



Best Practices for Meaningful Consumer Input in New Health Care Delivery Models

Background

Consumer engagement is important for the success of all models of health care delivery. Ensuring the presence of an active consumer voice is especially important for vulnerable populations with specialized needs—such as people with disabilities and frail elders. As new models for delivering care are implemented by organizations that may not have previous experience with these populations, consumer engagement is an important way for early identification of promising practices to expand and potential problems to correct. **The rapid feedback consumer engagement provides is critical to the success of new health care delivery models.**

The Affordable Care Act (ACA) laid the groundwork for the creation of health care delivery models such as accountable care organizations and integrated care systems for people eligible for both Medicare and Medicaid (dual eligibles). The degree of involvement by consumers in new models will depend on the way language such as "meaningful consumer input" is implemented by health care organizations; however, there is no current standard regarding best practices for involving consumers in health care delivery organizations.¹

The consumer voice is necessary to:

- provide the consumer perspective on major strategic decisions
- give feedback on the way current services are experienced by consumers
- raise new issues of concern to consumers

This issue brief outlines a framework for thinking about the best practices that are needed to ensure a meaningful consumer voice in new care delivery models.

1. Involvement in Multiple, Active Ways

“Consumer input” can mean anything from shared decision-making in the exam room to consumer involvement in developing care plans to organizational advisory and governance roles such as consumer membership on the board of directors. Surveys, comment cards and newsletters can be important parts of consumer outreach, but use of these methods alone does not allow consumers to raise new issues that are not on the organization’s agenda or to play a role in the organization’s decision-making. Active in-person dialogue between consumers and organizational representatives can make sure consumer voices are fully heard. Using multiple methods to engage consumers increases opportunities for consumer participation and gives consumers the ability to have their perspective heard in multiple settings.

Advocates should work to ensure:

- Consumers have opportunities for active, in-person interaction with organizational decision-makers.
- Consumers are engaged and using multiple practices such as:²

Boston Health Care for the Homeless Program

(Boston, Massachusetts)

Boston Health Care for the Homeless, a Massachusetts-based organization that delivers care to more than 11,000 homeless adults and families, has consumer representatives on their board of directors, a consumer advisory group that meets regularly, a consumer representative on their quality improvement committee, and consumer advisory board members at health fairs.

- consumers on the board of directors
- consumer advisory boards
- town-hall meetings
- focus groups
- resource fairs
- surveys
- comment cards
- newsletters

- Organizations offer a “ladder of engagement”—a pathway for consumers to participate in increasingly active roles within the organization, such as moving from focus group participant to advisory board member to serving on the board of directors.

Advocates can play an important role in developing multiple approaches by:

- Working with health plans, providers and policymakers to help these partners identify the kinds of support structures needed for effective consumer participation in engagement practices.
- Exploring areas for potential collaboration where advocates’ skills and experience with effective consumer engagement can be deployed to assist health plans in building this emerging area.
- Advocating for the dedicated investment of resources necessary to support these engagement and capacity-building efforts.

Inland Empire Disabilities Collaborative

(California)

The Inland Empire Disabilities Collaborative (IEDC) is a group with more than 400 members that brings together organizations from Riverside and San Bernardino (CA) counties serving seniors and persons with disabilities. Navigating services and resources from different organizations across a widespread geographical area can be inconvenient and overwhelming. Consumers often miss the opportunity to receive the full-scope of resources available in their county. The IEDC helps decrease the problem of fragmented resources. Facilitated by the Inland Empire Health Plan, the disabilities collaborative includes a wide variety of participants including care providers, county agencies, In-Home Support Services, and disability rights advocates.

2. Inclusion at the Highest Feasible Level of Governance

The governance structure outlines the way in which an organization is controlled and the levels at which decisions are made. For consumer input to have the broadest reaching impact on decision-making, consumers should be included at the highest level of organizational structure that is feasible.

Having a consumer-majority board of directors is a governance requirement for community health centers that fall under Section 330 (of the Public Health Service Act).³ Although this model may not be feasible for all organizations, consumer advocates should:

- Ask for transparency on how the current or proposed governance level was determined.
- Work for inclusion of consumers at the highest feasible level of governance. For example:
 - If a consumer-majority board is not possible, at least two consumer members should serve on the board. The mutual support and connection between the consumer members on a board can help avoid a sense of isolation or tokenism.
 - If having consumer members on the board is not possible, a consumer advisory board—an on-going meeting of consumers drawn from the community served by the organization—can provide a venue for the organization to actively engage consumers on topics that reflect organizational or consumer concerns. Although consumer advisory boards are typically consumer-led, having organizational involvement—through support by organizational staff handling meeting logistics and disseminating meeting minutes and agendas—is important for success. Further, a member of the board of directors should regularly attend consumer advisory board meetings and report back to the board.

3. A Representative Recruitment Process

Every group of consumers is made up of individuals with different preferences, values, needs and experiences. It is important for consumer input processes to represent this diversity of consumer views as much as possible and to identify individuals who are interested in using their personal experiences to create broader system improvements. The consumer input process should:

- Have criteria for deciding how representativeness will be evaluated and encouraged.⁴
- Consider demographic factors such as representation across gender, race and ethnicity, and socioeconomic factors.
- Consider non-demographic factors such as representation of different geographic regions served, different medical diagnoses, or different services used.
- Consult advocacy groups and organizational staff in the recruitment process.
- Include family members or other caregivers, such as patient care attendants, as appropriate.

Inland Empire Health Plan

(San Bernardino, California)

Inland Empire Health Plan (IEHP) is a non-profit public health plan serving low-income working families with children, low-income seniors and people with disabilities, including dual eligibles. IEHP has multiple avenues for community stakeholder engagement including two public policy participation committees and multiple collaboratives including a disabilities collaborative, which includes service providers from regional organizations that serve people with disabilities and seniors. IEHP strives for consumer representation across multiple areas including geographic distribution, age, type of disability (physical, cognitive, sensory, developmental), and dual-eligible status.

4. Dedicated Resources

Effective consumer engagement cannot exist without organizational commitment and support. Meetings—board of directors, consumer advisory boards or town hall meetings—need staff member commitment to reserve meeting facilities, distribute agendas, take minutes, and arrange food and transportation. Surveys require staff support for content creation, distribution and result analysis. Participants in any process require orientation and training. At a minimum, an effective consumer input process should:

- Designate specific organizational resources to be used to support consumer input structures.
- Empower consumers for maximum participation with ongoing training and support. As noted above, active consumer participation in a “ladder of engagement” requires having dedicated staff to support on-going consumer knowledge and skill acquisition in areas such as leadership, negotiation, and giving presentations.
- Consider collaborations with advocacy and community organizing groups who have existing skills and experience in consumer engagement with the relevant consumer populations. For example, a health plan starting a new initiative to engage its members could partner with local, trusted health care advocates—who already have the knowledge base, skills and networks in place—to begin conducting member focus groups. The advocates’ expertise augments the organization’s resources and allows the organization to build their effort effectively; consumers benefit through engagement efforts that are already sensitive to local community needs.

East Boston Neighborhood Health Center

(East Boston, Massachusetts)

East Boston Neighborhood Health Center—a community health center with more than 300,000 patient visits per year—has a consumer-majority board of directors consisting entirely of area residents. This organization has done a variety of training activities with its board members including the use of training materials from the National Association of Community Health Centers,¹ a weekend retreat, and bringing in expert speakers on board governance.

5: Address Barriers to Participation

Including consumers who have physical disabilities, behavioral health issues or other barriers to active engagement—such as income, literacy or language barriers—requires the organization to commit resources to encourage participation. Organizations should, at a minimum, address:

- **Transportation needs:** Events should be held at convenient locations for consumers and other participants (such as caregivers), near bus routes or other public transportation, or transportation should be provided if participants would otherwise not be able to attend. Transportation accessibility for consumers with physical disabilities is an important consideration.

- Physical accessibility:** Event locations should be accessible for persons with physical disabilities and with room arrangements compatible with assistive technology (for example, speech-generating devices for augmentative/alternative communication).⁵
- Cultural competence:** Organizations should be respectful of consumers' cultural and linguistic needs. For example, interpreters should be provided for non-English-speaking consumers. If speech-generating devices are used, additional time for use of the devices should be allotted.⁶ The cultural and linguistic needs of other participants such as caregivers may differ from the needs of consumers and should be addressed accordingly.
- Income accessibility:** Stipends for participation can help offset costs related to transportation, child or respite care, or time off from work. Supports such as provision of food and transportation are especially important to consider for enabling low-income consumers to participate.
- Time barriers:** The scheduling of meetings will affect different segments of the population differently. For instance, working people (especially in hourly wage jobs) will not be able to take time off from the work day to participate. On the other hand, participants who are senior citizens may not want to travel in the evening.
- Knowledge & skill-related barriers:** Organizations should provide orientation, training, and support for consumers to meaningfully participate in engagement activities, especially for consumers in roles such as membership on a committee, advisory board, or board of directors that require skills such as running a meeting, making presentations, or negotiating with others.

Colorado Access

(Denver, Colorado)

Colorado Access, a non-profit health plan that serves more than 300,000 members, provides services to multiple groups including low-income children, dual-eligible individuals, and consumers with behavioral health needs. For consumers served by its behavioral health service line, Colorado Access holds quarterly town hall meetings open to all members. The meeting location was selected based on ADA accessibility and proximity to public transportation. Staff members greet consumers along the entrances from the bus stop to the building to help guide them to the meeting location. Food and a gift card to a local market are provided. The security officer who is present on meeting days has training in the area of mental illness for the few instances where a member has needed security assistance.

6. Evaluation and Monitoring

Meaningful consumer engagement means consumers are included because their participation matters to the organization, not just to satisfy a requirement. Consumer engagement should be related back to the organizational mission and considered part of the process by which this mission is achieved. The engagement process should:

- Connect consumer engagement to the organizational mission with concrete goals. Examples of goals include obtaining consumer feedback for quality improvement, generation of new ideas, and improving communication with consumers.
- Evaluate process- and outcome-related goals. Examples of process-related goals are the number of consumers participating and whether different consumer populations are represented. Examples of outcome-related goals are process changes related to consumer input and new initiatives related to consumer input.
- Consider independent evaluation in order to obtain an external perspective on the organization's engagement processes.
- Require organizations to submit reports to relevant entities such as purchasers and regulators on their consumer engagement goals, processes, and outcomes.

Why Consumer Engagement Matters

Catching mistakes: The board of directors for one organization includes members from the Latino community. During a tour of a new facility prior to opening, the members noticed the Spanish language signage was incorrect. Having the chance to correct that mistake helped the organization provide a welcoming environment for their Spanish-speaking patients.

Improving communication: Commonwealth Care Alliance (CCA) is a non-profit care delivery system serving older adults and individuals with serious physical, cognitive, or chronic mental illnesses. CCA involves consumers in multiple ways including town hall-style community meetings. At a meeting focused on a particular immigrant community, community members asked for more information about CCA and the other communities it served. As a result, CCA began publishing a quarterly member newsletter in multiple languages that includes a consumer profile, educational information, stories and announcements.

Responding to family needs: The Memorial Regional Hospital (Hollywood, Florida) consumer advisory council had family members who talked about the challenges of spending months by the bedside of their loved ones, including trying to keep up with daily tasks like paying bills on-line. The council raised the money to outfit an unused waiting area with computers, which has become a family resource center staffed with volunteers. It was so popular with consumers that other facilities in the Memorial Health care System created resource centers also.

Starting new services: A public health system has an advisory board within the county's homeless services program consisting of county residents appointed by the board of supervisors, including designated seats for consumers. Every advisory board meeting has a designated item for the consumer subgroup regarding consumer concerns. This subgroup has produced new initiatives such as dental care for the homeless. This issue was brought from the consumers to the full advisory board which led to the formation of a pro bono dental program that provides services including restorative and reconstructive dental services. A program where previously homeless individuals provide mentoring and training services for homeless consumers also came out of the consumer advisory board.

The Future of Engagement

The new delivery models and payment systems created through the Affordable Care Act are being implemented with the goals of improving health outcomes and containing rising health care costs in patient-centered ways. Unless we simultaneously include strong new mechanisms for the people being served to have a voice in the design and ongoing operation of those systems, these goals will not be achieved. This brief largely focuses on the relationship between organizations and the consumers they serve, but true reform will also require organizations to extend their engagement toward the community of stakeholders that touch consumers' lives. Health care delivery systems that partner with stakeholders across multiple areas—from service organizations to consumer advocacy groups to government agencies—will generate the information exchange and resource sharing necessary to create the coordinated, patient-centered care consumers need to improve their health and their quality of life.

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¹ For example, the Medicare Shared Savings Program specifically requires beneficiary representation on an accountable care organization's governing body, although some flexibility is allowed. (Available at <https://www.federalregister.gov/articles/2011/11/02/2011-27461/medicare-program-medicare-shared-savings-program-accountable-care-organizations#h-28>). The Massachusetts State Demonstration to Integrate Care for Dual Eligible Individuals (Section D.iii.) requires that integrated care organizations have “meaningful consumer input processes in their ongoing operations, including but not limited to governing or advisory boards that include sufficient numbers of enrollees and representatives.” (Available at <http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/prev-meetings/120216-final-proposal.pdf>.)

² The Institute for Patient and Family Centered Care has assessment tools to help organizations find opportunities to increase collaboration with consumers, available at <http://www.ipfcc.org/resources/other/index.html>.

³ For more information, see the HRSA Bureau of Primary Health Care page on community health center governance requirements at <http://bphc.hrsa.gov/policiesregulations/governance/index.html> as well as the bureau's site visit guidelines section on governance, accessible at <http://bphc.hrsa.gov/policiesregulations/centerguide.html>.

⁴ Community health center Section 330 governance requirements provide one model for ways representation requirements can be implemented and evaluated. The text of the authorizing legislation including governance requirements is available at <http://bphc.hrsa.gov/policiesregulations/legislation/index.html>. The health center site visit guide is one example of how representation in governance can be assessed, available at <http://bphc.hrsa.gov/policiesregulations/centerguide.html>.

⁵ For more information on augmentative communication, see, for example, the ALS Association webpage accessible at <http://www.alsa.org/als-care/augmentative-communication/>.

⁶ For more information on cultural competence, see the U.S. Department of Health and Human Services Office of Minority Health website at <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=1&lvlid=3>.