Involving “Consumers” in New York State Quality of Care Programs

Dan Tietz, Consumer Advocate
Division of HIV Health Care
NYS Department of Health, AIDS Institute
(518) 486-7302  -  det01@health.state.ny.us
Purpose

• A Ryan White Title II initiative designed to improve the quality of HIV care for “consumers” - People Living with HIV/AIDS (PLWHA) in New York State.
Goals

• To involve PLWHAs and to educate them about Quality of Care initiatives.

• To exchange feedback between Quality of Care programs and the PLWHA community.

• To inform PLWHA about policy, HIV program changes, and to solicit recommendations directly from “consumers.”
New York State HIV Consumer
Quality of Care Advisory Committee

Structure

- Select number of committee members and represent PLWHA populations by geographic region, gender, race, ethnicity, and risk-groups;
- Represent existing consumer groups (Ryan White Title II Consortia, Ryan White Title I Planning Councils, Ryan White Title III and Title IV planning bodies, CPGs/PPGs, Designated AIDS hospitals, D&TCs, CBOs, LTI, etc.);
- Identify PLWHA leaders with strong knowledge of HIV health care and solicit them to join the Committee;
HIV Consumer Quality of Care Advisory Committee

Structure...continued

- Establish a nomination(s) process for committee leadership;
- Establish meeting dates, clear ground rules, roles, and responsibilities for committee members; and
- Ensure representation from consumer quality of care advisory committee at HIV Clinical Advisory Committee and other QOC meetings.
HIV Consumer Quality of Care Advisory Committee

Agenda Items

- Develop strategies to increase “consumer” awareness about Quality of Care initiatives;

- Solicit recommendations from committee members and receive feedback about Quality of Care initiatives;

- Present existing Quality of Care grantee activities (performance data release, indicators, educational materials, guidelines program, HIV Special Needs Plans, Prevention activities, etc.); and

- Brainstorm, recommend, and implement new consumer measures.
Past and Current Activities of HIV Consumer Quality of Care Committee

- Committee first met on July 24, 2002.

- Orientation and training was provided to educate committee members about New York State Quality of Care Program standards (ex.: training using consumer curriculum developed in 2001 by Joseph Rukeyser, Ph.D.: “Making Sure your HIV Care is the Best It Can Be.”

- Survey was developed, disseminated, collected, and summarized to assess the current involvement of consumers in quality of care programs (63 out of 114 facilities in New York State responded).
Past and Current Activities of the HIV Consumer Quality of Care Committee…continued

- Pilot testing of new performance indicators (ex.: lab work to assess patient’s awareness of essential lab results, prevention project for all grantee funded HIV facilities in NY State);
- Input into guidelines committees (participation in committees such as HIV Prevention Guidelines Committee);
- Review and comment on upcoming publications and materials (ex.: clinical HIV guidelines, consumer satisfaction surveys, and performance data releases);
- Input into the development and dissemination of a patient medical health journal; and
Presentation at the International AIDS Conference in Bangkok
Future AIDS Institute OMD QOC Consumer Activities

- Present information on consumer involvement in QOC initiatives to Ryan White/CDC Community Planning Bodies and PLWHA groups in New York State;
- Share success stories related to consumer involvement in QOC;
- Solicit funding for specific consumer initiatives (Interactive Patient Education, Self-Management, etc.); and
- Development of Best Practice Guide for health care providers: “Consumer Involvement in Quality of Care Programs.”
New York State Department of Health
AIDS Institute
Consumer Quality of Care Committee Members