

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

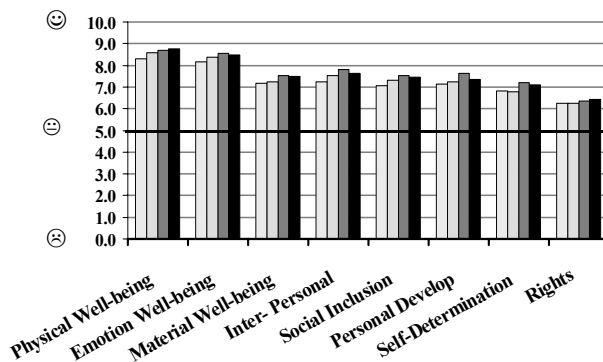
Among the adults supported by DDA, 57% are men, 71% are 25-54 years of age, and 27% are classified with severe or profound retardation. DDA funded residential support for 38% of the people, employment support for 27%, day habilitation for 47%, individual support services for 17%, community supported 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.

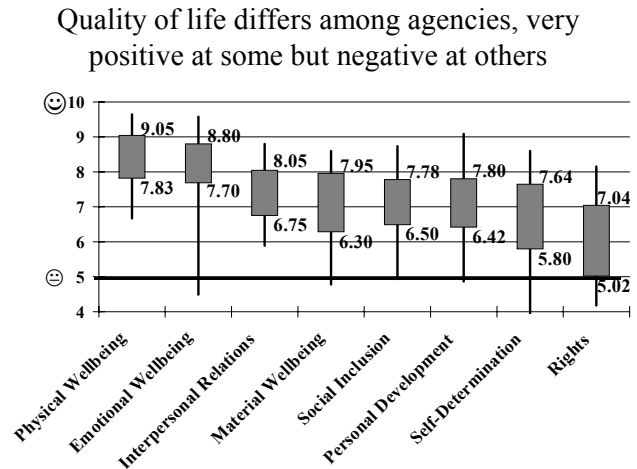
*Recommendation 1: Physical and emotional well-being are foundational to a life of quality and should be maintained, but increased attention should be focused on personal development, self-determination and rights.*

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 quality of life in half of the domains.
- f. Agencies that retain direct support staff and first line supervisors, and have good staff-supervisor ratios, have high quality of life in seven of the eight domains

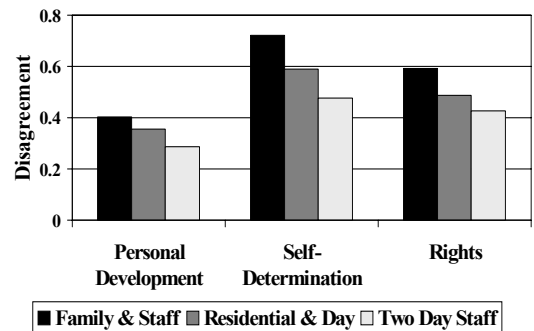


*Recommendation 2: Providers should recognize that their average quality of life scores reflect something about them and can them in enhance quality of life. The state system should focus on retaining direct support staff with appropriate levels of supervision.*

3. People who can respond for themselves report different quality of life than proxies report for the people who cannot respond, 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



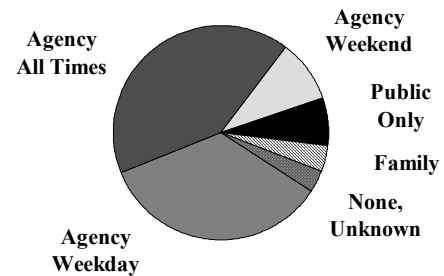
*Recommendation 3: Staff should recognize that their perceptions of a person's quality of life will differ from that of other staff and from the person themselves. Therefore, individuals should be involved as much as possible in decisions affecting them, and multiple staff and family perspectives can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

- a. Rights changed insignificantly from 6.3 in FY2002 to 6.4 in FY2005;
- b. Self-determination changed slightly more from 6.8 to 7.1, and personal development changed from 7.2 to 7.4;
- c. Self-determination and personal development had the strongest relation to rights in both self and proxy reporting;
- d. Both self and proxy respondents reported greater personal development for adults in supported employment;
- e. Individuals and proxies in the Western DDA region had reported higher self-determination than those in other regions.

**Self and proxy agreement on what affects rights**

Transportation is provided but not seen as available when wanted

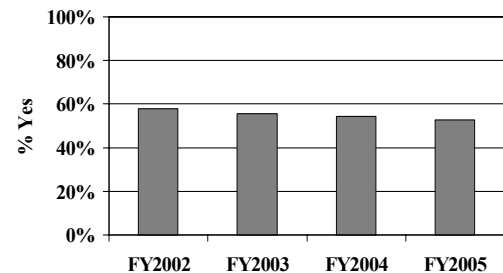


*Recommendation 4: Providers should focus on enhancing rights through enhancing self-determination and personal development.*

*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:
  - a. Staff asking permission before coming into the room increased steadily from 57% in FY2002 to 61% in FY2005;
  - b. Being able to lock the bathroom door was the only question that received more negative responses in each successive year;
  - c. 50% the adults had no, or only some, choice with whom they lived, and this changed little in four years;
  - d. Only half said they received the training they needed for employment, increasing to two-thirds for those with moderate or less retardation;
  - e. 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 available 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;

*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 people develop in ways seen by themselves as moving closer to desired employment.