October 19, 1999

To: NCQA Technical Advisory Group

From: Christina Bethell, PhD and Paul Newacheck, PhD

Re: Recommended measure for children with chronic conditions

Recognizing that specific information about care for children with chronic conditions fills a unique gap in HEDIS, the Child and Adolescent Health Measurement Initiative (CAHMI) has developed the Living with Illness Module described in the attached document. The LWIM is formally recommended for inclusion in HEDIS by the CAHMI national advisory committee.

The Child and Adolescent Health Measurement Initiative is a collaborative effort between FACCT and the National Committee for Quality Assurance (NCQA) to develop strategies and methods for both measuring and communicating the quality of child and adolescent health care provided by organized health care systems, including health plans and provider groups. The pediatric Living with Illness Module was developed under the rubric of the Child and Adolescent Health Measurement Initiative's (CAHMI) Living with Illness Task Force.

This LWIM will provide information from parents of children age 13 and under, identified as having a chronic condition, about their experiences with eight aspects of their child's care. The CAHPS® 2.0H Child Survey with the LWIM as described here is recommended as a replacement to the CAHPS® 2.0H Child Survey and data collection and reporting is recommended for every two years. Key differences from the CAHPS® 2.0H Child Survey are sampling frame (increase to age 13), survey length and content (add 22 items to identify children and incorporate 3 new measurement domains), sample size (increase substantially) and scoring (score CAHPS and other domains separately for children identified as having or not having a chronic condition).

The CAHMI Living with Illness Task Force considered a wide range of options for designing and testing quality measures for children with chronic conditions that would be appropriate and feasible for inclusion in HEDIS. Condition specific clinical measures are desirable, but were not considered feasible due to the relatively small number of children with any one chronic condition. A measurement approach that addresses basic aspects of care for children with a wide array of chronic conditions was deemed not only more feasible, but meaningful as a starting point for measurement in this area.

Thank you for your review and consideration of the LWIM. We anticipate and welcome questions and concerns to help clarify what is included in this measure work-up or elaborate on key issues. If you would like more information prior to the October 28<sup>th</sup> phone call, please do not hesitate to call Christina at FACCT at 503-223-2228 or make your request know to John Hochheimer at NCQA.