions related to physical well-being: 91% said the people they lived with never hit or hurt them, 81% felt that people had the right level of concern about their

#	Question	% ☺
37.	Do staff or people you live with hit or hurt you? ☺	91%
32.	On health, are people concerned the right amount?	81%
1.	Would you say that you are a happy person?	80%
25.	Do you get the services you need?	78%
4.	How safe do you feel in your neighborhood?	78%
35.	Do you have regular check-ups with a dentist?	77%
5.	Do you like yourself?	77%
23.	Learning things that will make you a better person?	77%
36.	Can you get the sleep you need without being disturbed?	76%

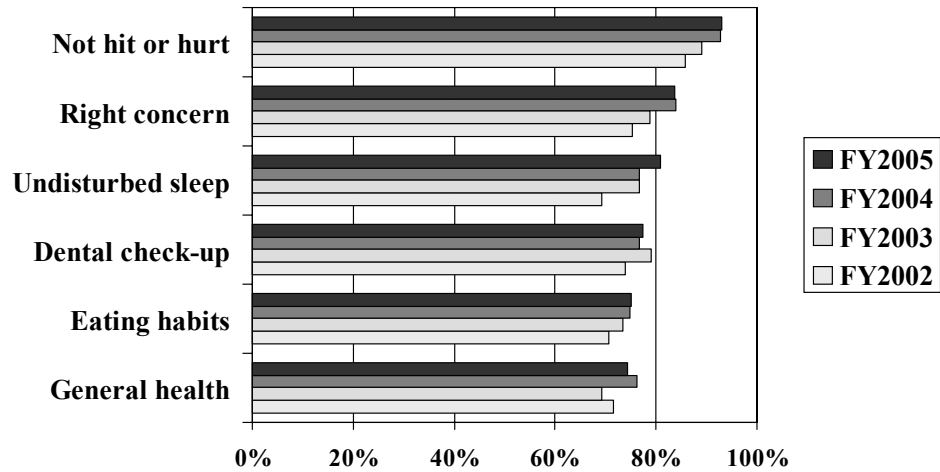
**Figure 19.** Questions with the Most Favorable Responses

health, 77% had regular checkups with a dentist, and 76% said they got the sleep they need without being disturbed. Three of the questions related to emotional well-being: 80% said they were a happy person, 78% felt very safe in their neighborhood, and 77% liked themselves. The remaining two questions related to personal development: 78% said they got the services they needed and 77% said they were learning things that would make them a better person. The percent who said the people they lived with never hit or hurt them increased each of the four years from 86% in FY2002 to 93% in FY2005 (indicated by ☺ following the question). The responses to the other questions varied slightly from year to year without any clear time trend. The high positive responses to these individual questions, along with the overall high responses suggest that community services in Maryland strongly support quality of life in three domains: physical well-being, emotional well-being and social inclusion.

### *Physical Well-Being*

People responded most positively and consistently in the domain of physical well-being. They perceived their physical well-being as high in FY2002 (average score of 8.30) and it increased in each following year (average score of 8.75) in FY2005. The 0.45 increase during the four years was the highest, and statistically strongest, among the eight domains. The average physical well-being score in the FY2001 pretest was 8.10, suggesting that the physical well-being has been increasing for even a longer period of time, although the people responding in FY2001 were not a random sample of people in the state. The percent who reported positive physical well-being increased from 87% in FY2001 to 94% in FY2005. The percent who reported negative physical well-being decreased more dramatically, from 8% in FY2002 to 3% in FY2005, while the percent reporting the neutral score of 5.0 varied between 2% and 5% over the four years. Scores varied less from one individual to another in physical well-being than any other domain.

All six indicators of physical well-being received more favorable responses in FY2005 than in FY2002, and the percent who gave the favorable response generally increased each year. (See **Figure 20.**) In FY2002, 86% of the people surveyed said they were never hurt or hit by staff or people with whom they lived.<sup>4</sup> This had



**Figure 20.** Percent with Favorable Response to Physical Well-being Questions, by Year

increased to 93% by FY2005. The question showing the least amount and least consistent change related to the person’s perception of their own health. As few as 69% reported “good” health in FY2003, and as many as 76% did so in FY2004. Positive responses to all six indicator questions generally increased during the four years, with statistically significant increases for all questions except dental check-ups and eating habits.

*Emotional Well-Being*

People reported their emotional well-being only slightly lower than their physical well-being, and their average scores increased from 8.15 in FY2002 to 8.49 in FY2005. Individuals varied almost as little in emotional well-being as in physical well-being. The increase in the percent of people reporting positive emotional well-being paralleled the increase of the percent reporting positive physical well-being for three of the four years.

*Social Inclusion*

The average scores in social inclusion were not as high as the average scores in physical and emotional well-being, but they increased the most (0.41 points) over the four-year period, from 7.06 in FY2002 to 7.47 in FY2005. Like physical well-being, increases occurred in each year. The percent with positive scores increased 6.2 points over the four-years, the most of any domain. This translates into a 31% reduction of the number with a non-positive score, second only to the reduction in the number with non-positive physical well-being scores. While social inclusion can still be improved, the quality of life in this domain was strongly enhanced between FY2002 and FY2005.

<sup>4</sup>Interviewers were taught to be alert to any possible indication of abuse and ask the respondent if they wanted to report this to the Ask Me! supervisor. To date, no potentially abusive situation has been reported to the supervisor that had not already been reported and handled by provider staff.

## Domains for Enhancement

Five questions received a negative (☹) response by 30% or more of the people (or at least one proxy) for the combined FY2002-FY2005 period. (See **Figure 21**.) Two of these questions were in the domain of rights:

#	Question	% ☹
49.	How often do you vote in government elections?	62%
24.	Do you get the information you need about sexuality?	52%
26.	Did you pick who you live with?	35%
52.	Have to ask and plan days ahead for transportation? ☹	34%
45.	Can you lock the bathroom door if you want to? ☹	33%

**Figure 21.** Questions with the Most Negative Responses: FY2002-2005

62% of the people said they never voted in governmental elections, and 33% said they could not lock the bathroom door if they wanted. One of the questions was in the domain of self-determination: 35% said they did not pick with whom they lived. One question was in the domain of personal development: 52% said they did not get the information they needed about sexuality. The fifth question related to transportation availability, not a domain of quality of life but a strong predictor of it. The question about locking the bathroom door was the only quality of life question that progressively received more negative responses each year between FY2002 and FY2005 (indicated by ☹ following the questions). The other two questions where negative responses increased each year related to transportation: having to plan days in advance and feeling separated from others. The question on voting showed a slight relation to the presidential election cycle, with the highest report of voting occurring in FY2005, when most of the interviews were conducted in the eight months following the November 2004 presidential election. The high negative responses to these individual questions, along with the overall low domain scores, suggest the need to enhance community services to support quality of life in the domains of rights, self-determination and personal development.

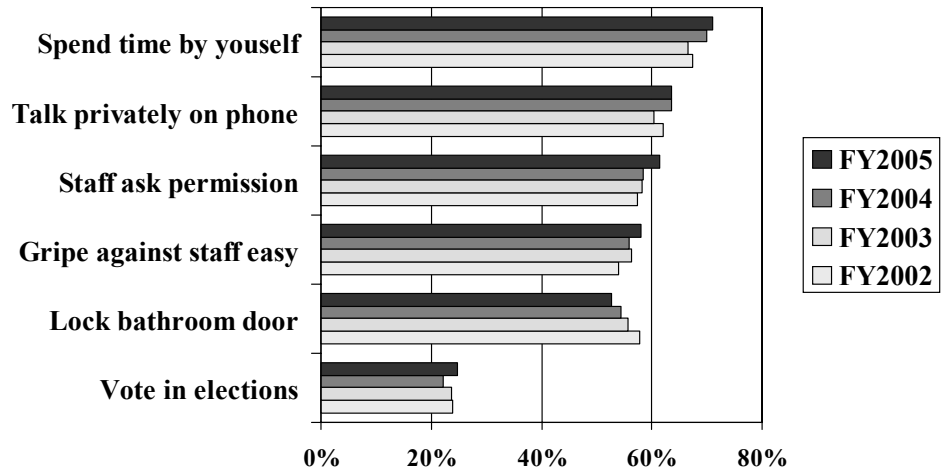
### *Rights*

In FY2002, people perceived their quality of life to be lower in the domain of rights than in any other domain. By FY2005, the differences had increased, since people's reporting of rights did not change statistically during the four years while they reported statistically significant increases in quality of life in the other seven domains. The lack of change extends back to the FY2001 when the average rights score was 6.30. In addition, the small amount of change that incurred in rights was inconsistent, going up slightly in three years and down slightly in one year. The percent who reported positive rights increased from 65% in FY2001 to 67% in FY2005, but the percent who reported negative rights also increased from 24% in FY2001 to 25% in FY2005. The only real change was in the percent with a neutral rights score of 5.0, which declined from 12% to 8% of the people. People also differed more in their scores on rights than in any other domain (standard deviation of 2.50).

The individual questions in the rights domain showed differences in direction that together account for the little overall change in the average quality of life score. The percent of people who reported that staff always asked permission before coming into their room increased each year<sup>5</sup>.

(See **Figure 22**.) In contrast, the percent of people who reported they could lock the

bathroom door if they wanted steadily declined each year from 58% in FY2002 to 53% in FY2005.<sup>6</sup> While correlations showed that favorable responses to three of the questions (staff asking, spending time alone, and gripes against staff) increased statistically over the four-year period of time, their increases were not enough to offset the decrease in ability to lock the bathroom door, and the lack of consistent change in telephone privacy and voting. Locking the bathroom door was the only quality of life indicator question where an increasing larger percent each year gave the unfavorable response.



**Figure 22.** Percent with Favorable Response to Rights Questions, by Year

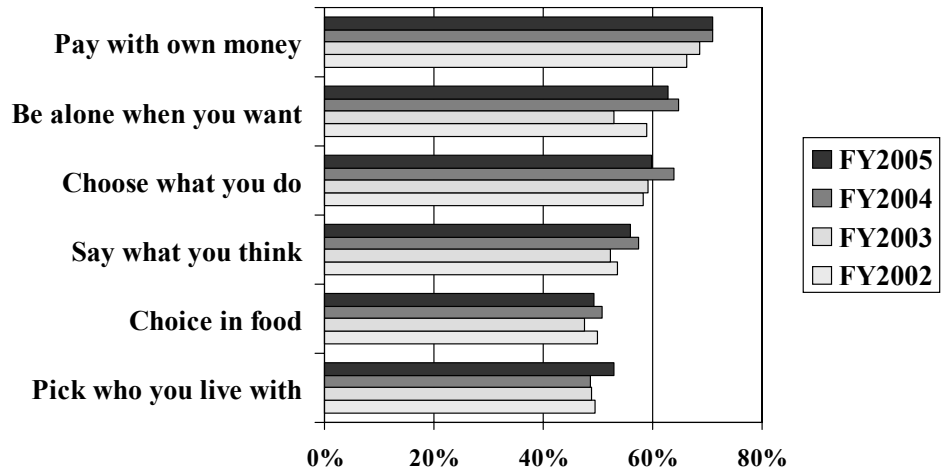
### *Self-Determination*

The average quality of life in the domain of self-determination increased significantly between FY2003 and FY2004, showing the biggest one-year increases (0.43) of any of the domains. However, this one year increase was offset by decreases in both the preceding and following years. Including the FY2001 pretest data on self-determination (score of 6.76) in analysis suggests that the quality of life in the domain of self-determination may not be increasing overall, and the significant increase between FY2003 and FY2004 was due to the particular sample in FY2004, or to something unique to that year, rather than reflecting any long-term increase in self-determination. The variation among individuals in their reports of self-determination (standard deviation of 2.44) was second only to the variation among them in reporting rights. While the percent reporting a positive score in self-determination increased over the four years, it translated into only a 22% reduction in the number of people not reporting a positive score, with only rights shown less reduction.

<sup>5</sup>The correlation with year is statistically significant; the t-test between the percent in FY2002 and FY2005 is not statistically significant.

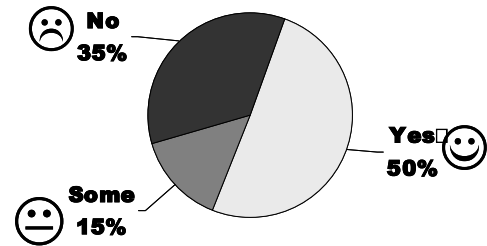
<sup>6</sup>The decline in ability to lock the bathroom door is statistically significant when correlated with year, and with a t-test between the percent in FY2002 and FY2005.

Only two of the six indicator questions for self-determination did not receive the most favorable response in FY2004. (See **Figure 23**.) One was paying for things with their own money, where the FY2005 report was the same as the FY2004 report, but otherwise showed a general increase during the period. The other question was about picking with whom they lived, to which favorable responses declined between FY2002 and FY2004, but suddenly jumped up in FY2005.



**Figure 23.** Percent with Favorable Response to Self-Determination Questions, by Year

The question on house-mate choice showed an increase in only FY2005. Over the four years, 35% of the people supported by DDA felt they had no choice at all with whom the lived. (See **Figure 24**.) An additional 15% said they had only some choice. Thus half of the people felt they had no or limited opportunity for self-determination in one of the most important areas of a person's life. This lack of choice with whom to live, combined with the decreasing right to have bathroom privacy, suggested a restriction on quality of life that most people would not accept.



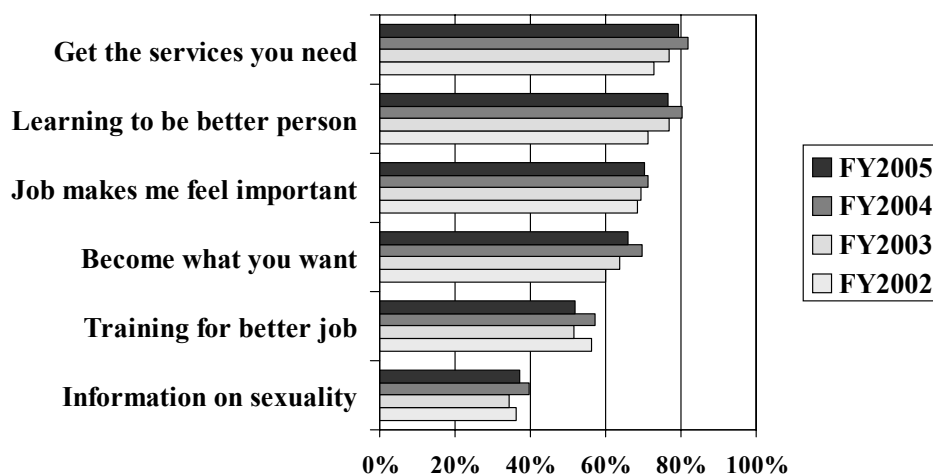
**Figure 24.** Percent Having Choice with Whom to Live

*Personal Development*

The average quality of life in the domain of personal development increased significantly between FY2003 and FY2004, showing the second largest one-year increases (0.41) of any of the domains. However, personal development had the biggest one-year decrease (0.29) of any of the domains in the following year. The overall change ( $\beta = 0.78, p = .009$ ), while statistically significant, was smaller than in any other domain except rights. The percent who had positive scores on personal development also declined significantly between FY2004 and FY2005. Over the four years, the percent not reporting a positive score decreased only 22%, tying self-determination for the second least decrease among the eight domains. On the other hand, the average personal development score in the FY2001 pretest was 7.11 in FY2001, which suggests a slow but steady increase throughout the five-year period, if it wasn't for the extra high

favorable reporting in FY2004. It is therefore not clear whether personal development has or has not been increasing. What is clear is that change in this domain has not been consistent.

Four of the six indicator questions in the domain of personal development showed a general four-year increase, but with an extra high reporting in FY2004. (See **Figure 25.**) No question had a steady increase in the positive response over all four years. The two areas lowest in FY2002 showed either no time trend or a negative trend. Just over half (54%) of the



**Figure 25.** Percent with Favorable Response to Personal Development Questions, by Year

respondents in the four years said they were receiving the training they need to get a job or a better job. An additional 21% were not sure, and 25% said they were not receiving training. Even among individuals with moderate or less retardation, only 66% said they received the training they needed to enhance their employment opportunities. Just over one-third (37%) of the people over the four years said they received the information they needed on sexuality, while over half (52%) said they did not receive the information they needed, or did not even know what the term meant.

The two remaining quality of life domains, material well-being and interpersonal relations, appear intermediate between those that are strong and those that need enhancement. The average scores, and the percent with positive scores, increased in both domains over the four-year period, yet still leave room for improvement. Further, self and proxy responders suggest different relationships of these domains to the three that need enhancement.

### Self and Proxy Differences

Many people with profound and severe retardation could not understand and answer the interview questions for themselves, and required proxies to report for them. Proxies reported average physical well-being scores of 9.24, significantly higher than 8.40 average self-reported scores. (See **Figure 26.**) Proxies also reported significantly higher emotional well-being than did self-respondents (8.82 and 8.28 respectively) and greater interpersonal relations (7.73 and 7.55). Proxies, however, reported lower quality of life than self-respondents in the other five domains. These data cannot identify how much of the proxy-self differences are due to true differences in the quality of life of people unable to respond for themselves and people able to respond, and how much is due to incomplete or biased knowledge by proxies.

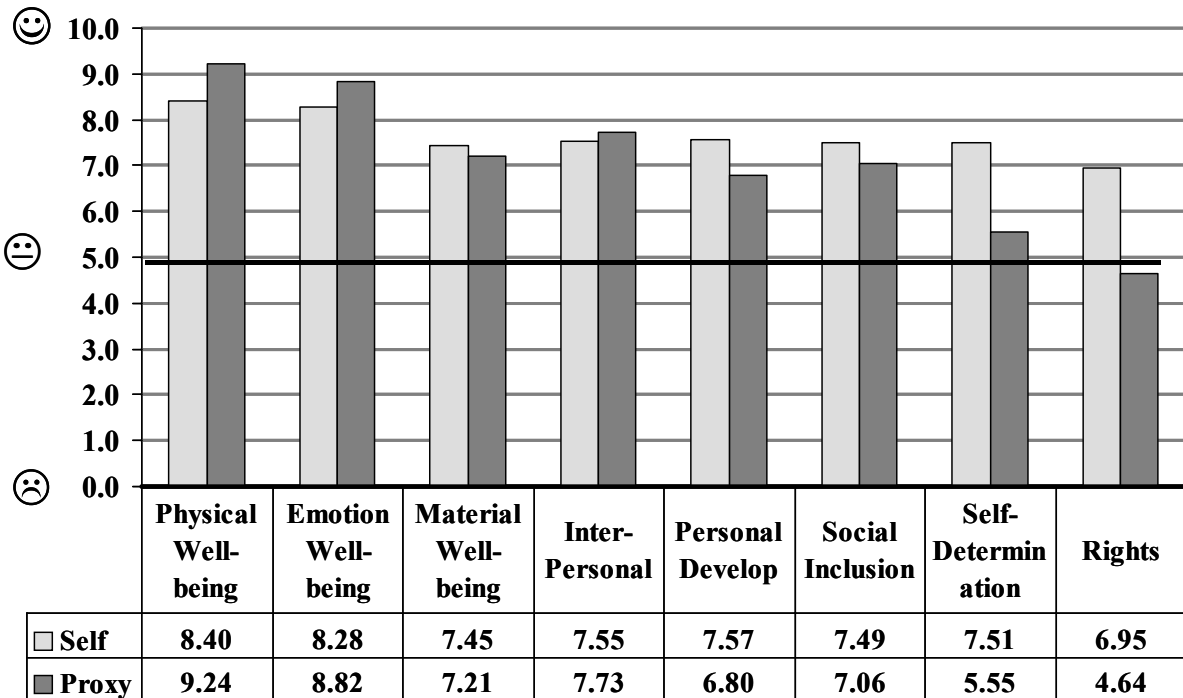


Figure 26. Average Quality of Life Reported by Self and Proxies

The eight quality of life domains are interrelated, and it is not clear if they have a hierarchy. Some domains received more attention in the literature than others, but that does not mean that they are more important than others, or that quality of life in some domains must precede quality of life in other domains. The mission statement of the Maryland DDA defined social inclusion, personal development, and self-determination as desired outcomes, and these were initially assumed to be the goals to target enhancement. The Ask Me! data, however, showed that the quality of life in the domain of rights was lower than the other domains, and did not change between FY2002 and FY2005. A path model was therefore fit to aid understanding of how to enhance the domain of rights through the DDA-specified goals of self-determination, personal development and social inclusion. The model assumed that physical well-being was foundational, closely followed by material and emotional well-being. In the model, a domain at the head of an arrow is predicted, or caused by, the domain to its left at the tail of arrow. The thickness of the arrow represents the size of the direct effect of one domain on another as measured by the standardized multiple regression coefficient ( $\beta$ ). The thinnest arrows represent  $\beta$ 's less than 0.10, while the thickest arrows represent  $\beta$ 's of 0.30 and above. Solid arrows represent positive effects; dashed arrows represent negative effects. When no arrow is shown between two domains, any effect is indirect, operating only through intermediate domains. Two path models at the individual level are shown in this section, one developed from self-reports and the other developed from proxy reports.

The path model developed from self-reporting is fairly complex. (See Figure 27.) Self-determination, personal development, material well-being and physical well-being are each related to all seven other quality of life domains. Social inclusion, interpersonal relations and emotional well-being are related to all other domains except rights.

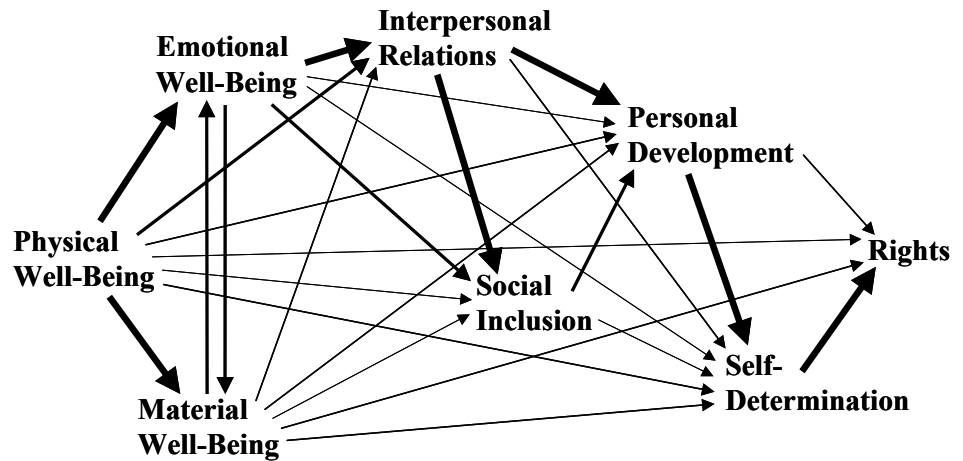


Figure 27. Path Model of Self-Reported Quality of Life Domains

The path model shows that the rights of individuals will best be enhanced by enhancing their level of self-determination ( $\beta = .34$ ), with personal development as the next best domain to enhance ( $\beta = .19$ ). Self-determination is best enhanced by enhancing personal development ( $\beta = .31$ ). The model shows that enhancing personal development will enhance rights directly, and will enhance rights indirectly as it enhances self-determination. Personal development will best be enhanced both directly and indirectly by enhancing interpersonal relations, as increased interpersonal relations affects social inclusion, which then affects person development. A pair of arrows is shown between emotional well-being and material well-being, as the data provide little guidance as to which might cause the other.

The path model developed from staff and family proxy interviews has fewer direct relationships than the one developed from self reports. (See Figure 28.) Proxies did not see any quality of life domain as related to all the other domains.

Like self-respondents, they viewed rights as best enhanced by enhancing self-determination ( $\beta = .52$ ). Proxies, however, saw self-determination about equally enhanced by enhancing material well-being ( $\beta = .25$ ) and personal development ( $\beta = .22$ ).

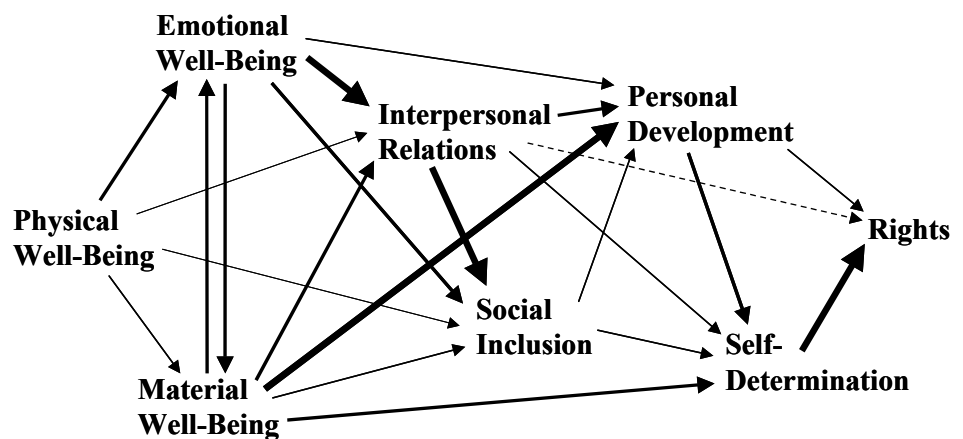


Figure 28. Path Model of Proxy-Reported Quality of Life Domains

A major difference between the path diagram for proxies and self-respondents is the role of interpersonal relations. Proxies reported a less strong relationship than self-respondents between interpersonal relations and personal development, and their reporting suggests that high levels of interpersonal relations

result in low levels of rights ( $\beta = -.12$ ). This suggests that staff and families view supports for people with profound and severe retardation as having to make a choice between developing good relations with other people and developing the person's individual rights. Staff and family also differed from self-respondents in that they saw no direct effect of physical and material well-being on rights, and that they saw no direct effect of physical well-being, emotional well-being and interpersonal relations on self-determination. Proxies, however, saw a much stronger relationship between material well-being and personal development ( $\beta = .30$ ) than did self-responders ( $\beta = .14$ ).

The path models shown assumed linear relations between the quality of life measures, that is, a unit increase in the first predicts a certain amount of increase in the second regardless of whether the first quality of life was low initially or high initially. The variance explained could be increased by only one point ( $R^2$  increase by 0.01) by adding a quadratic and a cubic term for one relationship in the self-respondent model (material well-being  $\rightarrow$  self-determination), and two relationships in the proxy model (physical well-being  $\rightarrow$  interpersonal relations and physical well-being  $\rightarrow$  personal development). A unit increase in material well-being for self-responders with low material well-being had a bigger effect on perceived rights than a unit increase in material well-being for self-responders with average levels of material well-being. After that, increases in material well-being started to have increasing impact on rights. Proxies reported higher person development and interpersonal relations for people with the lowest and highest levels of physical well-being, and lowest personal development and interpersonal relations for people with the middle range of physical well-being. These slight increases in model fit by adding curvilinear relationships, however, did not seem to justify the resulting increase in the complexity of interpreting the results.

## Differences Among Proxies

Proxy data from the FY2004 Ask Me! Survey were analyzed to determine the extent that the two proxies for the same person gave the same response to the survey questions. During that year, data were collected for 138 people from a day staff proxy and a residential staff proxy, for 115 people from a family proxy and a staff (generally day) proxy, for 101 people from a day staff proxy and another staff (generally day) proxy, for 9 people with an independent resource coordinator proxy and a staff proxy, and 55 people with only one proxy. Most proxy interviews occurred at the site of the day program and took about 30 minutes. The first proxy interviews generally took place immediately after the interviewers determined that people could not respond for themselves. Therefore, 59% of the first proxy interviews were with direct support staff in day programs, and an additional 18% were with other daytime staff (e.g., day supervisors, trainers, case managers and nurses). The second proxies interviewed were more diverse: 36% were residential staff, 28% were family or friends, 23% were day program staff, 11% were other staff and 2% were service coordinators. Interviewers conducted most (83%) of the first proxy interviews face-to-face while they conducted most (56%) of the second proxy interviews by telephone. The second proxy interviews occurred an average of 30 days after the first proxy interviews, with 38% occurring on the same day and 99% within six months. Thus some differences between proxies may be due to different modes of interviewing and different time frames, although these effects are expected to be small. A proxy "disagreement score" was

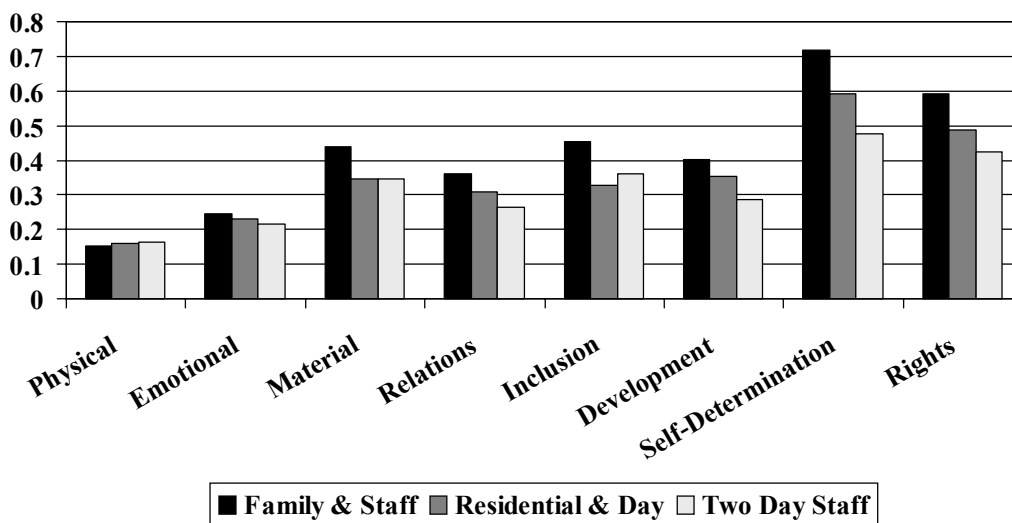
calculated as the absolute difference between the answers of the two proxies to the same question, with a score of 0 given when the answers were the same, a score of 1 for a positive/neutral or negative/neutral combination, and a score 2 for a positive/negative combination or when one answer was missing.

The two proxies for the same person had an overall disagreement score of 0.37. This was approximately equal to both answering two-thirds of the questions the same way, and one answering the remaining questions with the neutral response while the other answered with a different response, most frequently the positive one. Two proxies agreed most in the domains of physical (0.16) and emotional (0.23) well-being. These two domains had the highest reported quality of life by both self-responders and proxies, had the least variation among both self-responders and proxies, but also had proxies reporting significantly higher quality of life than self-respondents. Proxies disagreed with each other most in the domains of rights (0.50) and self-determination (0.60). These two domains had the lowest average quality of life scores and the greatest variation reported by both self and proxy respondents. These were also two domains where self-respondents reported significantly higher quality of life than proxies reported, controlling for other characteristics. Disagreement scores between proxies in the other four domains ranged from 0.32 to 0.38.

Of the three major proxy combinations, family and staff proxy pairs disagreed more than pairs of day staff<sup>7</sup> in seven of the quality of life domains. (See **Figure 29**.)

Only in the domain of physical well-being did two

day staff proxies appear to disagree more frequently than family and staff proxies. Stepwise multiple regression showed that proxy disagreement was statistically higher between family and staff proxies than between other proxy pairs in the domains of rights, self-determination, social inclusion, interpersonal relations and material well-being, controlling for characteristics of the consumer. The only characteristic of the consumer that affected proxy disagreement in more



**Figure 29.** Disagreement Between Proxy Combinations on Quality of Life

<sup>7</sup>The two day staff category generally involves a vocational staff and some other type of staff (nurse, trainer, manager, etc.), but also can include two vocational staff.

than two domains was receipt of behavior consulting services, which contributed to significant differences in the six domains other than self-determination and rights.

Five individual questions had proxy disagreement scores of 0.10 or less. Families and residential staff almost universally agreed (97% and 99% respectively) that they or other people in the household never hit or hurt the people for whom they were responding, but only 89% of day staff was so convinced. For comparison, 83% of self-respondents reported not being hit or hurt by the people living with them. The positive answer to feeling safe in the neighborhood was given by 96% of residential staff, 92% of day staff and 89% of family proxies. For comparison, 75% of self-responders gave the positive answer. The right amount of concern was about health was reported by 96% of residential staff, 91% of day staff and 95% of family proxies, while 75% of self-respondents indicated the right amount of concern shown on their health. Almost all residential (94%) and day staff (95%) said the person received all the services they needed, compared to 89% of family members and 72% of self-respondents. The fifth question with low disagreement (0.08) was voting in government elections, and only 2% of proxies of any type reported that the person voted often compared with 31% of self-respondents.

Proxies had disagreement scores greater than 0.60 on seven individual questions. Three of the questions were in the domain of self-determination, three were in the domain of rights, and one was in the domain of personal development. Proxies disagreed most about whether people could be alone with they wanted, with 41% of day staff reporting this possibility in contrast to 65% of residential staff and 73% of family members. These last two groups, who saw consumers at night and on weekends, reported the ability to be alone at about the same percentages as did self-respondents (71%), suggesting that choice of private time occurs most frequently at nights and on weekends which are outside the direct knowledge of day staff. Only 20% of family proxies reported that it was easy say something when they had a gripe against staff, compared with slightly over half (55-57%) of day staff, residential staff and self-respondents. Disagreement on whether individuals received the job training they needed was affected by different perspectives of staff and non-staff: 26% of day staff, 39% of residential staff, 63% of family and 63% of self-respondents report getting the training needed to get a job or a better job. Similarly, 46% of day staff, 54% of residential staff, 63% of family and 70% of self-respondents said the individual had a choice in what they did most days. Proxies had high disagreement with each other on whether people had a great amount of choice in their house mates even though only 17-20% of all types of proxies reported the consumers had a choice. The majority (56%) of self-respondents, however, reported a great amount of choice. Proxies also disagreed greatly on whether people could lock the bathroom door, with 15% of families, 32% of day staff and 36% of residential staff saying they could, compared to 66% of self-respondents.

## Enhancing Individual Quality of Life

Many factors affect a person’s quality of life. While the Ask Me! Survey cannot address issues of cause and effect, it can identify the factors that are associated with, or help predict, people’s quality of life. Some can be changed and suggest ways to enhance quality of life. Stepwise multiple regression was used to regress quality of life scores in each domain on characteristics of the individuals and the type of support they received. The standardized multiple regression coefficient ( $\beta$ ) shows the relative importance of a relationship independent of all the other relationships. Characteristics not shown had no independent statistical relationship with quality of life. Perceived availability of transportation had the best predictive power for all eight quality of life domains among self-respondents, and for all but personal development and rights among proxies. Anything that can be done to enhance people’s perceptions of transportation availability will enhance their quality of life, but the data offer little guidance on how to do this. Therefore, this section will focus on other characteristics associated with quality of life. (See **Appendix Table 7** for multiple regressions that includes transportation availability.) Proxies differed from self-respondents in the reporting of quality of life and how the domains related to each other. Additionally, who responded to the interview was found to be the second best predictor of quality of life in five of the eight domains. Therefore, the predictors of quality of life are analyzed in different sections for self-respondents and for proxies of people who could not respond for themselves.

### Self-Respondents

Self-respondents reported slightly higher levels of personal development and rights in FY2005 than in FY2002, although the changes were not statistically significant. Their reports of self-determination, however, significantly increased ( $\beta = .07$ ) during the four years with yearly improvements from 7.3 to 7.7. (See **Figure 30**.) Independent of when they were interviewed, people receiving supported employment services reported higher quality of life in the three focal domains of personal development ( $\beta = .11$ ), self-determination ( $\beta = .08$ ) and rights ( $\beta = .09$ ) than people who received other types of support. Supported employment services also predicted higher quality of life in the other five quality of life domains. This suggests that the best way to enhance people’s quality of life is to help them move into supported employment.

	Personal Development	Self-Determination	Rights
Survey year	-	.07	-
Employment support	.11	.08	.09
Western region	.09	.10	.-
Southern region	.06	-	-
Other agency trips	-.05	-.06	-.05
Family trips	-	-	.05
Age	-.06	-	-
Intellectual abilities	-	.13	.11

**Figure 30.** Predictors of Quality of Life Reported by Self-Respondents

The next strongest predictor quality of life was the DDA region in which the person lived. Those living in the Western region reported higher quality of life in personal development ( $\beta = .09$ ) and self-determination ( $\beta = .08$ ) than did self-respondents living in the other DDA regions. They also reported higher quality of life in the five domains not shown in the table. Rights was the only domain that showed no regional variability—it was equally low in all parts of the state. The multiple regression shows the magnitude of the higher quality of life in Western Maryland independent of other factors, including supported employment. However, since fewer people in the Western than the Central region had supported employment, the overall regional difference in quality of life was not quite as great as indicated by the multiple regression coefficients. Self-respondents in the Southern DDA region reported higher quality of life in five domains than did self-respondents in the Central and Eastern Shore DDA regions, but not quite as high as in the Western region. Those in the Southern region reported the same quality of life in the domains of social inclusion and self-determination as those in the Central and Eastern Shore regions, and, as mentioned above, the same level of rights as self-respondents in all the other regions. People in the Eastern Shore had higher quality of life than those in the Central region only in the domain of material well-being.

Objective aspects of transportation predict quality of life in different ways. The more frequently a different agency provided transportation, the lower their quality of life in the domains of personal development, self-determination, rights and emotional well-being.<sup>8</sup> However, only 21% of the self-respondents received services from more than one agency, and only one-fourth of these second agencies provided them transportation to weekday activities. Thus, while receiving services from two or more agencies did not directly affect the quality of life people reported, it affected their quality of life indirectly through the issue of who provided transportation to weekday activities. Since this analysis assumed that other agencies provided no weekday transportation when staff at the sample agency recorded nothing, the observed negative relation between other agency transportation and quality of life might reflect quality of life being lower when one agency did not know what another agency was doing. Agencies should be concerned about a person's quality of life, not just in providing services for which they are reimbursed. It was also found that the more frequently family or friends provided transportation, the greater rights people reported.

A few other characteristics of consumers relate to the quality of life they report. Older self-respondents reported less personal development than did younger self-respondents, but age had no relationship to any of the other domains. The classification that staff provided on the intellectual abilities of self-respondents offered some prediction of the level of self-determination, physical and material well-being. People with cerebral palsy reported higher interpersonal relations than did other self-respondents, and those with other neurological impairments reported lower levels of social inclusion. The quality of life self-respondents reported had no relation to gender, autism, behavior problems, blindness and vision impairments,

---

<sup>8</sup>Transportation was coded as none (0), one to four round trips per week (1) or five or more round trips per week (2). This measure was not available for people interviewed in FY2002 when transportation was collected with less detail.

deafness and hearing impairments, epilepsy and seizure disorders, head injury, mental disorders, orthopedic impairments, specific learning disabilities, and speech and language impairments.

Several characteristics about provider size and the type of services authorized by DDA were tested in addition to supported employment. Only one helped predict quality of life, and only in a single domain. Self-respondents at larger agencies reported greater material well-being than did self-respondents at smaller agencies. The number of agencies providing services and the DDA-authorization for residential support services, community assisted living arrangements, day habilitation services, individual support services and resource coordination services had no relation to the quality of life in any of the eight domains.

### People with Proxy Reporting

Proxy reports on quality of life differed from self-reports not only on the magnitude of scores, but also on what relates to those scores. Proxies, like self-respondents, reported increasing levels of physical well-being, interpersonal relations, and social inclusion during the four-year cycle. (See **Figure 31** and **Appendix Table 7**.) However proxies did not report increases in self-determination during the period that self-respondents reported, and proxies reported increases in emotional well-being and material well-being during the four-year period that self-respondents did not report. While self-respondents with employment support reported higher quality of life in all eight domains than self-

respondents without employment support, proxies saw employment support related to quality of life only in four domains: rights, personal development, social inclusion and emotional well-being. Proxies thought residential support services increased the personal development and rights of people who could not respond for themselves, while self-respondents saw no relationship between residential support and quality of life. Proxies for people in the Western region, like self-

respondents, reported higher levels of self-determination than did proxies in other regions of the state. Unlike self-respondents, however, proxies in the Western region also reported higher level of rights than did proxies in other regions, but reported the same quality of life in the remaining six domains. Proxies in the Southern region report higher quality of life only in the domain of material well-being, unlike self-respondents in the Southern region who reported higher quality of life in five domains.

Proxies never saw transportation provided by other than the sample agency as negatively related to quality of life like self-respondents did, and they saw transportation provided by the sample

	Personal Development	Self-Determination	Rights
Employment support	.17	-	.13
Residential support	.11	-	.10
Western region	-	.15	.17
Provider other trips	-	.09	-
Family trips	-	-	-.09
Intellectual abilities	.21	.25	.27
Hearing impairment	.09	-	-
Vision impairment	-	-.11	-
Cerebral palsy	-	-	-.09

**Figure 31.** Predictors of Quality of Life Reported by Proxies

agency to activities outside of weekday hours associated with increased self-determination and social inclusion that self-respondents did not see. Also unlike self-responders, proxies saw transportation provided by families and friends as adversely affecting rights.

Perhaps the greatest difference between proxy and self-reporting was the relationship of intellectual ability to quality of life. Proxies for people with severe retardation reported higher quality of life than proxies for people with profound retardation in five of the eight domains: rights, self-determination, personal development, interpersonal relations and material well-being. Self-respondents with higher intellectual abilities reported higher quality of life in only three domains, one of them being physical well-being which proxies did not see affected by intellectual abilities. Few other characteristics of individuals had a statistical relationship to the quality of life reported by proxies, and the only agreement between proxies and self-respondents was that older individuals had lower quality of life in interpersonal relations than did younger individuals.

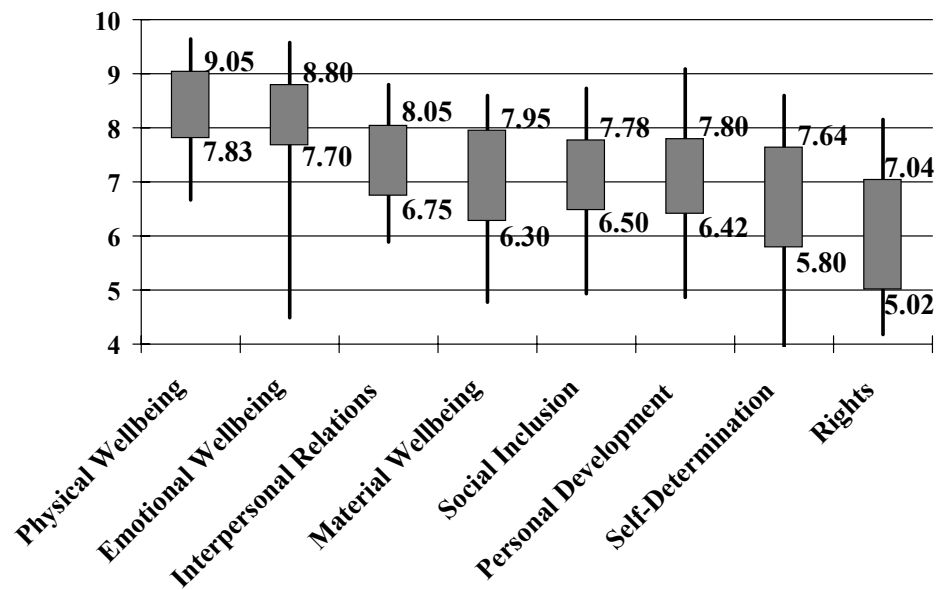
The number of people an agency supported had the opposite relation to material well-being among proxy reports than among self-reports. Proxies reported lower material well-being for people supported by larger provider agencies, while self-respondents reported higher material well-being at larger than at smaller agencies. These data cannot differentiate whether agency size affects people with profound and severe retardation differently than people greater intellectual abilities, or whether proxies (frequently agency staff) view agency size differently than supported individuals do.

## Quality of Life at Provider Agencies

The previous Ask Me! Survey report (Bonham, Basehart & Marchand, 2004) documented that the goals provider agencies wrote in their quality assurance plans affected the quality of life of the people they supported over the following one to three years. It also showed that some characteristics of provider agencies were associated with the average quality of life reported by self and proxy respondents. **Appendix D** shows the average quality of life scores in the eight domains that were reported by the people each agency supports. The average quality of life scores were statistically adjusted to the midpoint of the four-year cycle to account of the overall increase that occurred between FY2002 and FY2005 in seven of the eight domains. The detailed appendix information is summarized in this section.

### Quality of Life Variation

The average quality of life reported by their consumers varied from one provider agency to another. The average physical well-being score ranged from 6.67 to 9.64. Most (70%) of the provider agencies had scores between 7.83 and 9.05. One-fifth (20%) of the agencies had average physical well-being scores between 9.05 and 9.64. One-tenth (10%) had scores between 6.67 and



**Figure 32.** Range of Quality of Life Scores Among Provider Agencies

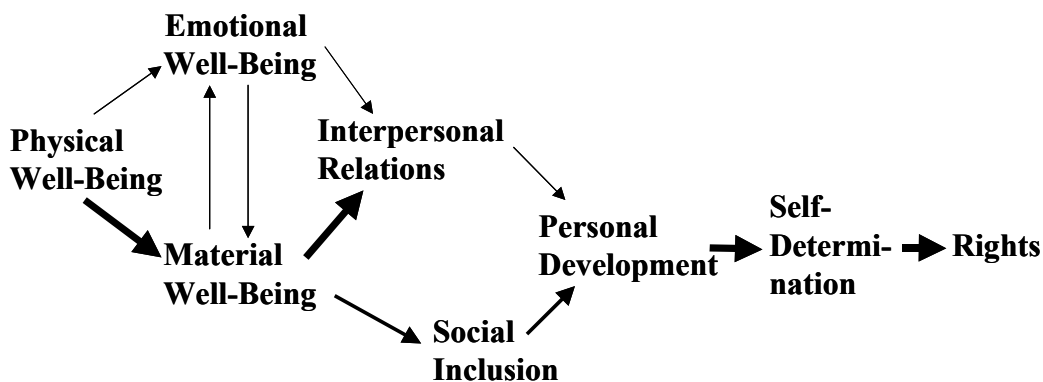
7.83. (See **Figure 32**.) In general, the 70% of community provider agencies whose average quality of life scores fell within the range shown by the solid boxes did not differ significantly from the overall Maryland average, nor from each other. The 20% of the community provider agencies that had average scores above than the solid boxes differed statistically from the 10% that had average scores below the solid boxes. The sizes of the solid boxes indicate that most provider agencies differed little in terms of the physical and emotional well-being reported by or for the people they supported. Agencies had the greatest statistical variation in rights and self-determination. Average scores in physical well-being scores and emotional well-being cannot get much higher at the agencies with the highest scores (e.g., 9.64 and 9.57 respectively), since the absolute maximum is 10.0. On the other hand, there is opportunity for substantial increase for provider agencies with the lowest scores in all domains except physical and material well-

being, as these lowest scores were below 5.0, indicating that the people supported by the provider had more negative responses to the indicator questions than positive responses.

Quality of life in the eight domains were interrelated at the provider level, just as they were at the individual level. No provider among the highest 20% on half or more of the domains placed in the lowest 10% on any domain, and only one provider among the lowest 10% on half or more of the domains placed in the highest 20% on any domain. The average quality of life scores were regressed on average characteristics of their consumers and services. The regressions identify what predicts agency quality of life in order to guide interpretation of agency scores and identify potential ways to enhance quality of life.

## Relationship of Domains

The average level of self-determination reported by people at an agency was the only domain that directly predicted the average level of reported rights ( $\beta = .84$ ). (See **Figure 33** and **Appendix Table 8**.) Since rights was the one quality of life domain not to improve during the four years, this suggests that agencies need to enhance self-determination before the average level of rights will increase. Therefore, rights was placed at the right side of the model with self-determination to its immediate left. Stepwise regression of self-determination on the other quality of life domains showed that only agency differences in personal development explained agency differences in self-determination ( $\beta = .58$ ). The average level of personal development was predicted by the average level of social inclusion ( $\beta = .42$ ) and interpersonal relations ( $\beta = .38$ ). The levels of both interpersonal relations and social inclusion were affected by the level of material well-being reported by consumers ( $\beta = .52$  and  $\beta = .41$  respectively). The level of interpersonal relations was also slightly predicted by the level of emotional well-being ( $\beta = .27$ ). The data provided no basis for hypothesizing the direction of causality between material well-being and emotional well-being, so they are shown with arrows of approximately equal magnitude going in both directions ( $\beta = .38$  from material well-being to emotional well-being and  $\beta = .32$  vice versa). The average physical well-being reported at an agency had a substantial relationship with material well-being ( $\beta = .50$ ), a moderate relationship with emotional well-being ( $\beta = .35$ ), and no direct relationship to any other quality of life domains.



**Figure 33.** Path Model of Relations Among Average Quality of Life of Provider agencies

## Understanding Agency Scores

Characteristics of community provider agencies included in this study predicted 40% to 65% of the variation among provider agencies in average score for the eight domains when transportation availability was included, and 11% to 45% when transportation availability was not included. Transportation availability was the greatest single predictor of quality of life in six domains, so anything that can enhance perceptions of transportation availability will enhance quality of life. (See **Appendix Table 8**.) However, perceived availability of transportation is not easily observable, and proxies reported transportation as much more available for people who could not respond for themselves than self-respondents saw was available to them. Proxies also saw transportation as much more available in FY2005 than in FY2002, whereas self-respondents saw no change. This is reflected at the provider level where the higher the percent of surveys that were completed by proxies, the higher the average level of transportation availability that was reported for the agency ( $\beta = -.44$ ). Transportation availability, however, will not be analyzed further since the scores were highly influenced by who reported and inclusion of transportation availability in the regressions suggested that some individual and service characteristics had statistical relationships with quality of life that were not found in any other analysis. This raised statistical concerns of multicollinearity and ecological fallacy that might confuse findings.

Provider agencies varied most in the average levels of rights and self-determination reported in the Ask Me! Survey. Agency characteristics also explained more of the variance in the average quality of life scores in these two domains (rights  $R^2 = .44$ ; self-determination  $R^2 = .46$ ) than in any of the other domains except physical well-being ( $R^2 = .47$ ). The agency characteristic that contributed most to the variation among agencies was the percent of adults who responded for themselves. The higher the level of self-response, the higher the level of reported rights ( $\beta = .48$ ) and self-determination ( $\beta = .45$ ). (See **Figure 34**.) The percent responding for themselves explained none of the variation among agencies in the other six domains.

Agencies in the Western DDA region had higher levels of rights reported than did agencies in the other three DDA regions ( $\beta = .22$ ). In addition, rights scores were higher at agencies that supported more people with head injuries and fewer people with epilepsy and seizures than at agencies with fewer people with head

	Personal Development	Self-Determination	Rights
% Supported employment	.31	-	-
Western region	.38	-	.22
% Multiple provider agencies	-	-.20	-
Ask Me! participation	.21	-	-
% Self-reporting	-	.45	.48
% Specific learning disabilities	.21	-	-
% Epilepsy, seizures	-	-.17	-.24
% Head injury	-	-	.16

**Figure 34.** Predictors of Average Quality of Life at Agencies

injuries or more people with epilepsy and seizures. The higher the percent of supported individuals with epilepsy and seizures, the lower the average score in self-determination also.

Agencies in the Western region had higher average reports of personal development than agencies in other regions, just like they had higher reports of rights. **Appendix Table 8** also shows that agencies in the Western region had higher reported levels of physical well-being, material well-being, interpersonal relations and social inclusion. Agencies in the Southern DDA region had higher reported levels of physical well-being, material well-being and interpersonal relations than agencies in the Central or Eastern Shore regions.

Independent of region, agencies who supported a greater percent of their people in employment had higher reported levels of social inclusion and personal development. Agencies with a larger percent of their people receiving support from other agencies had lower reported levels of self-determination than agencies who were the only provider of supports. Agencies with larger proportions in community supported living arrangements had slightly higher average scores on physical well-being and material well-being. Agencies that provided a higher percent of their consumers with transportation to weekday activities and had higher levels of public transportation use had higher reported levels of material well-being. The percent of the surveyed people receiving day habilitation services, individual support services, and family transportation had no relation to the agency's average quality of life score in any domain. Agency size had no relation to average reported quality of life, except that the largest agencies (who contribute most to the Maryland average) were likely to have quality of life scores about the Maryland average.

Agencies that had high participation in the Ask Me! Survey also had high reported levels of personal development, social inclusion and emotional well-being. High participation reflected that agency staff knew the people that DDA files showed had been authorized to support by the agency, that agency staff was able to get their consumers to agree to participation in the survey, that agency staff helped individuals to be present at the scheduled interview times, and that proxies were available for interviews when individuals could not respond for themselves.

In addition to those already mentioned, a few characteristics of the people supported affected one or two domains. The greater the percent with specific learning disabilities, the higher the levels of personal development and physical well-being. Agencies with a high percent of deaf and hearing-impaired individuals had low scores on interpersonal relations. Agencies with higher levels of intellectual abilities and high proportions with cerebral palsy had high reported levels of physical well-being. Agencies with high levels of mental disorders had low reported levels of emotional well-being. The percent with autism, behavior problems, blind and vision impairments, other neurological impairments, orthopedic impairments, and speech and language impairments had no effect on the average quality of life in any domain. Additionally, the average age and the gender ratio had no effect on average quality of life scores.

## Discussion

### Quality of Data

The Ask Me! Project collects important information from people with developmental disabilities that accurately reflects their quality of life in a consistent way across all community provider agencies. Ask Me! is people centered. It collects information on quality of life directly from the people receiving support when possible. It employs people who receive support as interviewers, which increases the probability that people can and will respond to the survey for themselves. It asks questions that people receiving support say are important to them, and it involves people receiving support in discussions and presentations of the findings. Its procedures allow everyone with the ability to consent to answer for themselves, even when deaf, nonverbal or with profound retardation. The procedures guarantee privacy and confidentiality in relaxed settings, and minimizes the error or bias that might creep in at each step of data collection. The procedures ensure that all people respond to the same questions, and this allows information to be compared across groups, provider agencies and time. The analysis can focus on people or on provider agencies to predict what contributes to quality of life, while controlling for differences among people and provider agencies.

Most people with disabilities respond for themselves and provide just as consistent responses to questions as do family or staff proxies, regardless of their level of intellectual abilities. Self-response is desired whenever possible, as proxies respond differently to many of the questions. Some of this difference may be due to differences between people who can and who cannot respond for themselves, but some of the difference must be due to proxies not knowing what the person truly feels, since two proxies for the same person frequently disagree. Analysis of proxy reporting indicates that the relationship of the proxy to the person influences the proxy's answers. Family and residential staff almost never indicate a person is hit or hurt at home, while day staff and self-responders are more likely to say this happens. Family proxies seldom say it is easy to say something when they have a gripe against staff, but most staff say it is easy. On the other hand, most family members think the individuals receive the training they need to get jobs while a minority of staff think the training is adequate. Proxies agree most in answers to objective questions, like those related to physical well-being or voting. They disagree most on subjective questions related to the individual's sense of self-determination and choice. There is every reason to believe that proxies give the best answers they can, and many will not answer a question because they really do not know. It is always difficult to know what another person thinks, and even more so when that other person has very limited ability to understand and communicate. Although the Ask Me! Survey makes every effort to get people to respond for themselves, it believes information from proxies is better than leaving that person unrepresented in information that is designed to enhance the system of support that affect him or her.

Analysis has shown that people with disabilities show no inclination to respond negatively to questions about their quality of life (nay-saying) or to select the last response read by the interviewer (recency effect). The data collected to date cannot rule out the possibility that people are giving more positive answers than they should, either because they think they are

supposed to give positive answers (acquiescence), or they are selecting the first answer category they hear (order bias). However, the Ask Me! procedures included many of the recommendations Finlay and Lyons (2002) recommend to reduce acquiescence. All of the Ask Me! methodological studies to date suggested that the data are valid and reliable, and it is unlikely that other methodological studies would change this overall assessment since any remaining bias is likely to be constant across provider agencies and over time. The value of Ask Me! is in its usefulness for enhancing support based upon the values and perceptions of the people receiving support.

## **Individual 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 FY2001 and FY2005 in seven of the eight domains. However, no statistical change in rights occurred during that time, and the changes in self-determination and personal development were smaller than in the remaining five domains. The change in rights and self-determination were not consistent from year to year overall, but did show a small steady increase for self-respondents.

The Ask Me! findings support a model that assumes the foundational nature of physical well-being, with increases in physical well-being leading to large direct increases in emotional and material well-being, and possibly leading to small direct increases in other quality of life domains. Increases in emotional well-being has large direct effects on interpersonal relations, moderate direct effect on social inclusion, a possible small direct effect on personal development, but no direct effect on rights. Material well-being directly affects interpersonal relations, social inclusion, personal development and self-determination. It may have some direct affect on rights. High levels of interpersonal relations directly increases social inclusion, personal development and self-determination. Interpersonal relations, however, had no effect on rights (self-respondents) or interfered with rights (proxy respondents). Both self and proxy respondents showed that social inclusion led to personal development and self-determination, but had no direct impact on rights.

Much attention of the support delivery system in the past has focused on the foundational domain of physical well-being of people. This attention is reflected by 93% of Maryland adults having a positive quality of life in this domain that continuously increase between FY2002 and FY2005, and had an average score approaching 9 on a 10-point scale. The potential for future increases in physical well-being, therefore, is limited by the maximum possible scores. However, some caution is appropriate when viewing these high reports of physical well-being, since the highest scores are reported by proxies for people who cannot answer for themselves. Almost all of those who cannot answer for themselves have profound and severe retardation, and it does not seem reasonable that these adults are much more healthy than adults with moderate, mild or borderline retardation. It is more reasonable to assume that proxies have a different perspective on physical well-being than do people who can respond for themselves. All six questions that self-advocates developed as indicators of physical well-being cluster together with reasonable scale reliability among self-respondents, but do not cluster and have low scale

reliability among proxies. Good eating habits is the most representative question in this domain among self-respondents, while overall physical health is the most representative question among proxies. Additionally, self-respondents and day staff are more likely to report being hit or hurt by others in their home than family and residential staff proxies report, suggesting a self-interest bias is likely.

Physical well-being cannot be ignored, since it is foundational to a life of quality. However, the focus of support system, whether at DDA or provider agencies, should now be on enhancing the quality of life in the domains with substantially less positive reporting and which have changed least during FY2002 through FY2005. In particular, a focus should be on rights. Although the data hint some progress has been made in this domain among self-respondents, the change has not been statistically significant, the average level of rights varies widely among agencies, and adults supported by one in ten provider agencies reported negative rights on average. Since only two-thirds of adults provide positive reports in the domain of rights, this domain has the most potential for enhancing people's overall quality of life. Further, the Ask Me! report for FY2004 showed that the average quality of life increased in the following years for three of the eight domains among agencies that including rights in their quality assurance plans. Focus on self-determination and personal development have the next most potential for enhancing overall quality of life, both directly and as they affect rights. Agency quality assurance goals of self-determination and personal development significantly enhanced quality of life over the following two years in two domains each. While rights is not expressly included in the mission of DDA, rights are highly related to self-determination and personal development that are expressed in the mission statement.

The third mission of DDA, social inclusion, has no direct impact on rights, and is a domain where significant progress in quality of life occurred between FY2002 and FY2004. Improvement can still be made in social inclusion, just as in interpersonal well-being and material well-being. While these three domains are intermediate between physical well-being and emotional well being and affect personal development and self-determination, enhancing them is unlikely to directly enhance rights.

The availability of transportation is highly related to people's quality of life in all eight domains, whether reported by the individuals themselves or their proxies. Transportation availability, like most quality of life domains, however, is a subjective interpretation of objective realities. Only proxies think that transportation availability has any relation to the frequency with which transportation is provided by an agency. Neither self-respondents or proxies indicates that transportation availability is affected by the transportation provided by families or by public transportation systems. Proxies reported an increase between FY2002 and FY2005 in transportation availability that self-respondents did not report. The things proxies thought affected the availability of transportation were totally different from the things self-respondents thought affected transportation availability. The availability of transportation and supported employment are related in the eyes of people who can report for themselves, probably because employment assumes, or is contingent upon, a person being able to get to the job site. Self-respondents, but not proxies, report transportation is more available in the Western DDA region than in other parts of Maryland. The Ask Me! data provide no information on why this is the

case, and discovering that reason might be valuable for enhancing people's quality of life. Of course it may be that people in the Western region are just more optimistic than people in the other parts of Maryland, in that they report higher quality of life in seven of the eight domains.

## **Quality of Life at Agencies**

Just as quality of life varied among people, the average quality of life varied among provider agencies. The variation was greatest in the domains of rights and self-determination and least in the domain of physical well-being. The average reported quality of life in the domains of physical well-being and interpersonal relations was positive at all the 116 agencies in Maryland that provided support in the community to ten or more people. However, about one in ten of the agencies had reports on rights that were negative.

Some of the differences among provider agencies in four of the quality of life domains can be explained by the intellectual abilities of the people they support: higher self-determination and rights with percents of consumers who can respond for themselves, greater physical well-being among adults with the greatest degree of retardation, and higher physical well-being and personal development when more of their consumers have specific learning disabilities in contrast with other developmental disabilities. Agencies with a high percent of people with epilepsy and seizure disorders had lower quality of life reported in two domains: self-determination and rights. Other characteristics of consumers had either no affect on the average quality of life reported, or affected the average score in only one domain.

The average quality of life reported for agencies in the Western DDA region was higher in six of the eight domains than that reported in the Central and Eastern Shore regions. It was also higher in the Southern region in three domains. The Ask Me! survey provides no information on how much of the regional differences may be due to characteristic of the supported people that are unrelated to their disabilities, characteristic of the agencies in the regions, or characteristics of the larger communities in the two regions.

Agencies with a greater percent of their people in supported employment, in community supported living, using their weekday transportation, and using public transportation have higher reported quality of life in some domains. At the individual level, only supported employment is related to quality of life. This suggests that providers who focus on community supported living arrangements, providing weekday transportation to employment or day programs, and helping people use public transportation are enhancing quality of life that is broader than the specific support.

The average quality of life in four domains was low at agencies with low levels of response to the Ask Me! Survey. Agencies not supporting many of the people DDA had assigned to them, agencies that did a poor job of convincing people of the importance of the Ask Me! Survey, and agencies that did a poor job of helping people get to the interview site had low levels of emotional well-being, material well-being, social inclusion and personal development than agencies that helped a large percent of their consumers to be willing to respond and had high proxy response for those who were judged by interviews to be unable to respond for themselves.

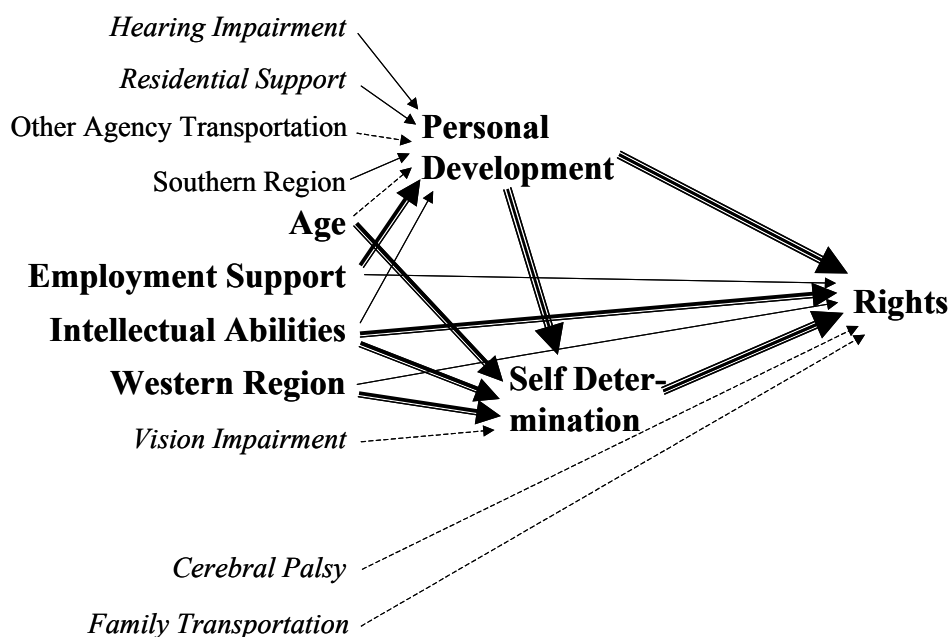
Many questions could be raised about why this relationship exists that the Ask Me! Survey cannot answer. Hopefully, agencies with low response rates will ask themselves these questions and be able to tell about the steps they are taking when others ask them questions..

## Enhancing Quality of Life

Provider goals make a difference. Many provider agencies had goals in their QA plans to improve physical well-being. These increased quality of life in the past, but have limited potential for future increases since people already report high levels of physical well-being. High physical well-being needs to be maintained, but more focus should be placed on other domains. The few provider agencies that set goals of self-determination and rights saw quality of life significantly increase in several domains. The relatively low levels of quality of life in these two domains, and the low amount of much change between FY2002 and FY2005, suggests that substantial improvements can occur in these two domains. Provider goals of personal development also had positive effects on increasing the quality of life and should be a third area for focus.

Rights is the quality of life domain most in need of enhancement. At both the individual level and the agency level, rights, self-determination and personal development are highly related, and high levels of one are

associated with high levels on the others. A model was developed on how to enhance rights by fitting it to both self- and proxy-reported data. (See **Figure 35.**) (The multi-lined arrows and large bold type show joint agreement; single-line arrows and regular type reflects self-responders; single line arrow and italics reflects proxy reporting; and dashed arrows indicate a negative relationship.)



**Figure 35.** Self and Proxy Agreement on What Affects Rights

The model shows that the best way to enhance rights is to enhance self-determination and personal development, and the best way to enhance self-determination is to enhance personal development. Both self and proxy responders indicated that increasing supported employment would be the primary way of increasing personal development, and self-responders said this also would increase the perception of rights directly. Enhancement efforts might focus on younger adults, as older adults are already at a higher level of self-determination and less likely to increase their level of

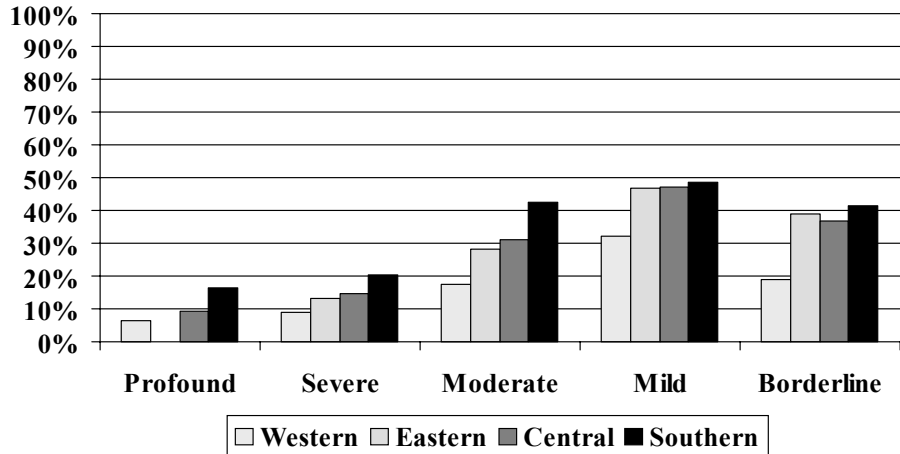
personal development. Intellectual abilities will have some effect on the level of rights and self-determination that can be achieved, but only proxies think intellectual ability has an impact on personal development. Both agree that receiving support in Western Maryland is associated with self-determination, and self-respondents indicate that it may have some direct effect on rights as well. Self-responders also indicate that receiving support in Southern Maryland is associated with higher personal development. Agencies should consider transportation, as self-respondents report lower personal development when another agency is relied upon to provide them transportation. Proxies did not see this relationship, but did think that family provision of transportation interfered with enhancing rights. Proxies thought that rights will be hindered by cerebral palsy and that self-determination will be limited by vision impairments. Proxies also thought that people with hearing impairments had the greatest potential for personal development, and that residential support contributed to personal development.

Each of the Ask Me! quality of life domains is measured by responses to six indicator questions. Part of the reason no overall change occurred between FY2002 and FY2005 in the domain of rights is that not all responses changed in the same direction. The most representative question of the six, talking on the telephone in private, changed little. While an increasing percent of people each year reported that staff requested permission before entering their rooms, a decreasing percent of people said they could lock the bathroom door if they wanted. Locking the bathroom door was the only quality of life question in the survey that progressively received more negative responses each year the survey was administered. An argument has been made that it is not safe to allow some people to lock the bathroom door, but what is the argument that people with mild retardation who can respond for themselves should be less likely to be able to lock their bathroom doors in FY2005 than they were in FY2002? Not being able to lock the bathroom door has an even greater impact for half of the adults who had little or no choice in the choice of housemates. Those who had the least choice in choosing with whom they lived also had the least opportunity to lock the bathroom door.

Self-responses showed that supported employment increased the quality of life in all eight domains, and proxy reports showed that it increased the quality of life in half of the domains. However, only half of the adults said they were getting the training they needed to get a job or a better job, and the proportion was lower in FY2005 than in FY2002. While as many as three-fourths of people with mild retardation who had support employment said they were getting training that would help them get a better job, as few as one-seventh of the people with profound retardation without supported employment said they received training to get a job. While it might be argued that most people with profound retardation could not be employed with support, since only 9% were employed at the time of interview, it is much more difficult to argue that 53% of adults with mild retardation could not be employed if they had support. Employment, of course, is affected by the available jobs in the community, not just by individual abilities and agency services. The Southern DDA region had a greater percent of people of all ability levels in supported employment than any other region, and the Western DDA region had a lower

percent. (See **Figure 36.**)

The Ask Me! Survey provides substantial information about the quality of life of people with developmental disabilities in Maryland. People supported by all community provider agencies supporting ten or more people were interviewed during the four years of FY2002 through FY2005. All providers have received



**Figure 36.** Percent with Supported Employment, by Region and Level of Retardation

the data provided by the people they support, along with an *Ask Me! Unleashed!* toolkit to help them convey key pieces of information to their staff, boards and prospective consumers and their families. This report analyzes the data for Maryland as a whole and provides information and recommendations on how agencies can use the information to enhance the quality of life of the people they support. The Ask Me! results also provide information to help DDA and provider agencies to work together for change in the larger system level to increase the probability that continued improvements can be made in people’s quality of life. This report now makes available the average quality of life, in the eight domains, that was reported by adults supported by each agency in Maryland. This provides addition information to consumers and their families as they seek the most appropriate supports. The Ask Me! Survey begins a new four-year cycle in FY2006, during which interviews will again be conducted at all agencies.

## References

- Basehart, S., Marchand, C., and Bonham, G. S. (2002.) A survey of quality of life designed by and for people with developmental disabilities. In Bradley, V. And Kimmich, M. (Eds.), *Developmental Disabilities: Challenges and Opportunities in a Changing World*. Baltimore, MD: Paul H. Brookes Publishing Co., Inc.
- Bonham, G. S., Basehart, S., and Marchand, C. B.(2000.) *Ask Me!<sup>sm</sup> Year FY2000: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., and Marchand, C. B.(2001.) *Ask Me!<sup>sm</sup> Year FY2001: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (November).
- Bonham, G. S., Basehart, S., and Marchand, C. B. (2002.) *Ask Me!<sup>sm</sup> Year FY2002: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (November).
- Bonham, G. S., Basehart, S., and Marchand, C. B. (2003.) *Ask Me!<sup>sm</sup> Year FY2003: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., and Marchand, C. B. (2004.) *Ask Me!<sup>sm</sup> Year FY2004: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (December).
- Bonham, G. S., Basehart, S., Schalock, R. L., Marchand, C. B., Kirchner, N., and Rumenap, J. M. (2004.) Consumer based quality of life assessment: the Maryland Ask Me! Project, *Mental Retardation*, 42(5):338-355.
- Bonham, G. S., Pisa, L. M., Basehart, S., Marchand, C. B., Harris, C., Heim, S and Ingram, A.. (1999.) *Ask Me!<sup>sm</sup> Year 2: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (November).
- Bonham, G. S., Pisa, L. M., Marchand, C. B., Harris, C., White, D. and Schalock, R. L. (1998.) *Ask Me!<sup>sm</sup> The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Services*. Annapolis, MD: The Arc of Maryland (February).
- Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation*, 25, 183-207.

- Dudley, J. R. (2001). When staff and consumers disagree about consumer satisfaction. *The NADD Bulletin*, 4,(6), 103-106.
- Gardner, J. F. (Ed.). (2000). Wingspread conference proceedings. Baltimore: National Center on Outcomes Resources.
- Gaudet, L., Pulos, S., Crethar, H., & Burger, S. (2002). Psychosocial concerns of adults with developmental disabilities: perspectives of the self, family member, and provider [Abstract]. *Education and Training in Mental Retardation and Developmental Disabilities*, 37. Retrieved March 15, 2005 from the World Wide Web: <http://www.addcec.org/etmrddv/TOC/etmrddv37n1.html>
- Gettings, R. M. (2001). Building a comprehensive quality management program for public developmental disabilities service systems: Organizing principles and primary operating components. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
- Hughes, C. and Hwang, B. (1996.) Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of Life. Volume 1: Conceptualization and Measurement* (pp. 51-63). Washington, DC: American Association on Mental Retardation.
- 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. <http://www.addcec.org/etmrddv/TOC/etmrddv37n1.html>.
- Lunsky, Y., & Benson, B. A. (1997). Reliability of ratings of consumers with mental retardation and their staff on multiple measures of social support. *American Journal on Mental Retardation*, 102, 280-284.
- Maryland State Data Center. (2002.) Population by age and sex (P12/P13), *Census 2000, Summary File 1*, [http://www.op.state.md.us/MSDC/census/cen2000/sf1/state/md\\_sf1.pdf](http://www.op.state.md.us/MSDC/census/cen2000/sf1/state/md_sf1.pdf) (9/19/02).
- Parsons, J. A., Baum, S., & Johnson, T. P. (2000). Inclusion of disabled populations in social surveys: review and recommendations. Chicago, IL: Survey Research Laboratory, University of Illinois at Chicago for The National Center for Health Statistics.
- Pennell, R. L. (2001). Self-determination and self-advocacy: Shifting the power. *Journal of Disability Policy Studies*, 11, 259-269.
- Perry, J., & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias and resident:proxy concordance. *Mental Retardation*, 40, 445-456.
- People on the Go. (1996.) *Signs of Quality*. Annapolis, MD: The Arc of Maryland.

- Schalock, R. L. (2001). *Outcome-based evaluation (2nd ed.)*. New York: Kluwer Academic/Plenum Publishers.
- Schalock, R. L. and Bonham, G. S. (2003). Measuring outcomes and managing for results, *Evaluation and Program Planning*, 26, 229-235.
- Schalock, R. L., Bonham, G. S. And Marchand, C. B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction, *Evaluation and Program Planning*, 23, 77-87.
- Schalock, R. L. and Keith, K. D. (1993.) *Quality of Life Questionnaire Manual*. Hastings, NE: IDS Publishing Corporation.
- Schalock, R. L. and Verdugo, M. A.. (2002.) *Handbook on Quality of Life for Human Support Practitioners*. Washington, DC: American Association on Mental Retardation.
- Stancliffe, R. J. (2000). Proxy respondents and quality of life. *Evaluation and Program Planning*, 23, 89-93.
- Whitney-Thomas, J. (1997). Participatory action research as an approach to enhancing quality of life for individuals with disabilities. In R. L. Schalock (Ed.), *Quality of life: Volume II: Application to persons with disabilities* (pp. 181-198). Washington, DC: American Association on Mental Retardation.

## **Appendix**

Appendix A. Sampling Procedures

Appendix B. Data Processing

Appendix C. Analysis Methods

Appendix D. Quality of Life at Maryland Provider Agencies

[PAGE INTENTIONALLY BLANK]

## Appendix A. Sampling Procedures

The Maryland Developmental Disabilities Administration supported 24,960 person-provider combinations in July 2001.<sup>9</sup> The number increased to 25,130 in July 2004. (See **Appendix Table 2.**) The number of agency designations on the DDA files declined from 171 in 2001 to 151 in 2002, primarily as a result of DDA developing and assigning new agency ID's that grouped different regional locations of one agency under a single ID. These designations, however, still included a few multiple components of the same agency. The files also included records for service coordination, services received from state institutions, and services received from agencies or organizational entities serving fewer than ten people that were excluded in the sample frame. DDA received quality assurance plans from 110 community-based provider agencies in 2000-2003. Although the number of person-provider records changed little between July 2001 and July 2004, the number of people with some form of DDA support increased by 803. About two-fifths of the people had a single provider record, and about one-third had two provider records. Six was the maximum number of provider agencies that any person had.

	DDA File				Sample Frame*			
	07/01	07/02	07/03	07/04	07/01	07/02	07/03	07/04
# of Provider IDs	171	151	147	149	136	142	134	138
# of Person-Provider Records	24,960	24,557	24,795	25,130	13,225	13,519	13,880	14,151
# of Persons Supported	12,469	12,568	12,971	13,272	11,539	10,908	11,226	11,377
Support by 1 provider	4,721	5,002	5,389	7,008	8,739	8,363	8,635	8,661
Support by 2 provider agencies	3,881	3,897	3,955	4,426	2,747	2,484	2,531	2,661
Support by 3 provider agencies	3,122	3,033	3,100	1,794	51	56	57	52
Support by 4 provider agencies	620	523	446	42	2	5	3	3
Support by 5 provider agencies	119	108	74	2	0	0	0	0
Support by 6 provider agencies	6	5	7	0	0	0	0	0

\* *Sample frame excludes records for children, institutional services and support coordination*

### Sample Frame

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

---

<sup>9</sup>Excel files transmitted by DDA to Bonham Research in July of each year contained records for each person-provider-service authorized by DDA. Thus a person receiving employment and CSLA supports from one agency, individual support services from another agency, and resource coordination from a third agency had four records in the file.

over at the start of the fiscal year (July 1). The sample selection procedures in FY2003 and FY2004 inadvertently missed about 44 people without a date of birth on the DDA files. The exclusion of these people had negligible effect for large provider agencies, and field staff included those without birth dates at two small provider agencies in FY2004.

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

The third step in developing the sample frame involved assigning a single identification number to a provider with multiple DDA identification numbers. The July 2002 DDA file made this task easier since the DDA had already made many of these combinations. Ask Me! had mistakenly combined UCP of Central Maryland and UCP of Western Maryland in FY2002, but separated them for subsequent years. In order to allow easy comparison from year to year, one of the DDA three-digit ID numbers assigned to a provider on the July 2001 files became the unchanging Ask Me! Provider ID. The July 2002 and later DDA files had provider agencies that did not appear on the July 2001 file, and the project assigned them two-digit numbers beginning with 051. Since ID numbers between 500-599 did not appear in the July 2001 DDA file, those numbers were reserved for special Ask Me! projects.

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

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

The final sample frame for FY2005 developed from the July 2004 DDA files contained 14,151 person-provider records involving 11,377 people and 138 community provider agencies. The primary sampling unit was the provider. The secondary sampling unit was the person within the provider. The identification numbers for the agencies providing employment or day support, residential support, other types of supports, and resource coordination were attached to the 1-4 records for each person to provide assistance in locating them irrespective of the provider through which they were selected. The number of different community provider agencies that supported a person was included on each person-provider record for subsequent use in calculating weights. Three-fourths of the people received support from a single provider and had

a single chance of being selected for the sample. Most of the rest received support from two provider agencies and had a double chance of being selected for the sample. A few had three or four provider agencies and three or four chances of being selected for the sample.

## **Provider Sample**

The final sample frames during the four-year cycle of interviews identified 151 provider agencies that provided support services in the community. These constituted the primary sampling units for the Ask Me! Survey. The number of person records in the sample frame associated with each provider was counted, and provider agencies were divided into five strata based on the total number of people the provider supported as of July 2001 . (See **Appendix Table 3.**) Stratum 1 included the 10 largest provider agencies supporting 300 or more people in each of the four years. They provide support to 4,770 of the 11,226 people (42%) in July 2003, the midpoint of the study. The only major change that occurred in this stratum was the inadvertent combining of UCP of Southern Maryland with UCP of Central Maryland in FY2002. Stratum 1 provider agencies were included in all four survey years.

Stratum 2 generally included provider agencies serving 130-299 people in July 2001, providing support to 4,082 (27%) people in July 2003. Stratum 2 provider agencies were included in the survey every other year. In July 2001, 21 provider agencies were assigned to Stratum 2. A large number of names listed for The Arc of Frederick County, however, turned out to be children, leaving the number of adults supported by the agency less than the threshold for Stratum 2. Therefore the agency was moved from Stratum 2 to Stratum 3 during sample selection in subsequent years and not selected for interviews again during the remaining three years. UCP of Southern Maryland was added to Stratum 2 in July 2002 when it was separated from UCP of Central Maryland (which remained in Stratum 1). The Arc of Carroll County grew above the threshold between Stratum 2 and 3 by July 2002. Since it had been sampled as a Stratum 3 provider for interview in FY2002, it was moved from Stratum 3 to Stratum 2 in FY2004. These changes resulted in 22 provider agencies in Stratum 2 with 11 selected for interview in even number fiscal years and 11 provider agencies selected for interviews in odd number fiscal years.

Stratum 3 included 40 provider agencies supporting 55 to 129 people in July 2001, and were included in the sample once every four years. They provided support to 3,472 adults (31%) in July 2003. The size of two provider agencies increased sufficiently between 2001 and 2002 to potentially move into Stratum 3 from Stratum 4, and the size of six additional provider agencies increased sufficiently between 2002 and 2003 to potentially move them into Stratum 3. Three provider agencies decreased in numbers between 2001 and 2002 to potentially drop them from Stratum 3, although one increased between 2002 and 2003 to justify keeping it in Stratum 3.

One

**Appendix Table 3. Maryland Provider Agencies by Number of People Supported and Year Included in the Sample**

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
<b>Stratum 1 (300+ People, Interviews Every Year)</b>									
109 ARC OF BALTIMORE	1,176	1,123	1,102	1,050	98-01	x	x	x	x
112 CHIMES INC (includes 350)	645	633	649	655	98-01	x	x	x	x
132 UCP CENTRAL MARYLAND (or 615, 810)	549*	297	309	300	00-01	x	x	x	x
811 ARC OF WASHINGTON CO	508	432	412	408		x	x	x	x
314 ARC OF PRINCE GEORGES CO	430	386	402	428		x	x	x	x
128 PROVIDENCE CENTER	406	407	405	414		x	x	x	x
311 MELWOOD HORTICULTURAL (or 310)	400	388	386	390	99-01	x	x	x	x
312 ARC OF MONTGOMERY COUNTY	348	344	368	385	98-01	x	x	x	x
104 ATHELAS INSTITUTE	340	350	353	381	00-01	x	x	x	x
303 CHI	339	349	384	398		x	x	x	x
Subtotal	5,141	4,599	4,770	4,809		10	10	10	10
<b>Stratum 2 (130-299 People, Interviews Every Second Year)</b>									
107 ACCFX GALLAGHER	283	288	295	301		x		x	
121 EMERGE	229	231	232	235	99-01	x		x	
135 ARC OF HOWARD COUNTY (or 113)	225	216	223	213	00-01		x		x
105 OPPORTUNITY BUILDERS	199	196	213	218	01	x		x	
301 ARDMORE ENTERPRISES	198	188	190	193		x		x	
156 ARC OF ANNE ARUNDEL COUNTY	197	178	169	169	00-01		x		x
614 DOVE POINTE, INC (includes 609)	187	183	184	183		x		x	
919 ALLIANCE	186	186	217	199		x		x	
328 REHABILITATION OPPORTUNITIES	184	192	197	205		x		x	
355 ABILITIES NETWORK (or 116)	181	187	232	261	98-01	x		x	
933 UCP OF SOUTHERN MARYLAND	*	187	186	190	*		x		x
302 ARC OF SOUTHERN MARYLAND	175	165	170	160	99-01		x		x
915 HUMANIM	170	184	200	219			x		x
158 CENTER FOR PROGRESSIVE LRNG (or 343)	167	161	150	137			x		x
108 BELLO MACHRE	162	170	178	181			x		x
124 ARC OF NORTHERN CHESAPEAKE	161	168	186	188	98-01	x		x	
827 CHANGE, INC	158	137	147	147			x		x
319 VOCATIONAL SERVICES INC	156	157	151	146			x		x
318 CENTER FOR LIFE ENRICHMENT	135	134	159	171			x		x
316 SPRING DELL CENTER	134	131	132	126		x		x	
806 FRIENDS AWARE, INC	134	135	132	132	99-01		x		x
824 ARC CARROLL COUNTY	111	119	139	148	98-01	x		x	
Subtotal	3,732	3,893	4,082	4,122		11	11	11	11
<b>Stratum 3 (55-129 People, Interviews Every Fourth Year)</b>									
805 ARC OF FREDERICK COUNTY (or 169)	134	81	81	82		x			
325 SOUTHERN MD VOCATIONAL INDUST	124	128	113	133	99-01		x		
320 MED SOURCE COMMUNITY SERVICES (or 817)	116	118	119	123				x	
335 SEEC	113	112	105	105	98-01	x			
149 CREATIVE OPTIONS	111	101	103	100					x
807 HORIZON GOODWILL INDUSTRIES	107	94	93	96	01	x			
142 NCIA/CBAI	106	102	111	121			x		
306 CSAAC	106	111	117	114		x			
812 WASHINGTON CO HDC	106	87	98	95				x	
106 LANGTON GREEN	105	106	105	105	00-01				x
125 PENN MAR	104	107	112	113	01	x			
611 BAYSIDE COMMUNITY NETWORK, INC	103	105	116	120		x			
610 WORCESTER CO DEVELOPMENTAL CENTER	100	97	94	93	01	x			
322 LT JOSEPH P KENNEDY INSTITUTE	99	99	90	108			x		
164 SPECTRUM SUPPORT (or 819 was R & D Instr)	98	79	81	107				x	

**Appendix Table 3. Maryland Provider Agencies by Number of People Supported and Year Included in the Sample**

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
608 SOMERSET COMMUNITY SERVICES INC	97	93	98	96	99-01				x
804 SCOTT KEY CENTER	97	99	108	104	99-01		x		
801 APPALACHIAN PARENT ASSN	90	90	90	84	99-01			x	
802 COMMUNITY LIVING INC	89	86	86	84	01	x			
830 TARGET, INC (or 341)	89	96	97	104					x
602 CAROLINE CENTER	86	90	94	94	98-01	x			
606 DELMARVA COMMUNITY SERVICES	86	89	90	91	00-01		x		
308 JEWISH FD FOR GROUP HOMES	81	82	85	86				x	
324 FAMILY SERVICES FD INC (or 160)	80	77	87	82					x
120 LIFE	79	80	78	75			x		
136 WORKFIRST	78	83	107	111				x	
309 JUBILEE ASSOCIATION OF MD	78	74	81	83	98-01	x			
126 PROGRESS UNLIMITED	76	77	78	77					x
129 RICHCROFT	76	80	101	104	99-01		x		
912 CSSD	70	65	64	56	01	x			
616 CHESAPEAKE CARE RESOURCES	69	64	61	61				x	
315 ROCK CREEK FOUNDATION	68	69	61	64					x
140 INTERVALS (or 346, became part of 112)	67	67	66	63			x	--	--
809 RAY OF HOPE, INC	63	56	56	54	99-01			x	
951 LOWER SHORE ENTERPRISES	63	75	82	89					x
334 JEWISH SOCIAL SERVICES AGENCY	62	38	41	45			x		
338 CHARLES CO HEALTH DEPT	61	36	46	43				x	
123 NATIONAL MS	58	57	53	48					x
119 JEWISH FAMILY SERVICES	57	59	61	57			x		
352 COMMUNITY SUPPORT SERVICES	57	53	63	66				x	
Subtotal	3,509	3,362	3,472	3,540		11	10	10	9
<b>Stratum 4 (10-54 People, Randomly Sampled in FY2002 and FY2003, Remaining Interviewed in FY2004-FY2005)</b>									
815 JEANNE BUSSARD CENTER	52	45	57	62				x	
351 CALMRA, INC	51	48	50	49					x
601 KENT CENTER INC	51	49	49	47	99-01	x			
101 PROGRESSIVE HORIZONS	50	52	59	58					x
932 TREATMENT & LEARNING CTR, INC	50	51	60	66				x	
624 BAY SHORE SERVICES, INC	50	49	62	66			x		
152 CENTER FOR SOCIAL CHANGE	49	59	77	84					x
607 EPILEPSY ASSOC OF EASTERN SHORE	49	59	59	62					x
818 LYCHER, INC	49	47	45	44					x
139 FORWARD VISIONS	45	53	60	60					x
134 ST PETERS ADULT LEARNING	44	43	39	40					x
931 UCP OF PG & MONTG COUNTY	44	36	27	25				x	
117 HARFORD CENTER	42	41	51	54				x	
605 CHESTERWYE CENTER	42	47	48	53				x	
619 BENEDICTINE SCHOOL	42	44	50	54	01	x			
151 SHURA	40	44	42	42					x
613 CHESAPEAKE DEVELOP UNIT (part of 621)	38	50	55	61				x	--
146 AUTUMN HOMES	37	39	36	32					x
323 FULL CITIZENSHIP OF MD	37	37	34	34				x	
165 MID ATLANTIC HUMAN SER CORP	35	30	27	24					x
305 CHARLES CO HARC	35	36	36	35			x		
333 HEAD INJURY REHABILITATION	35	35	35	38					x
143 FLYING COLORS OF SUCCESS (or 828)	34	31	33	33					x
952 DEAF INDEPENDENT LIVING ASSOC	32	26	27	23	99-01	x			
321 MARYLAND NEIGHBORLY NETWORKS	29	29	30	26				x	

**Appendix Table 3. Maryland Provider Agencies by Number of People Supported and Year Included in the Sample**

ID and Provider	Number of People				Year in Sample					
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05	
145 SELFPRIDE	28	28	29	26					x	
604 CHESAPEAKE GROUP HOMES (part of 621)	28	25	37	36				x	--	
803 COUNCIL FOR EC&A	28	28	29	26		x				
147 STARFLIGHT	27	21	23	27		x				
353 SECURECARE SERVICES	26	34	40	63				x		
327 MONT CO GOV DEPT OF FAM RESOUR	24	27	45	46				x		
621 CHESAPEAKE CENTER, INC (in FY2004 as 604)	21	17	14	12					--	
141 CARING HANDS, INC	20	20	19	17					x	
808 GOODWILL IND MONOCACY VALLEY	20	17	22	21		x				
330 VOCA CORPORATION	19	19	19	19				x		
154 KENNEDY KREIGER INST	19	10	8	12					x	
836 STAR COMMUNITY (was Anita Lynn Homes)	16	19	22	25				x		
910 LINWOOD CHILDREN'S CENTER	14	17	18	19				x		
920 VANTAGE PLACE (part of 915)	14	17	19	--					--	
163 PACT: HELPING CHILDREN	13	13	13	13				x		
313 NATIONAL CHILDRENS CENTER	12	10	9	10					x	
825 CARROLL CO BUREAU OF AGING	11	10	10	8				x		
153 NETCON & EARTHKINS, INC (closed)	10	26	36	42				x		
166 REM, INC	8	12	13	13					x	
354 EBED ENTERPRISES	5	7	9	12					x	
52 LEAGUE FOR PEOPLE WITH DISAB	--	2	9	23					x	
Subtotal	1,425	1,459	1,604	1,618		3	5	17	19	
<b>Stratum 5 (&lt;10 People by FY2005, 23 Provider agencies Not Included in Sample)</b>										
950 CHESAPEAKE HEAD INJURY CTR (part of 621)	12	13	9	1						
304 AMERICAN FOUND AUTISTIC CHILD	11	--	--	--						
623 SHOREHAVEN	10	5	4	4						
617 CROSSROADS COMMUNITY	8	7	7	4						
344 FAIRFAX OPP UNLIMITED	7	--	--	--						
831 MULTIPLE SCLEROSIS SOCIETY	7	7	7	4						
356 RESPITE CARE ASSOCIATES	6	3	--	--						
813 BETHESDA LUTHERAN HOMES	6	8	7	8						
834 HOPE HOMES OF MD	6	6	1	1						
157 MAXIM HEALTH CARE SERVS	5	5	2	2						
615 UCP EASTERN (with 132 UCP Central)	5	--	--	--						
162 NATIONAL MENTOR HEALTH CARE	3	3	6	3						
167 CTR FOR NEURO REHABILITATION	2	1	1	1						
168 EVERSHERE RESIDENTIAL SERVICES	2	3	4	5						
337 CALVERT CO HEALTH DEPT	2	3	1	1						
348 GRAFTON SCHOOL, INC	1	1	--	--						
814 ARCHWAY STATION	1	1	1	1						
822 WASHINGTON CO MENTAL HEALTH	1	1	--	--						
329 COMMUNITY SERVICES OF MD	1	--	--	--						
170 COPE HOMES, INC	1	--	1	4						
360 PSI SERVICES, INC (or 56)	--	11	--	--						
055 CHRISHARON'S INC	--	7	--	--						
054 CALVERT CO OFFICE OF AGING	--	5	5	3						
172 MARY T MARYLAND (or 51)	--	3	4	3						
057 SACRED CARE INC	--	2	--	--						
053 INNOVATIVE SERVICES, INC	--	1	5	6						
058 SERVICE SOURCE	--	--	--	5						
063 ESRO HOLDING PROVIDER	--	--	--	3						
059 S & G RESIDENTIAL SERVICES	--	--	--	3						

**Appendix Table 3. Maryland Provider Agencies by Number of People Supported and Year Included in the Sample**

ID and Provider	Number of People				Year in Sample				
	FY02	FY03	FY04	FY05	Pilot	FY02	FY03	FY04	FY05
050 LIFELINE, LLC	--	--	--	2					
060 HEBRON ASSOC FOR COMMUNITY SRVC	--	--	--	1					
062 MATTA WAY	--	--	--	1					
061 JOSHUA HOUSE	--	--	--	1					
Subtotal	97	96	65	67	0	0	0	0	
<b>Total Person-Provider Combinations</b>	<b>13,904</b>	<b>13,519</b>	<b>13,993</b>	<b>14,180</b>	<b>35</b>	<b>36</b>	<b>48</b>	<b>50</b>	
* UCP of Southern Maryland was incorrectly included with UCP of Central Maryland in FY2002.									
** Was not included as scheduled in FY2005 since most of the people had been interviewed in FY2004 when other agency components were selected as separate provider agencies .									

additional provider decreased between 2002 and 2003 to potentially drop it from Stratum 3. However, DDA obtained sufficient funds during FY2004 to make the distinction between Stratum 3 and Stratum 4 unimportant for sampling purposes, so no changes were made during the four-year cycle in whether agencies were classified in stratum 3 or stratum 4. The selection of stratum 3 agencies for interview in FY2002 was not entirely random. Five agencies that had participated in the FY2001 pretest for the first time were included in the FY2002 sample to provide them with data in sequential years. All other agencies in the stratum were then randomly assigned for interview during one of the four years. Intervals, a program of Chimes, was included in the FY2003 sample as an independent agency.

Stratum 4 included 46 provider agencies serving 10-54 adults. They provided support for 1,604 (14%) of the eligible people. DDA had sufficient funds in FY2002 to include only 3 of these agencies in the sample, and the three agencies with prior interviews were selected. Five agencies were randomly selected from the others in the stratum for interviews during FY2003, and five others for interviews during FY2004. When additional funds became available during FY2004, all of the remaining provider agencies in the stratum were sorted by the number of people they supported in July 2003, and then alternately assigned to be interviewed in either FY2004 or FY2005. Five provider agencies serving 10-19 people in July 2001 served fewer than 10 people in July 2003 and were dropped from Stratum 4. None had been selected for either the FY2002 or FY2003 survey, so they had no effect on the sample process. Two provider agencies increased support to 10 or more people in July 2004 and were returned to Stratum 4, and were joined by two other provider agencies that had gained this size by FY2005. Vantage Place, selected for interview in FY2005, had merged with Humanim before then, so was never included as an independent agency in the study. Chesapeake Group Homes, Chesapeake Developmental Unit, Chesapeake Center, Inc., and Chesapeake Head Injury Center were considered independent agencies for sample selection through FY2004, and two were selected for inclusion in the FY2004 sample. The high rate of multiple selection of the same people made the project realize they were programs of the same agency and should have been treated as such. Therefore, no interviews were conducted during FY2005 even though the third program had been selected for interview during that year. Since people supported by the two programs were independently sampled in FY2004, this report treats them as if they were independent agencies.

Stratum 5 provider agencies supported fewer than ten people. There were 19 such provider agencies in July 2001, 21 in July 2002, 20 in July 2003, and 23 in July 2004. Seven of the 19 provider agencies in July 2001 supported no one in July 2004 and ten of the 23 in July 2004 supported no one in July 2001. An additional three provider agencies supported people only in July 2002. Stratum 5 provider agencies were not sampled due to cost, confidentiality and discontinuity of services. Excluding these provider agencies, however, excluded only 34 people from the possibility of selection for interview during one of the four years, or 0.3% of the people supported by DDA, since some of the people supported by Stratum 5 provider agencies were also supported by provider agencies in other strata.

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

## **Person Sample**

A primary sample of 40 people and a secondary sample of 10 people was selected from each provider selected for participation in the survey, in order to achieve a goal of 30 completed interviews for each agency. In the FY2002 survey, the field staff received the names of only the 40 people in the primary sample for each agency with the expectation of a 75% response rate. The response rate in FY2002 averaged 68% and supplemental samples had to be selected for 9 of the 35 provider agencies. Even with the supplement, 21 provider agencies did not achieve the desired 30 surveys. In FY2003, FY2004 and FY2005, the field staff received all 50 names. They were instructed to go into the secondary sample only when the number of completed interviews from the primary sample appeared to be fewer than 27, and then only as far as need to achieve 30 people with completed surveys. Once the field staff initiated contact for a person in the secondary sample, however, they followed the complete field protocol to complete an interview for the person.

SPSS software was used to randomly select 50 person/provider records for the provider agencies serving 51 or more people. All records were selected for the provider agencies serving 50 or fewer people. This procedure resulted in a few people being selected twice for interviews in a single year.<sup>10</sup> These people were interviewed only once, generally at their employment or day program, and their survey data duplicated to appear as if they had been interviewed at both provider agencies.

During the FY2004 and FY2005 field work, some people were discovered at small provider agencies that had not been identified on the DDA files as served by these provider agencies. When a Stratum 4 provider had fewer than 40 people listed for interviews, Ask Me! interviewed all people 18 years of age and over that the provider reported were supported by DDA, and added their names to their control sheets. Ask Me! still missed new people served by larger provider agencies, but this was expected to have minimal effect on either state estimates or estimates for larger provider agencies.

---

<sup>10</sup>No attempt was made to identify if people had been interviewed in prior years.

Fieldwork discovered that not all people received support at the time of interview from the provider agencies identified in DDA files as the basis for sampling. This could be due to changes in support between July and the time of interview, or due to DDA July files not accurately reflecting supports. The fieldwork procedures attempted to track every sampled person regardless of where they received support.

The FY2005 survey encountered two new situations that had marginal effect on the sample design:

- The Maryland Department of Health and Mental Hygiene closed Autumn Homes after interviews had been completed for only five of the 32 people (one additional person had refused and a second was not available due to illness). The Ask Me! team decided it would not be appropriate to make further contact with the individuals and their families during the transition process, and classified the remainder as non-respondents.
- The Kennedy Kreiger Institute provides support to young adults transitioning from child to adult services. The nature of this support is generally short-term, and few of the young adults sampled in July 2004 were still supported by the Institute at the time of interview in January 2005. Therefore, the Ask Me! team decided to consider all fourteen of the young adults being supported at the time of interview to be in the sample.

## **Sample Control and Confidentiality**

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

The field status code provided the basis for the non-response adjustment to the weight. An average of 54.3% of the eligible people responded to the survey for themselves, varying slightly from year to year. (See **Appendix Table 4.**) An additional 21.2% had proxy respondents. The overall percent with proxy respondents did not differ much over the years, but the percent of sampled people with two proxies increased from 5.4% in FY2002 to 20.9% in FY2005 after the project made extra effort to find second proxies. The largest reason for non-response was the refusal of 10.8% of the selected persons to be interviewed, and this varied little from year to year. The 2.9% for whom guardians refused to let participate stayed about the same over the four years, as did the 4.2% that could not be found at the sample provider or any other provider, but who DDA still had on their files at the end of the fiscal year as eligible for support.

**Appendix Table 4. Final Field Status by Year**

		Number of People					Percent				
		FY 2002	FY 2003	FY 2004	FY 2005	Total	FY 2002	FY 2003	FY 2004	FY 2005	Total
Sample Response	Completed Self	738	784	1124	939	3585	56.0	53.8	57.5	50.2	54.3
	Completed 2 Proxies	72	248	367	390	1077	5.5	17.0	18.8	20.9	16.3
	Completed 1 Proxy of 2	44	55	30	44	173	3.3	3.8	1.5	2.4	2.6
	Completed 1 Proxy of 1	104	23	19	7	153	7.9	1.6	1.0	0.4	2.3
Sample No Response	Unknown if DDA Funded	84	73	35	85	277	6.4	5.0	1.8	4.5	4.2
	Guardian Refused	50	38	48	54	190	3.8	2.6	2.5	2.9	2.9
	Person Refused	131	175	198	212	716	9.9	12.0	10.1	11.3	10.8
	No Contact 6 Tries	22	13	46	57	138	1.7	0.9	2.4	3.0	2.1
	Cannot Schedule	25	3	13	10	51	1.9	0.2	0.7	0.5	0.8
	Provider No Helpful Info	8	1	33	16	58	0.6	0.1	1.7	0.9	0.9
	Language, Health	25	19	29	25	98	1.9	1.3	1.5	1.3	1.5
	Other Non-response	15	26	12	31	84	1.1	1.8	0.6	1.7	1.3
<b>Total Sample</b>		<b>1318</b>	<b>1458</b>	<b>1954</b>	<b>1870</b>	<b>6600</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
Not Sample	Died, Moved, Not DDA	27	30	66	52	175					
	<18 years, interviewer	41	6	2	1	50					
	Selection Not Needed	13	200	132	205	550					
<b>Total Not in Sample</b>		<b>81</b>	<b>236</b>	<b>200</b>	<b>258</b>	<b>775</b>					
<b>Total</b>		<b>1399</b>	<b>1694</b>	<b>2154</b>	<b>2128</b>	<b>7375</b>					

Ask Me! obtained information for 5,125 people over the four years. (See **Appendix Table 5.**) It collected information for as few as 11 people at one small provider interviewed once, and as many as 142 people at a large provider with interviews all four years. Ask Me! collected information for 76% of the people initially identified in the sample. It completed surveys for 90% or more of the sampled people at 22 of the 116 provider agencies, but completed surveys for fewer than half of the sampled people at five of the provider agencies, including Autumn Homes which was closed by the state while interviews were being conducted. The way provider agencies approached people or their guardians about survey participation may have influenced the percent of the sample with surveys. Provider agencies could have little influence on the percent of surveys with self-response, as the ability to respond for oneself was determined by the Ask Me! interviewers. Three-fourths (72%) of the interview information came from people responding for themselves, but this varied from a low of 8% to a high of 100%.

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.

**Appendix Table 5. Survey Response by Provider**

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2005	FY2002-FY2005
Total		76%	72%	54%	1,433	5,125
Abilities Network	(02 & 04)	62%	98%	61%	0	57
ACCFX Gallagher	(02 & 04)	90%	56%	50%	0	73
Alliance	(02 & 04)	66%	100%	66%	0	56
Anita Lynne Home Inc	(04)	95%	14%	14%	0	21
Appalachian Parent Assn	(04)	90%	77%	69%	0	44
Arc of Anne Arundel Co	(03 & 05)	70%	75%	53%	28	57
Arc of Baltimore	(02 to 05)	84%	74%	63%	37	138
Arc of Carroll County	(02 & 04)	88%	83%	73%	0	80
Arc of Frederick County	(02)	60%	97%	58%	0	25
Arc of Howard Co	(03 & 05)	70%	75%	53%	30	63
Arc of Montgomery Co	(02 to 05)	77%	75%	58%	37	136
Arc of Northern Chesapeake	(02 & 04)	83%	94%	78%	0	77
Arc of Prince Georges Co	(02 to 05)	66%	57%	38%	35	122
Arc of Southern Maryland	(03 & 05)	80%	79%	63%	38	81
Arc of Washington Co	(02 to 05)	74%	65%	48%	39	142
Ardmore Enterprises	(02 & 04)	90%	56%	51%	0	67
Athelas Institute	(02 to 05)	75%	77%	58%	31	132
Autum Homes (closed during interviews)	(05)	16%	60%	10%	6	6
Bay Shore Services Inc	(03)	44%	90%	40%	0	20
Bayside Community Network	(02)	78%	81%	63%	0	31
Bello Machre	(03 & 05)	81%	59%	48%	31	67
Benedictine School	(02)	88%	93%	82%	0	30
Calmra Inc.	(05)	67%	53%	36%	31	31
Caring Hands Inc	(05)	94%	47%	44%	16	16
Caroline Center	(02)	69%	67%	46%	0	27
Carroll Co Bureau of Aging	(04)	100%	91%	91%	0	11
Center for Life Enrichment	(03 & 05)	75%	83%	62%	29	58
Center for Progressive Learning	(03 & 05)	91%	54%	49%	36	77
Center for Social Change	(05)	80%	71%	56%	31	31
Change, Inc	(03 & 05)	73%	42%	30%	35	72
Charles Co HARC	(03)	94%	32%	31%	0	34
Charles Co Health Dept	(04)	55%	91%	50%	0	23
Chesapeake Care Resources	(04)	92%	41%	38%	1	45
Chesapeake Developmental Unit	(04)	73%	97%	71%	0	30
Chesapeake Group Homes	(04)	85%	83%	71%	0	29
Chesterwe Center	(04)	70%	100%	70%	0	33
CHI Center	(02 to 05)	75%	83%	63%	41	136
Chimes Inc	(02 to 05)	78%	72%	56%	33	125
Community Living Inc	(02)	70%	71%	50%	0	28

**Appendix Table 5. Survey Response by Provider**

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2005	FY2002-FY2005
Community Support Services	(04)	87%	67%	58%	0	33
Council for EC&A	(03)	65%	29%	19%	0	19
Creative Options	(05)	87%	64%	55%	36	36
CSAAC	(02)	90%	61%	55%	0	36
CSSD	(02)	55%	94%	52%	0	31
Deaf Independent Living Assoc	(02)	66%	100%	66%	0	21
Delmarva Community Services	(03)	78%	72%	56%	0	32
Dove Pointe Inc	(02 & 04)	67%	67%	45%	0	58
Ebed Enterprises	(05)	90%	59%	80%	12	12
Emerge	(02 & 04)	73%	78%	58%	0	68
Epilepsy Association of Eastern Shore	(05)	68%	90%	61%	28	28
Family Service Fd Inc	(05)	90%	8%	8%	37	38
Flying Colors of Success	(05)	93%	27%	25%	30	30
Forward Vision	(05)	76%	68%	57%	31	31
Friends Aware, Inc	(03 & 05)	80%	75%	60%	38	73
Full Citizenship of MD	(04)	88%	43%	38%	0	30
Goodwill Ind Monocacy Valley	(03)	100%	100%	100%	0	16
Horizon Goodwill Industries	(02)	62%	52%	38%	0	25
Harford Center	(04)	92%	37%	34%	0	35
Head Injury Rehabilitation	(05)	56%	100%	56%	20	20
Humanim	(03 & 05)	64%	88%	56%	24	56
Intervals (should be part of Chimes)	(03)	83%	39%	33%	0	34
Jeanne Bussard Center	(04)	88%	95%	84%	0	44
Jewish Family Services	(03)	79%	87%	68%	0	32
Jewish Fd for Group Homes	(04)	88%	79%	69%	0	43
Jewish Social Services Agency	(03)	65%	71%	46%	0	23
Jubilee Association of MD	(02)	72%	86%	62%	0	28
Kennedy Kreiger Institute	(05)	42%	45%	19%	11	11
Kent Center Inc	(02)	64%	80%	51%	0	25
Langton Green	(05)	76%	71%	54%	38	38
League for People with Disabilities	(05)	57%	92%	52%	13	14
Life	(03)	84%	51%	43%	0	37
Linwood Children's Center	(04)	95%	72%	68%	0	18
Lt Joseph P Kennedy Institute	(03)	69%	73%	50%	0	34
Lower Shore Enterprises	(05)	74%	97%	72%	37	37
Lycher Inc	(05)	71%	19%	14%	31	31
Maryland Neighborly Networks	(04)	97%	86%	83%	0	28
Medsorce Community Support	(04)	92%	28%	26%	0	46
Melwood Hort	(02 to 05)	76%	81%	61%	31	121
Mid Atlantic Human Services Corp	(05)	68%	13%	9%	16	16

**Appendix Table 5. Survey Response by Provider**

Provider	Survey Fiscal Years	Percent of Sample with Surveys	Percent of Surveys with Self-response	Percent of Sample with Self-response	# Complete Surveys	
					FY2005	FY2002-FY2005
Mont Co Gov Dept of Fam Resources	(04)	50%	68%	34%	0	19
National Children's Center	(05)	88%	71%	63%	7	7
National MS	(05)	25%	100%	25%	11	11
NCIA CBAI	(03)	84%	79%	66%	0	34
Netcon & Earthkins Inc (closed in 05)	(04)	83%	83%	67%	0	29
Opportunity Builders	(02 & 04)	63%	87%	55%	0	53
PACT: Helping Children	(04)	83%	100%	83%	0	24
Penn Mar	(02)	73%	69%	50%	0	30
Progress Unlimited	(05)	97%	27%	26%	39	39
Progressive Horizons	(05)	85%	85%	72%	34	34
Providence Center	(02 to 05)	70%	79%	55%	31	116
Ray of Hope Inc	(04)	46%	82%	38%	0	22
Rehabilitation Opportunities	(02 & 04)	79%	96%	76%	0	69
REM Inc.	(05)	83%	50%	42%	11	11
Richcroft	(03)	80%	69%	56%	0	38
Rock Creek Foundation	(05)	76%	100%	76%	29	29
Scott Key Center	(03)	82%	78%	64%	0	41
Securecare Services	(04)	87%	68%	59%	0	35
SEEC	(02)	71%	67%	47%	0	28
Selfpride	(05)	90%	17%	15%	21	21
Shura	(05)	75%	89%	67%	33	33
Somerset Community Services Inc	(05)	88%	74%	65%	43	43
Southern MD Vocational Indust	(03)	72%	79%	56%	0	29
Spectrum Support (was R & D Instr)	(04)	75%	90%	68%	0	30
Spring Dell Center	(02 & 04)	75%	74%	56%	0	66
St. Peters Adult Learning	(05)	85%	100%	85%	34	34
Starflight	(03)	68%	54%	37%	0	14
Target, Inc.	(05)	77%	79%	61%	37	37
Treatment & Learning Ctr Inc	(04)	80%	100%	80%	0	32
UCP Central Maryland	(02 to 05)	74%	63%	47%	32	122
UCP of PG & Montgomery Co	(04)	89%	92%	82%	0	24
UCP of Southern MD	(03 & 05)	67%	93%	62%	31	64
Voca Corporation	(04)	90%	24%	21%	0	17
Vocational Services Inc	(03 & 05)	81%	65%	52%	42	72
Washington Co HDC	(04)	98%	47%	46%	0	49
Worcester Co Developmental Ctr	(02)	67%	85%	56%	0	26
Workfirst	(04)	53%	100%	53%	0	24

[This page is intentionally blank.]

## Appendix B. Data Processing

### 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 non-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 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:

$$(1) \quad wtfinal = wtstrata * wtprovider * wtnonresponse * wtperson$$

or

$$(2) \quad wtfinal = wtstrata * wtresponse * wtperson$$

where  $wtfinal$  = final weight for the person

$wtstrata$  = number of provider agencies in the stratum / number of selected provider agencies in the stratum

$wtprovider$  = number of people supported by the provider / number of people in the provider selected for interview

$wtnonresponse$  = number of people in final provider’s sample / number of people interviewed

$wtperson$  = 1 / number of provider agencies serving the person

$wtresponse$  = number of people supported by the provider / number of people interviewed.

The difference between using  $w_{tprovider} * w_{tnonresponse}$  and  $w_{tresponse}$  revolves around the terms “selected for interview” and “in final provider’s sample.” These are not exactly the same, and the implications need to be tested empirically. An initial sample of 40 people 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 nonmoving adults for children (inappropriately), deceased people (questionably), interviewers (appropriately), and those ending support (appropriately). Neither will represent people who started receiving support during the year except for small agencies where all people were selected for interviews. It was expected that either estimating procedure would produce an accurate enough weight for statistical estimation.

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 6.**) 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 6. Weight Characteristics, by Year</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					
FY2002	11,539	11,564	3.00	39.00	12.00
FY2003	10,908	10,833	2.00	27.00	9.60
FY2004	11,226	11,160	1.00	35.00	7.25
FY2005	11,377	11,355	1.00	28.00	7.92
Final Statistical Weight					
FY2002	958	1,009	0.25	3.23	1.00
FY2003	1,140	1,139	0.21	2.82	1.00
FY2004	1,540	1,531	0.14	4.08	1.00
FY2005	1,433	1,434	0.10	3.55	1.00
Combined	5,071	5,113	0.10	4.08	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 4% in FY2002, 13% in FY2003, 20% in FY2004, and 11% of the people in FY2005.

## **DDA Authorized Services**

This report classified a person as receiving support if the DDA file contained a record for the person with the support. The person was further classified as receiving the support from the primary provider—the provider through which the person was selected. However, the DDA file as of July 1 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.

## **Transportation**

The scale of perceived transportation availability was constructed from five questions answered by respondents during interviews. Provider staff in FY2003, FY2004 and FY2005 recorded on a Transportation Form the number of round trips per week each interviewed person received from various sources and various purposes: 1) to employment or day activities from the provider through which the person was selected for interview, 2) to other activities from the provider through which the person was selected, 3) from other 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." The Transportation Form did not as clearly identify "trips" as "round trips" in FY2003 as it did in FY2004 and FY2005. Some provider agencies recorded much greater frequency of transportation than other provider agencies. The project researcher halved all FY2003 frequencies of trips greater than seven (i.e., once a day) on the hypothesis that the provider agencies

in these cases had counted each leg of a trip rather than a round trip, and placed an upper limit in FY2004 and FY2005 of 10 round trips per week from one source to one type of activity.

Provider staff in FY2002 recorded on a Background Form how frequently the provider through which the person was selected for the interview provided transportation in a week, using an ordinal scale from no transportation involvement to providing transportation three or more times per week. Staff recorded that a person did or did not receive transportation from other provider agencies, family, transit, paratransit and taxis during the past month. Analysis in this report on the relationship of trips per week to perceived availability of transportation and to the quality of life domains used the more detailed information from FY2003-FY2005. A check was made to determine that using only dichotomous variables (e.g., received or did not receive three or more trips per week from the sample agency) and including FY2002 data produced the same results.

## Appendix C. Analysis Methods

All analysis used SPSS 11.5 software (Statistical Package for the Social Sciences). Analysis using person-level data used a 99% level of confidence ( $p < .01$ ) to reduce the probability that minor and unimportant differences would be treated as significant, since more than 5,000 people had been surveyed interviewed over the four years. Analysis using agency-level data used a 95% level of confidence ( $p < .05$ ) since there were only 116 records over the four years. 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.

### Scale Reliability

The six questions for each of the eight core quality of life domains in the survey were combined to produce a single scale score. A scale score was not calculated for an individual if more than one-third of the questions in the domain had not been answered. The eight domains had low but acceptable scaling properties overall, with Cronbach's *alpha* of 0.61 to 0.70 (See **Appendix Figure 37.**) The scale reliability for people who responded for themselves was higher than for proxies for all eight quality of life domains. Proxies had particularly low reliability on the scale of physical well-being and interpersonal relations. They thought the question on overall health most represented the domain of physical well-being, whereas self-responders thought the question about good eating habits most represented the domain. Proxies, unlike self-responders, did not think the question on seeing and talking with family related to the other questions on interpersonal relations.

Scale	Cronbach's Alpha		
	Self	Proxy	Total
Rights	0.63	0.62	0.67
Self-determination	0.66	0.64	0.69
Personal development	0.70	0.55	0.66
Social inclusion	0.71	0.66	0.70
Interpersonal relations	0.69	0.46	0.65
Material well-being	0.65	0.60	0.61
Emotional well-being	0.68	0.66	0.66
Physical well-being	0.65	0.42	0.65
Transportation available	0.61	0.56	0.62

**Appendix Figure 37.** Scale Reliability by Respondent

The scale of transportation availability with five component questions had slightly less reliability than the eight quality of life domains. Again, self-respondents showed a greater reliability in answering these questions than did proxies.

### Statistical Significance

The statistical significance of any percent or mean is based upon its standard deviation, the number of surveys, and the proportion of the population with surveys. **Appendix Figure 38** shows the 95% confidence interval about selected percentages to assist an agency in deciding if the response to any specific question of people they supported is statistically different from the overall Maryland response. As an example, 30 people were surveyed at the agency and 80% of them gave the

favorable response. That response would be statistically different from an overall Maryland response of 65% or 95% (80% ± 15%) but not from an overall Maryland response of 66% or 94%, assuming the agency supported 150 or more people. The confidence interval is smaller when more than one-fifth of the total population was interviewed, and can be multiplied by 0.9 if one-fourth of the people were surveyed, 0.8 if one-third were surveyed, 0.7 if one-half were surveyed, and 0.5 if three-fourths were surveyed. If everyone was surveyed, there was no sampling, confidence intervals do not apply, and any difference is real. If in the previous example, the agency supported 60 people, the 80% reported by their consumers would be statistically different from an overall Maryland response of 69% or 91% (80% ± 0.7\*15%) Approximations can be made for intermediate numbers. For example, 15% of the 40 people surveyed at an agency supporting 80 people gave the negative response to a question. The confidence interval would be about 0.7 (one-half surveyed) \* 11% (about the middle of the cluster of 11%, 8%, 15% and 10%) = 8%, or different from an overall Maryland response of 7% and less or 23% and more.

	<i>Number of Surveys</i>				
	<i>30</i>	<i>60</i>	<i>120</i>	<i>1000</i>	<i>5000</i>
10% or 90%	±11%	±8%	±5%	±2%	±1%
20% or 80%	±15%	±10%	±7%	±2%	±1%
30% or 70%	±17%	±12%	±8%	±3%	±1%
50%	±19%	±13%	±9%	±3%	±1%

**Appendix Figure 38.** 95% Confidence Interval of a Percent, by Number of Surveys

Statistical significance for an average quality of life score cannot be summarized as easily as for a percent. The standard deviations (Std. Dev.) for the state were shown in **Figure 18** (page 21) and the 95% confidence interval for an agency is about 2.0 times the standard deviation divided by the square root of the number of surveys. For example, the confidence interval for an agency's score on rights based on 30 surveys is about  $2.0 * 2.50 / \sqrt{30} = 0.9$ , so an agency score of 7.25 is statistically different from the Maryland average while an agency score of 7.20 is not. Using the standard deviation for the agency would be more accurate than using the standard deviation for all of Maryland. Rather than calculating the confidence interval of each Maryland agency from the Maryland mean, however, his report has identified the 23 agencies (20%) with the highest average scores and the 11 agencies (10%) with the lowest average scores. These two groups are statistically different from each other. Most are statistically different from the Maryland average also, although a few of those in the top 20% may not be different at the 95% level of confidence. The remaining 70% have average scores that are generally not statistically different from the Maryland average, although some interviewed in multiple years may be.

## Multiple Regression

Multiple linear regression for people employed stepwise analysis with  $p = .01$  for entry and  $p = .02$  for removal. The regressions for provider agencies used  $p = .05$  for entry and  $p = .10$  for removal. The pairwise deletion of missing data option was selected. All variables were initially tested in the multiple regressions, dropping those having no statistically significant relationship with any of the quality of life scales, and then recalculating the regression coefficients. Variables with n categories (e.g., region) were recoded into a set of (n - 1) dichotomous variables. Only additive effects were included. Separate regressions were computed for self and proxy respondents, but other possible interactions were not considered. Standardized multiple regression coefficients ( $\beta$ ) indicate the

relative size of the relation. Only the  $\beta$ 's that had statistically independent relations to the quality of life scores are shown. The unadjusted multiple  $R^2$  shows the total amount of the variance in the quality of life scores that could be explained by all the significant characteristics and supports combined. **Appendix Table 7** shows the stepwise multiple regression results for the person as the unit of analysis. **Appendix Table 8** shows the stepwise multiple regression results for the provider as the unit of analysis.

## Path Analysis

The path diagrams use the standardized multiple regression coefficients from a series of multiple linear regressions. Path analysis tests the hypothesized relationships among different measures. Arrows represent statistically significant relationships. The variable on the left at the tail of an arrow is hypothesized to have a direct effect on the variable to its right at the head of the arrow. The thickness of the arrows is based on the standardized multiple regression coefficient ( $\beta$ ) and show the relative strength of relationship. The thickest arrow represents a  $\beta$  of 0.30 or higher. The thinnest arrow represents a statistically significant  $\beta$  of less than 0.10. The path analysis moves from left to right. The leftmost variables are independent to the study, and their causal interrelationships are not hypothesized by the study. As the path moves to the right, variables in the same vertical column are assumed to have no direct causal relationship on each other--any relationship they have is due to their relationships with the variables to their left.

## Quality of Life Score Adjustment

The reported quality of life increased significantly in seven of the eight domains between FY2002 and FY2005. The greatest increases came in interpersonal relations and social inclusion, with average increases of 0.142 and 0.141 points per year. (Refer back to **Figure 17**.) This overall enhancement of quality of life presents difficulty in comparing the average quality of life among provider agencies, as interviews were conducted every year at only the largest provider agencies. The average scores for interpersonal and social inclusion scores would be expected to be 0.4 higher for a small provider with interviews in FY2005 than for a small agency with interviews in FY2002 if they both had the same underlying quality of life that increased the same as in Maryland as a whole. To compensate for the year during which people were interviewed, quality of life scores were adjusted to the midpoint of the four-year period to make them comparable across all provider agencies. The quality of life scores for interviews conducted in FY2002 were increased by 1.5 times the annual change shown by the regression coefficient (B). FY2003 scores were increased by 0.5 times the regression coefficient. FY2004 scores were decreased by 0.5 times the regression coefficient. FY2005 scores were decreased by 1.5 times the regression coefficient. The **Appendix D** to this report shows the adjusted quality of life scores for each provider.



**Appendix Table 7. Standardized Multiple Regression\* Coefficients ( $\beta$ ) of Quality of Life Domains on Person and Support Characteristics (continued)**

Person and Support Characteristics	Personal Development				Social Inclusion				Self-Determination				Rights			
	Self	Proxy	Total		Self	Proxy	Total		Self	Proxy	Total		Self	Proxy	Total	
Self reporting			.16	.06			.17	.07			.32	.21			.36	.27
Transportation availability	.35	.17	.33		.31	.27	.31		.39	.27	.35		.33	.14	.28	
Year of survey	.05		.05	.05	.06	.10	.07	.08	.08	.07	.07	.07	.06			
Intellectual ability		.21	.21	.08	.10	.10			.10	.13	.25	.25	.17	.20	.09	.11
Trips by other provider agencies		-.05							-.05	-.06		-.04	-.04		-.05	
Provider trips to day activity					.06		.05	.05								
Provider trips to other activity						.10		.05		.09						
Trips by family and friends													.05	-.10	-.09	
Employment support	.09	.11	.16	.17	.10	.11	.06	.09	.09	.12	.07	.09	.06	.08	.07	.09
Residential support		.11	.11											.09	.10	
Resource coordination																
Western DDA region	.05	.09	.04	.08	.05	.09	.05	.07	.06	.10	.13	.15	.08	.10	.17	.17
Southern DDA region		.06		.06												
Eastern Shore DDA region																
Size group of provider																
Number of providers					.05		.04									
Deaf, hearing impairment		.11	.09		-.05											
Blind, vision impairment									-.09	-.11	-.04	-.04				
Epilepsy and seizure disorder			-.05	-.05												
Cerebral palsy														-.08	-.09	
Neurological impairment					-.06	-.06	-.05									
Head injury			-.04													
Age	-.06	-.06	-.05	-.05										.09		
<i>R</i> <sup>2</sup>	.15	.03	.13	.10	.16	.06	.12	.02	.11	.04	.12	.03	.19	.04	.17	.10
											.29	.18	.14	.03	.17	.15
																.27
																.20

\* Stepwise regression with p=.01 to enter and p=.02 to delete.

Characteristics not related: public transportation, community supported living assistance, day habilitation support, individual support services, number of provider agencies, gender, autism, behavior problems, orthopedic impairments, specific learning disability, and speech and language impairment.

**Appendix Table 8. Standardized Multiple Regression Coefficients\* ( $\beta$ ) of Provider Quality of Life Scores**

Provider Characteristics	Trans Available	Physical Well-being	Emotional Well-being	Material Well-being	Inter-personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
Average transportation availability		.67	.60	.63	.47	.42	.43	.48	.47
% Provider transports 3+ times/week		.23		.45	.43	.22	.21	.33	
% Using public transportation		.20	.22	.41	.37	.21	.35	.27	
% Supported employment services					.16	.20	.31	.19	.30
% Day habilitation services					.17				
% Community supported living	.17	.18		.18					
% Two or more provider agencies								-.15	-.20
Western DDA region	.35	.38		.33	.24		.18	.27	.28
Southern DDA region	.31	.34		.32	.20				
Eastern Shore DDA region		-.19							
% of sample with survey data		.14	.23	.26	.21	.25	.21	.32	.32
% Self reporting	-.44						.27	.69	.45
Average intellectual abilities		.51		-.27		-.39			
% Specific learning disability		.24					.21		
% Deafness, hearing impaired	.23				-.38	-.25		-.16	
% Epilepsy and seizure disorder		.12							-.17
% Cerebral Palsy		.16							-.16
% Head injury									.16
% Other neurological impairments			-.28						
% Mental disorders			-.25						
% Male		.18							
Average age						-.25			
$R^2$	.40	.65	.47	.45	.11	.57	.39	.43	.29
	.40	.21	.47	.25	.63	.46	.55	.44	

\* Stepwise regression with  $p = .05$  for entry and  $p = .10$  required for removal  
 Characteristics not related: % transported by other agencies, % transported by family, agency size, % receiving residential support, % individual support services, % autism, % behavioral problems, % orthopedic impairments, % speech and language impairments and % vision impairments.

## Appendix D. Quality of Life at Maryland Provider Agencies

### General Information

The *Ask Me! Survey* collects information from people receiving support funded by the Maryland Developmental Disabilities Administration (DDA) to determine their satisfaction with the quality of their lives. Quality of life, defined in eight domains, is the ultimate goal of support services:

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

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.

Some general findings should be kept in mind when looking at average quality of life scores of individual providers:

- Most people in Maryland with developmental disabilities report a good quality of life, particularly in the domains of physical and emotional well-being;
- The eight quality of life domains are distinct and all are important, but different people may place different importance on different domains when considering services;
- The quality of life has increased over the past four years for Maryland as a whole in most domains, so the numeric scores and the related symbols were statistically adjusted to the midpoint of the four-years;
- People receiving employment support and who respond for themselves report higher quality of life than people not receiving employment support or who cannot respond for

themselves; therefore the quality of life would be expected to be a little higher at providers with high percentages of people responding for themselves and that provide employment services;

- Provider quality assurance goals, particularly in the domains of rights and self-determination, can increase the quality of life of the people they support;
- The larger the provider, the more their scores contribute to the Maryland average, and therefore the more similar their scores will be to the Maryland average.

## Definitions and Symbols

Scores can range from 0.0 to 10.0, with a 5.0 score indicating people gave as many positive answers to the indicator questions as negative answers. Agency scores may vary some due to the random selection of people, but the highest 20% of scores (adjusted for time trends) are statistically different from the lowest 10% of scores (adjusted for time trends):

- Average score is in the top 20% of agencies on this domain
  - ◐ Average score is in the middle 70% of agencies on this domain
  - Average score is in the bottom 10% of agencies on this domain
- \* Statistically below the Maryland average (ten largest agencies only)  
\*\* Statistically above the Maryland average (ten largest agencies only)

<i>Fiscal year of survey:</i>	The fiscal year (ending June of the year) or years during which surveys were completed at the provider;
<i>Response rate:</i>	The percent of people with completed surveys among those selected and eligible for interview;
<i>Self response:</i>	The percent of people responding for themselves among those with completed surveys;
<i>Served by other providers:</i>	The percent of people responding who received support from at least one other provider agency;
<i>Number of people in survey:</i>	The number of people with completed surveys who were sampled at this provider;
<i>Number in residential services:</i>	The number of people with completed surveys who received DDA-funded residential services from this provider;
<i>Number employment services:</i>	The number of people with completed surveys who received DDA-funded employment services from this provider;
<i>Number in day habilitation:</i>	The number of people with completed surveys who received DDA-funded day habilitation services from this provider;
<i>Number with individual support:</i>	The percent of people with completed surveys who received DDA-funded individual support services.

## Abilities Network

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.71	8.35	7.42	7.89	7.80	7.32	7.91	6.88
◐	◐	◐	◐	◐	◐	●	◐









Fiscal year of survey:	2002 & 2004	Number of people in survey:	57
Response rate:	62%	Number in residential services:	0
Self-response:	61%	Number in employment services:	27
Served by other providers:	19%	Number in day habilitation services:	16
		Number with individual support:	36

## ACCFX Gallagher

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.03	8.77	7.62	8.30	7.51	8.08	6.76	6.18
◐	◐	◐	●	◐	●	◐	◐









Fiscal year of survey:	2002 & 2004	Number of people in survey:	71
Response rate:	90%	Number in residential services:	51
Self-response:	50%	Number in employment services:	9
Served by other providers:	41%	Number in day habilitation services:	40
		Number with individual support:	6

## Alliance

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.62	8.82	7.50	8.05	8.15	7.86	8.14	7.26
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	56
Response rate:	66%	Number in residential services:	0
Self-response:	66%	Number in employment services:	27
Served by other providers:	27%	Number in day habilitation services:	22
		Number with individual support:	10

## Anita Lynne Home Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.52	8.68	8.41	8.28	7.68	8.28	8.05	7.19
							









Fiscal year of survey:	2004	Number of people in survey:	21
Response rate:	95%	Number in residential services:	20
Self-response:	14%	Number in employment services:	0
Served by other providers:	5%	Number in day habilitation services:	20
		Number with individual support:	0

## Appalachian Parent Association

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.80	8.98	7.93	8.57	8.44	8.33	7.78	7.08
							









Fiscal year of survey:	2004	Number of people in survey:	44
Response rate:	90%	Number in residential services:	10
Self-response:	69%	Number in employment services:	10
Served by other providers:	5%	Number in day habilitation services:	35
		Number with individual support:	25

## Arc of Anne Arundel County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.30	7.79	6.98	7.43	6.65	7.35	6.43	5.73
							

Fiscal year of survey:	2003 & 2005	Number of people in survey:	57
Response rate:	70%	Number in residential services:	19
Self-response:	52%	Number in employment services:	2
Served by other providers:	65%	Number in day habilitation services:	0
		Number with individual support:	10









## Arc of Baltimore

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.31	8.11*	7.07*	7.31	7.19	7.23	6.70	6.44
							

Fiscal year of survey:	2002-2005	Number of people in survey:	138
Response rate:	84%	Number in residential services:	22
Self-response:	63%	Number in employment services:	50
Served by other providers:	28%	Number in day habilitation services:	72
		Number with individual support:	16









\* Statistically lower than Maryland average with the large number of people surveyed.

## Arc of Carroll County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.47	8.39	7.16	7.35	7.09	7.46	7.10	6.66
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	80
Response rate:	88%	Number in residential services:	25
Self-response:	73%	Number in employment services:	2
Served by other providers:	40%	Number in day habilitation services:	67
		Number with individual support:	20

## Arc of Frederick County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.95	8.26	7.82	8.35	7.48	8.14	8.03	7.64
							









Fiscal year of survey:	2002	Number of people in survey:	25
Response rate:	60%	Number in residential services:	0
Self-response:	58%	Number in employment services:	9
Served by other providers:	60%	Number in day habilitation services:	11
		Number with individual support:	24

## Arc of Howard County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.41	8.46	7.00	7.54	7.16	7.42	6.85	6.31
							

Fiscal year of survey:	2003 & 2005	Number of people in survey:	63
Response rate:	70%	Number in residential services:	26
Self-response:	53%	Number in employment services:	18
Served by other providers:	19%	Number in day habilitation services:	26
		Number with individual support:	5









## Arc of Montgomery County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.93**	8.40	7.81	7.70	7.31	7.43	6.94	6.32
							

Fiscal year of survey:	2002-2005	Number of people in survey:	136
Response rate:	77%	Number in residential services:	72
Self-response:	58%	Number in employment services:	36
Served by other providers:	38%	Number in day habilitation services:	62
		Number with individual support:	10

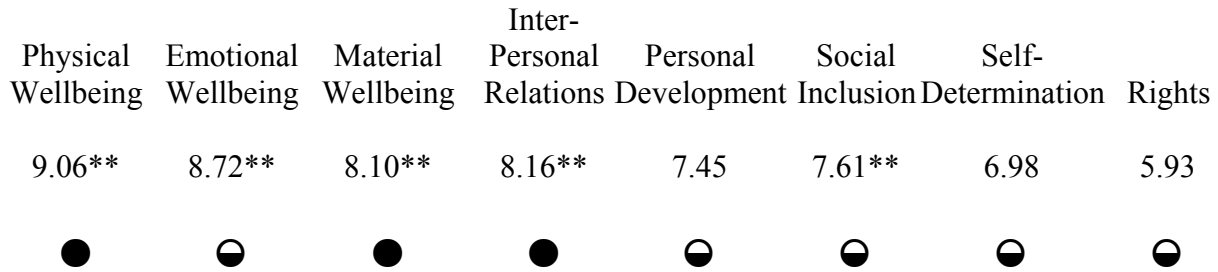
\*\*Statistically higher than the Maryland average with the large number of people surveyed.

## Arc of Northern Chesapeake

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.37	8.24	7.77	7.35	7.59	7.57	7.33	6.95
							

Fiscal year of survey:	2002 & 2004	Number of people in survey:	77
Response rate:	83%	Number in residential services:	30
Self-response:	78%	Number in employment services:	23
Served by other providers:	12%	Number in day habilitation services:	52
		Number with individual support:	12

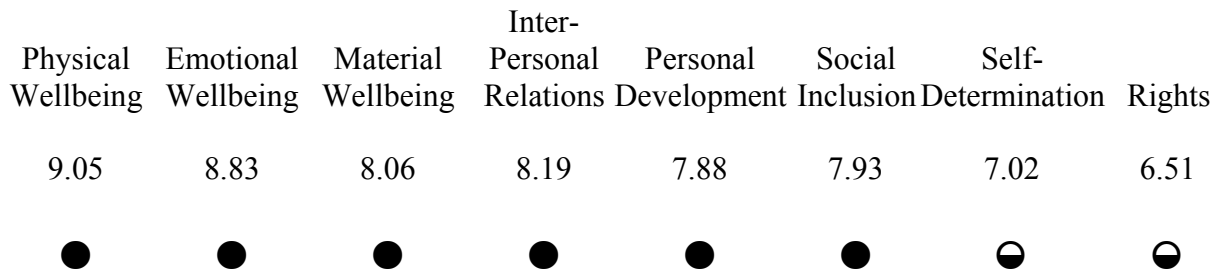
## Arc of Prince George's County



Fiscal year of survey:	2002-2005	Number of people in survey:	122
Response rate:	66%	Number in residential services:	42
Self-response:	38%	Number in employment services:	21
Served by other providers:	53%	Number in day habilitation services:	62
		Number with individual support:	22









\*\*Statistically higher than the Maryland average with the large number of people surveyed.

## Arc of Southern Maryland



Fiscal year of survey:	2002-2005	Number of people in survey:	117
Response rate:	80%	Number in residential services:	63
Self-response:	63%	Number in employment services:	18
Served by other providers:	30%	Number in day habilitation services:	25
		Number with individual support:	11









## Arc of Washington County

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.75	8.80**	7.45	7.80**	7.43	7.50	7.23	6.11
							

Fiscal year of survey:	2002-2005	Number of people in survey:	142
Response rate:	74%	Number in residential services:	57
Self-response:	48%	Number in employment services:	13
Served by other providers:	18%	Number in day habilitation services:	70
		Number with individual support:	43









\*\*Statistically higher than the Maryland average with the large number of people surveyed.

## Ardmore Enterprises

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.80	8.36	7.24	7.07	6.70	6.44	5.89	5.40
							

Fiscal year of survey:	2002 & 2004	Number of people in survey:	67
Response rate:	90%	Number in residential services:	16
Self-response:	51%	Number in employment services:	3
Served by other providers:	54%	Number in day habilitation services:	62
		Number with individual support:	1









## Athelas Institute

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.48	8.00*	6.94*	7.51	7.19	7.37	6.46	5.87
							

Fiscal year of survey:	2002-2005	Number of people in survey:	132
Response rate:	75%	Number in residential services:	18
Self-response:	58%	Number in employment services:	33
Served by other providers:	44%	Number in day habilitation services:	88
		Number with individual support:	21









\* Statistically lower than Maryland average with the large number of people surveyed.

## Autumn Homes

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.22	6.85	6.97	6.94	6.76	5.83	6.63	4.31
							









Fiscal year of survey:	2005	Number of people in survey:	6
Response rate:	16%	Number in residential services:	5
Self-response:	10%	Number in employment services:	0
Served by other providers:	17%	Number in day habilitation services:	0
		Number with individual support:	0

## Bay Shore Services Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.92	7.89	7.16	7.33	6.37	6.74	5.97	6.64
							









Fiscal year of survey:	2003	Number of people in survey:	20
Response rate:	44%	Number in residential services:	0
Self-response:	40%	Number in employment services:	0
Served by other providers:	55%	Number in day habilitation services:	0
		Number with individual support:	4

## Bayside Community Network

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
6.67	7.16	6.12	6.07	5.73	6.03	5.72	6.25
							









Fiscal year of survey:	2002	Number of people in survey:	31
Response rate:	78%	Number in residential services:	16
Self-response:	62%	Number in employment services:	1
Served by other providers:	0%	Number in day habilitation services:	26
		Number with individual support:	2

## Bello Machre

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.55	8.09	6.62	7.30	6.78	6.97	5.96	5.52
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	67
Response rate:	81%	Number in residential services:	53
Self-response:	48%	Number in employment services:	0
Served by other providers:	79%	Number in day habilitation services:	0
		Number with individual support:	2

## Benedictine School

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.34	9.03	8.61	8.64	9.08	8.73	8.60	7.90
							









Fiscal year of survey:	2002	Number of people in survey:	30
Response rate:	88%	Number in residential services:	28
Self-response:	82%	Number in employment services:	1
Served by other providers:	7%	Number in day habilitation services:	0
		Number with individual support:	4

## Calmra Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.90	8.59	7.37	7.86	7.23	7.85	7.05	6.28
							

Fiscal year of survey:	2005	Number of people in survey:	31
Response rate:	67%	Number in residential services:	22
Self-response:	36%	Number in employment services:	0
Served by other providers:	74%	Number in day habilitation services:	0
		Number with individual support:	5

## Caring Hands Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.75	4.49	6.24	6.80	7.15	7.31	6.02	5.34
							

Fiscal year of survey:	2005	Number of people in survey:	16
Response rate:	94%	Number in residential services:	16
Self-response:	44%	Number in employment services:	0
Served by other providers:	94%	Number in day habilitation services:	0
		Number with individual support:	0

## Caroline Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.12	8.25	6.21	7.65	7.40	6.65	5.97	4.87
◐	◐	○	◐	◐	◐	◐	○









Fiscal year of survey:	2002	Number of people in survey:	27
Response rate:	69%	Number in residential services:	14
Self-response:	46%	Number in employment services:	1
Served by other providers:	4%	Number in day habilitation services:	26
		Number with individual support:	10

## Carroll County Bureau of Aging

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.41	9.57	8.01	8.45	7.07	8.36	7.86	6.86
●	●	●	●	◐	●	●	◐









Fiscal year of survey:	2004	Number of people in survey:	11
Response rate:	100%	Number in residential services:	0
Self-response:	91%	Number in employment services:	0
Served by other providers:	82%	Number in day habilitation services:	0
		Number with individual support:	11

## Center for Life Enrichment

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.93	8.80	8.30	8.48	7.87	8.16	7.66	6.54
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	58
Response rate:	75%	Number in residential services:	0
Self-response:	62%	Number in employment services:	25
Served by other providers:	43%	Number in day habilitation services:	23
		Number with individual support:	9

## Center for Progressive Learning

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.20	8.17	6.80	6.70	6.53	6.85	6.20	5.24
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	77
Response rate:	91%	Number in residential services:	41
Self-response:	49%	Number in employment services:	0
Served by other providers:	75%	Number in day habilitation services:	0
		Number with individual support:	0

## Center for Social Change

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.48	7.86	7.09	6.88	7.34	7.30	6.63	6.40
							









Fiscal year of survey:	2005	Number of people in survey:	31
Response rate:	79%	Number in residential services:	23
Self-response:	56%	Number in employment services:	8
Served by other providers:	68%	Number in day habilitation services:	0
		Number with individual support:	0

## Change, Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.97	8.40	6.92	7.52	7.01	7.26	6.53	5.36
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	72
Response rate:	73%	Number in residential services:	0
Self-response:	30%	Number in employment services:	8
Served by other providers:	62%	Number in day habilitation services:	45
		Number with individual support:	10

## Charles County HARC

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.29	8.75	7.86	8.00	7.00	7.70	5.32	4.51
							









Fiscal year of survey:	2003	Number of people in survey:	34
Response rate:	94%	Number in residential services:	34
Self-response:	31%	Number in employment services:	0
Served by other providers:	85%	Number in day habilitation services:	0
		Number with individual support:	0

## Charles County Health Dept

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.42	7.91	5.70	7.50	6.37	6.52	6.75	6.22
							









Fiscal year of survey:	2004	Number of people in survey:	23
Response rate:	55%	Number in residential services:	0
Self-response:	50%	Number in employment services:	0
Served by other providers:	17%	Number in day habilitation services:	0
		Number with individual support:	23

## Chesapeake Care Resources

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.20	9.01	8.09	8.02	7.03	7.63	6.91	5.37
							

Fiscal year of survey:	2004	Number of people in survey:	44
Response rate:	92%	Number in residential services:	24
Self-response:	38%	Number in employment services:	7
Served by other providers:	5%	Number in day habilitation services:	41
		Number with individual support:	3

## Chesapeake Developmental Unit

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
6.96	7.72	6.79	6.73	6.53	6.91	6.88	6.07
							

Fiscal year of survey:	2004	Number of people in survey:	30
Response rate:	73%	Number in residential services:	0
Self-response:	71%	Number in employment services:	2
Served by other providers:	73%	Number in day habilitation services:	30
		Number with individual support:	1

## Chesapeake Group Homes

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.25	8.13	6.03	6.54	5.94	6.24	5.87	5.15
○	◐	○	○	○	○	◐	◐









Fiscal year of survey:	2004	Number of people in survey:	29
Response rate:	85%	Number in residential services:	29
Self-response:	71%	Number in employment services:	0
Served by other providers:	59%	Number in day habilitation services:	0
		Number with individual support:	0

## Chesterwye Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.83	8.56	7.19	7.25	7.18	7.58	6.82	6.66
○	◐	◐	◐	◐	◐	◐	◐

Fiscal year of survey:	2004	Number of people in survey:	33
Response rate:	70%	Number in residential services:	13
Self-response:	70%	Number in employment services:	4
Served by other providers:	3%	Number in day habilitation services:	31
		Number with individual support:	29









## CHI Centers

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.99**	8.52	7.97**	7.74**	7.59**	7.41	7.04	6.82**
							

Fiscal year of survey:	2002-2005	Number of people in survey:	136
Response rate:	75%	Number in residential services:	32
Self-response:	63%	Number in employment services:	27
Served by other providers:	38%	Number in day habilitation services:	98
		Number with individual support:	8

\*\*Statistically higher than the Maryland average with the large number of people surveyed.

## Chimes Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.39	8.15	7.01*	7.13	6.94	6.86*	6.75	5.98
							

Fiscal year of survey:	2002-2005	Number of people in survey:	125
Response rate:	78%	Number in residential services:	48
Self-response:	56%	Number in employment services:	19
Served by other providers:	27%	Number in day habilitation services:	82
		Number with individual support:	10

\* Statistically lower than Maryland average with the large number of people surveyed.

## Community Living Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.13	8.04	6.71	6.42	5.98	6.85	5.20	4.58
◐	◐	◐	○	○	◐	○	○









Fiscal year of survey:	2002	Number of people in survey:	28
Response rate:	70%	Number in residential services:	25
Self-response:	50%	Number in employment services:	4
Served by other providers:	82%	Number in day habilitation services:	24
		Number with individual support:	3

## Community Support Services

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.72	8.84	7.79	8.11	8.39	7.89	6.91	6.20
◐	●	◐	●	●	●	◐	◐









Fiscal year of survey:	2004	Number of people in survey:	33
Response rate:	87%	Number in residential services:	24
Self-response:	58%	Number in employment services:	31
Served by other providers:	3%	Number in day habilitation services:	31
		Number with individual support:	3

## Community Support Services for the Deaf (CSSD)

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.11	8.26	6.57	5.99	7.03	6.70	7.12	6.48
							









Fiscal year of survey:	2002	Number of people in survey:	31
Response rate:	59%	Number in residential services:	14
Self-response:	55%	Number in employment services:	2
Served by other providers:	26%	Number in day habilitation services:	0
		Number with individual support:	4

## Council for EC&A

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.34	8.10	7.57	7.40	6.86	7.31	7.05	6.54
							









Fiscal year of survey:	2003	Number of people in survey:	19
Response rate:	65%	Number in residential services:	17
Self-response:	19%	Number in employment services:	0
Served by other providers:	84%	Number in day habilitation services:	0
		Number with individual support:	1

## Creative Options

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.23	8.12	6.60	7.28	6.44	6.70	6.24	5.35
							









Fiscal year of survey:	2005	Number of people in survey:	36
Response rate:	87%	Number in residential services:	19
Self-response:	55%	Number in employment services:	0
Served by other providers:	44%	Number in day habilitation services:	12
		Number with individual support:	8

## CSAAC

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.36	8.92	8.26	7.71	7.97	7.79	7.29	6.68
							









Fiscal year of survey:	2002	Number of people in survey:	36
Response rate:	90%	Number in residential services:	33
Self-response:	55%	Number in employment services:	3
Served by other providers:	6%	Number in day habilitation services:	1
		Number with individual support:	0

## Deaf Independent Living Association

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.81	8.62	7.15	6.11	7.55	6.64	8.51	8.03
							









Fiscal year of survey:	2002	Number of people in survey:	21
Response rate:	66%	Number in residential services:	13
Self-response:	66%	Number in employment services:	3
Served by other providers:	19%	Number in day habilitation services:	5
		Number with individual support:	3

## Delmarva Community Services

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.31	8.11	7.39	7.38	6.41	7.23	6.59	5.72
							









Fiscal year of survey:	2003	Number of people in survey:	32
Response rate:	78%	Number in residential services:	19
Self-response:	56%	Number in employment services:	5
Served by other providers:	3%	Number in day habilitation services:	11
		Number with individual support:	5

## Dove Pointe Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.77	8.47	7.59	7.61	7.16	7.56	6.58	5.96
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	58
Response rate:	67%	Number in residential services:	20
Self-response:	45%	Number in employment services:	6
Served by other providers:	14%	Number in day habilitation services:	47
		Number with individual support:	9

## Ebed Enterprises

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.67	8.22	6.16	6.44	6.53	6.17	6.29	5.03
							









Fiscal year of survey:	2005	Number of people in survey:	12
Response rate:	90%	Number in residential services:	11
Self-response:	80%	Number in employment services:	0
Served by other providers:	75%	Number in day habilitation services:	0
		Number with individual support:	0

## Emerge

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.85	8.37	7.69	7.53	7.41	7.63	7.94	6.90
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	68
Response rate:	73%	Number in residential services:	45
Self-response:	57%	Number in employment services:	8
Served by other providers:	28%	Number in day habilitation services:	43
		Number with individual support:	21

## Epilepsy Association of Eastern Shore

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.11	8.43	7.74	7.58	7.62	6.89	7.69	7.34
							









Fiscal year of survey:	2005	Number of people in survey:	28
Response rate:	68%	Number in residential services:	11
Self-response:	61%	Number in employment services:	0
Served by other providers:	57%	Number in day habilitation services:	0
		Number with individual support:	8

## Family Service Foundation Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.13	8.32	7.74	6.82	6.71	6.36	3.96	4.18
							









Fiscal year of survey:	2005	Number of people in survey:	37
Response rate:	90%	Number in residential services:	26
Self-response:	8%	Number in employment services:	0
Served by other providers:	32%	Number in day habilitation services:	30
		Number with individual support:	1

## Flying Colors of Success

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.92	8.29	6.64	7.26	6.58	6.84	6.10	5.23
							









Fiscal year of survey:	2005	Number of people in survey:	30
Response rate:	93%	Number in residential services:	30
Self-response:	25%	Number in employment services:	0
Served by other providers:	97%	Number in day habilitation services:	0
		Number with individual support:	0

## Forward Visions

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.35	7.58	6.64	6.76	6.08	6.71	5.46	5.22
							

Fiscal year of survey:	2005	Number of people in survey:	31
Response rate:	76%	Number in residential services:	19
Self-response:	51%	Number in employment services:	0
Served by other providers:	61%	Number in day habilitation services:	0
		Number with individual support:	4

## Friends Aware, Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.04	9.03	8.22	8.30	8.05	8.22	7.89	7.23
							

Fiscal year of survey:	2003 & 2005	Number of people in survey:	73
Response rate:	80%	Number in residential services:	14
Self-response:	60%	Number in employment services:	7
Served by other providers:	32%	Number in day habilitation services:	43
		Number with individual support:	8

## Full Citizenship of Maryland

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.36	9.31	8.39	8.02	7.86	7.60	6.64	5.80
●	●	●	◐	●	◐	◐	◐









Fiscal year of survey:	2004	Number of people in survey:	30
Response rate:	88%	Number in residential services:	29
Self-response:	38%	Number in employment services:	20
Served by other providers:	20%	Number in day habilitation services:	20
		Number with individual support:	0

## Goodwill Industries of Monocacy Valley

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.28	8.28	7.62	7.31	7.33	7.15	8.29	6.79
●	◐	◐	◐	◐	◐	●	◐









Fiscal year of survey:	2003	Number of people in survey:	16
Response rate:	100%	Number in residential services:	0
Self-response:	100%	Number in employment services:	3
Served by other providers:	44%	Number in day habilitation services:	3
		Number with individual support:	0

## Harford Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.37	9.02	7.26	8.33	7.02	7.55	5.86	4.52
							









Fiscal year of survey:	2004	Number of people in survey:	35
Response rate:	92%	Number in residential services:	0
Self-response:	34%	Number in employment services:	0
Served by other providers:	40%	Number in day habilitation services:	35
		Number with individual support:	0

## Head Injury Rehabilitation

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.85	7.73	7.18	7.46	6.34	6.57	6.93	7.75
							









Fiscal year of survey:	2005	Number of people in survey:	20
Response rate:	56%	Number in residential services:	12
Self-response:	56%	Number in employment services:	7
Served by other providers:	0%	Number in day habilitation services:	6
		Number with individual support:	3

## Horizon Goodwill Industries

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.95	8.53	7.82	7.65	7.42	7.40	7.94	6.08
							









Fiscal year of survey:	2002	Number of people in survey:	25
Response rate:	62%	Number in residential services:	0
Self-response:	32%	Number in employment services:	0
Served by other providers:	32%	Number in day habilitation services:	23
		Number with individual support:	0

## Humanim

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.43	8.40	7.05	6.95	7.13	6.92	7.08	6.98
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	56
Response rate:	64%	Number in residential services:	3
Self-response:	56%	Number in employment services:	14
Served by other providers:	52%	Number in day habilitation services:	21
		Number with individual support:	2

## Intervals

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.04	8.95	6.71	8.16	7.48	7.20	5.49	4.72
							









Fiscal year of survey:	2003	Number of people in survey:	34
Response rate:	82%	Number in residential services:	23
Self-response:	32%	Number in employment services:	3
Served by other providers:	41%	Number in day habilitation services:	9
		Number with individual support:	2

## Jeanne Bussard Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.82	8.73	8.11	8.59	7.97	8.33	8.37	7.56
							









Fiscal year of survey:	2004	Number of people in survey:	44
Response rate:	88%	Number in residential services:	0
Self-response:	84%	Number in employment services:	6
Served by other providers:	48%	Number in day habilitation services:	40
		Number with individual support:	4

## Jewish Family Services

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.63	8.34	6.88	7.34	7.31	7.32	7.61	7.18
							









Fiscal year of survey:	2003	Number of people in survey:	32
Response rate:	79%	Number in residential services:	12
Self-response:	68%	Number in employment services:	0
Served by other providers:	47%	Number in day habilitation services:	0
		Number with individual support:	5

## Jewish Fd for Group Homes

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.26	8.63	8.33	8.27	8.12	7.94	6.93	7.09
							









Fiscal year of survey:	2004	Number of people in survey:	43
Response rate:	88%	Number in residential services:	38
Self-response:	69%	Number in employment services:	0
Served by other providers:	84%	Number in day habilitation services:	0
		Number with individual support:	5

## Jewish Social Services Agency

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.09	9.13	7.52	8.55	8.67	7.40	7.00	6.70
							

Fiscal year of survey:	2003	Number of people in survey:	23
Response rate:	65%	Number in residential services:	0
Self-response:	46%	Number in employment services:	4
Served by other providers:	22%	Number in day habilitation services:	4
		Number with individual support:	4

## Jubilee Association of Maryland

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.89	8.32	8.45	8.09	7.38	7.66	7.00	7.03
							

Fiscal year of survey:	2002	Number of people in survey:	28
Response rate:	72%	Number in residential services:	15
Self-response:	62%	Number in employment services:	6
Served by other providers:	61%	Number in day habilitation services:	13
		Number with individual support:	1

## Kennedy Kreiger Institute

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.57	7.90	4.78	7.60	6.36	5.48	5.74	4.67
○	◐	○	◐	○	○	○	○

Fiscal year of survey:	2005	Number of people in survey:	11
Response rate:	42%	Number in residential services:	0
Self-response:	19%	Number in employment services:	0
Served by other providers:	0%	Number in day habilitation services:	0
		Number with individual support:	0

## Kent Center Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.32	8.23	6.98	7.41	7.06	7.55	6.63	5.52
◐	◐	◐	◐	◐	◐	◐	◐

Fiscal year of survey:	2002	Number of people in survey:	25
Response rate:	64%	Number in residential services:	11
Self-response:	51%	Number in employment services:	7
Served by other providers:	8%	Number in day habilitation services:	11
		Number with individual support:	9

## Langton Green

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.50	7.94	6.58	6.65	6.49	7.15	5.89	5.01
●	●	●	○	●	●	●	○









Fiscal year of survey:	2005	Number of people in survey:	38
Response rate:	76%	Number in residential services:	36
Self-response:	54%	Number in employment services:	0
Served by other providers:	87%	Number in day habilitation services:	0
		Number with individual support:	1

## League for People with Disabilities

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.99	7.59	6.51	7.42	7.90	7.13	7.68	7.17
●	○	●	●	●	●	●	●








Fiscal year of survey:	2005	Number of people in survey:	13
Response rate:	57%	Number in residential services:	0
Self-response:	52%	Number in employment services:	13
Served by other providers:	8%	Number in day habilitation services:	0
		Number with individual support:	0

## Life

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.69	8.41	6.91	7.02	7.18	7.06	6.15	5.40
							









Fiscal year of survey:	2003	Number of people in survey:	37
Response rate:	84%	Number in residential services:	35
Self-response:	43%	Number in employment services:	0
Served by other providers:	86%	Number in day habilitation services:	0
		Number with individual support:	2

## Linwood Children's Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.29	9.25	7.83	8.79	8.57	8.55	7.95	8.15
							









Fiscal year of survey:	2004	Number of people in survey:	18
Response rate:	95%	Number in residential services:	17
Self-response:	68%	Number in employment services:	15
Served by other providers:	11%	Number in day habilitation services:	16
		Number with individual support:	0

## Lower Shore Enterprises

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.51	8.76	8.18	7.69	7.81	7.26	7.55	7.06
							

Fiscal year of survey:	2005	Number of people in survey:	37
Response rate:	74%	Number in residential services:	0
Self-response:	72%	Number in employment services:	37
Served by other providers:	51%	Number in day habilitation services:	0
		Number with individual support:	0

## Lt Joseph P Kennedy Institute

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.96	8.93	7.50	8.04	7.62	7.58	6.78	6.42
							

Fiscal year of survey:	2003	Number of people in survey:	34
Response rate:	69%	Number in residential services:	6
Self-response:	50%	Number in employment services:	3
Served by other providers:	56%	Number in day habilitation services:	9
		Number with individual support:	3

## Lycher Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.40	8.91	7.50	7.37	7.49	6.95	7.22	6.23
●	●	◐	◐	◐	◐	◐	◐









Fiscal year of survey:	2005	Number of people in survey:	31
Response rate:	70%	Number in residential services:	18
Self-response:	14%	Number in employment services:	0
Served by other providers:	45%	Number in day habilitation services:	17
		Number with individual support:	0

## Maryland Neighborly Networks

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.84	8.11	7.10	7.39	6.80	7.15	6.47	6.44
◐	◐	◐	◐	◐	◐	◐	◐









Fiscal year of survey:	2004	Number of people in survey:	28
Response rate:	97%	Number in residential services:	28
Self-response:	83%	Number in employment services:	0
Served by other providers:	96%	Number in day habilitation services:	0
		Number with individual support:	0

## Medsource Community

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.17	8.96	7.95	7.53	7.00	7.26	6.07	5.93
							









Fiscal year of survey:	2004	Number of people in survey:	46
Response rate:	92%	Number in residential services:	43
Self-response:	26%	Number in employment services:	0
Served by other providers:	89%	Number in day habilitation services:	0
		Number with individual support:	3

## Melwood Horticultural Training Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.62	8.57	7.73	7.42	7.68	7.18	7.08	6.48
							









Fiscal year of survey:	2002-2005	Number of people in survey:	121
Response rate:	75%	Number in residential services:	26
Self-response:	61%	Number in employment services:	59
Served by other providers:	28%	Number in day habilitation services:	53
		Number with individual support:	10

## Mid Atlantic Human Services Corp

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.29	9.00	7.37	7.60	7.16	7.78	6.78	6.17
							









Fiscal year of survey:	2005	Number of people in survey:	16
Response rate:	68%	Number in residential services:	12
Self-response:	9%	Number in employment services:	0
Served by other providers:	69%	Number in day habilitation services:	0
		Number with individual support:	0

## Montgomery County Department of Family Resources

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.66	8.53	7.65	8.52	7.50	7.52	7.04	6.21
							









Fiscal year of survey:	2004	Number of people in survey:	19
Response rate:	50%	Number in residential services:	0
Self-response:	34%	Number in employment services:	0
Served by other providers:	63%	Number in day habilitation services:	0
		Number with individual support:	19

## National Children's Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.64	9.23	8.59	7.93	8.22	7.93	8.04	7.79
							

Fiscal year of survey:	2005	Number of people in survey:	7
Response rate:	88%	Number in residential services:	7
Self-response:	62%	Number in employment services:	0
Served by other providers:	71%	Number in day habilitation services:	0
		Number with individual support:	0

## National MS

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.60	7.56	5.57	5.88	4.87	4.94	7.55	7.96
							

Fiscal year of survey:	2005	Number of people in survey:	11
Response rate:	25%	Number in residential services:	0
Self-response:	25%	Number in employment services:	0
Served by other providers:	0%	Number in day habilitation services:	0
		Number with individual support:	11

## NCIA CBAI

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.51	7.81	7.12	7.22	7.38	7.56	6.22	6.14
○	◐	◑	◑	◑	◑	◑	◑









Fiscal year of survey:	2003	Number of people in survey:	34
Response rate:	82%	Number in residential services:	31
Self-response:	65%	Number in employment services:	3
Served by other providers:	65%	Number in day habilitation services:	5
		Number with individual support:	8

## Netcon & Earthkins Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.73	7.16	6.75	7.36	7.28	6.42	6.64	5.92
○	○	◑	◑	◑	○	◑	◑









Fiscal year of survey:	2004	Number of people in survey:	29
Response rate:	83%	Number in residential services:	24
Self-response:	69%	Number in employment services:	0
Served by other providers:	93%	Number in day habilitation services:	0
		Number with individual support:	11

## Opportunity Builders

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.72	8.14	7.65	7.94	7.59	8.05	7.24	7.20
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	53
Response rate:	63%	Number in residential services:	0
Self-response:	55%	Number in employment services:	11
Served by other providers:	57%	Number in day habilitation services:	39
		Number with individual support:	7

## PACT: Helping Children with Special Needs

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
6.88	7.06	5.14	6.60	7.17	5.69	7.19	6.47
							









Fiscal year of survey:	2004	Number of people in survey:	24
Response rate:	83%	Number in residential services:	0
Self-response:	83%	Number in employment services:	0
Served by other providers:	12%	Number in day habilitation services:	0
		Number with individual support:	24

## Penn Mar

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.57	8.77	8.33	8.24	8.24	7.71	7.35	7.05
							

Fiscal year of survey:	2002	Number of people in survey:	29
Response rate:	72%	Number in residential services:	18
Self-response:	50%	Number in employment services:	1
Served by other providers:	10%	Number in day habilitation services:	16
		Number with individual support:	10

## Progress Unlimited

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.32	7.78	6.24	6.69	6.05	6.38	5.05	4.55
							

Fiscal year of survey:	2005	Number of people in survey:	39
Response rate:	97%	Number in residential services:	39
Self-response:	26%	Number in employment services:	0
Served by other providers:	74%	Number in day habilitation services:	0
		Number with individual support:	0

## Progressive Horizons

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.16	7.84	6.45	7.19	7.80	6.87	7.02	6.32

Fiscal year of survey:	2005	Number of people in survey:	34
Response rate:	85%	Number in residential services:	33
Self-response:	72%	Number in employment services:	0
Served by other providers:	79%	Number in day habilitation services:	0
		Number with individual support:	0









## Providence Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.32	8.17	7.25	7.56	7.62	7.78**	7.22	6.30

Fiscal year of survey:	2002-2005	Number of people in survey:	116
Response rate:	70%	Number in residential services:	0
Self-response:	55%	Number in employment services:	17
Served by other providers:	63%	Number in day habilitation services:	86
		Number with individual support:	9









\*\*Statistically higher than the Maryland average with the large number of people surveyed.

## R & D Instructional Services

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.08	7.93	6.87	7.89	7.31	7.19	7.23	6.38
							









Fiscal year of survey:	2004	Number of people in survey:	30
Response rate:	75%	Number in residential services:	0
Self-response:	68%	Number in employment services:	18
Served by other providers:	77%	Number in day habilitation services:	23
		Number with individual support:	7

## Ray of Hope Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.03	8.30	7.58	7.90	7.56	7.91	7.65	6.14
							









Fiscal year of survey:	2004	Number of people in survey:	22
Response rate:	46%	Number in residential services:	11
Self-response:	38%	Number in employment services:	0
Served by other providers:	73%	Number in day habilitation services:	0
		Number with individual support:	11

## Rehabilitation Opportunities

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.99	7.78	6.47	7.38	7.27	6.81	6.41	5.80
							









Fiscal year of survey:	2002 & 2004	Number of people in survey:	69
Response rate:	79%	Number in residential services:	0
Self-response:	76%	Number in employment services:	5
Served by other providers:	25%	Number in day habilitation services:	65
		Number with individual support:	0

## REM Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.02	8.44	7.59	7.67	7.13	6.65	6.09	4.65
							









Fiscal year of survey:	2005	Number of people in survey:	11
Response rate:	83%	Number in residential services:	10
Self-response:	42%	Number in employment services:	0
Served by other providers:	64%	Number in day habilitation services:	0
		Number with individual support:	0

## Richcroft

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.82	8.76	8.07	8.16	7.79	8.14	7.79	6.95
							









Fiscal year of survey:	2003	Number of people in survey:	38
Response rate:	80%	Number in residential services:	36
Self-response:	56%	Number in employment services:	0
Served by other providers:	84%	Number in day habilitation services:	0
		Number with individual support:	0

## Rock Creek Foundation

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.14	7.60	7.41	7.38	7.78	7.20	7.54	7.17
							









Fiscal year of survey:	2005	Number of people in survey:	29
Response rate:	76%	Number in residential services:	9
Self-response:	76%	Number in employment services:	13
Served by other providers:	38%	Number in day habilitation services:	7
		Number with individual support:	1

## Scott Key Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.28	9.10	8.06	8.49	7.91	8.26	7.82	6.71
							









Fiscal year of survey:	2003	Number of people in survey:	41
Response rate:	82%	Number in residential services:	0
Self-response:	64%	Number in employment services:	9
Served by other providers:	56%	Number in day habilitation services:	15
		Number with individual support:	0

## Securecare Services

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.92	8.43	8.02	8.03	7.99	7.76	6.91	6.35
							









Fiscal year of survey:	2004	Number of people in survey:	34
Response rate:	87%	Number in residential services:	29
Self-response:	59%	Number in employment services:	0
Served by other providers:	59%	Number in day habilitation services:	0
		Number with individual support:	5

## SEEC

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.20	9.04	8.50	8.05	7.45	7.63	5.72	5.29
							

Fiscal year of survey:	2002	Number of people in survey:	28
Response rate:	71%	Number in residential services:	0
Self-response:	47%	Number in employment services:	3
Served by other providers:	36%	Number in day habilitation services:	2
		Number with individual support:	0

## Selfpride

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.98	8.99	6.35	6.97	6.42	6.81	5.27	5.07
							

Fiscal year of survey:	2005	Number of people in survey:	21
Response rate:	90%	Number in residential services:	20
Self-response:	15%	Number in employment services:	0
Served by other providers:	43%	Number in day habilitation services:	0
		Number with individual support:	0

## Shura

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.81	7.69	6.72	6.91	7.67	7.45	6.32	6.57
○	○	◐	◐	◐	◐	◐	◐

Fiscal year of survey:	2005	Number of people in survey:	33
Response rate:	75%	Number in residential services:	28
Self-response:	67%	Number in employment services:	0
Served by other providers:	82%	Number in day habilitation services:	0
		Number with individual support:	0

## Somerset Community Services Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.43	8.38	7.77	7.39	7.21	7.24	7.00	6.19
◐	◐	◐	◐	◐	◐	◐	◐

Fiscal year of survey:	2005	Number of people in survey:	43
Response rate:	88%	Number in residential services:	16
Self-response:	65%	Number in employment services:	3
Served by other providers:	9%	Number in day habilitation services:	38
		Number with individual support:	4

## Southern Maryland Vocational Industries

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.04	8.75	7.27	7.72	7.73	7.36	7.30	6.95
●	●	●	●	●	●	●	●

Fiscal year of survey:	2003	Number of people in survey:	28
Response rate:	72%	Number in residential services:	12
Self-response:	56%	Number in employment services:	1
Served by other providers:	50%	Number in day habilitation services:	5
		Number with individual support:	2

## Spring Dell Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.72	8.31	7.37	7.71	7.62	7.78	7.22	5.54
●	●	●	●	●	●	●	●

Fiscal year of survey:	2002 & 2004	Number of people in survey:	66
Response rate:	75%	Number in residential services:	13
Self-response:	56%	Number in employment services:	18
Served by other providers:	36%	Number in day habilitation services:	41
		Number with individual support:	11

## St. Peters Adult Learning

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.17	7.07	6.00	7.07	7.23	7.48	6.90	5.76
○	○	○	◐	◐	◐	◐	◐

Fiscal year of survey:	2005	Number of people in survey:	34
Response rate:	85%	Number in residential services:	0
Self-response:	85%	Number in employment services:	19
Served by other providers:	21%	Number in day habilitation services:	15
		Number with individual support:	0

## Starflight

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.14	8.35	7.41	7.25	7.85	6.28	5.28	5.43
◐	◐	◐	◐	●	○	○	◐

Fiscal year of survey:	2003	Number of people in survey:	14
Response rate:	68%	Number in residential services:	14
Self-response:	37%	Number in employment services:	0
Served by other providers:	100%	Number in day habilitation services:	0
		Number with individual support:	3

## Target, Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.80	8.80	7.66	7.97	8.14	7.90	7.58	7.51
◐	◐	◐	◐	●	●	◐	●









Fiscal year of survey:	2005	Number of people in survey:	37
Response rate:	77%	Number in residential services:	8
Self-response:	60%	Number in employment services:	25
Served by other providers:	35%	Number in day habilitation services:	0
		Number with individual support:	6

## Treatment & Learning Center Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.03	8.59	7.58	7.97	7.55	7.52	7.48	7.08
◐	◐	◐	◐	◐	◐	◐	●

Fiscal year of survey:	2004	Number of people in survey:	32
Response rate:	80%	Number in residential services:	0
Self-response:	80%	Number in employment services:	27
Served by other providers:	19%	Number in day habilitation services:	27
		Number with individual support:	6









## UCP of Central Maryland

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.71	8.54	7.35	7.45	7.02*	7.13	6.99	5.66*
							

Fiscal year of survey:	2002-2005	Number of people in survey:	122
Response rate:	74%	Number in residential services:	56
Self-response:	47%	Number in employment services:	16
Served by other providers:	19%	Number in day habilitation services:	61
		Number with individual support:	36

\* Statistically lower than Maryland average with the large number of people surveyed.

## UCP of Prince George's & Montgomery Counties

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
7.98	7.84	7.77	7.50	7.46	6.91	7.94	6.86
							

Fiscal year of survey:	2004	Number of people in survey:	24
Response rate:	89%	Number in residential services:	0
Self-response:	81%	Number in employment services:	9
Served by other providers:	29%	Number in day habilitation services:	9
		Number with individual support:	15

## UCP of Southern Maryland

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.62	8.55	7.09	7.72	7.55	7.43	7.78	7.16
◐	◐	◐	◐	◐	◐	●	●









Fiscal year of survey:	2003 & 2005	Number of people in survey:	64
Response rate:	67%	Number in residential services:	10
Self-response:	62%	Number in employment services:	22
Served by other providers:	34%	Number in day habilitation services:	8
		Number with individual support:	9

## Voca Corporation

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.61	8.50	7.60	7.48	6.43	7.06	5.00	4.24
◐	◐	◐	◐	◐	◐	○	○









Fiscal year of survey:	2004	Number of people in survey:	17
Response rate:	89%	Number in residential services:	17
Self-response:	21%	Number in employment services:	0
Served by other providers:	94%	Number in day habilitation services:	0
		Number with individual support:	0

## Vocational Services Inc

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.94	8.75	7.93	7.82	7.62	7.66	7.03	5.71
							









Fiscal year of survey:	2003 & 2005	Number of people in survey:	72
Response rate:	81%	Number in residential services:	0
Self-response:	52%	Number in employment services:	23
Served by other providers:	65%	Number in day habilitation services:	43
		Number with individual support:	1

## Washington Co HDC

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
9.29	8.82	8.03	7.82	7.43	7.60	7.37	6.17
							









Fiscal year of survey:	2004	Number of people in survey:	49
Response rate:	98%	Number in residential services:	26
Self-response:	46%	Number in employment services:	1
Served by other providers:	27%	Number in day habilitation services:	30
		Number with individual support:	1

## Worcester County Developmental Center

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
8.52	8.09	7.46	8.07	7.93	7.59	7.31	6.97
							

Fiscal year of survey:	2002	Number of people in survey:	26
Response rate:	67%	Number in residential services:	3
Self-response:	56%	Number in employment services:	1
Served by other providers:	4%	Number in day habilitation services:	22
		Number with individual support:	2

## Workfirst

Physical Wellbeing	Emotional Wellbeing	Material Wellbeing	Inter-Personal Relations	Personal Development	Social Inclusion	Self-Determination	Rights
6.83	7.65	6.07	7.07	6.68	6.59	6.99	5.97
							

Fiscal year of survey:	2004	Number of people in survey:	24
Response rate:	53%	Number in residential services:	0
Self-response:	53%	Number in employment services:	16
Served by other providers:	17%	Number in day habilitation services:	24
		Number with individual support:	0