The ability to understand what is most important to an individual is foundational to the provision of person-centered care. The ability for providers and care managers to communicate and coordinate care based on a shared understanding of the individual’s goals directly impacts the outcomes and experience of the person receiving care. Although commonsense, application of these principles is anything but commonplace.

Goals to Care

How to keep the *person* in “person-centered”

The National Committee for Quality Assurance
Introduction

Health care and community-based organizations and care managers are increasingly incorporating person-centered care planning principles in their work. The movement from provider-centered instruction to person-centered participation is being driven by both the recognition of the value of person-centered care in helping individuals to achieve their desired outcomes, and by state and federal requirements.¹

Person-centered care begins with the individual’s goals and respects and addresses their preferences and needs. However, applying this ideal in a complex medical and social environment is difficult. Care managers responsible for helping individuals with their medical and long-term service and support (LTSS) needs must understand what is most important to the person. They must also have an effective system for coordinating care with others supporting the individual to support those preferences. Creating such a seamless and well-coordinated system is anything but simple.

While person-centered care planning places the individual at the center of WHAT care is to be provided, by WHOM and WHEN, the care manager is often at the center of HOW that care is coordinated. This report, intended for those who provide care management services, includes tips and tricks for coordinating goal-based care, illustrated with examples from organizations experienced in providing person-centered care to individuals with complex needs.

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Goals, Goals, Goals

The path for Tom, a middle-aged man with HIV, obesity, diabetes, hypertension and other health issues, could have led in many directions. He could have invested his time and resources in pursuit of intense medical treatment; he could have chosen not to address his medical conditions at all—or he could have done something in-between. But Tom’s passion, to be of service to his community, influenced his approach to medical care. With the support of his care team, Tom decided to work on his health, so that he could help others. “If I’m healthy, I can help the community. So I make sure I take my meds, get the proper checks that I need to have me healthy, to support me. And then I’m able to go out and help the community. But if I’m not healthy or strong through the medications, exercise regimen and testing, I’m no good to anybody.”

Organizations responsible for the coordination of medical care, behavioral health or long-term services and supports (LTSS) help older adults and those with physical, intellectual or developmental disabilities improve their health and social outcomes by developing and implementing individualized care plans based on the goals that are most important to the individual. Health and medical goals are highly individual and people’s engagement in setting goals has been demonstrated to affect not only their participation in and adherence to treatment, but their health outcomes and quality of life.2

Step 1: Elicit Goals
Identify what is important

People bring their needs, lifestyle preferences and desires to the goal setting/care planning process. Some can state their goals clearly, describe what’s most important in their lives and specify the services they need. Others may only hint at what is important in their lives, through stories or behavior. In these cases, the care manager can help people articulate goals.3,4

Goal-setting discussions are most successful when the individual trusts their care manager. Once trust is established, people tend to be more open to discussing their strengths and objectives. Care managers can listen for cues that indicate a readiness to set goals such as excitement about a topic, comments about current struggles or reflections on the past. When

2 http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_86.pdf
initiating goal discussions, care managers must acknowledge individuals as experts in their own lives and help them articulate what is important to them. Care managers may use information from assessments to prompt for goals. They can also help people prioritize their goals by putting “first things first” and breaking long-term goals into smaller, attainable action steps.

**Step 2: Negotiate Goals**

At times, the desires or priorities of the individual may not be immediately attainable or they may differ from those of family, caregivers, providers or care managers. The care manager can help the individual break down a long-term goal into smaller goals that help the individual progress toward their long-term goal, identify and suggest a complementary or supportive goal or help prioritize goals by importance or feasibility. A care manager who is respectful and accepts the individual’s goal without judgment can make suggestions that the individual will likely experience as supportive and person-centered.

When the individual’s priorities diverge from best clinical practices, preferences or “comfort” of family and caregivers, the care manager must consider and respect the individual’s preferences. In these circumstances, with the individual’s permission, the care manager can facilitate conversations with the others involved in the individual’s care about the individual’s goals. When an individual’s goals or priorities conflict with clinical recommendations, the care manager can ensure that the individual is fully informed about the options available and the consequences of their choices. In all cases, the care manager and the individual must work toward agreement on a shared goal and a plan to attain it. A shared goal may address a way for the individual’s preferences to be supported rather than pursuing treatment for their disease.

“If they do not have a legal guardian, we respect their choices and support them as requested. Sometimes it’s not nice, but then we provide the family education that people are allowed to make both good and bad decisions.”

—Care Manager
Case Examples

**Individual’s goals conflict with clinical recommendations (proxy decision maker)**

Sam, a 101-year-old man recovering from pneumonia, aspirated with every swallow. With food and secretions going into his lungs, his risk for developing pneumonia again was high. To mitigate this risk, his speech language pathologist suggested placing him on a feeding tube. Since Sam was unable to communicate, his care manager met with his family and a nurse to review the speech language pathologist’s recommendation. Together, they discussed his quality of life and weighed the pros and cons of the feeding tube vs. his continuing to eat and drink. Understanding the risks and his preferences, Sam’s family decided that he should be able to enjoy whatever food he is able to in his remaining days, and chose to forego the feeding tube.

**Individual’s lifestyle preferences and goals conflict with clinical recommendations**

Roger, a man experiencing morbid obesity, was repeatedly admitted to the hospital for various complications. He had successfully lost 200 pounds, but still weighed more than 500 pounds. Because of his health conditions and repeated admissions, Roger’s physicians and care manager felt his needs would be best met in a rehabilitation facility. Despite ongoing education about the additional care he could receive in the facility, Roger insisted on staying in his apartment. The care manager and physicians did not feel his home environment was safe, yet it was where he wanted to be. Respecting his desire to remain at home in spite of the conflict with clinical recommendations, the care manager arranged for home care services and clearly documented Roger’s choice, her recommendations, the physician’s recommendations and the resulting interventions.

**Individual’s goals conflict with family**

At their first meeting, Michael, an obese man with an intellectual disability, told his care manager, Julie, that he wanted to learn to swim and was interested in swimming lessons. Julie thought swimming would be good exercise for him. However, Alice, Michael’s mother, produced paperwork identifying her as the legal guardian and decision maker for her adult son, and stated that he would “absolutely not” attend swimming lessons. Despite Michael’s continued requests and Julie’s attempts to get Alice to consider the activity, Alice insisted that her son would not participate in swimming lessons.

Julie realized she needed to understand Alice’s needs and concerns in order to successfully meet Michael’s goals. On her third visit, Julie engaged Alice in a conversation about her objections to swimming lessons, and learned that Alice was afraid of the water. Fear was at the root of her refusal to allow Michael to take swimming lessons. Once Julie understood this, she and Alice were able to agree on a plan that would allow Michael to pursue his desire to learn to swim. Michael would take swimming lessons from certified instructors and would wear a life vest, and Alice would attend and assist as she desired.
When an individual’s goals conflict with the desires of the family or other influential caregivers, the care manager may act as a neutral party to explore all possibilities to resolve a potential conflict.

**Documenting Goals**

It is important to establish a shared understanding of what is important to the individual, how goals will be met—and how to know if goals have been met. The care manager should document goals and interventions with the individual present or, if the goals were documented after the discussion, review the documented goals with the individual prior to implementing the care plan.

Care managers may document a variety of goals, depending on the needs of the individual:

- **Health and well-being outcome goals** are personalized outcomes that the individual hopes to achieve. Outcomes can be specific to the symptoms of a disease (e.g., remain infection-free) or not (e.g., control pain sufficiently to allow five hours of sleep on most nights; walk at least one block). Outcomes may reflect quality-of-life domains that fall outside the traditional realm of medical care, such as the individual’s level of participation and satisfaction with their social role. Health and well-being outcome goals are holistic and often relate to or affect daily life, rather than management of a specific disease or condition.

- **Behavioral goals** concern an act, a specific behavior or a pattern of behavior. (e.g., stop smoking, eat a healthy diet). Behavioral goals may be intermediate steps toward achieving a health and well-being outcome (e.g., attend all medical appointments in order to remain healthy and participate in the community).

- **Care or service goals** identify the services to be provided. Similar to behavior goals, care or service goals can be used as action steps toward a health and well-being outcome (e.g., get a ramp installed to improve mobility into one’s home).

**Writing a SMART Goal:**

**Specific:** State the goal clearly. If the goal is “I just want to stay healthy,” ask what that means. For one person, it might mean staying out of the hospital; for another, it might mean being able to walk a certain distance three days a week.

**Measurable:** Identify and quantify the observable markers of progress, such as pain levels or number of days walked each week.

**Attainable:** Break the goal into smaller, actionable steps. Identify expected barriers and make a plan to address them.

**Relevant:** Make sure the goal reflects what’s important to the individual. Motivational interviewing can be used to tie clinical goals, such as blood pressure control, to the goal of staying healthy.

**Time-Bound:** Define the period in which the goal is to be attained. Agree when to check progress.

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Goals may be documented in the individual’s words or paraphrased by the care manager. Using an individual’s own words when documenting goals can help ensure that the goals truly reflect what matters most to the individual, but may make it more difficult to measure progress if key elements for a measurable goal are missing. To balance the need for accuracy in understanding what’s most important to the individual and the need to measure progress on the goal, care managers can help an individual recast ideas and concepts into the SMART format (Specific, Measurable, Attainable, Relevant, Time-Bound).

For example, when asked about her goals, Genevieve, an older woman with mobility challenges, told her care manager that she would like to be able to move, walk and do some of the things she likes to do. Genevieve and the care manager talked about the factors that impeded her daily activities. Those factors included joint pain and a body mass index of 28.

The care manager integrated Genevieve’s wishes with additional information she gathered through their conversations and Genevieve’s records. This information helped them develop SMART goals, which were documented in the care plan:

<table>
<thead>
<tr>
<th>Stated Goal</th>
<th>SMART Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The main one is to keep trying to move, walk and do some of the things I like to do.”</td>
<td>1. Member (Genevieve) will have a pain level of 4 or less, which will enable her to be more independent with her ADLs and IADLs.</td>
</tr>
<tr>
<td></td>
<td>2. Member (Genevieve) will lose 15 pounds over the next 6 months.</td>
</tr>
</tbody>
</table>

SMART goals are a good way to ensure that both the individual and care manager understand the ultimate goal. With SMART goals as a base, the individual and care manager can develop a plan to address barriers and identify interventions that will support attainment of the goal.

**Step 3: Support Goal Attainment**

Once goals are identified, agreed upon and documented, the individual, the care manager and the support team (family, caregivers and medical and LTSS providers) work together to help the individual attain them. In some cases, responsibility for attainment may lie solely with the individual, as in Jacob’s case, below; some individuals may need significant support from providers in order to make progress on their goals.

Faced with a life-threatening condition, Jacob, a man with diabetes, desperately wanted and needed surgery to remove two tumors from his head. Both his desire and ability to live a healthy life depended on it. He scheduled the surgery and prepared for it—but just prior to surgery, his doctor found that his blood sugar had spiked and the surgery could not be performed. The surgery was rescheduled several times, but just prior to the surgery date, Jacob’s blood sugar spiked and the surgery was cancelled.

Jacob was enrolled in a program responsible for coordinating care for his acute, primary and LTSS needs. He told his care manager, Sarah, about his fear of the surgery. “I don’t know about this. It’s complicated, it’s my head.” Sarah provided emotional support, attended doctor’s appointments with Jacob and reinforced education about the risks and benefits of the surgery. Jacob continually stated that he wanted the surgery, yet the scenario of scheduling and cancelling repeated several times.
Sarah realized that Jacob’s fear about the surgery was causing him to go off his diabetic diet, leading to the blood sugar spikes. Looking for ideas on how to help Jacob attain his goal to live a healthy life, Sarah called Jacob’s primary care physician to discuss ways to help Jacob get the care he desired. Together, they created a plan to minimize the factors that contributed to Jacob’s fear, increase oversight of his medical needs and increase emotional support. They presented their ideas to Jacob for his input. To reduce Jacob’s anxiety and minimize the opportunity for his blood sugar levels to affect the surgery, they suggested scheduling the surgery immediately after his blood sugar stabilized. They also recommended more frequent office visits, so the physician could closely monitor Jacob’s blood sugar and respond to his questions and concerns. Sarah also offered to accompany Jacob to the final pre-surgery office visit and the surgery.

In this example, the physician and the care manager collaborated to identify ways to help the individual get the care he needed and wanted. Person-centered care means that the individual is central to the care provided. Nothing is to be done for the person, without the person—however, sometimes providers and care managers need to communicate directly in order to explore options to present. Even when goals are person-directed, the reality of the effort or impact of the interventions necessary to achieve them can be intimidating. A care team can work together to support the individual in times such as these. Support may come in the form of a listening ear, encouragement or education. When people face complicated treatment decisions, the care team can help to translate complex information and lay out options in more understandable terms.

**Barriers to goal attainment**

Unexpected life events, such as the death of a partner, the loss of a job or housing, changes in health status and lack of financial or social resources, can inhibit goal attainment. Some people may stop following a treatment plan if their condition stabilizes and they feel they have attained a goal; some people may change their goal. Barriers and their impact on achieving goals can vary. Medical barriers, such as medication side effects, and social barriers, such as unstable housing, can affect outcomes. Care managers need to look at goals and challenges holistically and build supports that work in synergy.

**Recognizing and addressing barriers to success**

Barriers to attaining goals can be identified through documentation, behavior or conversations. Review of documentation may help identify historical patterns in behavior or needs. Helping people verbalize their experience—“Why do you think you are sick?” “Why do you need to go into the hospital?” “Can you think of anything that might prevent you from getting better?”—can help the care manager gain perspective.

Sometimes people do not know what the barriers are or why they cannot reach their goals. A conversation between an individual and the care manager can help identify issues. For example, if an individual says, “I don’t like taking medication,” a conversation might uncover that the issue is not taking the medication, but instead about the medication’s negative side-effects. Probing questions such as, “What don’t you like about medication? What do you like about it?”
can prompt that conversation. Once a barrier is identified, the care manager and the individual can form a plan to address it (e.g., ask the physician if there is an alternative medication with fewer side-effects).

**How a care manager can help people attain their goals**

Many factors can influence success in attaining goals. Sustaining motivation to change is key. A care manager can use motivational interviewing techniques to assess readiness to change, secure a commitment to change and reinforce motivation to stick to a plan that might include many steps. For example, a woman whose goal is to “keep moving, reduce pain and continue to go to church” has a supporting SMART goal to lose 15 pounds over 6 months.

To attain her goals, the woman and her care manager identify and agree on several interventions to address barriers—environmental (e.g., lack of transportation to a gym), habitual (e.g., snacking on junk food), financial (e.g., the cost of joining a gym is prohibitive), and/or clinical (e.g., doctor put her on an antidepressant that causes weight gain).

Care managers can help set expectations when discussing goals and identifying interventions. When reducing an overall goal into smaller, actionable steps, the care manager can identify the change agent for specific activities (e.g., “Individual will continue to participate in an exercise activity of her choice,” “Care manager will authorize admission tickets to the pool”).

The care manager can also connect an individual to services or supports outside the scope of the organization (e.g., volunteer services, pharmacist for a medication review), as appropriate.

The care manager can offer encouragement and support and make adjustments if an individual diverges from an agreed-on plan. “She knows that getting exercise is in her plan of care. And she’ll call sometimes and say, ‘I know I’m supposed to go out and take a walk, but my knee hurts really bad today, and my back hurts,’ and we’ll talk, and she’ll talk. And then, I’ll say, ‘Well, let me tell you about this TV show, called Sit and Be Fit.’”

Suggesting simple tools can have a big effect on a person’s life. One care manager helped an older woman develop a routine by establishing a calendar to help her document taking daily medication. “It remind[ed] me of taking my medication by noting it down, so it became like a habit.”

**Step 4: Monitor Goal Attainment**

Once a goal has been identified, a plan has been developed and necessary services or supports have been ordered, it can feel as if most of the work has been done. However, the

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most important part of the process—attaining a goal—has yet to occur. How will the care manager and the individual know when the goal has been reached?

When establishing goals, care managers and individuals should discuss how progress will be measured. Many organizations conduct assessments and review goals and care plans at predetermined intervals (e.g., quarterly, annually). Sometimes, care managers and individuals may find more frequent contact helpful. Regardless of when meetings are held, establishing clear expectations about what will be reviewed is a good idea. “By the next time we meet, you will be walking one mile every other day.” “I’m going to check in with you every four weeks to see how you are doing on your goals.”

Both goals and indicators must be tailored to the individual. For example, two people with mental health goals will monitor their progress differently. For one person, maintaining mental health is indicated by remaining drug-free and attending regular therapy appointments; for another, an improved PHQ-9 score and positive emotional changes indicate progress.

Documenting progress and identifying facilitators and barriers to goals can inform changes to the care plan. With limited exceptions (e.g., a legal representative oversees care), the individual determines whether a goal is attained. If the goal changes before it is reached, the care manager and individual can determine whether to modify the goal or the interventions, or whether to retire the goal. If the goal was not attained but is still desired, the care manager can work with the individual to understand the barriers to attainment and develop a new plan.

Attaining goals can be a long and challenging process, often requiring ongoing support from a care manager and others. Jim, a man with a history of drug abuse, was moved by John Lennon’s response to the question, “Do you believe that we can have peace?” He pondered the question, “…you know, that’s a wild question to ask, because I would think, ‘What would he say?’ Because, let’s face it, we all know we can’t have peace right now, and we’re not having it. But they asked him, ‘Do you believe that we can?’” Lennon’s response was, “If we want it.”

Jim felt that the message fostered hope for his own personal peace from the struggles he had borne since childhood. “It was so powerful … because that’s the only answer he could have given. Because if someone asked me, ‘Do you believe we could have peace?’ No, I don’t believe it. But I know that if we want it, we can. I know if I want to stop using, I can.”
It’s All About Teamwork

Attaining goals is difficult in the best of situations. A motivated individual with a clearly defined objective and unlimited time and resources may still need help from time to time. Complex health and social needs only make goal attainment that much harder. A care manager can help an individual identify and articulate goals, and the care manager can monitor and support the individual’s efforts; however, the care manager alone cannot help the individual reach their goals. Together the individual, their care manager and their network of family/friends/caregivers and providers (both medical and LTSS) must work together as a team.

Each person on the team may individually want what is best for the individual; however, there are often gaps and divisions in communication and approaches to care. This is particularly true between medical and LTSS providers. Using a person-centered approach to care planning can help bridge these gaps.

Person-centered care planning requires that the individual be at the center of care planning. To facilitate care planning efforts, the care manager often sits alongside the individual at the center of a network that constitutes the care team. In this capacity, the care manager’s relationships with the individual and other members of the care team are essential to providing person-centered care.

In person-centered care, the plan of care is built around the goals and preferences identified by the individual. The goals of the individual may address medical or social needs, and often require a range of expertise and perspectives to inform and implement the plan. For example, medical providers (e.g., physicians, nurses) provide clinical analysis, options for treatment and clinical support; LTSS providers help people in the community (e.g., provide personal care,
meals or transportation to medical appointments); and family and friends provide day-to-day support.

Aside from their connection to the individual, the members of the care team may have little or no affiliation with one another, much less access to shared information. Creating these connections and facilitating this communication often becomes the role of the care manager. Effective communication improves relationships, builds trust, fosters collaboration and positively affects outcomes.

**Working as a team**

The care needed to help an individual attain their goals may be coordinated through a formal team structure (e.g., the individual with a nurse and social worker; a team of medical professionals, therapists and social service providers) or through informal structures that cross organizational lines (e.g., health plan care manager, physician from a local clinic, home health nurse and home care attendant). Each team member plays a unique role; some are responsible for guiding care and services and others, for informing or implementing care.

A clear understanding of the various roles, along with trust among team members, can improve collaboration and communication. Trust among team members can specifically encourage the exchange of ideas and solutions—even if they oppose one another. It can create a “safe zone” where each team member feels comfortable expressing themselves when they disagree with others at the table. “I understand what you’re saying, but I don’t agree with you.”

Trust and respect lead to empathy, which can help each member of the team see things from another’s perspective. Ultimately, understanding and collaboration can lead to a better outcome than any single member of the care team could achieve alone.

**Communication—key to building relationships**

Open, trusting relationships depend on timely and effective communication. To coordinate care, care managers, providers, individuals and their families must share information about needs, services that are planned and delivered and changes in condition. For example, someone in need of cardiac care may be served by a primary care physician, a cardiologist, personal care attendants, transportation service providers and a meal delivery agency. The special diet prescribed by the cardiologist must be communicated to the meal delivery agency. The care manager, family and personal care attendants need to know that the prescribed medications can affect key symptoms, such as memory, which could result in confusion and missed appointments unless prompts and reminders are provided. If a hospitalization occurs, all in-home service providers must be informed so that services can be suspended during the hospital stay and resumed when the individual returns home.

Communication is easier than ever before. Technology provides options for faxing, e-mailing, live chats, text messaging and electronic record systems. Verbal communication can occur at “in-person” meetings, by phone and through the Internet. The choice of communication method can vary by preference, resources and capabilities of those involved—but it must fill the need. For example, clinical staff might find it challenging to attend meetings, but may be able to respond to e-mails between appointments. Families might prefer a phone call to discuss an issue, but may only be able do so after their work day is done. In addition, care managers must

> “People always think you can just throw together a team and it’s going to work. You know, the work is the trust that you have among your team members”
>  —Nurse Practitioner
consider the urgency of a message when determining the method of communication. Information regarding changes in condition or orders for new care may require a meeting, conference call or immediate submission of an order by fax or through the medical record system; clinical notes or records that do not require immediate resolution can be shared at a later meeting or mailed.

**Communication—key to seamless coordination**

To start off on the right foot, care managers can:

**Engage all appropriate parties**

Care coordination is only complete when all affected parties understand their roles and responsibilities. Gaps in care can develop when an individual or service provider is excluded from discussions. Discussions about care should include the individual, family/friends (as requested), personnel responsible for the care plan and providers of both medical and social supports. For example, discharge plans following a hospitalization frequently include orders for outpatient or home care. If an individual’s caregiver is involved in planning, medical providers can better understand and adapt the plan of care to the home environment, and can assess the caregiver’s ability to implement the care plan and offer training on unfamiliar activities.

**Establish a consistent communication system**

Regular communication between care providers and individuals can establish consistency in care coordination practices. Consistency can help prevent gaps in information by ensuring planned discussions about people and conditions. While individuals must be involved in all conversations that impact decisions, care managers may have additional conversations with other care managers and providers for purposes of coordination. For example, providers from a geriatric primary care clinic, home health agency and care management agency responsible for coordinating LTSS have monthly meetings to discuss the status and care plans for their shared elderly clients. They also maintain frequent communication between meetings, to stay current on individuals’ status and needs.

**Convene quickly to address urgent needs**

Crises can occur—and should be expected—and a care system should support timely, coordinated response. To coordinate care in urgent situations, the care team must have a system that allows rapid communication. For example, one organization holds an emergency team meeting when urgent issues arise: all members of the care team immediately meet in person or via conference line. When the emergency is over, the care team meets to review the actions taken, to determine whether the desired outcome was attained and to review the individual’s current status and care plan, in case revisions are necessary.

**Use communication to develop relationships, build trust and coordinate care:**

1. Engage all appropriate parties.
2. Identify common goals.
3. Identify and understand the strengths and needs of each individual or organization.
4. Identify opportunities for collaboration.
5. Remove barriers.
6. Establish a shared plan for communication. Including how to:
   a. Communicate regular (non-urgent) information.
   b. Convene quickly to address urgent needs.
Coordination
Relationships drive coordination. Taking the time to foster and nurture relationships can enable efficient, effective coordination and link all the care and services needed to ensure good outcomes for the whole individual, especially when conflicts or crises arise. Whether care coordination occurs virtually or in person, working in harmony can reduce risk and improve outcomes and efficiency.

“Alone we can do so little; together we can do so much”
—Helen Keller

For more information on Coordinating Care for Adults with Complex Needs, see: Policy Approaches to Advancing Person-Centered Outcome Measurement

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1Real names not used throughout this report.