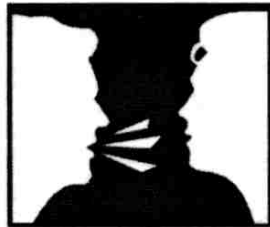


Ask Me!sm FY 2002

The Quality of Life of Marylanders With Developmental Disabilities



Receiving DDA Funded Supports

Prepared for the
Maryland Developmental Disabilities Administration

by
Gordon Scott Bonham, Ph.D.
Bonham Research

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

November 10, 2002

Executive Summary

The Ask Me!sm Project in FY2002 collected information about the quality of life of a sample of the 11,556 adults in Maryland supported through the Developmental Disabilities Administration (DDA) through 117 community providers. People associated with all community providers serving 55 or more people will be included in a four-year cycle, along with people served by a random sample of smaller providers. The *Ask!sm Me Survey* in FY2002 included 958 people served by 33 community providers. People who themselves received services conducted the interviews, allowing 77% of those surveyed to respond for themselves.

This report includes data from a representative sample of all people supported by DDA: 61% were men, 78% were 25-54 years of age, and 30% classified with severe or profound retardation (50% of those with severe and 20% of those with profound retardation answered for themselves). DDA supported residential services for 49% of the people, employment services for 35%, day habilitation for 54%, individual or family support services for 13%, community supported living assistance for 9%, and behavior consulting services for 9%. Three-fourths of the people received services from a single provider.

The findings from the project provide information to help support systems understand what contributes to the quality of life of people with developmental disabilities, to guide the state and individual providers as they improve services, and to persons to make informed choices about services. The findings provide the basis for the following recommendations:

1. A life of quality has many dimensions that are interrelated, and enhancement of people's quality of life should be the goal of all components of the developmental disability system.
 - a. Physical well-being, emotional well-being and material well-being appear foundational, relating to each other and to at least two other quality of life domains
 - b. Interpersonal relations and rights appear central, relating to each other and to at least five other quality of life domains
 - c. Social inclusion, self-determination and personal development are outcome goals defined by the Maryland Developmental Disabilities Administration (DDA), with personal development having a strong impact on the other two
2. People supported by the Maryland Developmental Disabilities Administration have a very positive view of their physical and emotional well-being. While these foundational domains of a life of quality should be maintained, greater attention needs to be given to other domains, particularly personal development and interpersonal relations.
 - a. 90% of people receiving services reported positive scores on their physical and emotional well-being
 - b. People showed the least variability in reporting physical and emotional well-being
 - c. Physical well-being relates to the fewest other quality of life domains, and the higher people report their physical well-being, the lower they report their rights

- d. Personal development is the DDA goal that related to all the other quality of life domains when personal and service characteristics were controlled
 - e. Interpersonal relations related significantly to all other domains as a central part of a life of quality, and was the strongest predictor of personal development
3. Rights (involving respect, dignity, equality, citizenship, access and due process) is the quality of life domain least understood, yet central to a person's well-being. The reasons the whole development disability system (internationally, Maryland and individual providers) does least well in this area needs to be explored in all possible ways.
- a. The domain of rights had the lowest scale reliability of the eight domains
 - b. Rights received the lowest average rating by people (2.4) and had the second highest variability
 - c. People served by four of the 33 providers gave negative average scores to rights
 - d. Rights, along with self-determination, showed the greatest regional differences
 - e. Providers with higher scores on physical well-being, higher average reimbursement rates for residential services, and higher average reimbursement rates for day services had lower average scores on rights than did providers with lower scores on physical well-being and lower reimbursement rates
 - f. Rights, highly related to self-determination, was affected by day reimbursement rates in the opposite way as self-determination.
4. Transportation availability and employment services offer the greatest predictions of people's quality of life, and are therefore logical areas to consider for service enhancements.
- a. Perceived availability of transportation had significant relationships with five of the eight quality of life domains
 - b. Transportation provided by the sampled agency increased people's sense of social inclusion and interpersonal relations
 - c. Transportation by other agencies positively increased material well-being, but decreased the sense of personal development
5. The disabilities people may 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 higher cognitive ability reported higher quality of life than people with lower cognitive ability in six of the eight domains, particularly rights
 - b. Cognitive ability offered less prediction of people's quality of life than did the availability of transportation
 - c. Men reported slightly lower quality of life than women in three domains, and slightly higher in one
 - d. No other personal characteristic offered prediction of people's reported quality of life, except cerebral palsy and seizures that related to single domains each
6. The mere presence or absence of services offer little prediction on the quality of people's lives. The focus should be on the quality of those services as judged from the perspective

of recipients.

- a. DDA supported employment services predicted slightly higher material well-being and rights than the lack of employment services
 - b. DDA supported residential services predicted slightly higher rights, but lower self-determination, than the absence of residential services
 - c. CSLA services were slightly related to higher physical well-being, but lower personal development
 - d. DDA supported day habilitation services and individual support services did not directly affect quality of life at the individual level, although agencies with a greater percent of their people in day habilitation services had higher scores on personal development
7. Service providers have potential to increase the quality of life of the people they serve. They should set and pursue goals informed by data from the people they serve, and should be held accountable for outcomes.
- a. People served by different agencies express significant differences in their quality of life in all domains, with variability among agencies greatest in personal development, self-determination and right
 - b. The same relationships among the quality of life domains were observed when providers were the units of analysis as when individuals were the units of analysis
 - c. The quality of life of people served by 20 agencies surveyed in both FY2001 and FY2002 increased in the domains of physical well-being, emotional well-being and material well-being
 - d. In the domains where quality of life did not increase overall, agencies with low scores in FY2001 had low scores in FY2002, and agencies with higher scores in FY2001 had higher scores in FY2002, especially in the domains of self-determination and personal development
 - e. Provider enhancements in any domain except physical well-being will potentially increase people's quality of life in all other domains; enhancement of physical well-being appears at the expense of rights
 - f. Agencies serving many people with mental retardation and with seizures had lower agency scores on rights and interpersonal relations, but other characteristics of their consumers did not directly affect agency scores
 - g. Large proportions of consumers in employment services related to high levels of personal development and emotional well-being, but high proportions in residential and support services had no relationship
 - h. Size of the agency and the proportion served by other providers had no association with quality of life
 - i. Self-respondents could answer more questions than could proxies (primarily staff), and reported differently than proxies for five of the eight domains
 - j. Only 9% of the people sampled for interview refused to participate