

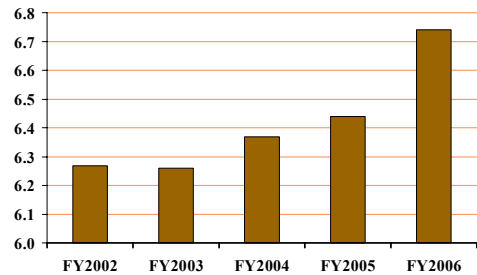
# Ask Me!<sup>sm</sup> FY 2006 Executive Summary

The FY2006 Ask Me! Project collected information between August 2005 and July 2006 for 1,225 adults with developmental disabilities served by 41 community provider agencies. Half of the people received day habilitation services and three-tenths received employment support. One-fourth lived in community residences staffed by agencies. Three-fourths (72%) of the survey responses came from the individuals, generally face-to-face with the person at their weekday program or employment site.

## Quality of Life Change in Maryland

The rights expressed by Maryland adults with developmental disabilities increased significantly between 2005 and 2006, from a scale score of 6.43 to 6.73 (see chart), or from 66.9% to 71.9% who expressed positive feelings about their rights. This increase was large enough to overcome no or insignificant increases in previous years, resulting in a 1.9% per year average increase over the years between FY2002 and FY2006. Self-determination increased next most over the period, at 1.6% per year on average. The quality of life increased in the other six domains increased an average of 0.8% to 1.2% per year.

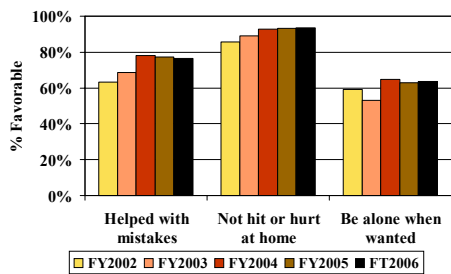
Rights increased significantly between FY2005 and FY2006



*Recommendation 1: Continually recognize that quality of life is multi-dimensional.*

*Recommendation 2: Continue to focus rights, self-determination and personal development, the three domains that still show the lowest quality of life.*

### Questions with most positive 5-year changes

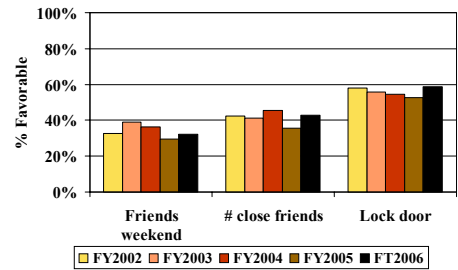


The three questions that increased most in favorable responses between FY2002 and FY2006 suggest specific ways community agencies are enhancing the quality of life of the people they support. The percent who said people helped them when they made a mistake increased from 63% to 77%. The percent who reported never being hit or hurt by people where they lived increased from 86% to 94%. Over 60% say they can now be alone when they want to be by themselves, although there is opportunity for this percent to increase further.

*Recommendation 3: Believe that system-wide and agency-specific efforts can enhance people's quality of life, while recognizing that they do not determine them.*

In FY2002, 58% reported being able to lock their bathroom door if they wanted. This percent steadily declined to 53% in FY2005, the only quality of life indicator question (out of 48) that had a significant decrease in favorable responses. The jump in favorable responses to 59% in FY2006 may indicate the downward trend has ended or even reversed. Two questions about friends also had an overall significant decline over the five years, although fluctuating from year to year. A declining percent say they see friends every weekend, probably because a declining percent say they have lots of friends from places other than work or home.

Questions with most negative 5-year changes



*Recommendation 4: Helping people develop friendships outside of weekday activities will contribute to quality of life.*

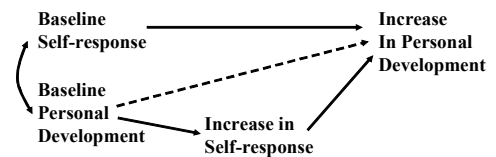
*Recommendation 5: Involve individuals in the decisions that affect their lives, including how an agency interprets and uses Ask Me! results.*

#### Four Year Change in Agency QOL

With FY2006 being the start of the second four-year cycle of interviewing, 38 agencies have been surveyed at least twice four years apart. The quality of life did not increase at all agencies. Interpersonal relations scores increased at double the average rate at six agencies and decreased at four agencies. The rights scores increased at least 0.20 scale points at 17 agencies while they decreased at 14 agencies.

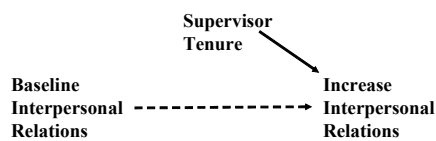
Agencies that supported a large percent of people who responded for themselves at the first (baseline) survey also had higher levels of rights, self-determination and personal development (see chart) reported at the first survey than agencies where fewer people could respond for themselves. What caused this could not be determined with just one survey, so a curved arrow is shown on the chart to indicate the unexplained relationship. With the most recent survey, it is clear that self-response affects rights, self-determination and personal development. The solid straight arrow shows that the higher the percent of people who responded for themselves during the first survey, the greater the increase in reported personal development. The chart for rights and self-determination would be the same. In addition, the greater the increase (or the less the decrease) in the percent of people responding for themselves, the greater the average annual increase in personal development, rights and self-

Personal Development and self-response contribute to each other



determination. (The dashed-arrow indicates a negative relationship, reflecting that agencies with high levels of personal development, rights and self-determination at the first survey had less potential for subsequent increases in personal development, rights and self-determination than agencies with low levels at the first survey.) In only the domain of personal development, however, did the baseline quality of life affect change in self-response. The greater the level of personal development reported at the first survey, the greater the increase is self-response over the following 4-5 year period (or less the decrease, since self-response tended to decline over the

### Supervisor tenure contributes to interpersonal relations



period). This suggests that agencies that promote personal development also promote the ability of individuals to understand questions and respond for themselves, while agencies that do not promote the personal development of the people they support cause individuals to lose their ability to express themselves.

The repeated surveys showed that agencies that retained their first line supervisors had significantly greater increases in interpersonal relations (see chart), material well-being and emotional well-being over the time period, controlling for the quality of life reported in these domains in the first survey.

*Recommendations 6: Place importance on stable staff, while remembering that staff have secondary importance to the people they support.*

### Proxy Knowledge

The *Ask Me! Survey* seeks to interview two proxies for each person who cannot respond for himself or herself. Direct care day program staff provided 49% of the proxy responses, direct care residential staff provided 29%, other agency staff provided 6%, and family and friends provided 16% of the proxy responses. Almost all proxies had known the person for two or more years and three-fourths saw the person daily, but these measures of interaction had little relation to how they answered survey questions. The individuals had expressed their feelings a lot to 58% of family proxies, 54% of residential staff proxies, and 36% of direct care day staff. Proxies answered three more questions on average when they reported the person had expressed their feelings a lot than when the person had not expressed feelings to them.

People responding for themselves reported lower levels of physical and emotional well-being than proxies reported. Both reported about the same level of material well-being and interpersonal relationships. People responding for themselves reported higher levels of personal development, social inclusion, self-determination and rights than proxies reported. People responding to the survey with the help of family or staff they wanted to be in the room with them reported quality of life generally in between self-respondents interviewed alone and proxies. In all eight domains, residential and day staff proxies reported higher quality of life than did family members. Residential staff reported higher quality of life than day staff in the domains of

emotional well-being, material well-being, interpersonal relations and rights. Two proxies for the same person disagreed on two-thirds of the questions. Proxies disagreed least in the domain of physical well-being and disagreed most in the domain of rights.

Proxies have a difficult time knowing how someone who cannot respond directly to survey questions would answer those questions. Proxies are more likely to answer based upon the context they share with the individuals than upon specific knowledge of the individuals' thoughts and feelings, although the amount the individuals express their feelings to their proxies makes some difference. Agreement between two proxies for the same person is also most likely due to a shared context than to specific knowledge. The type of proxy explained more variation in their reporting of people's quality of life than did characteristics of the individual or their support.

Although family and staff cannot know exactly what individuals think and feel when they cannot respond for themselves, decisions must be made on the supports that would best enhance quality of life. The findings from the *Ask Me! Survey* provide suggestions about whose impressions might be best for each quality of life domain:

- Physical Well-being: all family and staff appear to be overly optimistic with none likely to reflect the viewpoint of the person.
- Emotional Well-being: family members and non-direct care staff provide more reasonable perspectives than direct care staff.
- Material Well-being: direct care day staff are best relative to earning money, but direct care residential staff are best on the use of use of earnings and feeling well-off.
- Interpersonal Relations: all impressions appear to be useful as each sees the person in different settings.
- Social Inclusion: day staff see the inclusion offered through employment and residential staff see inclusion offered in the home and neighborhood.
- Personal Development: day staff appear to have the best insight in this domain, but are still influenced by their goals for the individuals rather than the individuals' goals.
- Self-determination: the family or staff to whom individuals most express their feelings will have the best insight, not the type of family or staff.
- Rights: this domain is the most difficult to determine for others, and Ask Me! data provided little evidence to determine who might have the best impressions.

*Recommendation 7: Involve people with various relationships and from various settings when making decisions for individuals who cannot communicate their own needs and desires.*