

Developing the Revised Ask Me!sm Survey

Executive Summary

Quality of life is both an important concept in program planning and in evaluating outcomes. Maryland began using the *Ask Me! Survey* statewide in FY2002 to measure the quality of life of the people supported by the Developmental Disabilities Administration. The *Ask Me! Survey* remained unchanged through FY2009, when agencies providing support in the community to people with intellectual and other developmental disabilities had participated in each of the two four-year cycles. Change occurred during those eight years in the measured quality of life, and in what individuals thought was important to their quality of life. The Ask Me! Project began soliciting ideas for revising the survey questionnaire during FY2008-09 and pretested new questions to be used starting in FY2010. This report describes the comprehensive review and revision of the survey. It documents the findings of the pretest conducted at four agencies during FY2009 and the relationships of the quality of life measured by the indicator questions in the first two cycles of the survey with the quality of live measured in the third cycle of the survey.

The Ask Me! Survey measures quality of life in eight domains: Rights, Self Determination, Personal Development, Social Inclusion, Interpersonal Relations, Material Well-being, Emotional Well-being, and Physical Well-being. It uses the principles of Participatory Action Research in identifying the important topics, collecting the information, using the information to benefit people with intellectual and other developmental disabilities.

The revision process included a review of quality of life studies and instruments developed subsequent to the original version of the *Ask Me! Survey*, a survey of agencies on their uses of the survey findings and their suggestions for revisions, a survey of parents of young children with disabilities, and focus groups with Ask Me! interviewers, self-advocate adults, and youth transitioning from the education to the disability support systems. (See chart.) A set of 34 potential questions was pretested mid way through the FY2009 survey. Six or seven questions that best indicated the domain from a conceptual and statistical perspective were then selected for the revised survey for use






Sources of input

- Literature, conferences, other surveys
- Statistical analysis of Cycle 1 and 2
- Focus groups (2008)
 - Ask Me! Advisory Committee (Mar)
 - Ask Me! interviewers: Central, Western (Apr)
 - People on the Go (Nov)
 - Transitioning youth: Baltimore, Frederick (May, Nov)
 - Parents of children: Prince Georges (Oct)
- Dedicated Surveys (2008)
 - Provider agencies: Mail (Feb)
 - Young parents: Web (May)

beginning August 2009 (FY2010).

The *Ask Me! Survey-2sm* contains five major changes from the *Ask Me! Surveysm*. The first involved a completely new set of questions for the domain of Interpersonal Relations that focused upon relationships with people other than staff, including romantic relationships. (See chart.) The second involved new questions about greater levels of assertiveness, both in decisions about ones' own life and providing leadership for others. The third area of change centered around work, and when working, about some qualities of work life. The fourth area was a new section on staff and services, which is expected to relate to the eight quality of life domains. It replaced the section on the perceived availability of transportation. The final change was not to the survey instrument itself, but to the data requested from agencies on the people interviewed. Cycle 3 of the survey will collect information on the level of supports needed rather than the level of intellectual disability, the place of residence rather than the frequency of trips from different sources, and the number of hours worked for pay to complement the attitudinal data reported in the survey.

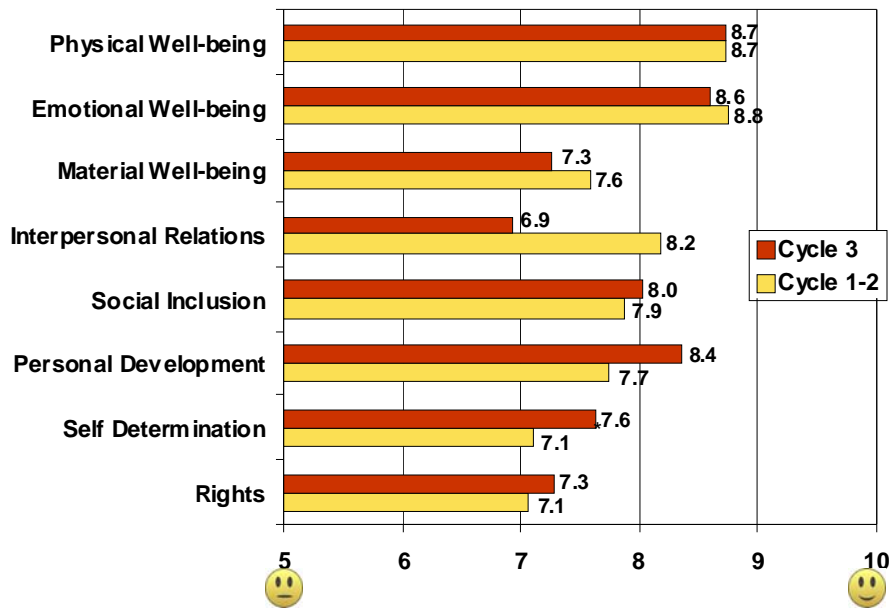
Changes

-  Friendships and romantic relations separated from staff relations
-  New questions on leadership, planning, speaking up, and saying "No"
-  New questions on quality of work life
-  New section on staff and services replaces old section on transportation
-  Support and residence data from agencies replace transportation data from agencies

Ask Me! peer interviewers administered the pretest questions immediately after the regular survey at four of the agencies involved in the FY2009 *Ask Me! Survey*. One agency was located in each of the four administrative regions of the Maryland Developmental Disabilities Administration. The agencies supported 61, 152, 413, and 1,052 adults. Responses came from 95 self respondents and 44 proxies for 131 individuals (8 individuals had two proxies). The pretest provided information to assist in the final selection of questions for the *Ask Me! Survey-2*, but also for comparing the domain scores that will be obtained in Cycle 3 for comparability to the domain scores that were obtained during Cycles 1 and 2.

The *Ask Me! Survey-2* will produce the exact same scores for Physical Well-being in Cycle 3 as the *Ask Me! Survey* produced for Cycles 1-2, as five the six questions remain the same. In the domains of Emotional Well-being, Material Well-being, and Interpersonal Relations, the Cycle 3 scores will be lower than the Cycle 1-2 scores. (See chart.) The Cycle 3 scores will be higher than the Cycle 1-2 scores for Social Inclusion, Personal Development, Self-Determination, and Rights. The discontinuity is most striking in the domain of Interpersonal Relations, where all six

Average domain score comparison



indicator questions were changed and the scores for the same individuals are statistically different. The differences were in the same direction for both self respondents and proxy respondents for six of the domains. In the domain of Emotional Well-being, self respondents had slightly higher scores on the new version than the older version, while proxies had lower scores on the new version. Regression equations are provided that can be used at the individual level to approximate 92% to 100% accuracy the score that would have been calculated if the other version of the survey had been used, controlling for whether the individual or a proxy responded.

The sampling procedures for Cycle 3 will be the same as for Cycles 1-2, with the only difference due to the growth, decline or merger of community support providers. In general, agencies will be surveyed one, two or four years after their last Cycle 2 survey based upon their size stratum.

This report includes some analysis of the new survey questions based on the pretest sample. The FY2010 annual report will include a much more extensive analysis based on the complete FY2010 sample responses. This analysis will show change over time for questions unchanged by the revisions, trends in the domains over time that likely would have been seen if the other survey questionnaire had been used, and the statistical properties of the new scales.