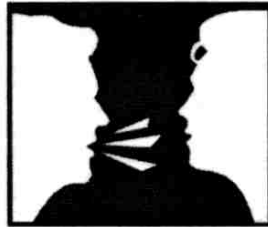


# **Ask Me!<sup>sm</sup> FY 2003**

## **The Quality of Life of Marylanders With Developmental Disabilities**



## **Receiving DDA Funded Supports**

Prepared for the  
Maryland Developmental Disabilities Administration

by  
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Bonham Research

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## 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 32 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 received 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 services to people with cognitive 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 fourteen years. Ms. Marchand has been associated with disability rights organizations at the local, state and national levels over the past twenty-two years in Maryland, Colorado, Minnesota and Washington, D.C. She received her Masters' 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.

Committed and skilled interviewers, who themselves have received service funded by the DDA, make The Ask Me! Project possible. In FY2003, 39 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 2.8 years of Ask Me! experience, with five interviewers having interviewed in all six years of the survey and three interviewers having interviewed for five years. One interviewer also served as a Regional Supervisor (RS) and two interviewers served as Quality Assurance Consultants (QA). Linda McKinley, a former interviewer, worked for Bonham Research as Data Entry Clerk. The Ask Me! FY2003 interviewers, with years interviewing in parentheses (), included:

Amy Grossman (1)	Courtney Moores (1)	Linda Cooper (2)
Amy Toblin (1)	David Wissinger (3)	Lori Powell (5)
Angela Weeda (1)	Diana Warther (1)	Michael Danzig (6)
Angie Lepore (2)	Faith Waugh (1)	Michael Raidt (4)
Bernadette Quinn (1)	Fran Appold (6)	Missy Perrott (2)
Betsy Partrige (4)	James Devore (6)	Patrick Rhinehart (1)
Branden Frahm (1)	Howard Holland (1)	Patty Worff (4)
Brenda Momyer (1)	John Sorensen (1)	Robert Haburchak (6)
Brian Plater (2)	Kenice Fleming (2)	Rose Marie Hancock (4)
Bridgette Pressley (5, QA)	Kenneth Capone (1)	Scott Heim (5)
Carlo Harris (6, QA)	Kevin Duckworth (4)	Tracy Wright (3, RS)
Carolina Cano (1)	Kim Witt (4)	Vernon DeHaven (4)
Carrie Krueger (1)	Kimberly Smith (4)	Vicki Mills (3)

Ask Me! has available a training manual for organizations interested in replicating 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 105, 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 long-term quality of life using questions developed by self-advocates. Three-fourths of those surveyed responded for themselves. The FY2003 survey was the second year of a four-year cycle to survey adults in Maryland supported by the Developmental Disabilities Administration (DDA) through community providers serving ten or more people. This report describes the FY2003 survey and presents findings from the combined FY2002 and FY2003 *Ask Me! Surveys* that together included 2,122 people served by 61 providers.

Among people supported by DDA, 57% are men, 74% are 25-54 years of age, and 31% are classified with severe or profound retardation. DDA funds residential services for 37% of the people, employment services for 31%, day habilitation for 45%, individual support services for 16%, community supported living assistance for 10%, and resource coordination services for 47%. People receive an average of 1.9 services and 76% receive services from a single provider.

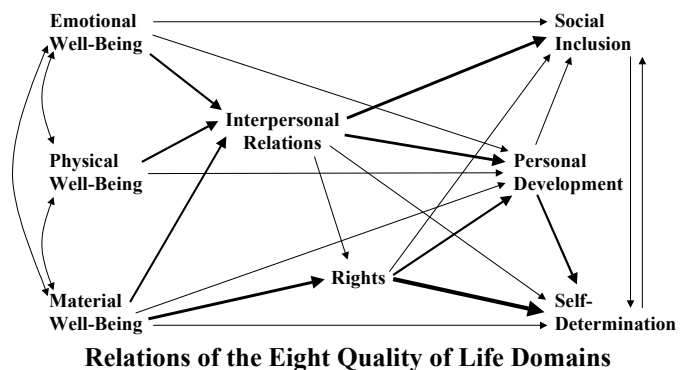
This report includes additional information from staff about transportation provided to the people interviewed, information from providers' quality assurance plans, and information from providers on their use of Ask Me! data. The findings provide information to help all parts of the support system to understand what contributes to the quality of life of people with developmental disabilities, to help the state and community providers to enhance services, and to help individuals and their families to make informed choices about services. Seven conclusions and recommendations are supported by the project's findings which are summarized below each conclusion.

1. A life of quality has eight dimensions that are interrelated, and the goal of all parts of the developmental disabilities system should be to enhance people's quality of life.

a. Interpersonal relations and personal development are central to a life of quality as they relate to all of the other quality of life domains

b. Social inclusion and self-determination, along with personal development, are the three stated missions of DDA, with social inclusion most affected by interpersonal relations, self-determination most affected by rights, and personal development equally affected by interpersonal relations and rights

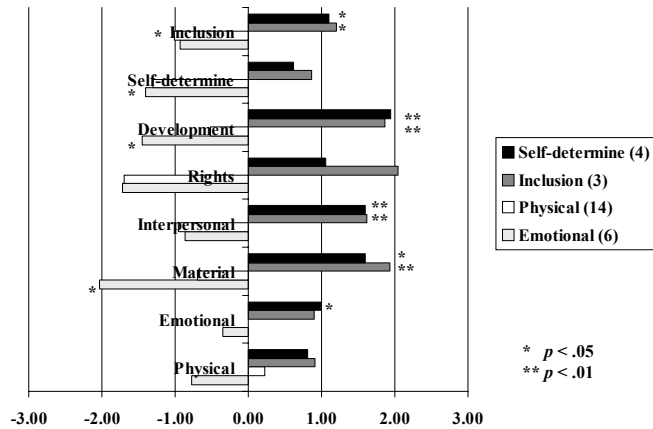
c. Physical well-being, emotional well-being and material well-being are foundational, relating to each other and directly affecting interpersonal relations, with material well-being also strongly affecting rights.



2. People who receive services from the Maryland Developmental Disabilities Administration

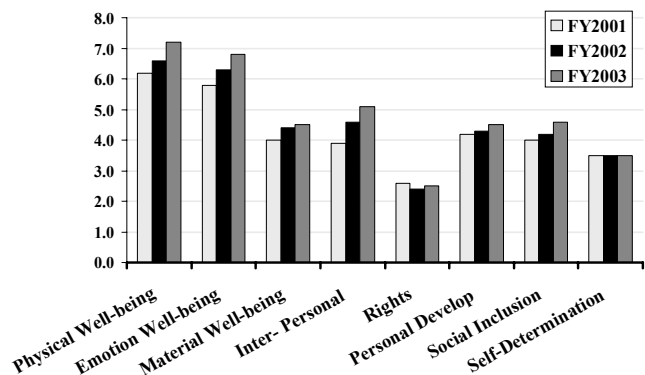
have very positive views of their physical and emotional well-being that vary little by provider. While these foundational domains should be maintained, greater attention needs to be given to other domains of a life of quality.

- a. 94% of the people in FY2003 reported positive scores on physical well-being and 93% reported positive scores on emotional well-being, both higher than in FY2002
- b. Both individuals and providers had the least variability in physical and emotional well-being, and the most variability in rights and self-determination
- c. Physical well-being did not directly affect DDA's goals of social inclusion and self-determination, and emotional well-being did not directly affect self-determination
- d. Personal development was the DDA goal that related to all the other quality of life domains, even when personal and service characteristics were controlled
- e. 75% of providers had physical well-being goals in their quality assurance plans, and they saw significant declines in social inclusion
- f. 31% of providers had emotional well-being goals in their quality assurance plans and they saw significant declines in personal development, self-determination and material well-being.



Quality of Life Change by Quality Assurance Goal

3. The Maryland developmental disabilities system needs to increase its attention on rights and self-determination.
  - a. Rights and self-determination received the lowest average rating by people (2.5) and were the only domains that did not increase between FY2002 and FY2003
  - b. 35% of the people reported zero or negative scores on rights and 28% reported zero or negative scores on self-determination
  - c. 8% of the providers had negative average scores on rights
  - d. Providers had the greatest variation in rights and self-determination, and much of the variation in these domains can be explained by provider characteristics
  - e. Less international research has been done on rights than any other domain, with self-determination being the third least researched domain



Average Quality of Life by Domain and Year

f. 25% of the providers had self-determination goals in the quality assurance plans, and their quality of life significantly increased in five of the eight domains.

4. Transportation and employment services offer the greatest predictions of people's quality of life, and are therefore prime areas to consider for service enhancements.

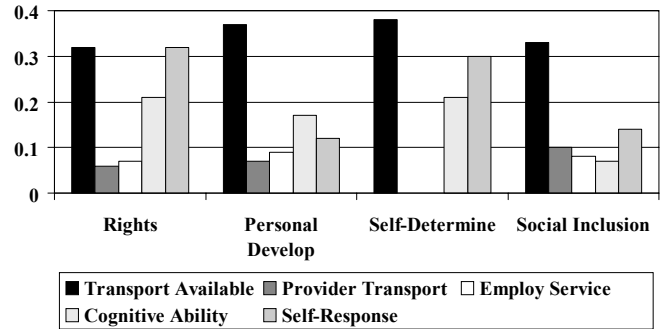
a. People's perceived availability of transportation had significant relations to all quality of life domains at both the individual and provider levels

b. In addition to people's perceptions, the more frequently providers transported people, the higher their quality of life in half the domains

c. The more providers rely on other providers to transport people they support, the lower their average quality of life in two domains

d. People with employment services reported higher quality of life in five domains, while people with day habilitation reported lower quality of life in the other three

e. Providers with larger proportions of people in employment services had higher quality of life in two of the domains.



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

5. The disabilities people have do not determine their quality of life, and no one should be overlooked in the pursuit of quality of life enhancements.

a. People with greater degrees of retardation reported lower quality of life in seven of the domains, but the percent with retardation affected only one provider score

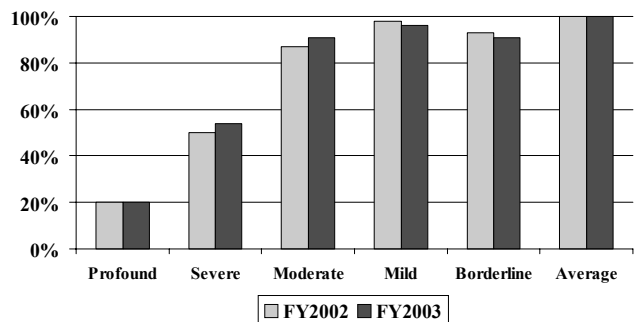
b. People who responded for themselves, independent of cognitive ability, reported higher quality of life in five domains than did proxies; the greater the percent of people at a provider who responded for themselves, the higher the provider's average score in three domains

c. Cognitive ability always offered less prediction of people's quality of life than did the availability of transportation

d. Hearing impairments, mental disorders and cerebral palsy had minor effects on people's quality of life in one or two domains

e. Providers with greater proportions of people with vision, language or hearing impairments had lower average quality of life in 3-4 domains, but these were less important than the average availability of transportation

f. Almost all people with moderate or

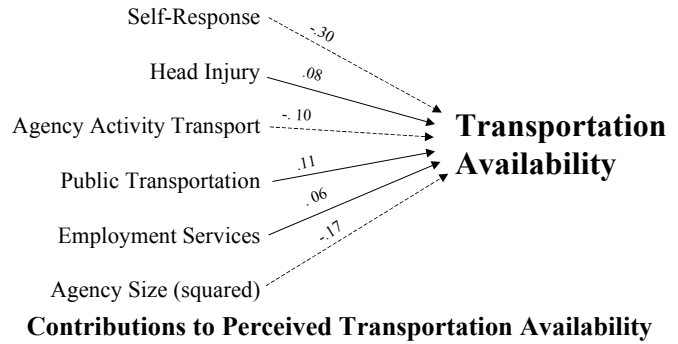


Percent Responding for Self by Cognitive Ability

less retardation answered quality of life questions themselves, as did 50% with severe and 20% with profound retardation.

6. The quality of services as judged by the recipients should be the focus, not just the provision of service, since the types of DDA authorized services other than employment had minimal predictions on people’s quality of life.

- a. Transportation services affected people’s quality of life, but people’s perceptions of the availability of transportation had a greater effect on their quality of life
- b. Agency-provided transportation had little direct effect on perceived availability of transportation
- c. DDA authorization of residential services, community supported living assistance, individual support services, and resource coordination offered no prediction of people’s quality of life in any domain.



7. Service providers can increase the quality of life of the people they support by setting appropriate person-centered goals.

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

