

Consumer-Led Evaluation Teams: A Peer-Led Approach to Assessing Consumer Experiences with Mental Health Services

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CQI
Consumer Quality Initiatives, Inc.

**Bringing the people's voice to behavioral health research...
and from research to practice.**

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Background

Consumer Quality Initiatives was asked by the National Empowerment Center to conduct an exploratory examination of consumer-led evaluation teams in order to identify best practices in consumer-run evaluation. Below we discuss our methodology for conducting this examination, the findings and our identified best practices for approaching this work.

Consumer Quality Initiatives

Consumer Quality Initiatives, Inc. (CQI) is a mental health consumer-directed (51% of the board is consumers) and staffed non-profit research and evaluation organization whose mission is to develop opportunities for the meaningful involvement of consumers and family members in all aspects of mental health research and program evaluation (www.cqi-mass.org). By doing so, we aim to study issues that are relevant to the community, initiate changes to improve the system for all, and narrow the gap between research/evaluation and practice. <http://www.cqi-mass.org/index.php4>

In existence since January 1999, utilizes a Community-based Participatory Action Research (CBPR) framework, with an emphasis on protocols that are designed to impact policy and practice directly. The goal of CBPR is to identify a research topic of importance to the community (consumers, families) with the aim of combining knowledge and action for social change that improve community health. CQI engages in both research and evaluation, and has lead several NIMH grants to develop a methodology for conducting CBPR with the mental health community.

National Empowerment Center

The mission of the National Empowerment Center Inc. is “to carry a message of recovery, empowerment, hope and healing to people who have been labeled with mental illness.” (<http://www.power2u.org/what.html>)

The National Empowerment Center is engaged in:

- Information and Referral
- Networking
- Conference Planning
- Lectures, Workshops and Consultation
- Publishing and Media
- Policy Issues
- Representation on National Boards
- Research
- Development of Educational Resources
- Development of Self-Help Resources

Methodology

The primary selection criteria for indentifying “consumer-led evaluation teams” were that they:

- 1) be operated independently by consumers and/or family members, and thus not administratively managed by the mental health authority or agency,
- 2) evaluate mental health programs by learning about the experiences of program clients and/or ex-clients

Through an extensive internet search for consumer-led evaluation teams we identified several different entities that appeared to fall into this category, many of them in Pennsylvania because of the requirement that there be one in each county. These organizations’ websites were then examined to determine their suitability for inclusion in this analysis. Website content and online reports were reviewed to provide an initial understanding of each consumer-led evaluation team.

Of the twelve we identified, we contacted four organizations based on the variety of location, size, and approach they offered. We sent to the organization’s executive director (email and post) an introductory letter inviting him/her to participate in a one-hour phone interview, and three agreed to participate. In addition, we made the decision to profile our own organization in order to capture the kind of variety discussed above. After conducting the interview and writing a profile of their organizations, the Executive Directors were also given the opportunity to review a draft of the report to ensure accuracy in the information presented.

Interview Guide and Interviews

In addition to information collected from the organizations' website, an interview guide was developed so that a comprehensive understanding of the organization, its history, and its work could be collected. The interview guide included questions on the following topics:

- *Organization*: Nonprofit/public status, history, mission, board/staffing, leadership, key partnerships.
- *Research and Evaluation*: Consumer satisfaction work, other research and evaluation, methodology (data collection, survey development, sample sizes), primary research and evaluation populations and levels of care, staff training, building internal research capacity.
- *Funding*: Past, current, future, funding mix.
- *Sharing Findings*: Sharing data with consumer and family member communities, providers, and policy makers; conferences, events, reports/papers, other.
- *Impact*: Programs, services, policy changes, noted improvements in quality of care, any formal attempts to measure impacts.

- *Future Directions*: Growing the organization, staffing, staff development, infrastructure, research and evaluation, impact.

During the telephone interviews, the interviewer (SPE) typed notes as close to verbatim as possible.

Analysis

Once the interviews were complete, we reviewed and analyzed information collected from websites and interviews for key themes and to identify innovative practices. Once narratives about each organization were written, Executive Directors of the organizations were given the opportunity to review a draft before publication to ensure accuracy of the information contained in this report.

Note on Terminology

For the purposes of this document, "consumer satisfaction" is a broad term covering a variety of ways in which consumers perceive the quality of services.

"Consumer satisfaction" covers a person's happiness/satisfaction with their services, and the kinds of questions asked tend to be very subjective. A good example of a question here is: "How satisfied are you with the staff here?" You can provide a scale of responses (very satisfied, somewhat satisfied, somewhat dissatisfied, very dissatisfied) and/or ask for an open-ended response.

"Consumer satisfaction" also covers a person's perception of a specific aspect of their services. Good examples of questions are: "When you've told staff that you have a health concern, how often do they respond to that concern?" Again you can provide a scale of responses (never, sometimes, usually, always), and/or ask for an open-ended response. While still subjective, these questions have a more objective element since a person is asked to consider how often something has happened. From a quality improvement perspective, these kinds of questions provide more "actionable" responses, meaning that someone who sees the data has a good idea of how respondents observe a specific issue, and the provider can take a specific action (eg, peers training staff, staff "sensitivity" training, improved policies for staff for handling concerns).

Overview of Consumer-Led Evaluation Teams

As noted by the President's New Freedom Commission on Mental Health report in 2003¹ and a growing body of literature on improving the quality of mental health care, a core flaw of our mental health system is the lack of consumer direction in program evaluation. Consumer directed must include defining outcomes, collecting and analyzing satisfaction data, and making quality improvement recommendations. As stated in a recent working paper, consumer involvement needs to:

...go beyond satisfaction measures to formally involve consumers in system design, implementation, and monitoring. To be meaningful, the participation has to be sustained over time and focused on crucial elements of the program. Consumers will only participate if they feel their voice has an impact (Forquer & Sabin 2002).

The typical mental health consumer survey methodologies have not been effective in producing high quality data due to poor sample representations and lack of respondent openness. The consumer run personal interviewing apparatus, with its familiarity with the "community," is the critical component to developing a consumer-driven system where evaluation findings are effectively translated into practice.

In addition, consumer interviewers are able to gain greater information from other consumers about negative experiences they have had with services because "greater feelings of safety, trust, confidentiality, and privacy may have influenced the interviewees' disclosures to other clients... If clients with extremely negative experiences speak more freely with other clients, the result will be more valid feedback." (Clark et al. 1999, p.962-963). Consumers are in fact capable of taking a lead role in consumer satisfaction evaluation, but only if they are provided with the resources to support training and infrastructure. (Delman and Beinecke 2005)

Consumer evaluation is an excellent organizing tool. Consumer groups don't have systemic data on program quality, and without data it is difficult to effect change. Consumer data collection allows them to learn about the specifics of a program's performance and to work with administrators to set benchmarks for improvement. When consumers have data, they are in a better position to organize around an issue, and conversely to work with state administrators. Consumer evaluation also provides both training and jobs to consumers interested in evaluation. It's a stigma buster, demonstrating that consumers can handle "professional" jobs.

While many core components of consumer evaluation are shared, the replication of the consumer led evaluation team model has resulted in a variety of innovative approaches to consumers and family members collecting data from their peers about satisfaction with services and then reporting feedback to providers, funders, and government administrators in order to improve quality of care around satisfaction and consumer-direction.

¹ <http://www.mentalhealthcommission.gov/>

Organizational Profiles

This report highlights the work of four consumer-led evaluation teams:

- Consumer Satisfaction Team, Inc. of Philadelphia;
- Vital Voices for Mental Health of Milwaukee.
- Consumer Quality Initiatives of Massachusetts;
- Consumer Quality Team of Maryland;

These four community-based organizations are run by consumers and family members, and focus exclusively on bringing the voices of consumers to mental health system planners and administrators. Although the organizations have many features in common, their differences highlight the variety of ways that consumer satisfaction work can be approached.

All but one of the organizations profiled is an independent 501(c)3 non-profit organization, and the other organization is currently housed under a mental health advocacy organization with plans to become an independent organization after a few years of operation.

The Consumer Satisfaction Team, Inc. of Philadelphia

Mission: “to ensure that specific publicly supported and funded services meet the expressed wishes and needs of the consumers of those services and that they promote maximal recovery of persons served.”

The Consumer Satisfaction Team, Inc. (CST) was created in 1990 in Philadelphia as the first consumer and family member run organization in the country to focus exclusively on quality assurance from the perspectives of mental health service consumers. CST has a large full-time staff of 27 that conducts consumer satisfaction interviews on a rotating basis at all facilities serving adults and children in the Philadelphia public mental health and substance abuse system. CST uses an open-ended interview method, then compiles notes from interviews and submits consumer feedback to governmental funding agencies and providers. CST staff also holds a biweekly accountability meeting with the funding agency administrators to determine whether each consumer’s issue has been addressed. In addition to program site visits, consumers and family members can also call the CST to report issues.

Vital Voices

Mission: “to advocate for excellence in mental health services through the voice of the people being served.”

Vital Voices for Mental Health in Milwaukee County was conceived in the 1990s by a broad spectrum of stakeholders from the community, including consumers, family members, county agencies, and providers, as part of a master plan to improve mental health services in the county. The goal of the initiative was to get consumer voices into

the system with the hope of improving services and satisfaction. Early on, the organizational founders decided that gathering consumer perspectives and reporting them to agency managers was not enough. A clear decision was made to fuse consumer satisfaction surveys with individual advocacy to ensure that consumers' individual needs were met by the system. Vital Voices spends about eight months of the year conducting individual consumer satisfaction interviews at a variety of providers and the remaining time administering the nationally recognized Mental Health Statistics Improvement Program (MHSIP) survey².

Consumer Quality Initiatives

Mission: "to develop opportunities for the meaningful involvement of consumers and family members in all aspects of mental health research and program evaluation. By doing so, we aim to study issues that are relevant to the community, initiate changes to improve the system for all, and narrow the gap between research/evaluation and practice."

Consumer Quality Initiatives was established in 1998, originally as The Massachusetts Consumer Satisfaction Team, after the consumer empowerment and recovery movement marched on the state Medicaid office demanding greater consumer involvement in planning services, and specifically to fund a consumer-led evaluation team. The mental health managed care carve-out, Massachusetts Behavioral Health Partnership (MBHP), then contracted with CQI to evaluate services through personal interviews with clients, and that has remained CQI's largest contract.

CQI has three lines of work. First, there is evaluation and in particular consumer and family member satisfaction interviews and surveys to evaluate mental health and addiction services throughout Massachusetts. Second, CQI has taken the lead in several participatory action research projects, including several that are NIH funded, which allows it to learn about consumer perspectives outside of the arrangement of the current service system. Third, CQI consults with academia and state government on meaningfully involving consumers in research and evaluation.

CQI currently has 5 full-time staff, a few part-time staff, and several on-call consumer interviewers. While CQI's largest contract is with MBHP to do consumer satisfaction surveys at a variety of provider levels, CQI also holds contracts with the Massachusetts Department of Mental Health and sub-contracts with university research centers and private evaluation consulting firms.

Consumer Quality Team of Maryland

Mission: "...empowers individuals who receive services as partners with providers, policy makers and family members, to improve care in the public mental health system and ensure services meet the expressed needs of consumers."

² <http://www.mhsip.org/whatis.html>

The newest of the consumer-led evaluation teams highlighted in this report, Consumer Quality Team of Maryland was funded in June 2006 by the Maryland Department of Mental Hygiene in response to a ten year campaign by consumers, providers and funding authorities led by the Mental Health Association of Maryland.

CQT interviewers make unannounced site visits to mental health facilities 3-6 times a year and conduct qualitative interviews with adult consumers to determine their satisfaction with services and to identify unmet needs or problems. CQT makes a verbal report to staff before leaving the site and follows up with a written report to the funding authority and the provider within ten days of the visit. Monthly meetings with representatives from each Core Service Agency, the Mental Hygiene Administration, and the provider associations allow CQT staff to go over reports in-depth and to make sure that individuals' complaints are being addressed.

Although the focus is on making sure individuals' needs are met, this process furnishes both real-time information about programs to the providers and funders, as well as information on emerging trends in people's needs, such as the loss of entitlements or social recreational programming as a result of recent budget cuts. The Funding Authority representative then gives CQT a written report stating what is being done to address concerns. The CQT staff has the opportunity to observe changes on subsequent site visits. Additionally, during every interview, consumers are given contact information for CQT and urged to call if difficulties continue. These calls are documented and followed in the same manner as the site visits.

Findings

A. Core Features of Consumer-Led Evaluation Teams

Interviews with directors of the four consumer-led evaluation teams and reviews of relevant materials revealed six core components shared by the organizations.

Core Features of Consumer-Led Evaluation Teams

- 1 – Created by consumers demanding input into service changes
- 2 – Consumer and family member run and staffed
- 3 – Strong connection with county/state agencies or managed care
- 4 – Collect consumer feedback through face-to-face peer-to-peer interviews
- 5 – Strong emphasis on provider and funder accountability
- 6 – Strong recovery perspective

1 Created by consumers demanding input into service changes

In each instance, the consumer-led evaluation team started in response to consumer demand for an increased consumer voice into service planning. State or county mental health authorities responded to these calls for involvement by allocating funds in their annual budgets for consumer satisfaction work. The closing of a state-run psychiatric hospital was the impetus for the Consumer Satisfaction Team, Inc. in Philadelphia to form. Consumers, family members, and advocates were calling for the City of Philadelphia to consider the preferences of former state hospital patients as they were moved to community living. The Philadelphia Department of Mental Health responded by allocating money for the creation of the Consumer Satisfaction Team.

During the 1990s, the provision of mental health care in Massachusetts was moving to a Medicaid managed care model, and the consumer community soon realized that they were completely out of the mix in planning services. After a march on the Medicaid office and negotiations with the Medicaid office, the Department of Mental Health and the managed care company, an agreement was reached to create a consumer lead entity to evaluate Medicaid services from a consumer perspective, which led to CQI.

In Milwaukee in the early 1990s, a representative group of consumers, family members, county officials and community agency representatives worked on a master plan for the county's mental health system. The people working on the plan went to Philadelphia to observe the work of the Consumer Satisfaction Team, Inc. to see if similar work could be done in Milwaukee. A plan was developed and the county issued a request for proposals (RFP). Two agencies submitted a joint proposal and were awarded the grant to develop the program, which eventually incorporated into a stand-alone organization to be run solely by people with mental illness and their family members.

Consumer Quality Team of Maryland was created in response to the efforts of a group of consumers, family members, providers, advocates, and state mental health agency administrators in the 1990s that pushed for the creation of a consumer-led evaluation team. Though it took years to secure funding, the partnership forged among these parties allowed the group to research existing programs and decide on the preferred method to collect consumer satisfaction information in Maryland in order to effect real-time change.

2 Consumer and family member run and staffed

These consumer-led evaluation teams are staffed by consumers and family members. The level of consumer directness of these programs is generally through the grant of authority to "do what needs to be done." However, the required and actual composition of the board varies, in terms of consumer and family member membership. Some boards of directors have a mandate requiring 51% of their boards be consumers. Other boards do not have such a mandate but strive to maintain a significant representation of consumers and family members.

3 Strong connection with county/state agencies or managed care

Though the impetus for the creation of consumer-led evaluation teams originated in the consumer advocacy movement, strategic partnerships with governmental agencies or private managed care organizations were essential for securing the funding and access to provider sites necessary to launch the organizations. Often, a few key individuals in government who truly believed in consumer empowerment partnered with consumer advocates to formulate plans and secure funding.

All of these consumer-led evaluation teams hold a contract with either the city, county or state mental health agency/authority to do surveys or interviews with consumers in the public mental health system. CST of Philadelphia's original contract is with the Office of Mental Health within the Department of Behavioral Health and Mental Retardation, but has expanded to include many other offices and departments. In Massachusetts, Consumer Quality Initiatives holds its largest contract with the managed care organization, but also contracts with the Massachusetts Department of Mental Health to do more focused needs assessments and case studies of the successful integration of empowered peer specialists in the services system.

Early on in their history and sometimes on an ongoing basis, these organizations faced resistance from providers regarding, among other things, the utility of the information that could be provided. Government's or managed care's support if not assertiveness in the face of these barriers are very important to the success of these teams. In the end, each organization must navigate their state or local system of mental health and addictions services to secure funding on an on-going basis.

4 Collect consumer feedback through face-to-face peer-to-peer interviews

All of the consumer-led evaluation teams conduct face-to-face interviews with consumers as their primary data collection method. The interviews usually take place at the program site where the consumer is receiving services. Vital Voices, CST and CQI also conduct surveys in people's homes, if the level of care received is community-based, such as case management. Some, such as CQI, have begun to use the phone in a limited way for people, such as parents of youth with mental health issues, who are too busy to meet in person.

5 Strong emphasis on provider and funder accountability

Ultimately, the purpose of collecting information from people using services about their satisfaction with and perspective of care is to ensure that consumers' needs are met. Consumer-led evaluation teams were created because most providers lacked the information they needed to be consumer-recovery oriented, and could in fact be completely insensitive to the perspectives of those seeking care and their preferences. The CST of Philadelphia has set a tone by having regular scheduled meetings with high levels of governmental authorities.

Moving the mental health system to a consumer-orientation requires providers and funders to be more accountable. The consumer-led evaluation teams highlighted in this

report provide models for how consumers and family members can create an accountability process focused on bringing the experiences and needs of consumers to the attention of providers and policymakers.

6 Strong recovery perspective

Although not the direct focus of their work, all of the consumer-led evaluation teams commented on their commitment to a recovery perspective. Consumer-led evaluation teams aim to move the systems towards recovery-oriented services.

Having consumer interviewers out interviewing at program sites allows provider staff and program participants to see consumers in recovery who are helping to increase consumer voice. Providing consumers with meaningful work is an inherent, though not always explicit, goal of consumer-led evaluation teams.

In fact, more and more teams are using recovery oriented quantitative measures. For example, the Commonwealth of Pennsylvania funded the Consumer Satisfaction Team Alliance of Pennsylvania the use of the Recovery-Oriented Systems Indicators³ (ROSI) statewide, both by mail and through personal interviewers of a smaller groups of individuals. In addition, CQI has incorporated aspects of the RSA⁴ (Recovery Self-Assessment) in its surveys.

B. Differing Approaches

Though consumer-led evaluation teams were found to have many core features in common, there were ways that their work differed. New consumer-led evaluation teams have the opportunity to make choices about how to approach the collection of consumer satisfaction data, based on stakeholder priorities, how the state or local mental health system is set up, organizational capacity, and the expected accountability process.

Approaches of the consumer-led evaluation teams highlighted in this report differed in four significant ways. First, the procedures for conducting interviews and collecting data can be approached quite differently – yet, still result in effective feedback for providers and mental health administrators. Secondly, the purpose for collecting the data can vary. Third, there are different approaches to holding providers, funders, and mental health administrators accountable. Fourth, consumer-led evaluation teams seem to take different approaches regarding whether to have full-time staff, part-time staff, or a combination of the two. The size of their respective budgets varies considerably.

³ Developed by Steven J. Onken, Ph.D., Jeanne M. Dumont, Ph.D., Priscilla Ridgway, M.S.W., Douglas H. Dornan, M.S., and Ruth O. Ralph, Ph.D., <http://www.nasmhpd.org/publicationsOTA.cfm>.

⁴ Developed by the Yale's The Program for Recovery and Community Health (PRCH), http://www.yale.edu/PRCH/tools/rec_selfassessment.html.

Options for Interviewing and Data Collection Methods

First and foremost, consumer-led evaluation teams value whatever consumers' value. Yet, there are different options for how to engage with consumers and how to collect vital information about their satisfaction with various aspects of the care they are receiving.

One approach is to use unstructured very open-ended interviewing techniques, which are more like conversations. Here, interviewers approach program clients to ask them about any needs or issues they want to discuss with limited prompting from the interviewer. An opening question might be here "How are things going for you here?"; "How do you think about the services you have been getting at this provider?"; "Is the programming meeting your needs?"; "Is there anything you'd like to see added to or changed in the program?" The interviewee guides the interview.

Another option is to use a list of predetermined questions, which can range from open-ended to close-ended. These questions can be broad like above, "If you were in charge of this program, what is the first thing you would change?" Questions can be more focused if you're trying to learn about something more specific from everyone. A few examples include: "What do you think about the psychiatrist on this PACT team?" "What was the admission process like?" "How does the program help you get employment opportunities?"

Close-ended (quantitative) questions require that the respondent choose from a limited number of answer options (e.g., very satisfied, satisfied, somewhat satisfied, not at all satisfied). Whether open-ended or close-ended questions are used, care is taken to ensure that the issues that matter to consumers are uncovered through the interviewing process. Close-ended questions are much easier to analyze with simple software, but open ended questions can reveal information that a team might not have predicted.

Vital Voices uses mostly close-ended, quantitative question surveys for their interviews but include some open-ended questions. Vital Voices' interviewers ask people to fill out a simple written survey, and then the interviewers go over the survey with the respondent to get more information about satisfaction or dissatisfaction with aspects of their care (i.e. "You are dissatisfied with groups, why is that?"). This method allows the collection of both "hard" numbers for program administrators, but also provides details about why respondents feel the way they do about their care.

The Consumer Satisfaction Team in Philadelphia and the Consumer Quality Team in Maryland use qualitative, open-ended interviews more frequently. Interviewers are trained to facilitate conversations with people about their experiences with services. During the course of the interview, consumers indicate if they are satisfied with the services and if they have needs that are not being met. During training, interviewers learn how to ask questions that are open-ended so they are not leading consumers to answer in a particular way. The CQT concludes interviews by asking 5 quantitative questions taken from the Mental Health Statistics Improvement Program (MHSIP).

For CQI it really depends on the project. CQI often uses very open-ended questions when conducting a needs assessment, and more qualitative questions when evaluating a program that is new and there's not much known about it and kinks probably still need to be worked out. CQI uses close-ended questions for more "established" kinds of services (e.g., inpatient), and if someone answers on the dissatisfaction side of the scale interviewers ask that person to explain why s/he is dissatisfied in his/her own words.

Purpose of Collecting Data and Reporting

The two primary reasons for these teams to interview consumers are to: 1) evaluate the program, and 2) make sure the respondent's needs are being addressed.

All teams except for CQI focus on making sure individual's needs are addressed. Most interviews are confidential, however, when there is a specific need not being met, the respondent is asked if his/her name can be shared with the agency that can address this need. In some cases this is the provider, but when there is a concern about retribution, it is usually the provider's funder. Accountability reports, meetings, and the analysis of collected data provide information about programs as well as the mental health system.

CQI does not typically advocate for respondents unless there is a rights violation or an abuse. In that case, CQI will follow the approach of the other organizations, and also share relevant contact information to report violations. CQI will also provide clients the contact number of the managed care company if they want to make a complaint directly to it. CQI generally chooses to protect the confidentiality of individuals who participate in surveys. CQI's focus is on providing data on themes heard from a sample of consumers surveyed, rather than details about an individual's specific issue. Therefore, individuals are told that taking part in the survey will not impact their individual services, but will provide feedback to providers about how to improve the quality of care for all clients. CQI believes that it can be most effective at advocating for program and systems improvement overall, as it is statewide and is unable to make site visits on a rotating basis as other consumer-led evaluation teams do.

Reporting and Accountability Process

The consumer-led evaluation teams share findings with providers and policymakers in a variety of ways. One method for ensuring accountability is to meet directly with providers to share findings. Another approach is to meet with state administrators regularly and then hold them accountable to follow up with providers so that consumers' concerns raised during interviews are addressed. All of the teams do both, either simultaneously or one after the other.

Vital Voices and CQI meet directly with providers to share results, discuss concerns, and brainstorm ways to solve problems. The provider agencies or mental health administrators who fund and oversee provider sites are given a chance to comment on findings, and describe steps they have taken or will take to remediate areas of concern.

Vital Voices sends the report with the summary of consumer and provider findings to the county mental health agency, and then meets with the county to address systematic concerns. Vital Voices later conducts follow-up surveys with consumers to see if providers have addressed their concerns, and they continue to advocate for individuals who reported they were not getting what they needed from the providers.

Consumer Quality Initiatives writes a report detailing their findings and recommendations. CQI then meets with the provider to go over findings, with the managed care staff present. The managed care organization is then responsible for holding providers accountable for making changes to services. The providers are given the opportunity to respond to the findings of the report, and their responses are included in the final report that goes to the managed care organization. Ultimately, accountability follow-up is handled by the managed care organization.

Staffing Mix

Consumer-led evaluation teams seem to take a variety of approaches regarding how to staff their organizations. CST of Philadelphia has an entirely full-time staff, all of whom engage in interviewing and contribute to report writing. Consumer Quality Initiatives has a combination of full-time staff who are involved in all aspects of the work, part-time staff who may specialize in one or two tasks (interviewing, administrative work, report writing), as well as several on-call interviewers. Consumer Quality Team of Maryland has both full-time and part-time staff, all of whom engage in interviewing and reporting. CQT has found that part-time work often meets the needs of consumers who are on SSI or SSDI and who are working towards recovery. Vital Voices has a small staff, given its smaller geographic area, who works full or part-time depending on their position.

Budgets

Consumer-led evaluation teams vary in staff size, scope of work, number of funders, and geographic coverage, therefore their budgets likewise vary. As the organization that covers the smallest geographic region, Vital Voices in Milwaukee had an annual budget of \$134,697 in the 2008 fiscal year. Consumer Quality Team in Maryland had a budget of \$354,200 in 2008. CQI has a budget of about \$500,000, to cover the entire state. Consumer Satisfaction Team, the oldest organization highlighted in this report, had an annual budget of \$3,315,336 in 2008. Such a large budget is possible not only because of the significant commitment of public funding agencies in the Philadelphia area to their mission, but also because CST works with multiple consumer populations across a variety of public agencies.

Depending on a variety of factors, consumer-led evaluation team budgets can vary widely. Most organizations start with a modest budget and grow over time, as the organizations hone their approach to consumer satisfaction work, gain increasing respect from state administrators, diversify the scope of their work, and secure contracts from

multiple state agencies, universities, or health care organizations. CQI has looked to secure NIH funding for its work.

C. Innovative Features of Consumer-Led Evaluation Teams

While the consumer-led evaluation teams highlighted in this report have many features in common, each organization has unique approaches to its work. These innovations show the diversity of work that can fall under the rubric of consumer satisfaction.

Highlighted below are “best practices” or innovative features of each of the organizations included in this report.

Vital Voices, Milwaukee County

A) A Focus on Consumer Advocacy

Vital Voices makes a significant commitment to direct consumer advocacy. When Vital Voices formed, they decided that it was not enough to simply report their findings to providers and administrators in hopes that changes would be made. They wanted to make sure that consumers’ concerns got addressed. So they made advocacy part of the interview process and started a Consumer Helpline so people did not have to wait for interviewers to show up at their program to make a complaint. The following are some Vital Voices’ advocacy success stories:

- Convincing a case manager to communicate with her client via email as much as possible since that was the client’s preferred method of communication.
- Connecting a homeless consumer to case management services, which in turn helped her obtain government benefits and other services.
- Ensuring that a client was able to get his anti-psychotic medication after going without it for two days because of social worker error.

The Vital Voices Helpline receives several calls a week from consumers about specific concerns that need to be addressed. Vital Voices staff explains to callers how to self-advocate and they can give referrals, but they also will do direct advocacy for people as needed. Follow-up surveys are done with Helpline callers in order to find out if their needs were addressed. When Vital Voices interviewers conduct interviews, they encourage people to call them when they have concerns.

B) Follow-up Surveys to Make Sure Needs Addressed

Vital Voices tries to follow up with each client about complaints, to ask the client whether the issue has been addressed, whether he/she is satisfied with the issue, whether the client needs additional advocacy and whether the client is satisfied with Vital Voices’

efforts. According to follow-up surveys, 90-95% of consumers' complaints that Vital Voices follows up on with providers are eventually addressed.

C) Consumer/Family Members Administering the MHSIP Survey

Vital Voices administers the Mental Health Statistics Improvement Program⁵ (MHSIP) survey annually. The MHSIP survey provides a way for providers to evaluate how they are doing in comparison to other organizations and to their own performance over time. Each fall, Vital Voices administers MHSIP surveys to approximately 500 people at community-based agencies. The county then analyzes the data and gives results to agencies so that concerns can be addressed. Vital Voices receives copies of the reports and then uses the results to figure out what areas of consumer satisfaction and quality of care need addressing. One of the areas that frequently comes up through the MHSIP is insufficient consumer input into treatment planning. With that information at the program level, Vital Voices can then find out why that is. The MHSIP, on its own, does not explain why. Yet, the MHSIP is administered every year to the same programs, which allows Vital Voices and the county to see trends over time.

Consumer Quality Initiatives, Massachusetts

A) Data-Driven Reports

CQI's satisfaction surveys focus on generating quantitative data-driven reports for policy makers and providers that have the potential to have a broader impact on system change, beyond addressing individuals' and even individual program needs. The results of these surveys generate statistics at the provider-level, and also analyze across providers how people in a number of hospitals have answered the questions, or, at times, how a question has been answered across provider levels of care. Thus, CQI is able to present to trade groups (hospital, outpatient) the aggregate responses of, for example, 300 consumers at 20 provider sites, demonstrating industry trends.

B) Expanding from Consumer Satisfaction into Community-based Participatory Action Research

Early on CQI's executive director recognized that it would have little impact on system reform by only helping currently funded programs to improve. It thus aimed to go right to the consumers outside of the program context to ask what research they wanted to see. An early example was the community's recommendation to look at the needs of youth aging out of mental health services. CQI hired and trained several young adults to participate with them in developing an open-ended questionnaire, interviewing young adults across the state, and then writing a report, which recommended a complete overhaul of the little that was being done. The key was that the young adults made the presentation to DMH staff and stakeholders, and thus many of those recommendations have taken hold over the years.

⁵ <http://www.mhsip.org/whatis.html>

C) Emphasis on building community capacity for research and evaluation

Realizing that it could not conduct all the important consumer-driven research/evaluation that needed to be achieved, CQI developed a researcher training curriculum for consumers, and has several contracts to conduct that training, while engaging in participatory research with the trainees. In addition, CQI found that universities, which obtain a large amount of research funding, were not warm to consumer participation in research. CQI began to advocate for greater involvement, and now consults with several universities on the meaningful involvement of consumers in the production of research. In addition, CQI's Executive Director is currently one of two principal investigators on a National Institutes of Mental Health funded community-based participatory action research project. Following up on a previous grant, a team of consumers will be hired to be community research associates, go through an extensive training on how to conduct research, and then participate in any part of the research process that they choose.

The Consumer Satisfaction Team, Philadelphia

A) Encompassing Reach Across Provider Type and Governmental Agencies

As the first consumer evaluation team in the United States, CST has continued to expand its reach over time across most levels of care and several government agencies related to behavioral health care. CST staff makes unannounced visits every day of the week to a large variety of program sites including:

- day treatment programs,
- drop-in centers, clubhouses,
- detoxification facilities,
- rehabilitation and recovery programs,
- outpatient clinics,
- inpatient facilities,
- crisis centers, as well as
- children's residential treatment facilities and schools.

With community-based services, CST interviews consumers in their places of residence. In addition to regularly scheduled visits to these provider types, CST also takes on special projects to look at specific service types, such as crisis response centers, partial hospitalization programs, therapeutic summer camps and case management services for consumers. The special projects allow for the collection of consumer perspectives around an identified problem area.

Over the years, CST has also expanded to include provider sites under the purview of multiple governmental agencies. Its annual contract began with the Philadelphia Office of Mental Health under the Department of Behavioral Health, but has expanded to include the Coordinating Office for Drug and Alcohol Abuse Programs, the Delaware County Office of Mental Health, and the Philadelphia Department of Human Services.

B) Interview Team Staffing Approach

Because CST interviews across a wide variety of provider types, CST's large staff is organized into teams based on governmental agency/service or population focus: Drug and Alcohol Team, Department of Human Services Team, Family Team, and Mental Health Team. Everyone in the organization, including the Executive Director, is an interviewer. Each team has a team leader who coordinates interview schedules and oversees the work of that team. The team based approach allows CST to staff each team with consumers or family members who have experience with that service type. In addition to hiring staff with experience with the mental health system, CST staff now includes people with experience in substance abuse, child and adolescent services, and former and current clients of Department of Human Services.

C) On-going Family Member Survey

Consumer Satisfaction Team regularly solicits the input of family members during visits to provider sites, if family members are present, and receives and documents phone calls from family members. In addition to talking directly with family members in-person or by phone, CST conducts an ongoing survey to ascertain family members' perspectives on their loved one's services.

Consumer Quality Team of Maryland

A) Balancing Staff's Individual Needs with Team Building

Because CQT is a start-up team, particular emphasis has been placed on providing regular training and support to staff. CQT's personnel policies reflect a commitment to employee wellness and provide options and supports for employees dealing with a current mental health issue. In addition, CQT has on-call interviewers who can be available if a staff member needs to take a leave of absence.

CQT also has a training and supervision process that is supportive of individual needs and is focused on team building. They use a training manual, but the personal training period varies widely depending on the employee's background. For some people, interviewing is a totally new activity or they may have limited knowledge about some areas of the public mental health system, so their training may last 2-3 months. Others are more experienced and can be trained in as little as 5 weeks. Training is tailored to support and encourage each employee's professional growth.

To support team building and ongoing training, every Friday is an in-office day so staff can finish up reports, plan the next week and do training activities. Role-playing and roundtable discussions about what came up during the past week are utilized. There is a focus on collaboration and team-teaching; individual staff members and teams share challenges that they faced during the week and all team members participate in brainstorming how to improve.

B) Outside Assessment of Consumer Evaluation Work

As the mental health system continues to move towards evidence-based practices, the decision was made to have the work of Consumer Quality Team of Maryland evaluated by an outside agency from the beginning. The first year evaluation focused on staff member perspectives on the organizational start-up process. The second year evaluation was broader and included the perspectives of consumers, providers, advisory board members, and Core Service Agency staff.

The outside evaluators used a variety of methods to collect feedback, including phone interviews, surveys and focus groups. The information collected is used to change and improve the evaluation process. For example, interviews with CQT staff revealed that they needed something to clearly identify them when they went to a site to interview consumers. The organization purchased badges and polo shirts that clearly identified them as CQT staff members. In response to consumer feedback, a toll-free number was obtained and added to the promotional materials. In response to provider feedback, reports were changed to provide an executive summary of the report. In addition to critical information used for improvements, the evaluation allows Consumer Quality Team staff to hear positive feedback from stakeholders and to better document the ways their work is making a difference.

C) One Consumer Evaluation Program for the State

Maryland is one of the smaller states, in terms of its geographic area. The CQT began as a pilot program in three jurisdictions. After just six months of operation, the CQT oversight committee, with the support of the providers in the pilot jurisdiction, asked for and received from the Mental Hygiene Administration funding to take the program statewide. The decision was made to locate the CQT office in central Maryland (Baltimore), and to expand the program out from the pilot area. When the more distant areas of the state are reached, the teams will stay overnight in the area, visiting multiple locations. This will not only minimize the program's administrative costs, it will also ensure fidelity to the program and to the collection of comparable data.

D. Future Directions and Expanding Impact of Consumer-Led Evaluation Teams

Consumer-led evaluation teams are looking to the future with an eye towards how to expand their impact. Two themes arose about expanding the influence of the organizations. Three out of the four organizations were working to expand their work to other populations and provider types.

- Consumer Quality Team of Maryland has expanded its adult program visits from 3 jurisdictions to 14 jurisdictions, and plans to cover all 23 jurisdictions. In addition, plans exist to then begin visiting the child and adolescent mental health programs.

- Vital Voices is planning to branch out into consumer evaluation of services for alcohol and other drug abuse (AODA) services, and hopes to evaluate newly developed housing programs for people with mental illness and/or a history of homelessness.
- Consumer Quality Initiatives of Massachusetts continues to expand its work to both addiction programs and services for people with physical disabilities. Within mental health, CQI continues to evaluate and research peer run and peer specialist⁶ services. In addition, it has been working to establish a participatory action research center.

Expansion often requires an increase in the size of the staff and greater administrative capacity (e.g., accounting, contract management). It also means that other kinds of work expertise will need to be brought in, including consumer staff of non-mental health services. Business or organizational consultants can often be useful here.

Increased funding will either be secured by contracting with other health agencies or through subcontracts with other research and evaluation organizations. For instance, the Consumer Satisfaction Team of Philadelphia has expanded by contracting for consumer satisfaction work with the Department of Human Services. Other consumer-led evaluation teams are contracting with large providers for more focused projects, or with other research or evaluation organizations that might bring different skills and capacities to consumer satisfaction work.

Recommendations for Creating and Sustaining a Consumer-Led Evaluation Team

Based on the findings presented above about the core features of consumer-led evaluation teams, differing approaches, and innovative features of the four organizations highlighted in this report, we have developed a set of recommendations for those planning to start a consumer-led evaluation team in their own community.

1. When starting a consumer-led evaluation team, establish its mission and goals. One issue is whether a team plans to focus on evaluating systems and programs, and/or responding to clients' personal issues. The idea is to fill an unmet need(s)

Regardless, the ultimate goals for these teams is to see that providers and (quasi-)governmental funders are held accountable for addressing the findings and reports of the team. An effective accountability process requires mutual respect and regular communication.

2. Start small and get it right. In the beginning, focus on a particular provider type or limited geographic area. Over time expand out to a larger geographical area or to other service delivery areas, such as child and adolescent services.

⁶ Peer specialists are people in recovery who are trained, and increasingly certified, to provide paid peer-to-peer support at a variety of mental health programs.

3. Develop a strong, collaborative relationship with both the agencies who are in a position to hold providers accountable (e.g., government, managed care) and the providers themselves. This buy-in is especially important since the providers often facilitate the recruitment of consumers to be interviewed.
4. Determine how you want to collect consumer perspectives and spend time honing your methods for collecting consumer satisfaction information. Discuss the pros and cons for different types of data collection approaches (i.e. open-ended versus close-ended questions; consumer comments verbatim versus statistics). It may be that the method you use depends on the circumstances.
5. Think through data management and reporting procedures. Consider what types of information providers and other stakeholders will value and what kind of data will move them to action. Then, create an organized and efficient method for moving from data collection to data storage to analysis and reporting.
6. Carefully think through how you can protect the confidentiality of the responses of the people you interview.
7. Provide people hired with the appropriate level of supervision, training and support. Meet the specific vocational needs of individuals. Some staff may need "reasonable accommodations"⁷ so that they can perform their "essential job functions." Consumers working for consumer-led evaluation teams are a powerful reminder to providers and other consumers that recovery is real.
8. Have an effective training program for new staff. Determine whether you want staff to specialize in particular tasks (interviewing, writing reports, meeting with providers) or to be "generalists", who participate in all or most phases of the data collection and reporting process. Consumer satisfaction work can require many skills – interpersonal, time management, analytic thinking, writing, and presenting information.
9. Once the organization is established and policies and procedures become solidified, consider how to diversify your funding portfolio. For example, look for opportunities to do consumer satisfaction work for other governmental agencies, providers, consumer groups and universities.

⁷ Per federal (Americans with Disabilities Act) and sometimes state law