



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

Advancing the Practice of Client- and
Family-Centered Care for Colorado
Department of Health Care Policy
and Financing

A Report by the Institute for
Patient- and
Family-Centered Care

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**ADVANCING THE PRACTICE OF CLIENT- AND FAMILY-CENTERED CARE
WITHIN COLORADO DEPARTMENT OF HEALTH CARE POLICY AND
FINANCING:**

A REPORT BY THE INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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I. EXECUTIVE SUMMARY

With grant support from Colorado Health Foundation, the Colorado Department of Health Care Policy and Financing retained the services of the Institute for Patient- and Family-Centered Care (IPFCC) to conduct a site visit and review of key documents to assess the agency's engagement of clients and families in partnering to improve services, develop policy and program recommendations.

A three-day site visit occurred on July 24-26, 2012. Beverley H. Johnson, President/CEO of the Institute for Patient- and Family-Centered Care and Mary M. Minniti, CPHQ, a quality improvement leader and Program and Resource Specialist participated on the site visit. During this time, 14 internal meetings were held representing all the key programs and leadership of the agency. Over 117 unique individuals attended these meetings. Additionally, IPFCC reviewed documents including agency policies, job descriptions, contracts, print and on-line informational materials as well as the strategic plan.

The full report outlines in detail the observations, both strengths and opportunities, made during the site visit. Given the level of agency participation, there is both passion and commitment to improving client and family engagement. Opportunities exist to strengthen communications and relationships both within the agency and with clients, families, and other stakeholders. When meeting with stakeholders, both paid advocates and clients and families, there was a sense of optimism about recent efforts the agency has made to build mutually beneficial partnerships. Leveraging this positive momentum, specific recommendations were outlined for consideration. These strategies were informed by organizations across the health care continuum that have been successful in creating healthy and collaborative relationships with clients and families. Some exemplars and their outcomes are highlighted in the report.

The strategies outlined in the report fall into five broad categories:

- Leadership's role in advancing client- and family-centered practices within the agency.
- Infrastructure development and appropriate resource allocation to support meaningful client and family participation as advisors.
- Alignment of human resource, and workforce development in supporting staff to effectively engage clients and their families.
- Improvement of communication approaches by partnering with clients and families in its development; integrate data that informs and engages stakeholders.
- Influence care providers to integrate patient- and family-centered care practices into the client experience and measure outcomes.

The Colorado Department of Health Care Policy and Financing's identification of client and family engagement as a strategic priority is the first step in transforming relationships with clients and families as well as other stakeholders into positive, productive and meaningful collaboration. It is the conclusion of the full report, that by identifying key implementation actions, HCPF will accelerate the adoption of a client- and family-centered culture and ensure the "lived experience" of this population will inform programs, policy and care experience improvements.

II. INTRODUCTION

This report is a profile, a snapshot in time, of the Colorado Department of Health Care Policy and Financing (HCPF). The report provides a summary of the observations and recommendations of the Institute for Patient- and Family-Centered Care for advancing the practice of client- and family-centered care and developing effective partnerships with the clients and families served by the agency.

The report is based on a review of HCPF's key documents and a three-day site visit, July 24-26, 2012, by Beverley H. Johnson, President/CEO of the Institute for Patient- and Family-Centered Care and Mary M. Minniti, CPHQ, a quality improvement leader and Program and Resource Specialist.

During the site visit, 14 internal meetings were held representing all the key programs and leadership of the agency. Over 117 unique individuals attended these meetings. At least 18 staff attended more than one internal meeting.

Two "stakeholder" sessions were held. In the first meeting, representatives from State Medical Assistance and Services Advisory Council, Benefit's Collaborative and Mental Health Advisory Group were in attendance. A total of 25 individuals participated in that meeting including staff. Based on self-report, only two attendees received direct services from the agency and the other participants represented advocacy organizations. In the second session, nine attendees representing external stakeholders attended. Four individuals identified themselves as clients or family members receiving services from HCPF. The remaining participants were advocates representing different organizations that promote the interests of clients and families. Staff attended as observers. One client attended both sessions.

A Site Visit Highlights Report was sent to the HCPF Leadership August 17, 2012 with a list of opportunities and draft recommendations. This report builds on the Highlights Report. It is intended to be a guide to facilitate a long-term process of change in organizational culture that builds on HCPF's commitment to client- and family-centered care and to enhancing its ability to collaborate effectively with the clients and families the agency serves. The report is also intended to be an information resource on emerging best practices for effective partnerships within a client- and family-centered framework.

III. CLIENT- AND FAMILY-CENTERED CARE

Client- and family-centered care^{*1} is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, clients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with clients and families of all ages, at all levels of care, and in all settings. This approach shifts the relationship between health care professionals, and clients, and families from the traditional focus of “*doing to and for*” them. Instead, it embraces the approach of partnering “*with*” clients and families. It acknowledges that they are essential allies for quality and safety within any health care setting.

The core concepts of client- and family-centered care are:

- **Dignity and Respect.** Health care professionals listen to and honor client and family perspectives and choices. Client and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care professionals communicate and share complete and unbiased information with clients and families in ways that are affirming and useful. Clients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Clients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Clients, families, health care professionals, and leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

In client- and family-centered care, clients define their “family” and determine how they will participate in care and decision-making. Client- and family-centered care and cultural competence are inextricably linked. Respect for the beliefs, priorities, practices, and approaches to decision-making for individuals and families from diverse cultures and backgrounds is an essential aspect of client- and family-centered practice.

Client- and family-centered care offers the framework and strategies for bringing about transformational change in the organizational culture of health care organizations and agencies. In long-term care communities, the term frequently used, is resident-centered care. Resident-centered concepts and strategies are very similar to client- and family-centered care.

Collaborating with clients and families and bringing their unique expertise directly into the planning, delivery, and evaluation of health care policies and practices to improve quality, safety, and the experience of care is fundamental to client- and family-centered care. A growing body of evidence reports that partnering with patients, clients, and residents in hospitals, ambulatory care settings, home care, long-term care communities,

* The Institute for Patient- and Family-Centered Care uses the terms client- and family-centered care and patient- and family-centered care interchangeably.

and other settings across the continuum of care leads to better health outcomes, wiser allocation of resources, and greater satisfaction for individuals and families and promotes greater satisfaction for staff and clinicians.

The Institute of Medicine's report released in 2012, *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*, states:

"A learning health care organization is anchored on patients needs and perspectives and promotes the inclusion of patients, families and other caregivers, as vital members of the continuously learning team" (page S-11).

"When patients, their families, other caregivers, and the public are full, active participants in care, health, the experience of care, and economic outcomes can be substantially improved" (page 7-1 & 7-2).

Don Berwick, former administrator for the Centers for Medicare & Medicaid Services, gives further affirmation that the partnerships of patient- and family-centered care can lead to economic efficiency. At the IPFCC International Conference in June 2012, he stated, "The most direct route to the Triple Aim is through implementation of patient- and family-centered care in its fullest form."

In recent years, two important transformational changes in the health care system—the recovery model in behavioral health and the patient-centered medical home—have positive synergy with the HCPF's interest in partnering in more significant and effective ways with the clients and families the agency serves. Partnerships with clients/patients and families are fundamental to both of these transformational changes. They are grounded in partnerships at the clinical level and in all aspects of delivery system redesign.

Implementing client- and family-centered care relies on: support and encouragement from senior organizational leaders; open, respectful communication; consistent staff liaison support for collaborative endeavors with clients and families; and training in effective collaboration for leaders, staff, clinicians, clients, and families.

A. FRAMEWORK FOR OBSERVATIONS AND RECOMMENDATIONS

As the Institute for Patient- and Family-Centered Care seeks to understand the practice of client- and family-centered care within a public agency, we look for the following indicators that suggest clients, and families are partners in health care delivery, policy and program development:

- An explicit statement in key documents that clients, and families are partners in providing input to key issues that impact care through program delivery and/or policy.
- The extent to which the agency ensures that the programs funded encourage clients, and families to participate in care and shared decision-making.
- The presence of systems for sharing useful information with clients, and families and connecting them with peer and community support.

- Hiring procedures and staff and leadership orientation and education programs that promote collaboration and the practice of client- and family-centered care.
- Clients, and families serving as advisors, with a structure in place that supports their participation in policy and program development, safety and quality improvement initiatives, agency staff education, and evaluation.

These five indicators serve as a framework for the agency observations and recommendations that follow. Additionally, we have incorporated best practice examples into the report to emphasize how meaningful, collaborative relationships with clients, and families can improve the experience for staff and leaders of the agency, and the people they serve. The recommendations are intended to be specific, concrete actions for you to consider. The Colorado Health Foundation is funding this assessment effort and our recommendations can form the basis of possible future funding to support implementation.

It is not the intent of this report to obligate the agency to implement every recommendation made. It is the agency's responsibility to consider these recommendations within the context of their mission, the environment, resources available, and constraints outside their control. Then, the agency can decide on its own unique path forward that will build greater client and family engagement by developing authentic partnerships with the clients, families and the community.

IV. OBSERVATIONS

The participation of key leaders and staff in the site visit showed a tremendous amount of interest and passion about improving client and family engagement. Opportunities exist to strengthen communications and relationships both within the agency and with clients, families, and other stakeholders. When meeting with stakeholders, both paid advocates and clients and families, there was a sense of optimism about recent efforts to partner with them. At the same time, there was discomfort with conflict and displays of behavior that were not grounded in mutual respect. There are many opportunities to build on the strengths noted below and make tremendous changes that will benefit clients, families and those who serve them.

There have been a number of changes within the agency since the July 2012 site visit. HCPF has renamed the The Client Services, Eligibility and Enrollment Office and elevated the Clinical Services Office to a senior level. Additionally, two new senior offices were created: the Policy and Communications Office, headed by Tom Massey and the Community Partnerships Office headed by Lorez Meinhold. The Administration and Innovation Office has a vacant leadership position and staff from that office has been temporarily reassigned.

A group of key leaders and staff has begun to meet bi-weekly to take the recommendations from IPFCC, prioritize them into a set of actions, identify short term opportunities within their operational control, and to explore additional funding from the Colorado Health Foundation and others. Serving as an adhoc Steering Committee, they began by reviewing the IPFCC's August 2012 Site Visit Highlights Report. Both the Highlights Report and this fuller report will inform their work.

A. STRENGTHS

The agency has many positive attributes. During the site visits, the IPFCC team observed various structures to support partnerships with clients and families, met dedicated and engaged staff, and reviewed operational processes for evidence of client and family input. Building on these strengths will create a strong foundation for supporting effective client- and family-centered care approaches. These observations are highlighted below:

Structures:

- Five-year strategy map explicitly identifying client engagement as a key component and priority.
- A draft Quality Report that links to national priorities, and explicitly sets a goal (D) to provide patient- and family-centered care.
- Website information provided in 17 languages.
- Colorado Governor's Council on Disabilities is a resource that provides access to broad representation of the disability community.
- Establishment of Care Coordination Committee working on consolidating the different approaches with the goal of creating a standardized and best practice approach.
- Regional Care Collaborative Organizations contracts have integrated a general expectation of client and family engagement.

- Numerous tri-agency collaborations with DHS (Dept. of Human Services), and CDPHE (Dept. of Public Health and Environment) are underway with the support and direction of the Governor's office. These efforts provide opportunities for efficient client and family engagement.
- Community-based Family Health Coordinators link clients to Medicaid services and provide a potential mechanism for recruitment of client and family advisors.
- Accountable Care Collaborative program at HCPF has a clear expectation for robust stakeholder involvement and quarterly reports on client and family involvement.
- Home Health, Hospice and Private Duty Nursing have regulations that require involvement of clients and families on the care team and have a broad definition of family.
- Administration and Innovation Office has internal resources for workforce development and quality improvement that can support the cultural and operational changes needed to become more client- and family-centered. (Note: as of 11/2/2012, we are aware the functions of this office have been dispersed at the time. The functions remain a strong internal resource and necessary.)

People:

- Leadership commitment to becoming more client- and family-centered and demonstrating it through attendance and participation with staff at IPFCC site visit meetings.
- Explicit statements by numerous staff that articulated a commitment to meaningful client and family partnerships.
- Growing awareness that the current state of reactive communication and sharing of information is not effective coupled with a strong desire to create new ways of proactively working with clients and families.
- Successful at securing additional grant dollars (federal and other) to fill gaps and finding resources to be innovative (e.g., dissemination of laptops into the communities to improve access to services.)
- Stakeholders mentioned a positive shift in agency responsiveness to their concerns and issues. They characterize their recent interactions as sincere and meaningful. ("They listen more!") These stakeholders seem to want to move forward positively with real collaborative problem solving.
- Recognition by staff that the agency needs to address physical, economic and transportation barriers to participation of clients in advisory roles.
- Sincere desire to make information more affirming and useful (i.e. website, letters, presentations, etc.) and to include clients more systematically in these communication mechanisms.
- Openness to creative and innovative ways to utilize the website and the upcoming addition of additional staff with web development skills so that these ideas can be implemented.
- Interest in utilizing technology (e.g., email and cell phone usage) as additional mechanisms to share information and updates efficiently and effectively with clients.
- HCPF has partnered with community organizations that have experience engaging clients in improvement and program development.

- HCPF content experts in sharing complex information; readability; training; and use of LEAN approaches. These people can help support organizational change and enhanced partnerships with clients, and families.
- Smart, articulate and creative staff.

Processes that utilize client and family involvement:

- EPSDT orientation materials that were co-created by parents and co-presented with Family Voices partners.
- Inclusion of clients in workgroups on Long Term Care Reform work.
- Direct consumer involvement in development of PEAK.
- Healthy Communities flyers such as *We Care About Your Health* were tested for their effectiveness with clients.
- Client input utilized in the development of general information and educational materials.
- Established behavioral health pay rates for peer specialists thereby recognizing the value of trained peers in service delivery programs.

B. CHALLENGES AND OPPORTUNITIES FOR IMPROVEMENT

- There are no shared definitions of client and family engagement or stakeholder engagement. No standards or guidelines exist about these collaborative relationships and the roles of the various individuals who would participate.
- There is a general perception among staff that the current process of stakeholder involvement is time-consuming and not always productive.
- There is tension between some client and advocacy groups and the agency. There is lingering concern that it will be difficult to change this dynamic.
- While leadership changes are an inherent part of the political process for this agency, there has also been significant staff turnover. Embarking on this cultural change effort to embed partnerships into agency processes will require clarity of purpose, long-term leadership commitment, and investment in resources for staff preparation and education. Turnover could impact both the cultural change and operational implementation of new ways to partner with clients and families.
- There were numerous mentions of the fragmented information technology (IT) system. The perception is that current information technology systems contribute to unnecessary costs, poor service to clients, and do not provide meaningful data. This creates frustration for staff and a sense there is “no time” to do the right thing with clients and families. Attention must be paid to how the software can support your efforts and not be a barrier as you move forward. The site visit team did not explore which IT systems were of concern.
- The complexity of the Medicaid system, its programs, and the rapidly changing rules and regulations creates a burden on staff, clients, and families to “keep up” and respond effectively. This has helped fuel distrust among staff and clients and families served.

V. RECOMMENDATIONS FROM EMERGING BEST PRACTICES FOR POSITIVE AND MUTUALLY BENEFICIAL PARTNERSHIPS

“Collaboration means that no one interest group is always right. It means taking what you think, and what I think, and what someone else thinks, and coming up with something that works for everyone”

Bev McConnell Crider Director, Patient and Family-Centered Care
Children's Hospital of Michigan

“Be transparent and share as much information and insight with patient and family advisors as they begin to work on a particular issue. There are no secrets. We need to share the flaws in our system with patient and family advisors, so they can work with us to improve.”

Bernard Roberson, Administrative Director, Patient and Family
Centered Care, Georgia Health Sciences Medical Center, Augusta, GA

The following best practices for agency infrastructure have been shown, in a variety of organizations, to lead to effective partnerships. The IPFCC team recommends that HCPF give serious consideration to adopting these practices for the agency.

A. Leadership

- **Appointing Executive Sponsor(s) for advancing the practice of client- and family-centered care and developing meaningful, sustained partnerships with clients and families that receive services from your organization.** Because of the size and the complexity of the HCPF agency, we recommend that there should be two Executive Sponsors. This will enhance the importance and visibility of client- and family-centered care, demonstrate commitment in all aspects of the agency, and ensure that two individuals at a senior level are available to remove barriers to effective partnerships. The role of an executive sponsor is to monitor the progress of the effort, remove barriers that threaten forward momentum, send a clear message of the priority of partnership, model successful relationships with clients and families as well as clearly articulate any constraints/limitations for this work.
- **Linking the mission of the agency and defining collaboration with clients and families and related processes as essential to achieving the mission.** At this particular point in time, it is especially important to define collaboration as mutually beneficial partnerships that helps carry out the mission of the organization and use agency resources in a just, efficacious, and legally appropriate way. There are boundaries to this partnership. The public, clients, and families, are not charged with running the agency; this is the responsibility of agency staff, but the insights and perspectives of citizens, especially clients and families, are vitally important. It will take time to develop trust in this new way of working. Establishing a set of values, which guide the way your mission is achieved, provides an opportunity to embed the core concepts of client- and family-centered practice within agency infrastructure.
- **Creating the expectation for partnerships with clients and families in all**

programs, departments, and settings as central to a learning organization and to assuring quality, safety, and efficiency throughout the agency. . . . AND ensuring that this involvement in change and improvement starts at the beginning of these initiatives. Agency senior leaders need to convey this expectation for partnerships with clients and families and ensure that processes and resources are in place that will ensure effective partnerships. Another role for leadership is to insist that planning for new policies and programs involve clients and families early in the planning process. Leadership's modeling of meaningful partnerships sends a powerful message to staff of the importance of collaborative partnerships. Leaders must also be willing to stop a process when clients and families should be involved and there are no advisors prepared and available to participate.

B. Client and Family Partnership: Resources and Setting the Stage

- **Appointing a staff liaison for collaborative endeavors, an individual with strong facilitation skills and access to organizational leaders. This person must be comfortable with the populations and communities served and needs dedicated time to encourage and support the participation of client and family advisors.** Clearly best practice is to designate an individual or a team that is the "go to" place for partnerships for the agency. The new Office for Community Partnerships can be the coordinating hub for the many ways that the agency partners with the clients and families it serves. The new 2012 organizational chart wisely depicts a direct reporting line between this Office and the agency Executive Director. The liaison position:
 - Serves as the key staff person for recruiting, selecting, orienting, and supporting client and family advisors.
 - Assists staff across all departments in understanding the roles of clients and families at meetings, or on committees and task forces.
 - Educates, formally and informally, about the principles and benefits of client- and family-centered care, advisory councils, and other collaborative endeavors. In a transparent manner, this individual must also be candid and constructive about the challenges.
 - Monitors and tracks issues identified and worked on by client and family advisors.
 - Communicates with senior leadership about partnerships.

Further guidance for staff liaisons is listed in Appendix A.

- **Identifying a variety of ways for clients and families to serve as advisors.** The term "advisor" is used to describe any role that enables clients, residents in long-term communities, and family members to have direct input and influence on policies, programs, and practices that impact the care and services they receive.

The table below outlines the differing levels of engagement that clients and families can be involved in. As the engagement moves further into the agency, the preparation for these roles increases. It is important that attention is paid to which level of engagement is most appropriate in a given set of circumstances. For instance, if there is a quick turnaround required for project/task, ad hoc input, or

structured consultation requires less staff and client time than an ongoing committee leadership role.

| Depth of Engagement | Client and Family Role | Things to Consider |
|-------------------------|--|--|
| Ad Hoc Input | Survey or Focus Group Participants | Ensure diversity and representation, validity |
| Structured Consultation | Council or Advisors-provides input | Early consult supports partnership model |
| Influence | Occasional Review/Consultants to project | Allows flexible ways to participate; requires background/orient. |
| Negotiation | Member of Improvement Team | Training in QI approach; topical orientation |
| Delegation | Co-Chair of Group | High level of expertise or skill |
| Advisor Control | Implementer or peer support role | Strong training component, mentoring and compensation |

Adapted from Mid-Valley Behavioral Care Network

Below is a list of roles that clients and families have had in many agencies and organizations. When a specific role was discussed during the site visit as being relevant to HCPE, it is indicated within the parentheses:

- ✓ Members of task forces (Care Coordination workgroup).
- ✓ Members of advisory committee (The ACC groups: Dual Eligibles Advisory Subcommittee, Quality and Health improvement, Provider and Community Relations, Payment reform).
- ✓ Members of quality improvement team (LEAN events).
- ✓ Members of an e-group that provides input on various projects through email and other technologies that allow virtual participation.
- ✓ Speakers in new hire orientation or in-service sessions for new employees to the agency (Workforce development activities).
- ✓ Paid program staff or policy consultants.
- ✓ Peer coaches/mentors for other clients, and families.
- ✓ Educational and support group facilitators (Chronic Disease Self-Management services).
- ✓ Members of committees hiring new leaders and staff (Human Resources).
- ✓ Participants in a program needs assessment process (Convening representative group of clients and families to capture views on rule-making and participate in conference on the proposals under consideration, Long Term Care Advisory Committee).
- ✓ Ambassadors and recruiters of new members for advisor positions within the organization or across a geographic region or population.
- ✓ Reviewers and co-authors of online, audiovisual, and written materials: (Letter improvement for providers, DME, and client letters related to determinations and appeal process, nomenclature project, website redesign)

- ✓ Participating in a panel of clients and families sharing their experiences with your agency.

Appendices C and D provide guidance on working effectively with clients and family advisors.

- **Identifying the qualities, experience, and skills of client and family advisors who will serve in the roles described above.** The following are qualities and skills often shared by effective advisors:
 - ✓ Shares their insight and personal experience in ways that others can learn from them.
 - ✓ Sees beyond his/her own personal experience.
 - ✓ Sees the "big" picture.
 - ✓ Respects diversity and differing opinions.
 - ✓ Listens well and can hear other points of view.
 - ✓ Collaborates with others on solutions.
 - ✓ Demonstrates a sense of humor and ability to connect with people.
 - ✓ Interested in more than one agenda item or issue.
 - ✓ Provides a compelling reason for being an advisor.
 - ✓ Passion for improving health care.
 - ✓ Representative of the clients and families served by the agency.
- **Establishing a comprehensive plan to recruit, orient, and prepare client and family advisors to work with agency staff and leaders.** The agency already has a network of partners in communities across Colorado. Leveraging those partnerships to assist in the recruitment of clients and families can be an effective way to broaden representation beyond those already participating with the agency. Clarity about the current opportunities for input and collaboration is important prior to recruitment. Developing a selection process that is systematic and screens for those who possess the skills and aptitudes to participate effectively creates a win-win situation for both the agency and advisors. Discussing both the work of the council or committee, and the "culture" of the organization and the "do's" and "don'ts" of their new roles is necessary to ensure a successful integration of advisors into the organization. Inviting seasoned advisors to help conduct the orientation is a practice that yields positive results and demonstrates the partnership model in action. Some topics to include in orientation include:
 - ✓ Introductions and the sharing of personal and family stories.
 - ✓ The mission and goals of the agency.
 - ✓ Who's who in the organization.
 - ✓ The role of the council or committee, how it fits within the agency's structure, and how it can assist the agency in achieving its mission and goals.
 - ✓ The roles and responsibilities of all members, officers, and staff on the council or committee.
 - ✓ Meeting attendance expectations of members.
 - ✓ Confidentiality training and agreements including HIPAA and client and resident privacy.

- ✓ How the meeting is conducted: Robert’s Rules of Order (if they are used), committee reports, reaching consensus, and approval of minutes.
- ✓ How to prepare for a meeting - what to wear, what to do ahead of time, what to bring.
- ✓ Reimbursement procedures if applicable.
- ✓ Speaking their language — Jargon 101.

- **Investing in client and family leadership development.**

Regardless of the background an advisor brings to the organization, most advisors mention the opportunity to learn something new as a motivation for taking on this new role. Providing on-going training and learning opportunities can help advisors be more effective in meetings. Many organizations provide training in communication skills, meeting facilitation, and other topics for employees that also have broad application for advisors. Encouraging advisors and supporting their participation in a workshop or attending a conference on a topic related to their assignment is a way to build skills of advisors. Many organizations have found it beneficial to send advisors with staff to shared training experience like the IPFCC Seminar. Shared learning builds bridges and creates a common foundation for positive, constructive relationships.

C. Workforce Development and Human Resource Alignment

- **Developing a comprehensive plan to prepare staff, clinicians, and administrative leaders to work collaboratively with clients and families in developing, implementing, and evaluating new policies and programs within the agency and across the state and in ongoing change and improvement.** The Policy and Training Department and its efforts related to workforce development can support staff and leaders in developing the skills and confidence in working collaboratively and effectively with clients and families. This Department could focus on:
 - ✓ Developing training on how best to engage clients and families as advisors, meeting facilitation skills, and conflict management.
 - ✓ Providing more staff training on writing for readability.
 - ✓ Developing culture change strategies that fosters a strengths-based approach to service delivery and enhances further understanding of the lived experience of the clients and families served by the agency.
 - ✓ Developing training on the key communication and teamwork skills needed to participate effectively in collaborative endeavors. This can include topics such as conflict resolution, accepting and giving feedback, raising issues effectively, and communicating with empathy.

The Workforce Development Section could support this recommendation by aligning its training curriculum to prioritize training programs that emphasize positive communications and conflict resolution. The section currently provides training in Crucial Conversations, Crucial Confrontations, and the Respectful Workplace. These courses all support this recommendation.

The Section could support culture change efforts by expanding the scope of the current new employee orientation to include presentations by community members and providing training in the “Language of Caring” to all employees.

- **Aligning the human resource system of hiring, competencies, and performance management to support client and family partnerships.**

The Workforce Development Section could assist with managing and facilitating the cultural changes that need to occur within HCPF. It is also poised to develop and implement a competency model that will shape future employee selection, performance management and training programs. The HR section will need to be responsible for implementing changes in its practices to support these efforts.

Hiring for fit is an approach to identifying key values, attributes and attitudes that describe the culture of the organization. Being explicit in this way, individuals can make informed decisions about joining the agency. As you move toward a more client- and family-centered culture, updating job descriptions to reflect the competencies needed for success, using behavioral interviewing to assess an applicant’s experience and attitudes in this area, and including the values of client- and family-centered partnerships in performance evaluations are essential for change and long-term sustainability. Organizations that have advanced this partnership model beyond a few advisors participating in a limited way have made changes to their human resource system so that it becomes “everyone’s job” to collaborate with clients and families in care experiences and in quality improvement and health care redesign. Consider asking for client input when developing behavioral competencies so that they can be communicated and understood by everyone associated with the agency. Appendix B is a useful resource to review regarding personnel practices to consider.

D. Alignment of Communications

- **Creating a responsive communication strategy that reinforces the importance client and family partnerships.** Transparency in communication is best practice of agencies that have created trusting and mutually beneficial partnerships with their clients and families receiving services. Developing information in a variety of formats that is useful, affirming and helps the individual to more fully participate in decisions about their health is the measure of a robust communication mechanism. Additionally, it is important that staff that interacts daily with clients have reliable, up-to-date information to share about the programs and processes in the agency.
- **Create and send messages about client and family partnerships consistently and positively out to staff, reinforcing that client and family engagement is an important agency priority.**
- **Increase opportunities for clients and families to be full partners in their health care and in their relationship with HCPF through communication approaches such as:**

- ✓ Create repository “web portal” to access benefits info and key documents and critical reminders of action needed by client that is personalized. If there are limitations to the current resources and software codes, the agency should explore alternate ways to outreach to clients and families.
- ✓ Develop a strategy for use of email as a mechanism for sharing information, promoting prevention and health/wellness and understanding and using benefits effectively and responsibly.
- ✓ Provide individuals fiscal information about their health care expenditures and utilizations on a regular basis in the context of like individuals averages in the program.
- ✓ Create video of FAQs with client involvement.
- ✓ Create innovative, low cost ways to share information
- ✓ Further the use of stories and faces of clients as narrative for conveying messages on the website (may be some privacy issues and may need to go through advocacy partners).
- ✓ Develop mini videos to explain benefits to providers and clients.
- ✓ Create on-line tutorials and on-demand information available to clients, families and others.

E. Measuring the Impact of Client and Family Partnerships

- **Ensuring that there is a system in place to track learning, changes, and new initiatives evolving from partnerships with clients and families and to document results.** Working in partnership with advisors creates value for an organization. Generally, stories of these positive relationships and their benefits are shared extensively. While this anecdotal evidence spreads enthusiasm, to sustain momentum a more robust system of measurement is needed. Identify ways to systematically measure in both quantitative and qualitative ways the impact of integrating advisors into your organization at all levels. The most successful organizations that have sustained and expanded their client- and family-centered practices have made a compelling business case.

At a minimum, start with describing the work of advisors in its own annual report or as a specific section in your annual agency report and disseminate it widely. Capturing concrete and specific accomplishments in a written report is one way to demonstrate outcomes. It is difficult to go back and try to capture these changes, so plan ahead. Develop a form and/or process that is simple. This increases the likelihood that documentation is done consistently across the organization. Here are some items to track that can be incorporated into ongoing reports:

- ✓ Number of advisors involved as well as their roles and activities.
- ✓ Department or program areas represented.
- ✓ Staff involved in collaborative endeavors.
- ✓ Issues addressed, products developed, classes taught, peer support programs coordinated, and other activities—describe these issues, materials, activities, and outcomes (when available).
- ✓ Evaluation of participation in collaborative meetings.
- ✓ Summarize evaluations of classes taught to other clients, families, staff, leaders, and new employees.

- Count the # of people who participate in classes.
- Capture quotes from participants in classes.
- Summarize stories that they share.
- ✓ Take photographs (or scan) of products, activities, and changes in physical spaces.
- ✓ Maintain a collection of all the products developed collaboratively.
- ✓ Record the number and type of media events where advisors' work is featured.
- ✓ Explore possibility of using several questions to measure patient and family engagement including involvement in shared decision-making (i.e. Patient and Family Perceptions of Care, see Appendix F).
- ✓ Prepare point of care measuring tool focused on shared decision-making.

To begin, a simple excel database can track advisors, their participation, and hours volunteered. This is a great first step. Over time look for ways to capture not only process measures but also outcomes measures. This can include cost savings for implementing ideas developed collaboratively and cost savings from better, more appropriate utilization of costly hospital and emergency services.

F. Create Expectations for Client and Family Partnerships in the Care Experience

- **Identifying strategies to build accountability for client- and family-centered practices for direct client service providers.** As you advance partnerships with clients and families, you can influence the providers funded by your agency whose practices do not engage patients and families meaningfully in care planning and decision-making. Look for opportunities to strengthen agency expectations in this area. Here are some ways to positively impact the care experience:
 - ✓ Leverage stakeholder/partner accountability by establishing clear expectations of quality review to include client- and family-centered standards.
 - ✓ Encourage providers to link self-management goals and clinical goals in early part of encounter.
 - ✓ Incentivize programs to expand peer involvement and explore innovative programs that utilize community members as non-medical support systems and connections to services such as lay community health workers (Grandma, Baby Boomer role).
 - ✓ Consider the possibility of partnering with advisors to develop a tool like CareOregon's "Better Together Guide" that promotes collaboration and positive change in the care experience for clients and families as well as clinicians.
 - ✓ Prepare individuals to be more effective clients and patients. The program "Ask Me Three" is a simple change that can be implemented in most practices without a huge cost.

VI. ONE APPROACH: MILESTONES, ACTIVITIES, AND TIMEFRAME TO INCREASE CLIENT AND FAMILY ENGAGEMENT

At the request of the agency, we have created one approach to implementation of these recommendations, proposed activities in the first year and milestones over a five-year period. This is just one example of many paths an organization can take on the transformational journey through effective partnership with clients and families. Any approach should be considered a series of plan-do-study-act cycles that will create learning in the organization. This learning will inform next steps. For that reason, any plan of this nature, is a best guess that will, by necessity, need to be modified based on actual experience. Each activity is listed under a particular unit that should take the lead.

A. Executive Team – First Six Months:

- Establish the two executive sponsors for this transformation.
- Engage in a full discussion with agency leaders about the benefits and concerns about full participation of clients and families as advisors. Establish boundaries that will mitigate concerns.
- Consult with leaders of other agencies who have embraced this cultural change for learning and mentoring opportunities.
- Identify key areas that are poised to make changes in the next six months to a year and determine what level of engagement you will support for those initiatives.
- Provide guidance to agency directors about any boundaries and limits for client and family participation.
- Charter a Steering Committee to ensure recommendations and action is coordinated throughout agency. Executive sponsors would attend these meetings and a diverse cross section of the agency would be represented on this group. Eventually, at least two – three client/ family advisors would join this group.

Executive Team – Six Months and Beyond:

- Develop a set of values that guide the ways in which agency business is to be conducted. Use an inclusive process to develop these values that involves stakeholders; especially direct recipients of services from the agency, as well as staff representatives, and community partners.
- Create opportunities to interact directly with clients and families receiving services on a regular basis. This will provide an opportunity for leaders to appreciate the perspectives and life experience of clients and families; both the positive and negative impacts of HCPF's policies and programs. It also models that leaderships sincerely values the importance of listening to clients and families to others in the agency and with community partners.
- Set numerical targets for client and family participation on existing committees and improvement efforts.
- Through conversations with direct reports, identify the support that they will need to be fully and effectively engaged with client and family advisors. Utilize this information as leadership development is created.
- Review progress and barriers for developing the agency infrastructure to support client and family engagement every quarter and make adjustments to better support collaborative endeavors.

- Integrate the progress in developing client and family partnerships into the annual report and celebrate successes and learning. Be transparent about learning for all.

B. Community Partnership Office – First Six Months:

- Convene existing stakeholders to discuss their expectations about their role in the process, identify what works well for them, and what changes they could make or would like the agency to make to improve collaboration and respectful relationships. Discuss the unique role and information that clients and families have to share about their “lived experience.”
- Explore ways to fund and hire a liaison to work directly in the recruitment, selection, mentoring, and internal coordinating role with clients and families to ensure consistent preparation and onboarding of advisors to committees, workgroups, task forces, and other collaborative endeavors.
- Develop all process related to preparing client and family advisors for positive partnership with the agency.
- Identify innovative incentives to encourage client engagement and remove barriers to their participation.
- Through conversations with direct reports, identify the support that they will need to be fully and effectively engaged with client and family advisors. Utilize this information as an employee development program is created.

Community Partnership Office – Six Months and Beyond:

- First cohort of client and family advisors participate in orientation and training, and are assigned roles with selected projects.
- Database is developed to track the advisors and their impact on the organization.
- A speaker’s bureau of client and family advisors becomes available to share their stories as a learning opportunity for staff. It would be important to work collaboratively with the Policy and Communications Office on this recommendation.
- Work in cooperation with the Policy Office to develop policies/guidelines that reflect the best practices with client and family advisors and other stakeholders. These policies/guidelines should include definitions, expectations, and goals for said partnerships.
- Create a request process that enables staff, managers, and others to request advisor input and participation in program and policy changes.
- Create an evaluation process that measures the collaboration and experience of both advisors and staff involved in collaborative endeavors.

C. Policy and Communications Office – First Six Months:

- Discuss with staff the importance of working effectively with client and family advisors. Ask them to identify any concerns they have and the support that they will need to be fully and effectively engaged with client and family advisors. Utilize this information as an employee development program is created.
- Designate an individual from this office who takes the lead in working collaboratively with clients and families to improve messages about client- and

family-centered care, agency commitment to partnering with the people they serve, and how individuals and families can participate.

- Leverage current change efforts as priorities to increase and diversify client and family participation.
 - ✓ Involve clients on the nomenclature project.
 - ✓ Work with Health Programs Office to involve clients on the letter project – (e.g. DME, determination and appeals)
- Increase internal communication about programs and benefits for call center staff and perhaps front desk staff, so they can more effectively and promptly respond to client questions and concerns. Work with Client Services to develop this method of communication.
- Look for effective, time efficient ways to share information with staff (e.g. electronic bulletin board, all staff meetings, HCPF Happenings newsletter, brown bag sessions/ program update) that reinforces the principles of client- and family-care, expectations for partnerships, and examples and updates on current collaborative endeavors.
- Conduct focus group with clients and families to determine what information is most important and the methods/ preferences for how this information is communicated.

Policy and Communications Office – Six Months and Beyond:

- Create annual or semi-annual summary on how clients and families are engaged in the work of the agency (use pictures, other visuals, numbers of participants, show products, and specific tangible changes made). This information can be integrated into the agency annual report, agency public communications updates and other mechanisms that would highlight the value of advisors in participating in important agency transformations.
- Create a website development working group that improves the website and information access by clients. Involve client and family advisors in this work.
- Develop multi-modal communication mechanisms (e.g. website, letters, audio and video information, email) to provide timely information to stakeholders. Involve clients and families in development of these materials.
- Develop a policy that explicitly outlines client and family partnerships and the ways they will inform program and policy development – include the provision of stipends to remove economic barriers to participation. Collaborate with the Community Partnership Office on this activity.

Depending on resources and capacity – the following activities may be more appropriate for the second year of implementation:

- Explore capacity for website to handle audio and video capability.
- Consider a social media strategy as an additional way for outreach to clients and education of staff for buy-in about that strategy.
- Explore ways to create multi-media approaches that are positive, affirming messages about agency partnerships with clients, families and the community.
- Develop mini- videos to explain benefits to clients, families and the general public.

- Create on-line tutorials and on-demand information available to clients, families and others. Collaborate with Finance Office on data reports available through secured website.

Administrative and Innovation Office (Current vacant Director position necessitated staff be reassigned. The recommendations will fall under the Office that currently is providing leadership support to those departments)

D. Finance Office – First Six Months: (Note: Workforce Development and Human Resources currently resides in this office)

- Identify a staff champion/lead for client and family engagement for this office.
- Discuss with staff the importance of working effectively with client and family advisors. Ask them to identify any concerns they have and the support that they will need to be fully and effectively engaged with client and family advisors. Utilize this information as an employee development program is created.
- Develop training module for all staff on client- and family-centered care to promote shared language and understanding of the key concepts/principles. Provide interactive opportunities for staff to brainstorm ways this partnership approach can be integrated within the functions of their units. Surface questions that can be addressed through a transparent Q and A process throughout the agency. Though developed by the workforce development staff, this module would be offered agency wide and integrated into new hire orientation.
- Develop a workforce development plan to offer training on effective ways to engage clients and how to facilitate meetings with clients and families effectively.
- Integrate the feedback provided by managers about staff needs for support. Determine if other workforce development is needed based on this feedback.
- Identify opportunities for staff to go into the field, solicit information on the client and families in their own communities and partner with other community agencies to embrace and expand the practice of partnerships.

Finance Office – Six Months and Beyond:

- Identify competencies for collaborating with clients and families, update job descriptions, identify ways to “hire for fit” using behavioral interviewing, participation of clients and families in interviews, and on-boarding practices that include the advisors in orientation.
- Explore developing on-line training modules on patient- and family-centered care for annual staff training.
- Provide opportunities for communication skills training especially responding to feedback and giving feedback.
- Develop analytic reports about average cost and ranges per clients within each program. These kinds of reports can be shared with staff and members of advisory or improvement teams to help shape and inform their deliberations. Eventually, with client input, it can be used as information on decision-making around service choices, quality and cost.

- Improve data and information technology systems with goal of providing information useful to understanding client outcomes and enhancing partnerships to improve outcomes.
- Provide real data to advisory groups on overall costs of care, impact of wide variation in individual costs and its impact on quality outcomes; frame data in context that is meaningful to clients and the agency.
- Provide individual clients fiscal information about their health care expenditures and utilizations on a regular basis to promote wise stewardship of resources.

E. Client Services, Eligibility and Enrollment– First Six Months:

- Identify a champion/lead for client and family engagement.
- Through conversations with direct reports, identify the support that they will need to be fully and effectively engaged with client and family advisors.
- Solicit input from agencies on suggested clients and families from different geographic areas that could be interviewed about what works well and doesn't work in the call center/ customer service department.
- Mine the data of frequent callers to conduct a systematic series of structured interviews or focus groups to get to the root causes of numerous calls.
- Conduct quick survey with callers as PDSAs are being conducted. As these small tests of change are being trialed, ensure that you have predicted the impact it will have on clients. Create 1-2 questions that can confirm your prediction or provide you with client perspectives on the change.

Client Services, Eligibility and Enrollment– Six Months and Beyond:

- Consider simplifying the client experience of calling numerous numbers to a central number to respond to issues. Involve clients and other stakeholders on this initiative.
- Conduct focus group with frequent callers to hear about worked well or ways the service could have been improved. Determine which opportunities for improvement would be high client satisfiers. Use this information to prioritize changes.
- Identify how client and family advisors could participate in other LEAN improvement events.
- Recruit clients and families for advisor opportunities throughout the agency.

F. Health Programs Office– First Six Months:

- Identify a champion/lead for client and family engagement in this office who works in partnership with the agency liaison.
- Review the charters and ground rules of existing advisory groups; set targets for increased membership of clients and families to these groups.
- Review contracts and regulatory opportunities to promote contractor alignment with client- and family-centered practice (e.g. establishing client and family advisors input requirements in contracts for direct services).

- Leverage stakeholder/partner accountability by establishing clear expectations of quality review to include client- and family-centered standards.

Health Programs Office– Six Months and Beyond:

- Identify opportunities for client and family input on policy, planning, and payment changes.
- Encourage providers to link self-management goals and clinical goals as part of the visit encounter.
- Incentivize programs to expand peer involvement and explore innovative programs that utilize community members as non-medical support systems and connections to services, for example lay community health workers (Grandma, Baby Boomer role).
- Consider the possibility of partnering with advisors to develop a tool like CareOregon’s “Better Together Guide” that promotes collaboration and positive change in the care experience for clients and families as well as clinicians.
- Work in partnership with the communication office to integrate client participation in development of program information.
- Identify concrete ways the office can influence the experience of care for clients and families through relationships with direct service providers and restructuring payment on contracts.
- Hold quarterly listening sessions around the state to share upcoming opportunities for input and to solicit what’s working well and what could be improved in the program services.

G. Clinical Services Office– First Six Months:

- Identify a champion/lead for client and family engagement.
- Through conversations with direct reports, identify the support that they will need to be fully and effectively engaged with client and family advisors. Share this information with the workforce development program.
- Engage staff to consider how quality and health improvement functions can be informed by client and family input.
- Convene a listening session with clients and families to have them share stories of health care experiences and how they define quality.

Clinical Services Office– Six Months and Beyond:

- Identify ways the quality review process can evaluate how well service providers engage clients and families in care.
- Develop a workgroup of clients and families to provide input on Health Improvement programs. Have them explore the question of – how to engage the Medicaid community in population health and provide ideas on ways to reduce the disparities in health among the Medicaid / CHP+ recipients.
- Determine effective ways the clinical services office can champion client- and family-centered care at the clinical level among partners in the state.

H. Audits and Compliance Office:

- Participate in employee and leadership development opportunities related to client- and family-centered care.
- If client grievances are handled through your unit, help identify clients and families who approach issues in a proactive way and alert them to advisor opportunities with the agency.

I. MILESTONES – END of YEAR ONE

- Designated Leadership Champions and accountability.
- Infrastructure established to support partnerships with clients and families.
- Initial systematic gathering of input from staff, stakeholders, partner organizations and clients and families to inform client and family partnership planning.
- Messages about agency commitment to a meaningful partnership with clients and families at all levels of service deliver are embedded in the website and key client documents.

MILESTONES – END of YEAR TWO

- Integration of client- and family-centered competencies into all job descriptions is complete.
- All employees affirm client- and family-centered behavioral expectations.
- Each relevant Office has least one major initiative that involves client and family advisors. This could include a cross-discipline or agency-wide endeavor.
- Contracts include explicit targets for client and family engagement in the experience of care, in quality/safety improvement, and in program development.
- Providers are incentivized to develop collaborative self-management programs with client and family participation.
- Website becomes a robust resource for connecting with the agency.
- Website functionality encourages full participation by clients and families in providing virtual input on key program changes that impact them.
- Staff development opportunities on meeting facilitation, conflict management, effective communication, and collaborative problem solving are available.
- Ongoing evaluation of the participation of clients and families occurs in all collaborative endeavors.

MILESTONES – END of YEAR THREE

- Tri-agency initiatives have client and family representation on committees.
- Shared decision-making support is available to all clients making decisions around preference-sensitive conditions.
- A leadership development program for clients and family advisors is launched and creates a network of advisors across the agency and the state sharing learning and experiences.
- Website becomes a robust resource for engaging clients and families in managing their health care needs and services.
- The “Hiring for Fit” process is fully in place, including involving clients and/or family advisors on selected hiring committees.

- Performance standards integrate effective collaboration with clients and families as an expectation. Performance evaluations are aligned with these standards.
- Information systems provide useful data for utilization of services and participation in collaborative endeavors.
- Recognition programs honor leaders, staff, clients, families, and other stakeholders for excellence in client- and family-centered care and in partnerships.

MILESTONES – END OF YEAR FIVE

- Client and family leaders serve as co-chairs on key committees including quality, communications, and health programs.
- Clients and families rate HCPF services as respectful, inclusive, and affirming.
- Staff experience increased job satisfaction and rate client and family partnerships as beneficial.
- Annual report highlights the story of a client leader and the key outcomes achieved through partnerships with clients and families.

VII. EXEMPLAR PROGRAMS AND OTHER RESOURCES

The following exemplars for client- and family-centered care have been selected to be most helpful to HCPF. They are safety net organizations providing services to populations similar to those served by HCPF and/or they are a government agency.

A. Minnesota Department of Health and the Minnesota Department of Human Services



“Health Care Home,” the term used for the medical home in **Minnesota**, is a key component of the state’s 2008 health reform legislation. The Health Care Home initiative at the state level jointly operated by the Minnesota Department of Health and the Department of Human Services, the state’s Medicaid agency. Partnering with patients and families has been central to the evolution of the health care home model in Minnesota; beginning with a federally funded, quality improvement initiative in 2004. The vision for the Minnesota Health Care Homes is to bring about transformational change in the design and delivery of primary care. It requires a fundamental change in patient-provider relationships, supported by appropriate financing systems and measurement of results. The model focuses broadly on the continuum of health care and conveys expectations for engagement of the patient, family, and community. To that end, there are expectations that two or more participant [consumers] representatives must be included on the quality improvement teams of each clinic.

This engagement is modeled at the state level where there is an active Patient and Family Consumer Council for Health Care Homes. The council developed a charter and the group provides advice for the Health Care Home statewide program. Members of this council serve on other committees, as well as on Health Care Home certification site visit teams.

The Minnesota Health Care Program (Minnesota Medicaid and MinnesotaCare) has mature systems for the involvement of stakeholders, especially clients and families. In having traveled the journey for some time, they have insights helpful to local and statewide primary care initiatives. As Jeff Schiff, the medical director for Minnesota Health Care Programs, including Medicaid and the State Children’s Health Insurance Program, has said: “It is possible to create the expectation that they (clients and families) will be heard without shouting, that their input is a truly essential part of the policy process”. He shared the success they have achieved in partnership with Lance Hegland, a client representative who serves on the Medicaid Advisory Council.

In reflecting about what has been most helpful to him in preparation for his role, Hegland cited the 2009 Institute for Patient- and Family-Centered Care Intensive

Training Seminar offered in Minnesota and mentioned aspects that were most useful to him:

The chance to hear about the role of a client advisor and learn directly from others who have participated successfully was critical. It provided me with resources and ideas of what has worked. Managing the relationships and expectations is what I see as most frustrating to clients that have come and gone from these positions. Some clients don't understand that the role is broader than just coming in and complaining. It's hard for agency staff to hear just complaints; clients get frustrated because they weren't adequately prepared to work together with the agency on solutions bigger than their own situation. If I hadn't had the opportunity for training and the leadership development, I would have been passive in my role and gotten frustrated that nothing was changing. I also believe staff need to be prepared and trained as well. In other community groups, I have seen no structure, so the meetings are chaos. At other times, I have seen the agency create so much structure, that clients and community members feel like the decisions have already been made and their role is to listen to the agency proposals and agree with what they've already designed.

The Minnesota Department of Human Services engaged a health services policy analyst to staff the Health Services Advisory Council, one of several stakeholder groups that advises the Department. The analyst, Ellie Garrett, came with extensive experience in developing effective community partnerships. She describes how important structuring the conversation is to the success of these relationships. However, even more importantly, she stresses the central role that leaders play in setting the stage and modeling the behaviors you expect of all staff. As she reported, "Leadership should clearly understand what they want to know from the client and family perspective and what is on the table for input. It is essential they listen seriously to the dialogue. This requires that the leaders show up, share relevant facts and information to help ground the advisors in the subject at hand, listen to advisors and not try to influence them. It requires they tee up the discussion, and thank them in the end."

Minnesota has a rich culture of collaboration that is reflected in the work of both the Minnesota Department of Health and Department of Human Services. Input from patients and families is crucial and advisors partner in many aspects of the state's work. With the Health Care Home program that involvement extends from the practice site to the state agency's oversight.

B. Mid-Valley Behavioral Care Network



Established in 1997, Mid-Valley Behavioral Care Network (BCN) provides services to Medicaid recipients in a five county area in western Oregon. Because the Oregon Health

Authority contract required consumer involvement, developing real partnerships with clients and families and integrating them into policy, and program development was a key consideration early in their initial planning. The leaders created an expectation that charters of key committees reserved seats for clients and created a staff liaison position, called a Consumer Affairs Specialist. An individual with a mental health condition filled this role. Because the role was to serve as a connector to the larger population served by the program, it was hoped that someone with a “lived experience” would be able to bring credibility to the partnership and thereby build trusting relationships with the organization through outreach efforts.

As a result of this thoughtful planning and integration, BCN currently has over 40 active advisors on committees. The Governing Regional Advisory Council requires 25% membership by clients and or family representative. The Quality Management Committee (QMC) has 40% membership requirement and the current chair of the QMC is a client. Preparing advisors for their roles on committees is thorough. For example, all new QMC members meet with the agency Director and Chair for orientation. The Chair hold a caucus with consumers after each meeting to debrief and solicit agenda items for the next meeting. Seasoned advisors mentor each other.

The BCN is committed to ongoing evaluation of the participants’ experience and the effectiveness of ongoing committees and of each advisor’s development and participation. The evaluation forms, which are shown in Appendix E, were co-created with consumers to ensure there was a measure of “real” collaboration among the partners.

In consulting with Kathy Savicki, Clinical Director, about the early formation of BCN, she shared the process of naming the role of clients and families in the partnership. She shared this recollection, “In the mental health world, there is also lots of controversy about naming, and we ended up using consumer advocate as what was most acceptable in the beginning. Now our folks seem to mostly use ‘advocate’ and ‘peer’. In recent years some folks have felt that ‘consumer’ implied passive acceptance of services, and they’ve liked ‘client’ better as it implies a relationship in which you hire a professional (like a lawyer or accountant) to serve you. So my advice is to ask the group of people involved for their preferred language.”

C. Contra Costa Regional Medical Center

Patients and Families as Partners



Contra Costa Regional Medical Center (CCRMC) is a public hospital in Martinez, California. CCRMC is committed to providing health care that is “welcoming, accessible, safe and respectful for everyone.” They partner with “patients, families and community representatives and leaders in every area of hospital operations,” including behavioral health.

In March 2010, the Medical Center held a value stream mapping event (a process used in Lean continuous improvement efforts) for individuals and their families who have experienced a behavioral health emergency. This event brought together patients, family members, law enforcement, ambulance drivers, contract community agencies, and Medical Center staff to identify the current issues and problems and design the ideal future.

This event was followed by four one-week long rapid cycle improvement sessions held from May through October, which involved over 800 person-hours, including patients and family members, and led to meaningful changes for those in need of behavioral health services. These sessions were focused on specific improvements such as changing the way patients experiencing a behavioral health emergency access Psychiatric Emergency Services (PES), improving the discharge process, and enhancing communication between families and behavioral health service providers. Anna Roth, Chief Executive Officer of CCRMC and Health Centers, recalled how patients and families have influenced the entire process—from the initial decision to focus on behavioral health, to the timing of changes, to developing ideas for rapid cycle improvements.

When asked to talk about how best to name these roles for patients and families, Anna Roth, RN, MS, MPH, Chief Executive of Contra Costa Medical Center responded, “Great question about naming. I am copying the chair of our Behavioral Healthcare Partnership, Teresa Pasquini, as well as the Executive Director of Mental Health Consumer Concerns of Contra Costa County, Brenda Crawford both of who have seats on the executive team of CCRMC and HC. They both have deep knowledge about naming and the implications both here at CCRMC and in their roles as community leaders and advocates. I have found their perspective invaluable and hope they will weigh in here, as it was the leadership of these two and their colleagues that led our organization through this discussion and came to our name “Healthcare Partners.” Her response was typical of leaders that have truly formed meaningful relationships with their partners. Without hesitation and with sincere respect, she reached out to those who are in these roles to share what were important considerations around these roles and what makes them work besides their “title.” Here is what her colleagues shared:

“Thank you for including me in this discussion Anna. Speaking for myself as a family member representative to numerous “advisory” boards and committees in our community, it was so important to distinguish this new hospital group (in 2009) based on equity principles. We needed to feel equal in the conversation and not dismissed as “advisory only.” There had been a sense of tokenism at other advisory body tables and not a true willingness to get into the weeds about the complexities of our system. At other county boards, there is focus on mostly positive experiences and defensiveness when I advise about negative experiences. Or, I am simply ignored.

The Behavioral Healthcare Partnership was different. We were invited to tell all, the good, bad and ugly and advise about what we thought would help make it better for the patients, the families, and the staff who served them both. We created shared agenda, shared decisions and shared the work. The term partnership allowed us all to own the responsibility of improving our system together. It removed blame and shame and made us

accountable to each other and for each other. Most importantly it kept us focused on the patient and family and not positioning for power.

I still sit on "advisory only" boards and commissions. We are still often dismissed and our lived experiences ignored. The difference is huge between partners and advisers."

Teresa Pasquini

"P.S. The "stigma" comes from being ignored or marginalized and not being invited to participate."

"Teresa has said it all! The full inclusion of consumers and family members of services in any transformational process is key to the success of all activities. Because of scheduling it is difficult for me to attend most of OPs meetings at the hospital however, I know I always have a seat and a voice that will be listened too, and respected whenever I can attend."

Brenda Crawford

Anna Roth believes that leaders should not only communicate but also demonstrate a commitment to community transparency and involvement. The two individuals above were selected by the advisory council membership to serve on the CCRMC Executive Operations Team. In addition to meeting weekly, a monthly public event is held in the lobby of the hospital where leaders report current improvement efforts and results. The entire community is invited to come and hear how patients and families are partnering with providers and staff to improve the health care for the county. This routine sends a message to staff as well as the community that partnerships with the community served by Contra Costa Medical Center is a highly held and practiced value.

D. High Plains Research Network

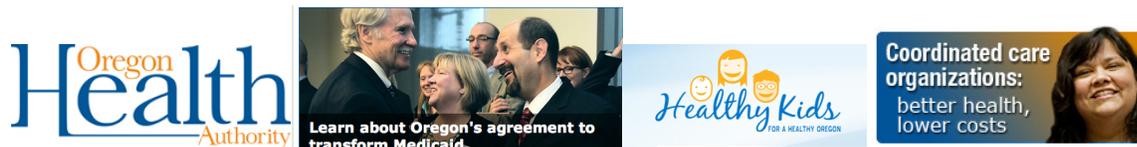


In Colorado, Jack Westfall, MD, MPH has more than a decade of experience in facilitating an effective Community Advisory Council (CAC) for translational research initiatives as part of the High Plains Research Network. The group was formed to enhance research and program improvement efforts and to ensure that the Network was responsive to the priorities, concerns, and perceptions of people living in the region. The Council has participated in all aspects of the research process, including interpretation of results and dissemination of findings. An innovative approach used before beginning work on any project in the HPRN is a "topical boot camp." It provides the CAC with specific scientific information for a particular project topic. Because it is paced to ensure understanding of the topic, members are prepared to participate fully in all aspects for the project.

The agency might consider inviting Jack Westfall to share his perspectives with key personnel about what are effective ways to engage the community and the lessons learned. In addition, it might be useful for key HCPF staff to attend one of the Boot Camps used to prepare advisors for a particular issue (i.e., colonoscopy screening,

asthma control, medical home implementation), one of their in-person meetings, and one of their structured telephone calls. The latter is an effective way to ensure ongoing involvement, but respect people's time, other commitments, and the challenges presented by geography.

E. Oregon Health Authority



Oregon has a long history of community engagement in the development of their health programs and services. There are numerous taskforces, including the Medicaid Advisory Committee, that have representation of community and consumer representatives. In the development of Oregon's Patient-Centered Primary Care Home standards, patient and family advisors were consulted on the standards and more importantly on how to communicate the standards to the general population. Standards such as access were described in the voice of a consumer: *"Make it easy for us to get care and advice for us and our family members. Provide flexible, responsive options for us to get care in a timely way."* Care Coordination was described as *"When we need to go to other providers or places for care or services help us coordinate and plan our care without delays and confusion."* See Appendix F for the entire standards in patient- and family-centered language. In the ongoing standards committee, a seasoned patient advisor who has access to a network of advisors across the state has been appointed by the Governor to serve on this Oregon Health Authority Taskforce.

In the development of legislation for Oregon's version of Accountable Care Organizations called Community Coordinating Organizations, an extensive community outreach effort was undertaken. There were 133 people involved in four taskforces. From September 26 through October 13, 2011 the Oregon Health Authority (OHA) held eight community meetings around the state in Roseburg, Medford, Pendleton, Florence, Bend, Portland, Eugene, and Astoria. The purpose of the meetings was to provide an overview of proposed changes to the Oregon Health Plan (OHP) that would allow for the development of Coordinated Care Organizations (CCOs) and to solicit input from communities about the new approach. In total, more than 1,000 Oregonians attended the eight sessions. Each of the meetings received strong interest and participation. One theme emerged about the importance of including clients and beneficiaries perspectives and experiences: **Partnering with clients and beneficiaries in CCO development and evaluation would be important to achieving success.** In response to community input, legislation governing the CCOs requires Community Advisory Councils that are made up of 50+% of individuals who will receive Medicaid services in each CCO geographic area. They provide input to each CCO Governing Board and each Governing Board must have two representatives from the CAC on the board.

F. CareOregon – Medicaid Insurance Provider



Member Advisory Council

As a participant in the Oregon initiative called “Patients and Families as Leaders”, CareOregon was an exemplar in working effectively in partnership with the Medicaid population. As a health plan providing coverage to Oregon Health Plan recipients in the Portland Metro area, leadership set the stage for building these partnerships by establishing a diverse internal steering committee made up of staff and leaders. Leaders had made a commitment to expand their partnerships with members of the health plan. This steering committee systematically gathered the evidence about effective partnerships in healthcare, sought out best practices for partnership and began to share that information more broadly in the organization. They approached this effort by collaborating with local human and social service agencies that had a reputation for excellent relationships with the population they served. They conducted site visits to other Advisory Council meetings across the state.

This is how they approached identifying next steps to establish Member Advisory Council in their own words:

“Listening to our members was crucial, so in 2010 CareOregon established a Member Advisory Council (MAC) and Member Leadership Program. We started with focus groups to learn how members thought the MAC should be organized. Focus group members not only told us how to organize the Council, 15 became the inaugural Council. They provide advice to CareOregon about how to improve service and communications efforts, and have established an improvement agenda for the year ahead. The MAC sponsored its first Member Summit in January 2011, inviting members in the metro area to share their views. Going forward, they will have an advocacy role in Salem, listen to other members to identify needs, and participate on staff committees. Finally, we’ve included many member stories on our new web site—www.careoregon.org—designed to provide a more interactive, user-friendly experience for members, providers and community partners.”
Annual Report 2010

As CareOregon began to realize how inspirational, productive and effective partnering with their members had become, they made a strategic decision to create a Member Centricity Department led by a Director passionate about including the members in all aspects of the organizational mission. MAC members helped guide the priorities of this department. Shortly after creating the department a staff liaison was hired to be the staff connector for the MAC.

The members of the MAC received a thorough orientation to CareOregon's mission, values, and programs. The organization invested in the development of the members by seeking out community programs that could help them succeed in their new roles. One class called "Popular Culture" was cited as most important in the start-up of the MAC. Offered by Multnomah County, the curriculum was highly interactive and taught skills related to meeting facilitation and group dynamics. MAC members participated together and used the skills they learned to create by-laws for the Council. Additionally, CareOregon leaders and MAC members traveled together to attend the IPFCC Intensive Training Seminar on Patient- and Family-Centered Care. During this time, together they created an action plan on how to take the new knowledge and examples of partnerships they heard and embed them in CareOregon's plans to invite members to be advisors to the organization. It was the beginning of the MAC's interest in reaching out to members to engage them in their own health. Since the theme of partnership resonated with the group, they spent the next six months working with providers and members in developing a tool called "Better Together Guide." The tool for use during an office visit helps encourage conversations between doctor and patient that can establish agreements on what each person (patient and provider) will do to build a positive partnership toward improved health. More information can be found at the website:

<http://www.careoregon.org/TransformingHealthcare/Members/MemberAdvisoryCouncil.aspx>

Other organizational profiles can be found in the recent Institute for Patient- and Family-Centered Care publication, *Partnering with Patients, Residents, and Families A Resource for Leaders of Hospital, Ambulatory Care Settings, and Long-Term Care Communities*. While most examples are set in health care delivery settings, the principles and ideas outlined can be translated into a public service agency setting that funds health care services.

G. Other Useful Resources and Perspectives:

There are print materials and websites that present useful tools and perspectives as you create meaningful, and authentic partnerships with clients and stakeholders. These resources will be especially helpful for key leaders and those with direct responsibilities for facilitating effective partnerships with clients, families, and other citizens.

Developing Effective Citizen Engagement: A How-To Guide for Community Leaders developed by the Center for Rural Pennsylvania, a legislative agency of the Pennsylvania General Assembly, contains excellent practical information. In discussing the benefits of citizen engagement, the guide states: "A more engaged citizenry can lead to better organizational decisions, more efficient resource allocation, reduced conflict, and enhanced quality of life for community residents." It offers realism about the level of commitment required: "...getting all the pieces in place to get citizens involved and make their experiences positive can be daunting, take considerable time and resources, and involve significant organizational risk" (page, 21). The guide's detailed process and infrastructure recommendations for partnerships that benefit the agency and the communities served are consistent with the best practice recommendations provided by the IPFC team. An insight from this guide is useful to consider:

"Success is not automatic. Making it happen involves a long-term commitment to developing skills and a willingness to fail before succeeding...It requires a firm belief that all the work and change will result in a better outcome in the long-run" (*Developing Effective Citizen Engagement: A How-To Guide for Community Leaders*, 2008, page 4).

The publication, *Public Deliberation: A Manager's Guide to Citizen Engagement*, offers further thoughts about citizen engagement:

"First is a shift from information exchange models to information processing models of citizen engagement. Second is a shift from citizens as consumers to active shapers of government policies and programs (Cornwall and Gaventa, 2001 in, page 5, 2006).

http://www.whitehouse.gov/files/documents/ostp/opengov_inbox/ibmpubdelib.pdf

In the recently published Institute of Medicine report, *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*" 2012, the IOM makes ten key recommendations. The fourth recommendation states:

"Involve patients and families in decisions regarding health and health care, tailored to fit their preferences. Patients and families should be given the opportunity to be fully engaged participants at all levels, including individual care decisions, health system learning and improvement activities, and community-based interventions to promote health." S-23

"In a learning health care system, patient needs and perspectives are factored into the design of health care processes, the creation and use of technologies, and the training of clinicians." 5-5.

"...involving patients in improvement initiatives ensures that patients' values and perspectives guide system design..."

The substance of this particular recommendation underscores the fundamental value to the agency/organization and to the experience of care that such robust patient and family involvement provides. The continuous feedback loop that is created when relationships are built on mutual respect and honest communication establishes a flexible environment grounded in continuous improvement.

<http://www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx>

A report entitled *"Public Engagement on Facilitating Access to Antiviral Medications and Information in an Influenza Pandemic: Workshop Series Summary,"* sponsored by the Board of Health Sciences Policy and the IOM, describes the process they used to engage the community in sharing their perspectives in the event of potentially limited resources in a pandemic event. While the results of community feedback is of interest, we are citing this report as one model of a systematic approach to community engagement. This kind of approach could be useful to HCPF in broadening the participation of clients, families and other stakeholders.

https://download.nap.edu/catalog.php?record_id=13404

Some health care organizations strongly stepped in the patient- and family-centered care

practice have found the skills training referred to, as the “Language of Caring” are useful tools for staff and leaders. Chatham-Kent Alliance in Canada is an exemplar in patient- and family-care. A description of why it is being used in their setting is available at:

<http://www.youtube.com/watch?v=MpH9upLokPY>

More information about this series of training modules can be found at:

<http://www.quality-patient-experience.com/language-of-caring.html>

Appreciative inquiry is the approach that IPFCC uses in learning about an organization and its commitment to partnerships with clients and families. With this approach, we look for strengths, affirm these attributes, and build on the strengths of all involved. This positive, reinforcing approach is a learned skill and may be helpful to HCPF leaders and staff as you move forward with your commitment to client and family-centered care. Further information about this organizational development approach can be found at: <http://appreciativeinquiry.case.edu/>.

Vancouver, British Columbia has embraced partnership with clients and families in a number of ways. Below are some efforts that provide a framework and perspective helpful as you think about the larger community you serve and will influence in your efforts.

1. *The Patients as Partners Initiative* in BC. “Patients as Partners is a philosophy promoted by the Ministry of Health, with the work accomplished through organizations and agencies in the community. PasP is guided by a provincial committee comprised of patients, involved organizations and agencies.” Their annual report of 2011 is available at http://www.chsrf.ca/Libraries/Researcher_on_Call/PasP_AnnualReport_Final.sflb.ashx
2. *Integrated Primary and Community Care Patient and Public Engagement Framework* developed by a workgroup representing the following organizations:
 - a. B.C. Ministry of Health www.gov.bc.ca/health
 - b. ImpactBC www.impactbc.ca
 - c. Interior Health www.interiorhealth.ca
 - d. Fraser Health www.fraserhealth.ca
 - e. Northern Health www.northernhealth.ca
 - f. Provincial Health Services Authority www.phsa.ca
 - g. Vancouver Coastal Health www.vch.ca
 - h. Vancouver Island Health Authority www.viha.ca

This framework could be useful to enhance and support your engagement of patients, residents and families. More information available at: http://www.chsrf.ca/Libraries/Researcher_on_Call/IPCC_PPE_Framework.sflb.ashx

3. *Patient Voices Network*
“This non-profit organization is a community of BC patients, families, caregivers, and others who wish to use their experiences for positive change to the health care

system. They provide training to interested patients and families who wish to partner with health care to promote positive change among other activities.” More information is available at: <http://www.patientvoices.ca/>

VIII. WAYS THE INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE CAN ASSIST COLORADO DEPARTMENT OF HEALTH CARE POLICY AND FINANCING

The IPFCC mission is to advance the understanding and practice of patient- (client) and family-centered care. The Institute accomplishes its mission through education, consultation, and technical assistance; materials development and information dissemination; research; and strategic partnerships. Below are some of the ways, IPFCC could assist your agency in embedding partnerships with clients and families into the way you approach your work:

- Consult on the development of future grant proposals to fund implementation of report recommendations.
- Work with Client- and Family Engagement Steering Committee as an adhoc consulting member.
- Facilitate leadership and stakeholder retreats to create a set of principles to guide the development of future partnerships so that they function in a manner that is mutually respectful and beneficial.
- Conduct training on client- and family-centered care for staff, leaders and strategic partners.
- Assist with the initial orientation for client, and family advisors; and for staff who will serve as liaisons for collaborative endeavors with patients and families.
- Provide train-the-trainer support to the training department to build a curriculum for staff development.
- Mentor new staff liaison in development of screening, recruitment, and selection materials for client and family partner roles.
- Provide review of policies and other documents as created.
- Provide technical assistance both on-site and off-site to support new advisors and staff working together in new ways.

IX. CONCLUSION

The Colorado Department of Health Care Policy and Financing's identification of client engagement as a strategic priority is the first step in transforming relationships with clients and families as well as other stakeholders into positive, productive and meaningful collaboration. Creating an infrastructure to support client, family, and community engagement is an important first step in changing the experience for these important partners. Engaging in dialogue that helps staff understand the populations' "lived experience" and leveraging this understanding into improvement teams as changes are made is essential. This partnership will ensure that processes, programs, services, policies, and information flow for decision-making result in more responsive services that honor client and family needs, values and priorities.

In order to sustain this culture, embedding the expectations of a client- and family-centered culture will require leadership and workforce development. Technical skills need to be augmented by attitudes and skills that communicate a respect for clients and their families. Aligning these values and expectations into all aspects of the agency's hiring, on-boarding, staff and leadership development activities is key to success.

Providing the same level of attention to supporting clients and families in participating successfully in collaborative endeavors is needed as well. Leaders set expectations, and then the agency can provide opportunities for client and family advisors to develop skills needed for these new ways of working together. Transparent communication invites collaboration in meaningful ways.

Part of the honest exchange of information will require leaders to share what topics; programs and operations are open for discussion, input or redesign, and what is outside the boundaries of the organization to change. In that way, staff, clients, families, and other stakeholders can move forward to create mutually beneficial relationships that help develop solutions to improve health care access and outcomes for the people served while demonstrating sound stewardship of financial resources.