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Individual and Family Engagement in the Medicaid Population: Emerging Best Practices and Recommendations

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Introduction

Engagement, broadly defined, is an active partnership among individuals, families, health care clinicians, staff, and leaders to improve the health of individuals and communities, and to improve the delivery of health care. Collaborative individual and family engagement is an important strategy for developing a patient- and family-centered system of care.¹ Research shows that engaged individuals and families actively working with their health care teams have better outcomes, often choose less expensive options when participating in shared decision-making, and express greater satisfaction with their health care experiences.²

The Institute for Patient- and Family-Centered Care (IPFCC) outlines action-oriented recommendations and strategies to support enhanced individual and family engagement efforts in Medicaid. Specific suggestions for leaders in Medicaid agencies, their staff, and organizations serving these populations include:

1. Advance individual and family engagement best practices as a strategic priority within the Medicaid agency.
2. Expand opportunities for individuals and families to engage with Medicaid staff and managed care entities to influence policies, programs, and practices.
3. Support direct care service providers in acquiring the knowledge and skills to develop effective partnerships with individuals and families.
4. Encourage and support individuals and families in engaging more fully in their health and with their health care team.

While there are no magic formulas or quick fixes for improving health care and care delivery, there is a growing body of knowledge regarding what works to foster engagement of individuals and families, and what does not.

Individuals who were interviewed by IPFCC stated a preference for the label “individuals” rather than “patients,” since the term patient is only one of many roles they have. For this reason, the term individual engagement, rather than patient engagement, is used in this brief. In recognition that many who receive Medicaid services are under the age of eighteen, this brief also includes family engagement. Evidence shows that engaging families improves care and leads to better outcomes and satisfaction in both the pediatric and adult populations.³

Individual and family engagement occurs at four levels:

- **At the clinical encounter** in direct care, care planning, and health care decision-making.
- **At the practice or organizational level** in quality improvement and system redesign.

ABOUT THE INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

Founded in 1992 as a nonprofit organization, the Institute for Patient- and Family-Centered Care (IPFCC) works to advance the understanding and practice of patient- and family-centered care in all settings where individuals and families receive health care and support. The core concepts of patient- and family-centered care include respect and dignity for all; the sharing of unbiased information in useful and affirming ways; encouraging and supporting participation in care decision making to the level a patient and their family choose; and collaboration in program development, implementation, and evaluation of health care services. IPFCC has worked collaboratively with many national organizations to advance the practice of patient- and family-centered care, and to support the development of mutually beneficial partnerships with patients and families. Patient and family engagement is a key strategy to create a patient- and family-centered health system.

ABOUT STATE HEALTH AND VALUE STRATEGIES

State Health and Value Strategies, a program funded by the Robert Wood Johnson Foundation, provides technical assistance to support state efforts to enhance the value of health care by improving population health and reforming the delivery of health care services. The program is directed by Heather Howard at the Woodrow Wilson School of Public and International Affairs at Princeton University.

ABOUT THE ROBERT WOOD JOHNSON FOUNDATION

For more than 40 years, the Robert Wood Johnson Foundation has worked to improve the health and health care of all Americans. We are striving to build a national Culture of Health that will enable all Americans to live longer, healthier lives now and for generations to come. For more information visit www.rwjf.org. Follow the Foundation on Twitter at [www.rwjf.org/twitter](https://twitter.com/rwjf) or on Facebook at [www.rwjf.org/facebook](https://www.facebook.com/rwjf).

- **At the community level** in bringing together community resources with health care organizations, individuals, and families.
- **At the policy level** in setting public policy locally, regionally, and nationally.

Engagement is a complex phenomenon and requires the health care programs, as well as the individuals and families served by the programs, be open to creating a trusting relationship based on shared goals. Successful engagement also requires a change in mindset and behaviors for many Medicaid leaders, health care professionals, individuals, and families.

Individual and family engagement strategies seek to create mutually beneficial partnerships that enhance health, well-being, and the management of chronic conditions, and by doing so, improve the cost-effective delivery of patient- and family-centered care. Research shows that patients who lack the skills to manage their health care incur costs 8 to 21 percent higher than those of patients who are highly-engaged in their care, even after adjusting for health status and other factors.⁴ Similarly, research studies assessing an individual's level of activation using Insignia Health's Patient Activation Measure™, have shown that 60 percent of Medicaid patients fall into the lower levels of activation.⁵

For engagement in the care experience to be mutual and sustained, interactions need to be authentic and intentional. They also should take into account the preferences, strengths, beliefs, and culture of the patient and his or her family. For engagement at the clinic, community, program, and/or policy level, organizational leaders must believe that the “lived experience”⁶ of individuals and families can inform health care transformation and improvement. Providing opportunities for meaningful partnerships with individuals and families requires a commitment by Medicaid leaders and health care professionals. Mechanisms must be in place so that the input and perspectives of Medicaid beneficiaries are sought out, listened to, and acted upon.

Methodology

To develop these recommendations, IPFCC utilized a two-pronged approach that included a targeted literature review and in-depth interviews. The literature review helped determine what characteristics, strategies, and tools are associated with effective individual and family engagement in Medicaid settings. IPFCC conducted interviews with Medicaid beneficiaries and their family members, as well as state agency representatives, clinicians, researchers, and innovative program leaders. Additionally, IPFCC spoke with representatives of managed care plans in states

that have adopted Medicaid engagement strategies in order to better understand how different engagement approaches are operationalized. For a full list of interviewees, see Appendix A.

The interviews provided IPFCC insights about successful approaches to individual and family engagement, and how to address challenges. Since these recommendations reflect the viewpoints of Medicaid providers, beneficiaries, and administrators, they are grounded in what is possible and sustainable. In addition, the authors recruited engagement experts to serve as steering committee members and reviewers for this brief. For a full list of advisors, see Appendix B.

Overcoming Roadblocks

Engagement is created through collaborative relationships and requires changes in behavior by health care professionals, as well as patients and families.⁷ Given the diversity and unique challenges of the Medicaid population, effective individual and family engagement strategies require a respectful, strength-based approach that is systematically applied with flexibility and persistence, in addition to dedicated resources. Health care system barriers, as well as challenges faced by the individuals receiving care, serve as roadblocks to engagement. Examples of deterrents to the development of successful partnerships include:

- Messages from Medicaid agencies, health plans, and providers are often overly complex and use jargon, thereby creating confusion and stress for many individuals and families.
- Despite best intentions, some health care service organizations and Medicaid agency personnel utilize practice styles and systems that discourage active engagement.
- Many providers are unaware of the impact that health literacy⁸, trauma, and other social factors have on an individual and his/her family's ability to reliably and consistently engage in their own health.
- Within most communities and health care organizations, individuals and families aren't prepared to take an active role in health care decision-making and behavior change.
- Evidence-based interventions that are collaborative and strength-based—such as coaching for patient activation, motivational interviewing⁹, shared-decision making, self-management support, and peer-to-peer support—are not readily available or effectively integrated into most care settings.

“Patients, families, and their advocates increasingly understand the wisdom of this partnership. Too often, standing in the way is the health care system itself—whether by intention or not—because of its fragmentation, paternalistic professional culture, abundance of poor process design, and lack of experience on the part of health care leaders and clinicians with practical methods of engaging patients.”

—The National Patient Safety Foundation’s Lucian Leape Institute, 2014.¹⁰

Effective engagement initiatives involving Medicaid agencies, providers, and the community exist and can serve as models to address common roadblocks to engagement. This brief describes Oregon’s successful engagement initiative, and provides other examples of successful programs in the recommendations section that follows. In addition, visit <http://www.ipfcc.org/advance/topics/medicaid-engagement.html> for additional resources and examples.

Oregon: A Case Study

Individual and family engagement efforts in Oregon highlight the collaborative work of Oregon’s legislature, the Oregon Health Authority (OHA), state Medicaid Advisory Committee (MAC), Northwest Health Foundation, CareOregon, community groups, and care providers.

Over time, individuals representing the Medicaid population have become progressively more involved with the OHA’s work on policy and program implementation. OHA established task forces to advance patient-centered primary care homes, to explore best practices in patient and family engagement, and, more recently, to promote individual responsibility and health engagement. Increasingly, individuals and families in Oregon have been included as equal members of these influential OHA task forces. MAC undertook a project to explore issues around person- and family-centered care. They invited a broad range of experts, including individuals and families, to inform the committee on how best to engage the Medicaid population. OHA adopted, and is implementing, a series of MAC recommendations including the development and use of a “multidimensional framework for individual and family engagement in Oregon” included in Appendix C.¹¹

OHA also worked collaboratively with the Northwest Health Foundation to support the development of the Patient-Centered Primary Care Institute (PCPCI),¹² which brings together technical experts, providers, staff, patient advisors, policymakers, academic centers, and other stakeholders to share valuable practice transformation knowledge and resources. PCPCI provides webinars, on-site coaching, and learning collaborative events for primary care clinics throughout the state to help them achieve patient-centered primary care home recognition.

Through legislative mandates, Oregon has developed requirements for meaningful participation of community

advisory councils (CACs) with the Medicaid coordinated care organizations (CCOs). CACs are groups of 16 to 20 individuals selected to represent a geographic area and whose role is to work closely with their CCO on services, coverage, and evaluation of Medicaid services. According to state legislation, 51 percent of the membership of each CAC must be comprised of clients or family members receiving Medicaid services. The remaining members generally tend to be community representatives from public health, disability services, or other agencies who work with individuals served by Medicaid.

OHA also created the Transformation Center¹³ to capture the learnings gleaned by the CCOs and to widely disseminate best practices in health system transformation, including the engagement of individuals, families, and communities. In May 2014, the OHA Transformation Center hosted the first statewide, in-person gathering for Community Advisory Councils. CACs from around the state gathered to share successes, learn together, and support each other in health system transformations.

CareOregon, a Medicaid managed care organization, established a member advisory council in 2010. The recruited council members first participated in a variety of educational activities that included learning about the role of advisory councils, meeting other advisors from across the country, and participating in a class to understand group dynamics and meeting facilitation. The advisory council subsequently improved internal processes for CareOregon, helped to expand dental coverage, and began to create partnerships in the broader health care community. In collaboration with clinicians and staff, they developed the *Better Together* guide to help CareOregon members prepare for clinic visits. Advisory council members are passionate about outreach on preventative health care, partnership with health care providers, and self-management support. Their conversations with the Oregon legislature influenced the establishment of CACs and the mandate to include Medicaid beneficiaries in the creation and ongoing operations of CCOs.

Other innovative local programs developed across Oregon to better engage individuals in care include:

- The Willamette Valley Community Health Marion-Polk Obstetric Mentoring Service (MOMS) program provides support and care to pregnant women struggling with substance abuse. Services include outreach mentors, weekly contact with a peer mentor, and coordination of care utilizing a team including the mentors and public health nurses. The services of the peer mentor, a mom who participated in the program and experienced success, is key to engaging these women. The peer mentor develops empathetic, authentic relationships with program participants, and helps them build their skills, knowledge, and confidence to have a healthy birth and end the cycle of substance abuse in their families. As one MOMS program participant noted in her interview, “No one had tried to engage me before. I had been homeless for several years. I had looked for help and been turned away. I didn’t have

any hope. The outreach worker found me and gently said she noticed I was pregnant and wondered if I would like to know about a program that could help me. I wasn't doing well. Soon, I had a mentor who met with me weekly. She had been where I was. She didn't judge me and knew about resources that could help me have a healthy drug-free baby. That meant a lot to me." Since its inception 332 infants (99.4 percent) of enrolled MOMS participants tested negative for illegal drugs at birth.

- CareOregon created the health resilience specialist role to collaborate with primary care clinics in encouraging individuals to stabilize and improve their health. The health resilience specialist is based in a primary care clinic setting and performs outreach to individuals identified as high utilizers of health services, and who have complex medical and mental health/substance use disorder needs. Functioning as a liaison between the primary care clinic, specialty medical clinics and other community/social services, the specialist sees individuals in their homes and other community settings. The health resilience specialist also builds the knowledge and skills of all clinic staff on topics important to engagement efforts, such as motivational interviewing and trauma-informed care. Preliminary data shows a reduction in inpatient and emergency department visits among high utilizers engaged by health resilience specialists.

Recommendations and Key Action Steps for Medicaid Agencies

Based on this research, IPFCC has practical, action-oriented recommendations for Medicaid agencies seeking to engage individuals and families in improving their health and the health care system. By implementing specific action steps within four broad categories of recommendations, Medicaid leaders will achieve significant and positive change in individual and family engagement.

"[Engagement] can begin with simple information-sharing, move on to dialogue, and evolve into a partnership. Whatever form it takes, engagement changes the focus, from taking action to improve health and health care for the people, to taking action with the people—a simple yet radical notion."

—Report of the Patient and Family Engagement Work Group 2013, World Innovation Summit for Health.¹⁴

1. Advance Individual and Family Engagement Best Practices as a Strategic Priority Within the Medicaid Agency.

Medicaid leaders should initially focus on making internal changes that promote effective and sustainable individual and family engagement within the Medicaid agency.

Medicaid agencies should:

- Create a strong and cohesive strategic plan for individual and family engagement within the agency, and a means to achieve this vision through operational activities linked to the strategic plan.
- Appoint an executive sponsor or "champion" within the Medicaid leadership team responsible for overseeing the execution of the strategic plan. The champion will communicate the value of partnerships with internal and external constituencies, remove system barriers, and oversee measurable progress.
- Provide resources and incentives to educate agency staff partnering with individuals and families in their health care in an effort to improve health care for all. Training topics should include best practices in patient activation, cultural competence,¹⁵ trauma-informed care,¹⁶ health literacy, and patient- and family-centered practices including patient-centered communication.
- Establish clear directions for leaders to act as role models for staff, including actively participating in forums with individuals and families serving as Medicaid advisors.

Medicaid advisors in this context are individuals and families who partner with agency staff in improving Medicaid programs and services. These advisors are individuals or family members of individuals who receive, or have received, Medicaid services. Advisors offer agencies input into patient care and organizational processes and advocate on individual and family needs from a broad perspective. As one Medicaid agency leader noted during an interview, "To build these partnerships [with individual and family advisors], we have to demonstrate we will do what we said we'd do. This is hard work and it's important that we listen, demonstrate empathy, and, at times, agree to disagree. In the beginning it takes more time, but we're making better decisions in partnership with our advisors. Significant policy changes around contracting services based on client participation in task forces are being achieved."

2. Expand Opportunities for Individuals and Families to Engage with Medicaid Staff and Managed Care Entities to Influence Policies, Programs, and Practices.

For an engagement initiative to be successful, the Medicaid agency must create and broaden opportunities for individuals

and families to have meaningful dialogue and partnerships on a variety of policies, programs, and practices. To apply lessons from best practices of engagement within health care delivery settings Medicaid leaders should:

- Assign a staff liaison who supports advisors in partnership roles, and creates formal and informal mechanisms for individuals and family members to collaborate with Medicaid staff to improve policies, programs, and practices.¹⁷
- Offer training and mentorship opportunities that prepare individuals and families to serve as effective advisors with the agency and its related care contractors.
- Reduce financial barriers to engagement in advisory activities by providing individual and family advisors with small stipends to cover transportation or child/respite care costs.
- Develop opportunities for individuals and families to participate in the improvement and ongoing evaluation of the services, processes, and policies of the organization. Consider communication and information technology strategies—such as client portals, websites, automated text, and calling systems—as good beginning areas for collaborative endeavors.
- Create explicit expectations that Medicaid managed care and other contracted entities meaningfully engage individuals and family members as advisors, mirroring the actions taken by the agency.

An advisor who is the parent of a Medicaid beneficiary commented during an interview, “I am hopeful that my participation will result in positive change. My questions have helped staff realize how their messages, although well-meaning, are complex and confusing to parents juggling complex care for their children. Over time, we’ll see how the information we’ve shared will help others in the system.”

States can also look to Colorado for emerging best practices regarding engagement. Building on recommendations from a 2012 report, the Colorado Department of Health Care Policy and Finance (DHCPF), which administers the state’s Medicaid program, instituted a new focus on the role of effective communication, and is expanding new processes for individual and family involvement. DHCPF identified an executive sponsor, established a person-centered approach project team made up of key staff, and hired an individual- and family-centered care project manager who acts as an engagement liaison and staff resource. To build effective engagement strategies and competence, education and training plans for all DHCPF employees are underway. The project manager is working with Medicaid units that need support to involve clients in benefits design, obtaining clients’ input on key initiatives, and preparing clients and others to serve as advisors.

DHCPF changed its organizational structure to accommodate new roles and responsibilities to support this level of engagement. It is also exploring a formal recruitment and “on-boarding” process for advisors. Finally, Colorado Medicaid leaders are actively supporting cultural transformation efforts related to engagement, and they are participating in venues seeking individual and family input.

3. Support Direct Care Service Providers in Acquiring the Knowledge and Skills to Develop Effective Partnerships with Individuals and Families.

Individual and family engagement is achieved across the diverse Medicaid population when direct care service providers demonstrate skills in cultural competency, health literacy, motivational interviewing, trauma-informed care, patient-centered communication,¹⁸ patient activation and coaching skills, and individual and family engagement. To promote engagement activities in direct care environments, Medicaid agencies should:

- Explore partnerships with community organizations, foundations, or others to create technical assistance resources for direct care providers and staff to expand their knowledge and skills.
- Promote the adoption of shared decision-making tools by identifying and reducing barriers to implementation in direct care organizations.
- Disseminate evidence-based best practices for individual and family engagement by hosting webinars and workshops for providers and staff.
- Offer coaching for providers on-site that builds competency in self-management support and the key engagement skills.
- Provide enhanced payment and/or non-monetary incentives, such as recognition of direct care sites that have created opportunities for ongoing engagement of individuals and families.

In developing engagement strategies, Medicaid agencies should consider the approach and experience of “Team Up for Health,” a California HealthCare Foundation initiative to advance self-management support in five safety net clinics and one primary care/multispecialty group practice. This project provided the clinics and group practices with technical assistance to further individual and family engagement at three levels—in individual care, in quality improvement at the organizational level, and in expanding use of community resources. Each organization received support to partner with individuals and families through communication and collaborative skills coaching geared toward improving the direct care experience and creating advisory programs. This initiative resulted in tools, developed

by individual and family advisors, to maximize a primary care visit.

In the project's evaluation, clinic leaders, clinicians, and staff emphasized the positive value of partnering with individuals and families. As one "Team Up for Health" participant commented during an interview, "Patient and Family advisors—culturally this was a change to the organization. The value they brought has been huge." Similarly, another participant observed, "We did not expect how much of a difference the patient advisors would make." Since this effort, The Center For Care Innovations and others have provided technical assistance to safety net clinics and group practices, building on the lessons learned about effective engagement at all levels of care.

4. Encourage and Support Individuals and Families to Engage More Fully in Their Health and with Their Health Care Team.

To increase individual and family engagement in direct care, Medicaid agencies, in concert with contracted managed care entities, direct care organizations, and involved community organizations, should:

- Collaborate with individual and family advisors to create messages and informational materials that explicitly welcome Medicaid clients as valued members of their own care team, and that encourage them to involve their families in their care.
- Inform individuals, families, and the community about concepts like shared decision-making and self-management, and routinely invite them to actively engage in their care and with their care providers at the level they choose. Offer incentives for their participation in these activities.
- Provide infrastructure and/or training to ensure that individuals and families have access to evidence-based peer support and peer-led self-management programs, such as the Living Well with Chronic Conditions Program in Oregon,¹⁹ which is based on the Stanford Chronic Disease Self-Management Program.
- Invite individuals and families, through a variety of mechanisms, to share their stories of how they successfully partnered with their care team to improve their health and health care, and disseminate these examples broadly to inspire others.

In Minnesota, the Mayo Clinic developed a set of shared-decision making tools that employ user-centered design. Implementation of these tools has helped facilitate important conversations between patients and providers about treatment choices. More importantly, according to Mayo Clinic staff, these tools have helped patients from

disadvantaged populations more actively participate in the care decision-making process.²⁰

Several *Aligning Forces for Quality* (AF4Q) communities implemented a Patient Partner program, where patients serve as members of their ambulatory care practice's quality improvement leadership team. Patient Partners know firsthand about the challenges patients face in managing chronic diseases, as they have either managed their own chronic condition or have cared for someone with a chronic illness.²¹ The perspective of patients familiar with chronic disease management has proven to be an invaluable tool for practices working with Aligning Forces for Quality—South Central Pennsylvania (SCPA). More experienced Patient Partners mentor new Patient Partners, serve on a steering committee, and help develop training materials. "Patient Partners have a great impact on patient engagement," said Christine Amy, SCPA project director. "Providers have become used to quality measures, but struggle with patient engagement. It's a different perspective entirely."

"...the extent to which patients feel informed about their health, and confident about taking a role in their care decisions predicts their engagement independently of and more strongly than [typical differences among populations]. That suggests that clear information can help level the health care playing field across population groups."

Langer Research Associates, "Empowerment and Engagement Among Low-income Californians: Enhancing Patient-Centered Care," Blue Shield of California Foundation Survey, September 2012.²²

Conclusion

The question for state Medicaid agencies is not whether to encourage individuals, families, agency staff, and providers to embrace engagement as a means of improving health and health care, but rather *how* best to do so to achieve the greatest improvements in outcomes. Strong leadership within Medicaid programs is necessary to set the expectation that collaboration with those served by Medicaid is valued and benefits everyone. Medicaid leaders can take action to promote, support, and reward programs that create strong partnerships with individuals and families in the care experience, and improve health care. When invited to collaborate, individuals and families are often eager to help make a positive contribution.

A related challenge for Medicaid agencies and other entities implementing engagement strategies is how to measure the outcomes of patient and family engagement initiatives. Systematic measurement can shed light on the factors that encourage and sustain meaningful engagement, but there are few rigorous measures for monitoring the effectiveness of engagement specific to the Medicaid population. Without such measures, Medicaid programs will find it difficult to make timely and

appropriate changes to their engagement programs. For insight into the effectiveness of various strategies, Medicaid programs could utilize the Patient Activation Measure (PAM) for measuring activation levels before and after specific engagement initiatives. A recent report from the National Quality Forum (NQF) provides recommendations for measure development related to individual and family engagement.²³ Forthcoming work on behalf of the Centers for Medicare and Medicaid Services to identify, develop, and support implementation of electronic clinical quality measures, including individual and family engagement measures,

Appendix A: Interviewed Individuals

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Suzanne Brennan, *medicaid director*, Department of Health Care Policy & Financing, Denver, Colo.

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Cliff Coleman, MD MPH, *family practitioner*, Department of Family Medicine, Oregon Health and Science University, Portland, Ore.

Olivia Covey, *client and family centered care & engagement stakeholder liaison*, Department of Health Care Policy & Finance, Denver, Colo.

John R. Corlett, *vice president government relations and community affairs*, The MetroHealth System, Cleveland, Oh.

Tara DaVee, *community advisory council member*, Trillium Coordinated Care Organization, Springfield, Ore.

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Susan Edgman-Levitan, PA, *executive director*, Stoeckle Center for Primary Care Innovation, Massachusetts General Hospital, Boston, Mass.

Rick Ellsmore, *parent*, Arvada, Colo.

Tom Ewing, MD, *chief medical officer*, PacificSource Health Plans, Eugene, Ore.

will also inform Medicaid leaders on how best to measure and evaluate engagement efforts in the future.²⁴

Across the nation, promising practices demonstrate the power of individual and family engagement in their health and in the improvement of Medicaid programs, policies, and services. As leading state Medicaid agencies have discovered, effective relationships with individuals and families are transformative for both the agency and the clients. Developing these engaged relationships in Medicaid is a journey well worth pursuing.

Joshua K. Graves, MBA, QMHA, *chief administrative officer*, Catholic Community Services, Salem, Ore.

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Dianne Hasselman, *director of value based purchasing*, Center for Health Care Strategies, Hamilton, N.J.

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Nancy Judkins, *community health engagement advocate*, CareOregon, Portland, Ore.

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Kathryn Lueken, MD, *chief medical officer*, Willamette Valley Community Health, Salem, Ore.

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Appendix B: Issue Brief Advisors

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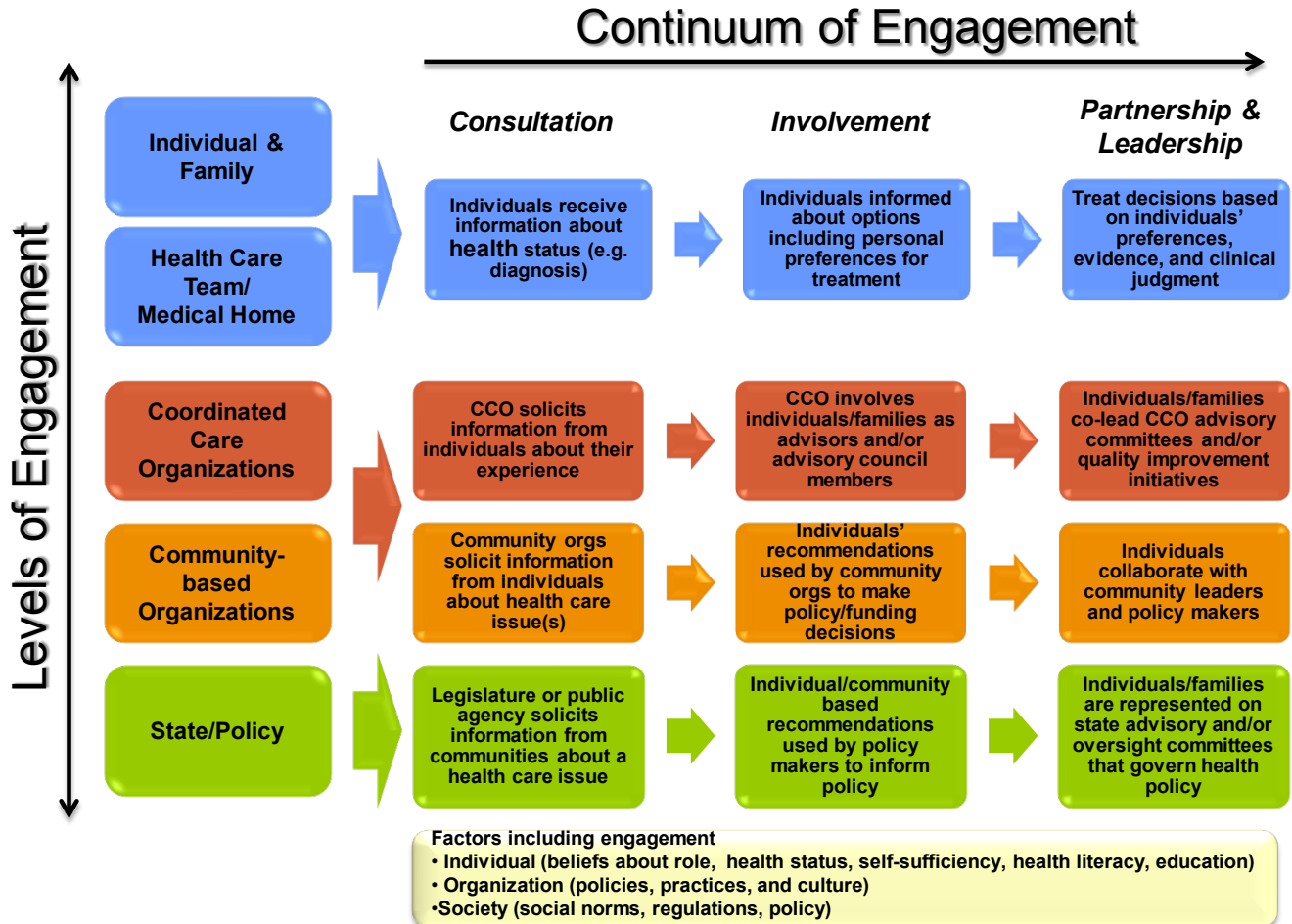
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Appendix C: Multidimensional Framework for Individual and Family Engagement in Oregon

A Multidimensional Framework for Individual And Family Engagement In Oregon



Adapted from Carman K L et al. Health Aff 2013;32:223-231

Endnotes

1. Carman KL, Dardess P, Maurer M, et al. “Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies.” *Health Affairs*, 32(2): 223-231, February 2013, <http://content.healthaffairs.org/content/32/2/223.full> (accessed October 2014).
2. Hibbard JH and Greene J. “What the Evidence Shows About Patient Activation: Better Health Outcomes and Care Experiences; Fewer Data on Costs.” *Health Affairs*, 32(2): 207-214, February 2013, <http://content.healthaffairs.org/content/32/2/207.full> (accessed October 2014).
3. Wolff JL and Roter DL. “Hidden in Plain Sight: Medical Visit Companions as a Resource for Vulnerable Older Adults.” *Archives of Internal Medicine*, 168(13): 1409-1415, 2008.; Botelho RJ, Lue BH and Fiscella K. “Family Involvement in Routine Health Care: A Survey of Patients’ Behaviors and Preferences.” *The Journal of Family Practice*, 42(6):572-576, 1996.; Sayers SL, White T, Zubritsky C, et al. “Family Involvement in the Care of Healthy Medical Outpatients.” *The Journal of Family Practice*, 23(3):317-324, 2006.; Wolff JL and Roter DL. “Family Presence in Routine Medical Visits: A Meta-Analytical Review.” *Social Science and Medicine*, 72(6): 823-31, 2011.
4. “Patient Engagement.” *Health Affairs*, February 2013, www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=86 (accessed October 2014).
5. Insignia Health holds exclusive rights to PAM per a technology transfer from University of Oregon, for more information and graphics visit, www.insigniahealth.com/solutions/patient-activation-measure (accessed October 2014)
6. In this context, the term “lived experience” is used to describe a person with first-hand knowledge of the care experience within the context of their unique values, beliefs, perceptions, and their cultural experiences.
7. Edgman-Levitan S, Brady C and Howitt P. *Partnering with Patients, Families, and Communities for Health: A Global Imperative*. Doha, Qatar: World Innovation Summit for Health’s Patient and Family Engagement Working Group, 2013.
8. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, communicate and understand basic health information and services needed to make health care decisions.”; Somers SA and Mahadevan R. *Health Literacy Implications of the Affordable Care Act*. Hamilton, N.J.: Center for Health Care Strategies, Inc., 2010.
9. Motivational interviewing (MI) engages individuals to explore their change readiness and engages them in selecting behaviors they will adopt or eliminate to address their health goals. MI is evidence-based, relatively brief, specifiable, applicable across a wide variety of problem areas, complementary to other active treatment methods, and learnable by a broad range of professionals.; Miller WR and Rose GS. “Toward a Theory of Motivational Interviewing.” *American Psychologist*, 64(6): 527–537, 2009.
10. *Safety is Personal: Partnering with Patients and Families for the Safest Care*. Boston: National Patient Safety Foundation’s Lucian Leape Institute, 2014.
11. *Person- and Family-Centered Care Engagement Medicaid Advisory Committee Full Report and Recommendations*. Salem, OR: Oregon Health Authority, 2013.
12. *About the Institute*. Portland, OR: Patient-Centered Primary Care Institute, 2014, www.pccpi.org/about-institute (accessed May 2014).
13. *About the Transformation Center*. Portland, OR: Oregon Health Authority Transformation Center, 2013, <http://transformationcenter.org/transformation-center/> (accessed May 2014).
14. Edgman-Levitan, Brady and Howitt. A.
15. In health care, cultural competence describes the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural and linguistic needs.

Betancourt JR, Green AR and Carrillo JR. *Cultural Competence In Health Care: Emerging Frameworks And Practical Approaches*. New York: The Commonwealth Fund, 2002.
16. Trauma-informed care is an approach to care that is cognizant of the impact trauma has on an individual’s ability to fully engage with others. Its goals are to develop a trusting relationship that is non-judgmental, empathetic, and supports the individual to make

choices based on his or her values, preferences, and readiness. While research indicates that mental health practitioners have greater understanding of the role of trauma in care, research indicates most other health care providers do not possess this knowledge.

Bloom SF. “Creating Sanctuary: Healing from Systematic Abuses of Power.” *Therapeutic Communities: The International Journal for Therapeutic and Supportive Organizations*, 21(2): 67-91, 2000.

Bloom, S and Farragher, B. *Restoring Sanctuary: A New Operating System for Trauma-Informed Systems of Care*. New York: Oxford University Press, 2013.

17. Minniti M and Abraham M. *Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons*. Bethesda, MD: Institute for Patient- and Family-Centered Care, 2013.
18. Patient-centered communication aims to reduce language barriers and ensure safe, clear, and effective health care interactions, especially for vulnerable populations. Wynia M and Matiassek J. *Promising Practices For Patient-Centered Communication With Vulnerable Populations: Examples From Eight Hospitals* New York: The Commonwealth Fund, 2006.
19. *What is Living Well?* Portland, OR: Oregon Health Authority, 2014, http://public.health.oregon.gov/DiseasesConditions/ChronicDisease/LivingWell/Pages/le_workshop_info.aspx (accessed October 2014).
20. Victor Montori, MD, *director*, Health Care Delivery Research Program, Mayo Clinic Center for the Science of Health Care Delivery, Minneapolis, Minn. Interviewed by telephone, 14 February 2014.
21. <http://forces4quality.org/node/7382> (accessed October 2014)
22. Empowerment and Engagement Among Low-Income Californians: *Enhancing Patient-Centered Care, 2012 Blue Shield of California Foundation Survey*. San Francisco: Blue Shield of California Foundation, 2014, http://www.blueshieldcafoundation.org/sites/default/files/publications/downloadable/empowerment%20and%20engagement_final.pdf (accessed October 2014).
23. “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps in Person-Centered Care and Outcomes,” August 15, 2014. National Quality Forum. http://www.qualityforum.org/Publications/2014/08/Priority_Setting_for_Healthcare_Performance_Measurement__Addressing_Performance_Measure_Gaps_in_Person-Centered_Care_and_Outcomes.aspx.
24. “Call for Measures.” *Centers for Medicare & Medicaid Services*, <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/CallForMeasures.html> (accessed October 2014).