

Ask Me!sm FY 2006-2009



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

Judy Volkman, BA
Sarah Sorensen, MPS
The Arc of Maryland

December 2009

Authors

Gordon Scott Bonham has been the project's researcher from the initial development of the original questions to the present. He is President of Bonham Research, a private human services research and evaluation company. His 38 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 is an Emeritus Board Member of The Arc of Baltimore.

Judy Volkman is the Ask Me! Project Manager at the Arc of Maryland and is in charge of all the field work activities. She was supported by Nolie Rife, Suzy Fletcher and Brenda Davis as regional coordinators. Ann Shipley scheduled interviews and arranged transportation.

Sarah Sorensen is Assistant Director of The Arc of Maryland. Ms. Sorensen holds a Master's Degree in Policy Sciences from the University of Maryland Baltimore County. In addition to her responsibilities on 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.

Committed and skilled interviewers, who themselves receive support funded by the Maryland Developmental Disabilities Administration, make The Ask Me! Project possible. In FY2009, 29 peer interviewers worked for The Arc of Maryland, conducting an average of 91 interviews. The interviewers have an average of 5.8 years of experience, with three being new to the survey in FY2009 and six having ten or more years of experience. One interviewer conducted telephone interviews and keyed most of the survey data (DE). The Ask Me! FY2009 interviewers, with their years of experience shown in parentheses (), include:

Alisha Wright (1)	Emerald Coleman (3)	Michael Raidt (10)
Anne Bates (6)	Greg Gray (6)	Patrick Rhinehart (6)
April Carr (4)	James Devore (12)	Peggy Nazelrod (4)
Bernadette Quinn (5)	John Giles (2)	Reta Cooper (2)
Brian Plater (8)	Kathy Gentile (1)	Robert Heil (6)
Bridgette Pressley (11)	Linda Cooper (9)	Scott Heim (11)
Carolina Cano (7)	Lois Southard (1)	Valerie Smith (4)
Christy Scott (3)	Lori Powell (11)	Vernon DeHaven (10)
Crystal Stephens (3)	Marianne McNally (4, DE)	Vicki Mills (9)
Diana Warther (7)	Michael Carter (2)	

Ask Me! has a training manual available 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 Judy Volkman, The Arc of Maryland, 49 Old Solomons Island Rd., Suite 205, Annapolis, MD 21401, 888-272-3449, jvolkman@thearcmd.org.

This report can be viewed or downloaded as an Adobe Acrobat file from the website of the Maryland Developmental Disability Administration, <http://www.dhmd.state.md.us/dda/ReportableInc/Ask09Report.pdf>. It, and other publications listed at the end of this report, can be accessed through the website of Bonham Research, <http://www.bonhamresearch.com>.

Ask Me!sm FY 2006-2009

Executive Summary

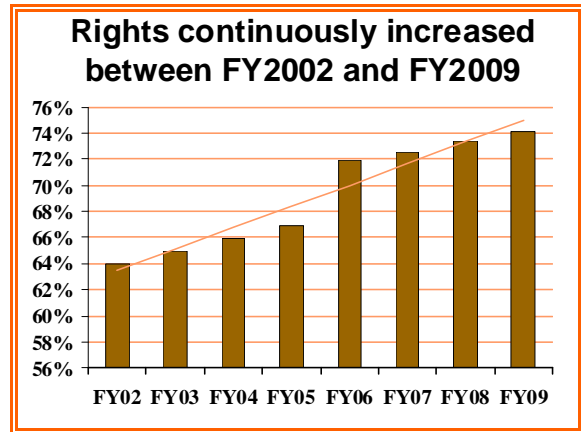
The FY2009 Ask Me! collected information between August 2008 and June 2009 for about 1,200 people with developmental disabilities 18 years and over who are supported by 45 community provider agencies. Over the four years between FY2006 and 2009, Ask Me! Surveys were conducted for about 5,000 people at 120 agencies supporting ten or more adults. These represent about 13,000 people at the 155 community provider agencies that received funds from the Maryland Developmental Disabilities Administration (DDA). Peer interviewers directly interviewed 77% of the sampled people, including 19% of those classified with profound intellectual disability. They interviewed proxies for those unable to respond for themselves.

Quality of Life Change in Maryland

The quality of life in eight domains has been measured in two ways annually in Maryland from between FY2002 and FY2009. The first is the percent reporting a positive quality of life, and the second is the average quality of life on a scale of 0-10. The increase between FY2002 and FY2009 of the two measures had three general patterns:

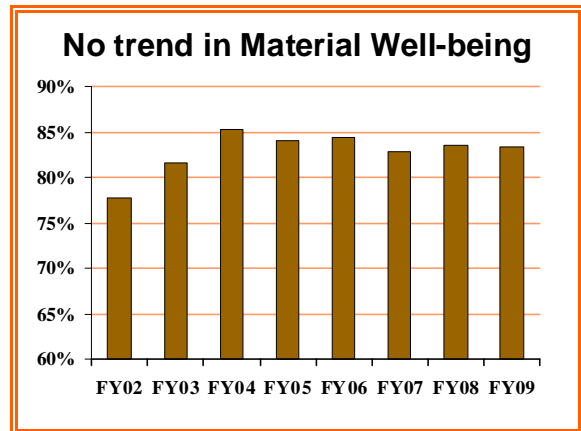
Consistent linear increase

- Rights--10.1% in positive quality of life (see **chart**) and 0.6 points in the average quality of life;
- Self-Determination--8.3% positive, 0.5 average;
- Social Inclusion--5.9% positive, 0.5 average;
- Personal Development--6.8% positive, 0.4 average.



Mixed linear and curvilinear increase

- Physical Well-being--4.4% positive linearly, 0.4 average with a plateau;
- Emotional Well-being--4.3% positive linearly, 0.4 average with a plateau;
- Interpersonal Relations--7.4% positive with peak, 0.6 average with a plateau.

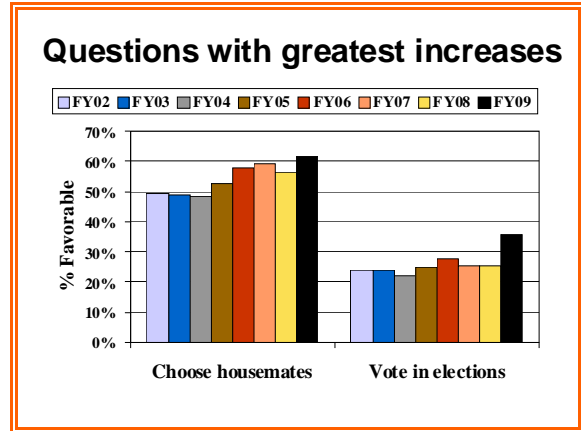


No statistical pattern of change

- Material Well-being--5.7% positive, 0.2 average, highest in FY2004 (see **chart**).

Quality of life remained highest throughout the eight years in the domains of Physical Well-being and Emotional Well-being. It remained lowest in the domains of Self-Determination and Rights. The differences, however, decreased.

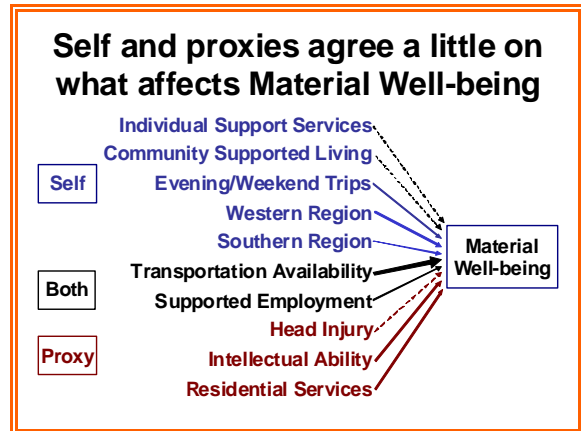
People interviewed in FY2009 gave significantly more favorable responses to six questions than people interviewed in FY2008. The greatest one-year increase was in voting, from 25% to 36%, (See **chart**.) The second greatest increase came in choosing house or roommates, from 57% to 62%. Choosing house or roommates also had the greatest average increase over the eight years of the Ask Me! Survey—2.0 percentage points per year. This was followed by people helping them when they make a mistake—1.9 percentage points per year—and is it easy to say something when you have a problem with staff—1.8 percentage points per year. Together, 34 of the 48 indicator questions had significant increases in favorable responses. No question had a significant decline over the eight years.



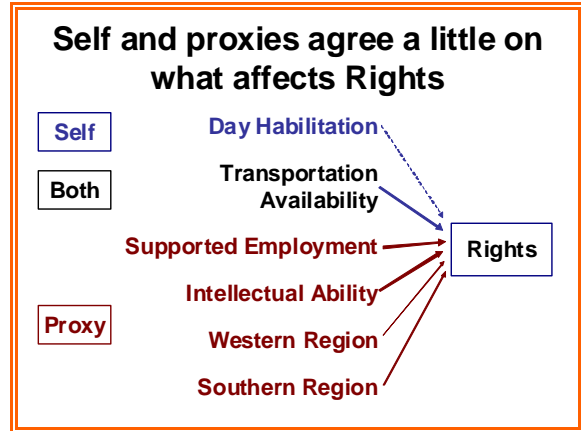
Person and Service Characteristics and Quality of Life

People who respond for themselves reported lower quality of life in the domains of Physical Well-being and Emotional Well-being than did proxies for people who could not respond for themselves. Self respondents reported higher quality of life than did proxies in the other six domains and in Transportation Availability. Self and proxy reports often differ on what characteristics relate to quality of life.

In the domain of Material Well-being, which changed least over the past eight years, both self and proxy respondents reported higher Material Well-being for people who received supported employment services and for people who consider transportation more available (solid arrows in the **chart**.) Self respondents who lived in the western or southern DDA regions, and/or whose agencies took them places other than work or their day programs, reported higher Material Well-being than those living in the central or eastern regions and/or who did not receive evening and weekend trips. Self respondents with individual support services and community supported living arrangements reported lower Material Well-being than those not receiving these services (dashed arrows), possibly because they were more aware or had more control over their financial affairs. Proxies reported higher Material Well-being for those with head injuries, those with greater intellectual abilities, or those receiving residential services than for those with other personal characteristics or services.



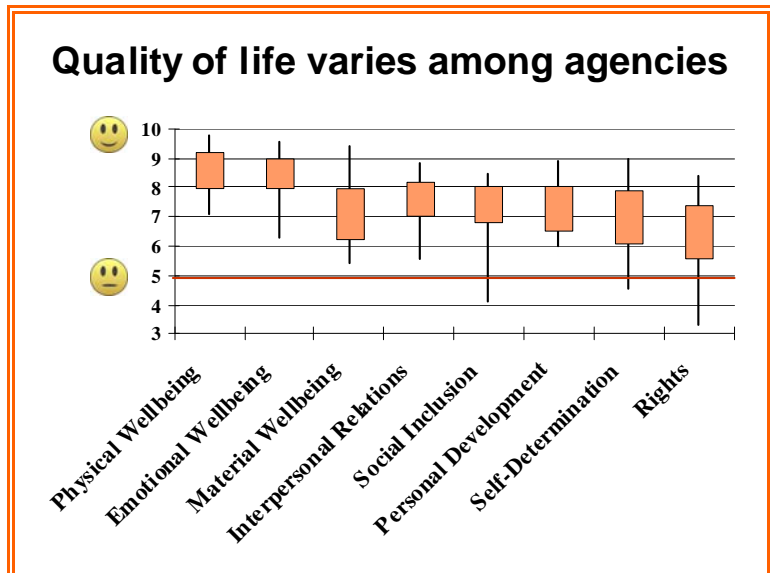
In the domain of Rights, which has changed the most over the past eight years, both self and proxy reports show that greater perception of Transportation Availability is related to greater Rights. (See **chart**.) Self respondents receiving day habilitation report lower rights than those receiving only other types of services. Proxies may not be too different in this respect, as they report higher Rights for the few who were in supported employment compared to those who received day habilitation or no support for weekday activities. Only proxies reported greater Rights for people with more intellectual ability, and for people who lived in the western and southern regions of Maryland.



No characteristics of individuals and their services were as strongly associated with quality of life as who responded (or the ability to respond) and the perceived availability of transportation. The latter had the strongest relationship to quality of life in six domains, and who responded had the strongest relationship to quality of life in two domains.

Quality of Life at Maryland Agencies

Survey data are available for 119 community agencies between FY2006 and FY2009. Physical Well-being varied between 7.1 and 9.8 among the agencies, with 70% between 8.2 and 9.2. (See **chart**.) The difference in Emotional Well-being between the highest and the lowest agency was greater than in Physical Well-being, but 70% of the agencies were in a narrower range. Agencies varied the most in Rights (3.3 to 8.4), with six agencies having unfavorable scores. They varied next most in Self-Determination, with four having unfavorable scores.



Characteristics of the people agencies support, and the services agencies provide, explain the least variation (14%) in Interpersonal Relations and the most (42%) in Rights. One-third of the variation in Material Well-being can be explained by western and southern geographic location (higher than central and eastern location) and intellectual ability (higher at agencies supporting

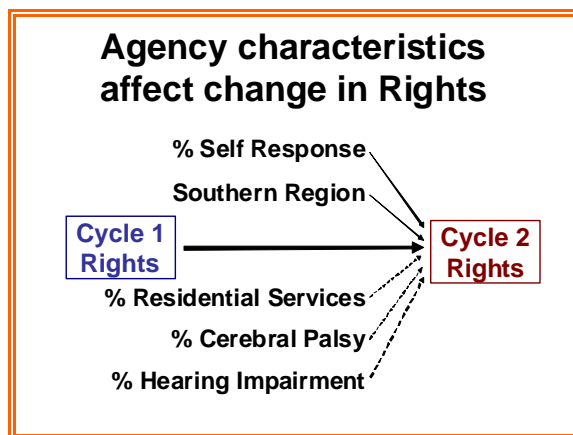
people with greater intellectual abilities). Two-fifths of the variation in Rights can be explained by the percent who responded for themselves (higher Rights with greater self response), southern location (higher Rights than in other areas), cerebral palsy (lower Rights with higher percentages), hearing impairments (lower Rights with higher percentages), and residential services (lower Rights with higher percentages). The characteristics associated with the quality of life in more than one domain were as follows:

- Western DDA region (higher in 6 domains);
- Southern DDA region (higher in 3 domains);
- Greater intellectual ability (higher in 3 domains);
- Greater self response (higher in two domains, lower in one domain);
- Greater percent with cerebral palsy (lower in 3 domains);
- Greater percent with supported employment (higher in 2 domains);
- Greater percent with residential services (lower in 2 domains).

Survey data were collected for 108 agencies in both the FY2002-FY2005 cycle and the FY2006-FY2009 cycle. Quality of life scores by agency in the two cycles were most similar in the domains of Interpersonal Relations and Self-Development. They were least similar in the domain of Emotional Well-being. Material Well-being scores declined for about as many agencies as they increased, and in only 5% of the agencies did it increase by 1.0 point or more. In contrast, average Rights scores increased for 75% of the agencies, and increased by 1.0 point or more for 21% of the agencies.

No agency characteristic had a significant relationship with change in Material Well-being. The level of Material Well-being in the second cycle was only associated with the level of Material Well-being in the first cycle. While southern region, intellectual abilities, supported employment, and behavior problems affected the first cycle’s reporting of Material Well-being, these characteristics had no independent direct effect on the second cycle’s reporting.

The level of Rights reported during the second cycle was affected by the level of Rights reported during the first cycle, but also by five other characteristics. Given the same level of Rights reported in cycle one, southern agencies and/or agencies with higher rates of self response had higher rights reported in the second cycle than agencies in other DDA regions and/or agencies with lower rates of self response. Rights started out higher at agencies with high self response, and increased more rapidly among those agencies between cycle one and cycle two. Agencies in the southern region did not start out with higher Rights than agencies in other regions, but Rights increased faster among southern agencies over the four years more than at agencies in other regions. Rights increased less rapidly between the two



cycles at agencies primarily providing residential services, those with larger percentages of people with cerebral palsy, and those with larger percentages of people with hearing impairment.

Discussion and Suggestions

The increases between FY2002 and FY2008 in the quality of life of adults in Maryland with developmental disabilities suggest that the *Ask Me! Survey* has been effective in giving a voice to people supported by Maryland community provider agencies, and that DDA, community agencies, and advocates are listening. DDA initially set its 'Management by Objectives' goal to increase Personal Development based on FY2002 findings. The FY2004 and FY2005 *Ask Me!* reports identified rights as the only domain in which significant increases had failed to occur. The FY2004 report included the recommendation:

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

The FY2005 report recommended:

Providers should focus on enhancing rights through enhancing self-determination and personal development.

While DDA did not change its official goal, it increased its training on Self-Determination and Rights. The Arc of Maryland increased its efforts to promote Self-Determination and Rights. Apparently many community agencies followed the recommendations, especially in the southern DDA region. As a result, the quality of life increased more, and more consistently during the second four-year cycle in Self-Determination and Rights than in the other six domains. Increases still occurred in the other domains, and seem to be continuing to increase in all but Material Well-being.

The increases in quality of life between FY2002 and FY2009 show that quality of life is dynamic, not static. Yet the strongest predictor of the quality of life reported for agencies was the quality of life reported for the agencies four years before. The *Ask Me! Survey* provides information that agencies can use in evaluating how they are contributing to the quality of life of the people they support and how they compare to other agencies. The survey also provides information to DDA to set and pursue system goals, and to individuals and families as they seek support for living a life of quality. Based upon the survey findings highlighted in this report, the researcher offers the following suggestions:

Suggestion 1. Increase the emphasis that is placed on Material Well-being, without neglecting the progress that has been made in Self-Determination and Rights. The greatest impact on Material Well-being potentially comes from expanding paid work opportunities through supported community employment.

Suggestion 2. Help people be aware of all the transportation available to them to move about their community, as perceptions of transportation availability are strongly related to perceptions of quality of life. The objective number of trips known to staff has little relation to perceptions of availability, but transportation is seen as more available in western and southern Maryland, at smaller than larger agencies, and by proxies more than self respondents.

Suggestion 3. Community agencies should set specific goals to enhance quality of life in domains with relatively low scores, and research concrete strategies for achieving them. Otherwise quality of life will remain similar to the current levels for the people they support.

Suggestion 4. Educate staff and families about how the self respondents they support view quality of life. Knowing this information could help to reduce potential bias when deciding what might enhance the quality of life for people unable to respond for themselves.

Suggestion 5. DDA could identify existing data on individuals and agencies that can be linked with the Ask Me! data to identify other factors that potentially affect quality of life.