Executive Summary

Introduction

People with complex needs—multiple chronic conditions, physical, intellectual or developmental disabilities and severe and persistent mental illness—face a difficult-to-navigate maze of medical care, behavioral health care and long-term services and supports (LTSS). Failure to effectively navigate the maze can adversely affect outcomes and needlessly increase the cost of care. To streamline and simplify care delivery and decrease fragmentation, state Medicaid programs and the Centers for Medicare & Medicaid Services (CMS) are increasingly integrating benefits through systems which emphasize person-centered, continuous, coordinated, and comprehensive care. Currently, health care quality measurement is focused primarily on single-condition medical outcomes. Quality measures are needed to evaluate how well an organization helps achieve the goals that matter to the individual. Measures of individual goal achievement, if implemented widely, have the potential to significantly impact the quality of care delivered to adults with complex needs. This Case Studies project was designed to lay the groundwork for developing performance measures of person-centered, goal-oriented, integrated care. We sought to understand the current state of practice and to identify promising approaches for providing care in organizations responsible for integrating medical care, behavioral health care and LTSS. We also sought to identify opportunities for quality measurement to drive practice transformation.

Aims

1. To understand how information on individual goals and goal achievement is incorporated in care plans, shared across providers and settings, used to support care and to track achievement and how the information might be used to support quality improvement and monitoring.
2. To understand and identify best practices for eliciting and documenting individual and family goals for care.
3. To describe goals and goal achievement for people with medical and LTSS or behavioral health needs.
4. Describe the usability of patient-reported outcome measures (PROMS) to elicit goals, provide the care manager with information about an individual's current functioning and well-being, provide a measure of progress on individual goals over time, and provide a population wide indicator of goal attainment and well-being over time.

Methods

We conducted case studies in two phases using different qualitative methods. We chose a purposeful sample of eight sites that 1) were experienced at providing either integrated medical care and LTSS, or medical and behavioral health care and 2) provided care to people who were eligible for Medicaid alone or with Medicare and Medicaid (dually eligible).

In Phase 1, two researchers visited each site for three days and collected data from three sources:

- Semi-structured interviews with site leadership, care managers and other providers
- Observation of the assessment, goal setting and/or care plan development process

- Review of a small sample of individual assessment and care plan records.

In Phase 2, we returned to 2 sites from Phase 1 that systematically elicited goals and documented them in the care plan. We added a third site, which differed from the original eight. It was a private pay continuing care retirement community that conducted goal-setting with residents and that had services available on-site, but did not directly provide medical care or supportive services.

Two researchers, including one research staff member and one consultant with expertise in goal elicitation, collected data from three sources:

- Semi-structured interviews with care managers about goal setting and their reactions to structured instruments for identifying goal targets
- Observation of the assessment, goal setting and/or care plan development process.
- Review a small sample of records to abstract documented care plan goals.

Findings

Integration Challenges: We observed a number of challenges to integrated care delivery across the eight sites visited and throughout the various components of care delivery. Interdisciplinary teams were not always well integrated, and there was redundant assessment and care planning performed by different care managers and providers. Care plans were often inaccessible to care managers, other providers and individuals. Technology was ineffective in supporting comprehensive communication within the interdisciplinary care team and between the team and the individuals served.

Promising Practices in Assessment and Care Planning: We observed a strong commitment to supporting individuals' independence and well-being across the eight sites despite the integration challenges. Care managers valued their relationships with the individuals they serve. All sites used in-home assessments, which enabled care managers to understand the individual's life and surroundings and identify the supports and services necessary to help the individual live as independently as possible. Social and health disciplines are involved in care planning, often pairing a nurse and social worker to conduct assessments and develop care plans. Sometimes, we saw care plans guided by goals.

We saw care managers matched to the individuals they serve based on skills (e.g., behavioral health focus or nursing). One site had an EHR accessible by all members of the care team. Another site had an electronic dashboard that was accessible to collaborating organizations, and that was used to share information across institutions and providers. Often, summaries of care plans or "to-do" lists were shared with primary care providers (PCP); sharing of the full care plan was less common. Occasionally PCPs and other clinical providers participated directly in assessment and care planning. We also observed creative approaches to communicating with individuals with language and cultural barriers, including the use of community health workers as interpreters.

Remaining Gaps in Delivering Integrated Care: Integrated care is an emerging system. Research is needed to identify ways to decrease redundancy in assessments; to include the goals of the individual in care plans; to improve communication among members of interdisciplinary teams and with the individual; and to share care plans among care managers, team members and individuals. One area that would benefit from further study is the effect of filtering that occurs when care managers summarize a care plan and provide a PCP with only limited relevant information or a “to-do” list. It remains unclear the degree to which this process provides PCPs and other providers with the most actionable information at the expense of withholding contextual information from the care plan that could be of value.

Goal-Setting Challenges: Many care managers experience challenges setting goals with individual, including individuals with difficulty or disinterest in setting goals, or with unambitious or unrealistic goals. They described situations when families want to set goals for the individual, and they reported that occasionally their own or their program goals were incompatible with individuals’ goals.

Promising Practices in Goal Setting: Despite these challenges, care managers described a number of promising practices for eliciting and negotiating goals. These included creating a relationship of trust with the individual, listening to the individual and being present in the conversation. They stressed the importance of respecting the individual, including the individual’s right to make choices that the care manager would not make. In a trusting relationship, care managers said they could use natural conversation to elicit goals, and would help to break goals into small, incremental steps that reflected the individual’s goals, priorities, strengths and readiness to change. Our analysis demonstrated that although documented care plan goals do not match the goals expressed by individuals word-for-word, both individuals and care managers agree that documented goals reflect or address many of the individuals’ priorities.

Views on Person-Reported Outcome Measures: Individuals and care managers were generally responsive to the use of a standardized quality-of-life PROM to help elicit and define goals as part of the goal-setting conversation. Care managers felt that the use of a PROM could prompt discussions about hidden concerns. The majority of individuals and care managers were interested in tracking progress toward goals and assessing well-being. Many expressed concerns that using a PROM would duplicate other aspects of the assessment.

Remaining Gaps in Goal Setting Practices: Although we were able to observe promising practices in goal setting at a small sample of sites, many of the sites included in Phase 1 of the study do not systematically ask individuals about their goals or record their goals in the care plan. Often, goals are assumed (remain independent at home) or discussed, but not documented. Even when documented, goals are written as free text, and not easily extracted. Individuals describe goals in terms of health, social and functional outcomes, whereas care plan goals tend to focus more on services and appointments needed to achieve outcomes.

Conclusion

These case studies aimed to understand current practice and identify promising approaches for providing person-centered, goal-oriented, integrated care. In many settings, care plan goals are substantially aligned with goals identified by individuals as most important. However, in some organizations, care planning is more service-focused than person-centered. Given the varying interpretations of “integrated” care, how care teams are defined, how information is shared among care team members and how care plan goals are developed and documented, there is a clear need for quality standards and performance measures. Quality standards could help organizations implement practices and systems that support effective, timely, interdisciplinary collaboration in the delivery of care and services that address individuals’ priorities.

There is also a need for performance measures that can assess how well organizations help people achieve the outcomes that matter most to them. Person-reported measures of quality of life could be a method for measuring such outcomes over time, but research is necessary to identify the best approach for integrating such measurement into a goal setting and monitoring process to ensure that an approach is relevant to individuals and not overly burdensome for care managers. A systematic approach to measuring outcomes individuals identify as most important could be valuable for both individual care plan development and organization-level quality measurement.

Table of Contents

1. Introduction

People with complex needs—multiple chronic conditions, physical, intellectual or developmental disabilities and severe and persistent mental illness—face a difficult-to-navigate maze of medical care, behavioral health care and long-term services and supports (LTSS). Failure to effectively navigate the maze can adversely affect outcomes and needlessly increase the cost of care. People who are eligible for both Medicare and Medicaid face even more complexity because the state Medicaid and federal Medicare programs are governed by different, sometimes conflicting rules and benefits. To streamline and simplify care delivery and decrease fragmentation, state Medicaid programs and the Centers for Medicare & Medicaid Services (CMS) are increasingly integrating benefits through systems which emphasize person-centered, continuous, coordinated, and comprehensive care[1] (CMS, 2012) provided through a variety of models such as managed care organizations (MCO), accountable care organizations (ACO) or provider-based programs such as patient centered medical homes, health homes and Programs for All-inclusive Care (PACE), among others (collectively referred to as "integrated care organizations"). Although integrated care has the potential to improve health outcomes and reduce the cost of care for people with complex needs, there are no systems in place to evaluate the quality and outcomes of care delivered by organizations responsible for integrating care.

NCQA's quality framework for integrated care starts with what matters most to the individual as the basis of goal setting. Quality measures are needed to evaluate how well an organization helps achieve the goals that matter to the individual. Measures of individual goal achievement, if implemented widely, have the potential to significantly impact the quality of care delivered to adults with complex needs. Currently, health care quality measurement is focused primarily on single-condition medical outcomes, but people with complex care needs are not well-served by this model. Single disease guidelines are often not appropriate, and are sometimes harmful, for people with multiple conditions. Disease-specific guidelines tend not to be relevant to people with complex needs, where overall quality of life and function in specific prioritized areas is more important than the outcome of a single medical condition. Holding integrated care organizations accountable for helping people achieve their self-defined goals will support a shift toward a whole-person approach to care. But developing measures of goal attainment is not easy.

We face significant challenges in developing measures of individual goal achievement. In earlier research we learned that few organizations use a person-centered approach to goal-setting. Even where goals are aligned with what matters most to an individual, organizations face challenges in capturing, documenting, storing and sharing information in a systematic way that could be feasibly measured. To construct reliable performance measures, it is necessary to understand promising practices for goal-setting and the types of information available for measuring goal achievement.

This Case Studies project was designed to lay the groundwork for developing performance measures of person-centered, goal-oriented, integrated care. We sought to understand the current state of practice and to identify promising approaches for providing care in organizations responsible for integrating medical care, behavioral health care and LTSS. We also sought to identify opportunities for quality measurement to drive practice transformation.

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[1] Center for Medicaid and CHIP Services. Policy Considerations for Integrated Care Models. July 10, 2012.

2. General Approach

We conducted site visits in two phases to understand current practices in assessment, goal setting and care planning, and in integration of care across providers and settings. We used different qualitative approaches in our study design (interview, observation and review of documents). Care planning and goal setting involve complex interactions between individuals and care managers that can be best explained through different methods of inquiry. Qualitative study designs are ideal for exploring concepts that are not well described or understood. The qualitative description approach used for both phases of the study is well-suited for health related research.

3. Phase 1

3.A. Methods

Our specific aims for Phase 1 were to understand how information on individual goals and goal achievement is incorporated in care plans, shared across providers and settings, used to support care and to track achievement and how the information might be used to support quality improvement and monitoring.

3.A.1. Site Selection

To identify Phase 1 case study sites, NCQA conducted an environmental scan of states that deliver integrated care to people with complex needs, then consulted a Stakeholder Advisory Panel to discuss the findings from the environmental scan and to seek suggestions for specific potential case study sites. Sites recommended by the panel and other sources were invited to participate. We then chose a purposeful sample of sites that 1) were experienced at providing either integrated medical care and LTSS, or medical and behavioral health care and 2) provided care to people who were eligible for Medicaid alone or with Medicare and Medicaid (dually eligible).

3.A.2. Data Collection

Two researchers visited each site for three days and collected data from three sources:

- Semi-structured interviews on the processes for assessment, care planning, eliciting goals, sharing information with other providers both internal and external to the site, identifying and responding to an individual's change in condition and quality monitoring. Interviews were conducted with site leadership, personnel directly involved in care management (i.e., assessment and care planning) and other providers not directly involved in care management (e.g., primary care provider [PCP], therapist). (Refer to Appendix A for interview guides.)
- Observation of the assessment, goal setting and/or care plan development process. At each site we observed 1–3 assessment/care planning sessions that were conducted in people's homes to identify whether and how goals were elicited and used to develop the care plan. At some sites, we also observed multidisciplinary care team meetings used to coordinate care and solve problems for people undergoing transitions or with significant challenges.
- Review of a small sample of individual records. We reviewed the records of the individuals whose assessments we observed, and we reviewed additional records at each site. The purpose of this review was to understand how sites structured their record system, how

they documented assessments, goals, care plans and significant changes in condition and whether they documented information sharing among providers.

3.A.3. Analysis

At the conclusion of each site visit, the researchers who conducted the site visit drafted a summary that included their observations about the processes for assessment, care planning, goal setting and information sharing. Following each site visit, the entire research team identified and categorized similarities and differences observed across sites.

3.B. Phase 1 Findings

3.B.1. Study Sample Description

Phase 1 of our research was designed to help us understand how information on people's goals and goal achievement is incorporated in care plans, shared across providers and settings and used to support care and track achievement, and how the information might be used to support quality improvement and monitoring.

Eight study sites with varied geography and model designs were selected to participate in the Phase 1 site visits (Table 1).

Table 1: Phase 1 Case Study Sites

Site ID	State	Organization Type	Primary Population(s) Served	Program Focus (in addition to general medical care)	Lives Served
1	Arizona	MCO: Medicaid MCO, Medicaid Managed LTSS & Medicare Advantage SNP	Adults 65+	Behavioral Health & LTSS	11,688
2	California	MCO: FIDE-SNP	Primarily adults 65+*	Behavioral Health & LTSS	2200
3	Minnesota	MCO: FIDE-SNP	Adults 65+	Behavioral Health & LTSS	4,453
4	New York	Health Home	Adults all ages*	Behavioral Health & LTSS	6,500
5	Ohio	MCO: Medicaid MCO	Adults 65+	Inpatient Behavioral Health	2,160
6	Pennsylvania	PACE	Adults 50+*	Behavioral Health & LTSS	500
7	Pennsylvania	Provider Collaborative: Primary Care Practice, AAA & Home Health	Adults 65+	LTSS	60
8	Wisconsin	MCO: FIDE-SNP	Adults all ages*	Behavioral Health & LTSS	760

*Nursing home level of care.

Abbreviations:

- AAA = Area Agency on Aging
- CCRC = Community Care Retirement Community
- FIDE-SNP = Fully Integrated Dual Eligible Special Needs Plan

Across the 8 sites, we interviewed 116 leaders, care managers and providers (PCPs, behavioral health providers and a home care agency manager). We observed 8 interdisciplinary care coordination meetings) and observed 18 assessment/care planning sessions with the individual present (Table 2).

Table 2: Number of Interviews and Observations Conducted in Phase 1

Site ID	Interviews			Observations	
	Organization Leaders	Care Managers	Providers*	Care Coordination Meetings	Care Planning Observations
1	6	10	4	1	2
2	5	7	1	0	4
3	6	2	4	0	2
4	7	4	4	0	2
5	4	6	1	3	2
6	6	4	2	3	1
7	10	8	3	1	2
8	4	4	4	0	3
Total	**48**	**45**	**23**	**8**	**18**

*Providers include PCPs, behavioral health providers and a home care agency manager.

3.B.2. Team Composition

All sites use an interdisciplinary team to coordinate care and services. However, we found variation in the composition of the care team and the degree of involvement of different care team members. Some members are routinely included in the team (labeled "Standard") while others are consulted as needed (Table 3). For example, most care teams include registered nurses and social workers, but participation by PCPs (doctors or nurse practitioners), physical, occupational or recreational therapists and others, such as behavioral health providers, is less frequent (details in the "Care Management Processes" section below).

Table 3: Team Composition and Type of Involvement in Assessment and Care Planning by Type of Organization

Organization Type	Registered Nurse	Social Worker	Primary Care Provider (MD or NP)	Therapy (Physical, Occupational and/or Recreational)	Behavioral Health (including Psychiatry)	Pharmacy
Managed Care Organization	Standard	Standard	Consulted	Consulted	Consulted	Consulted
PACE	Standard	Standard	Standard	Standard	Consulted	Consulted
Health Home	Standard	Standard	Consulted	Consulted	Consulted	Consulted
Provider Collaborative	Standard	Standard	Standard	Consulted	Consulted	Consulted

Standard = routinely included in the team; Consulted = included in the team or consulted as necessary

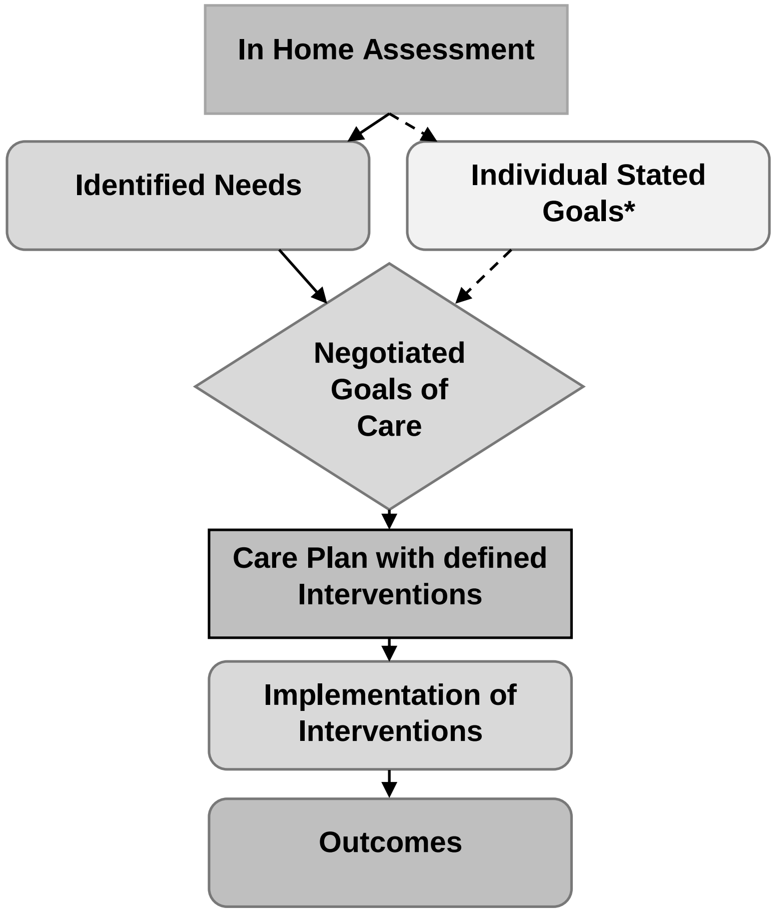
3.B.3. Care Management Processes: Assessment and Care Planning

All of the organizations we visited conduct in-person assessments, usually in the individual's home, to collect information and identify strengths and deficits. (Figure 1). All sites assess the individual's needs during this in-home visit. This was cited by several interview subjects as critical for care planning. Providers who conduct home visits describe how providing care in the home helps them gather and share information. *"When you go into their home, it's more than just clinical because you can kind of see their environment. A lot of times, their caregiver or family are there, so you can kind of get to see what support they have. And from that, glean a lot more than you can than if they come to your office. When you're in their home, you can kind of see, what are their limitations, what are the problems that we're going to have giving care, when you're right there."*

Most organizations use explicit goals of care to drive the care plan (Figure 1), however the focus and documentation of goals in the care plan vary by individual provider and organization. For example, in several sites, maintaining independence at home is an assumed goal for all participants. In the eight organizations observed in phase 1, the goals documented in the care plan are most frequently drawn from the comprehensive assessment, and tend to reflect short-term objectives (six months or less). In some cases, goals may be automatically generated from risks identified in the assessment (e.g., if the assessment showed the individual to have uncontrolled diabetes, diabetes control might be automatically generated as a goal in the care plan). At some sites, care managers directly ask individuals about their goals, and these may be documented in the narrative notes, but are not typically seen in the care plan. For example, one individual discussed a long term goal of wanting to live on her own outside of her parents' house. The individual and care manager discussed the long term goal and identified steps to achieving the goal. One step is to save enough money for a down payment on an apartment. The goal documented in the care plan was "patient will save $X each month."

Four of the eight sites have systems for tracking achievement of care plan goals. Organizations document individuals' progress on their goals through a percentage of completion, generalized terms (met/unmet) or in narrative notes. The focus of goal attainment may be on whether the individual achieved the specified outcome or whether the care manager provided the specified service.

Figure 1: Care Management Workflow



*Individual stated goals are not consistently included in assessment and care planning across sites.

3.B.4. Variation in Care Management Processes: Managed Care versus Provider-Based Organizations

<u>Managed Care Organization.</u> The MCOs we observed use nurses, social workers or other human service professionals to establish and maintain relationships with individuals being served. Their responsibilities include assessing needs, arranging for and coordinating services and facilitating communication among care team members. Some MCOs employ specialized care managers for specific populations—such as social workers with behavioral health care experience, for people with behavioral health needs, or registered nurses for people with complex medical needs. MCOs may directly employ care managers or delegate care management responsibilities to provider or community-based service organizations.

Medical directors, pharmacists, physical, occupational and recreational therapists and other specialists employed or contracted by the MCO, may participate in assessment or care planning activities when needed for problem solving in complex cases. PCPs may also be involved in care management activities, however they are most frequently used to provide patient history, orders for medication, durable medical equipment, services or consultation in acute or complex situations. Several MCOs contract with large medical groups, and they delegate care management to the medical groups, providing only “wrap-around” care coordination for services covered by the MCO, but not provided by the medical group. One MCO contracts with a physician group that provides home-based primary care, and PCPs from this group collaborate closely with MCO care managers.

Provider-Based Organizations. The provider-based organizations (PACE plan, provider collaborative and health home) function differently from the MCOs in directly providing health care services. Like MCOs, the provider-based organizations we observed use nurses and social workers in care management roles, with the social worker typically having primary responsibility to establish and maintain the relationship with the individual. A broader team (e.g., physicians, nurse practitioners, physical therapists, occupational therapists) supports assessment and care planning activities. Among the 8 case study sites, the PCP is more directly involved in assessment and care planning in provider-based organizations than in MCOs.

3.B.5. Information Sharing

Despite efforts to align care and services, we found that fragmentation and communication challenges persist. Most sites do not use a common, shared care plan accessible to care managers, providers and individuals served. Only one site we visited has a fully integrated electronic health record (EHR) system; all others use separate systems for care management and medical records that are not interoperable. This is particularly true in MCOs, but even in provider-based organizations there is limited sharing of the care plan with providers not directly affiliated with the organization.

Federal and state regulatory requirements mandate core elements of program operations, such as sharing care plans among providers. For example, the Code of Federal Regulations states that Medicare Advantage Special Needs Plans must "coordinate communication among plan personnel, providers, and beneficiaries" (§422.101(f)(2)(v)). Many MCOs meet the requirement to share information by obtaining a signature on the care plan by the individual and mailing the care plan to the PCP. However, the level of detail shared and the use of the information by the PCP varies. Some MCOs share the entire care plan, whereas others share only brief summaries of the care plan that focus on the medical elements requiring immediate PCP attention or a "to-do" list for the provider. Sites that share summaries instead of the full care plan explain that they do so because PCPs have limited time and are best used at the top of their license. The Medical Director of one MCO stated, "*We generate a plan, which we try and make very specific, very actionable, and very to the point, because we understand physicians are really busy, so if you send them a 12-page (care plan), they'll just gloss over and not know what to do with it. (Instead, we) generate a plan that the physician, at his highest license, should act on. …that's where we try and engage them."*

PCPs caring for individuals enrolled in MCOs acknowledged during interviews that MCOs have a wealth of information about supportive services, but they are unsure of how to use this information. One PCP stated *"I think there's just a dearth of knowledge by clinicians as to what's out there, and what's available. …We know the gaps, but it's not even worth putting them down on paper, because we don't know what to do about it. And it doesn't seem like we have the skill set or the knowledge base to deal with them. …"* The same provider also acknowledged the importance of having a care team to fill in some of these gaps: "*But, I just always know, with my (care managed) folks …the rest of their needs are going to be met, because there's someone looking at the comprehensive package. It's comforting as a clinician, because it's not my skill set."*

Sharing Information within the Care Team**.** Each care manager's communication strategy is based on the preferences, resources and the needs of the other team members. Care managers become the communication hub, sending and receiving information by e-mail, phone and occasional face-to-face communication with various providers. Care managers in the provider-based organizations have more direct access to the PCP than those in MCOs. In some MCOs, care managers occasionally attend medical appointments with the individual to communicate face-to-face and develop a relationship with the physician. Other factors influence information sharing, such as caseload and travel time: a larger case load or wider geographic area limits the ability of the care manager to have face-to-face communication with individuals and providers.

Overcoming Information Sharing Challenges. Organizations need creative solutions to address a variety of communication challenges in the communities they serve. One organization that serves a large immigrant population hires people who are familiar with the community to act as community health workers and interpreters. Another organization serves a transient population. This organization was the only one we observed using an integrated EHR system, and thus is able to connect with other organizations' electronic systems, including those in area emergency rooms and prisons, allowing the organization to find and deliver care to the individuals it serves.

3.B.6. Care Plan Integration

Despite efforts to align care and services, fragmentation and communication challenges persist. There are redundancies in conducting assessments, collecting histories and developing care plans. Care managers and providers explained that completing an assessment with the individual can build the relationship, meet regulatory requirements and verify that the individual's situation has not changed or confirm the accuracy of previous assessments. At times, miscommunication or uncertainty results in redundancies. However, redundancies provide occasional benefits; for example, repeated assessments occasionally yield additional information, particularly assessments done in a home setting rather than in a clinic setting. A geriatrician describes her work with an MCO, *"Over the years, we have duplicated efforts. And, often, we find very different outcomes in the different settings … the care managers are doing these home-based [assessments], and will get different outcomes than we get in the settings where we see people, you know, in a clinic."*

4. Phase 2

4.A. Methods

Our specific aims for Phase 2 were:

1. To understand and identify best practices for eliciting and documenting individual and family goals for care.
    a. The extent to which documented goals reflect people's words and ideas about what really matters;
    b. How people speak about and characterize the goals that matter most to them;
    c. How people describe the relationship of care and services to their goals; and
    d. How goals are negotiated among people, family/caregivers, case managers and providers.

2. To describe goals and goal achievement for people with medical and LTSS or behavioral health needs.
    a. The focus of goals and how these vary;
    b. The extent to which individual goals are captured in assessments and/or care plans and tracked over time; and
    c. Evidence of goal achievement.
3. Describe the usability of patient-reported outcome measures (PROMS) to elicit goals, provide the care manager with information about an individual's current functioning and well-being, provide a measure of progress on individual goals over time, and provide a population wide indicator of goal attainment and well-being over time. (Phase 2)

4.A.1. Site Selection

Originally, we targeted four sites for Phase 2, expecting to return to half of the eight sites visited in Phase 1. Based on findings from Phase 1, we invited two sites that systematically elicit and document goals in the care plan to participate in Phase 2 (sites 4 and 8). These sites use structured and individualized approaches to eliciting goals, and document them in care plans. On the recommendation of Stakeholder Advisory Panel members and other experts in goal elicitation, we invited two additional sites to participate in Phase 2. However, one of the invited sites withdrew from the study due to the lack of consistent documentation of goals. We were unable to secure a fourth site in the time available, leaving Phase 2 with three site visits.

4.A.2. Data Collection

Data was collected from the following sources: (Refer to Appendix A for interview guides.)

- **Paired Individual - Care Manager Interviews.** At two sites we conducted separate interviews with individuals and their care manager/care team to assess the goal setting process from both perspectives.
    - Care Manager/Care Team Interviews: A researcher conducted semi-structured interviews with care managers or care teams (2-3 people) to obtain information about 1) how they elicit, negotiate, prioritize, and document the goals of the people they serve; 2) specific experience with goals, goal-setting and goal achievement for specific individuals (see Individual Interviews below) and 3) their reactions to the Collage Lifestyle Survey and the PROMIS-29 as instruments for identifying goal targets, assessing the current status of individuals, individuals' progress toward achieving goals, and organization-wide goal attainment
    - Individual Goal Interviews. A consultant trained and experienced in goal elicitation interviewed individuals whose care managers were also interviewed and whose care plans were abstracted about 1) what matters most to them and 2) their reactions to the goals documented in their care plans. An interviewer with training in motivational interviewing and eliciting goals guided interview subjects through a discussion about what matters most to them, to elicit their goals. Later, the interviewer read the documented care plan goals and asked the individual for a reaction to those goals. This enabled a concordance analysis between the documented care plan goal and what the individual described as what matters most. These interviews also provided insight about the goal setting process at each site.

- **Paired Life Coach Interview – Observation of Goal Setting.** At one site a researcher conducted interviews with the organization life coach similar to the Care Manger/Care Team interview described above but did not pair this interview with an individual interview. Alternatively, the researcher observed goal-setting sessions with the interviewed life coach and individuals.
- **Individual PROM Interviews**. At all 3 sites we conducted interviews to elicit people's perspective on the value of a standardized quality-of-life PROM as a tool for goal setting and tracking goal achievement. Individual participants were asked to complete the PROMIS-29. After completing the PROMIS-29, the individual was interviewed about his or her perceptions of how the PROMIS-29 might be used in goal setting and measurement of progress toward goals. We asked specifically about whether the tool could provide insight into their well-being, help them identify goals in collaboration with a care manager, and measure their progress toward achieving goals or detecting change in well-being over time.
- **Documented Goals Record Review.** At all three sites we reviewed care planning records to abstract documented care plan goals. This sample included the individuals interviewed about goals (Individual Goal Interviews above) as well as indiviudals who were not interviewed. Records included a mix of older adults with and without disability, younger adults with physical or developmental disability and adults with serious and persistent mental illness. Research staff reviewed the care plans for each individual and copied the goals verbatim.

4.A.3. Analysis

Qualitative Analysis of Interviews. All interviews were recorded and transcribed, and NVIVO 9 was used for data management and analysis. A coding template based on interview questions and specific aims was created. The coding template was then systematically applied to the transcripts, allowing for open coding to capture relevant data that may have been missed in the initial template development. To establish credibility of the coding, one of two researchers coded the data using low inference codes to classify the data. A second researcher then reviewed the coding. The two researchers discussed coding results, differences and emerging categories. Exemplar quotes were selected by one researcher to illustrate the codes; accuracy of quotes as representative of codes was affirmed by the second researcher.

Classification and Quantitative Description of Care Plan and Interview Goals. Care plan goals were classified into domains using an iterative process. We used the same classification system to code the goals elicited during the interviews; two domains were added to the classification system based on the goals elicited during the interviews.

Concordance Analysis. For each of the eight individuals who participated in goal interviews, each piece of text coded as "what matters most," "important to individual" and "goal description" was entered into a table. Inductive analysis was used to group text into goals, which were briefly summarized. The goals from the individual's care plan were also entered into the table.

To analyze concordance, the investigators compared the care plan goal, individual goals and text, making three judgments that were entered into the table:

1. Were the care plan goals aligned with what mattered most to the individual or to the goals of the individual? (e.g., logically related, flowing from one to another)

2. Was the care plan goal offered spontaneously by the individual prior to the care plan goal being read?
3. Did the individual affirm or reject the care plan goal?

4.B. Phase 2 Findings

4.B.1. Sample Description

For Phase 2 we returned to 2 sites from Phase 1 that systematically elicit and document goals in the care plan (see Table 4). One site is a health home with a focus on mental health in an urban setting in New York, serving individuals across an age spectrum with chronic conditions, physical disabilities and mental health challenges (Site 4). The second is a Medicaid MCO primarily serving adults with physical disabilities (Site 8). The third site (Site 9) is a private pay continuing care retirement community in Massachusetts, primarily serving older adults. Individuals at site 4 primarily had serious and persistent mental illness, individuals at site 8 were a mix of younger and older disabled adults and individuals at site 9 were older adults.

Table 4: Phase 2 Case Study Sites

Site ID	State	Organization Type	Primary Population(s) Served	Program Focus (in addition to general medical care)	Lives Served
4	New York	Health Home	Adults all ages*	Behavioral Health & LTSS	6,500
8	Wisconsin	MCO: FIDE-SNP	Adults all ages*	Behavioral Health & LTSS	760
9	Massachusetts	CCRC	Adults 65+	LTSS	200

We conducted 8 paired care manager-individual interviews at Site 4 and 8 (7 care manager/team interviews – 8 individual goal interviews; note one care manager provided care for two individuals; see Table 5). Individuals interviewed about goal setting included a mix of adults with serious and persistent mental illness (SPMI) and physical disability (see Table 6). We additionally conducted 3 interviews with life coaches at site 9 which were paired with observation of 5 goal-setting sessions between the interviewed life coach and individuals. Finally we conducted 11 individual PROM interviews in a separate sample of individuals not connected to the care manager/team/life coaches interviewed. We additionally reviewed the records of the 8 individual goal interview participants and 34 additional individuals.

Table 5: Interview and Record Review Participants

	Care Manager/ Team/Life Coach	Individual Goal Interview*	Individual PROM Interview	Record Review Participants
Site 4	3	4	4	19**
Site 8	4	4	3	13**
Site 9	3	***	4	10

*Individual Goal Interviews were linked with Care Manger/Team/Life Coach interviews. Individuals were selected from interviewed care manager case load.

** Record review included the 4 individuals who participated in the individual goal interview

***At site 9 we observed 5 goal-setting sessions with the life coach, not an interview

Table 6: Individual Goal Interview Demographics

Site	Relevant Conditions	Age	Gender	Race/ Ethnicity	Education
8	unknown	73	F	Black	< HS
8	PD	57	F	Black	SC
8	SPMI	58	F	White	< HS
8	PD	52	M	Black	SC
4	SPMI	62	M	White	< HS
4	SPMI	30	F	White	CG
4	SPMI	23	M	Black	R
4	SPMI	48	F	White	R
Summary		*46% >65*	*70% Female*	*70% White*	*30% <HS*

Abbreviations

- SPMI: Serious and persistent mental illness
- Education: <HS: Less than high school; SC: Some college; C: College graduate; R: Refused

4.B.2. Characteristics Needed for Successfully Eliciting Goals

Four major themes about successful goal-setting emerged from the 11 care manager interviews.

- Listen and be present. All but one care manager interview included a reference to the need to listen and be present when eliciting goals from individuals. One care manager explained, *"You have to be so present in the conversation, even though you know you have to ask certain questions and want to get a certain amount of information. If you're not present, you'll lose those subtleties in what they're saying to you."* Some care managers assess the individual's needs and goals through conversation, during which they *"listen to hear the issues that [the individual is] saying or voicing without even being aware of it"* and "*listen to the client and really hone in on what's important to them."*

- Respect the Individual. Many of the care managers emphasized the need to respect the individual in goal-setting encounters. One described the critical role of respect: *"By being respectful and professional ... and relatable and approachable, so it's, those are just as important, too, as the actual work we do."* The emphasis on respect was evident when one care manager explained, *"I'm not going to dismiss the client. We never dismiss the client."*

- Trust. Most care manager interviews contained references to the need for trust in the relationship between the care manager and individual. According to one care manager, *"The skill that's really important as a coach in this goal-setting process is to be able to build a trusting relationship, even if it's not a deep relationship."* Another care manager described how asking about the individual's life *"shows that I have regard for her, that I am concerned about her well-being, also her role as a mother and not just a member."* It is important to earn individuals' trust because, *"If they can't open up to us and trust us or listen to us or take what we say seriously, it's really hard to help people."*

- Self-Reflective. Three care managers acknowledged the need to be self-reflective during goal setting. In describing her reaction to an elderly individual who, when asked about goals said, *"I just want to do what I'm doing now and I don't want to do any more than that,"* the care manager said, *"I guess I always grapple with, is that OK?"* Another said, *"So when the relationship becomes strained or it starts to shuffle the foundation, sometimes I step back and it's important to me professionally to step back to prevent my personal values from coming into play."*

4.B.3. Eliciting Goals Techniques

Care managers described a number of approaches they use to eliciting goals.

- Nudging or Pushing. All of the care manager interviews contained references to the need to nudge or push individuals in the goal-setting process. Most references described how the care manager encouraged an individual to simply set a goal or to set a more ambitious goal. For example, one care manager explained, "*So you have to, actually, kind of, help them along like, 'Oh, I see that your diabetes isn't under control. Let's make that a goal'."* When an individual is struggling with setting a goal, one care manager said, "*I help them along."* Another said, "*Some people are more willing to accept a little bit of nudging or pushing."* The assessment can be used as a jumping off point for encouraging an individual. *"I dig from the challenges or things that I've noticed in their assessment ... and then I say things like, 'You know, your blood sugars are a little high. How do you feel about those?'"*
- The Individual Is the Expert. In tension with the nudging or pushing approach is the view that the individual is the expert on his or her goals, which was referenced in every care manager interview. In some instances, care managers acknowledged individuals' expertise on personal limitations, what they want and their own interests. By emphasizing to individuals that they are the experts, care managers build a sense of individual ownership of the goal. One care manager told individuals during goal setting, *"Of course, you know yourself best,"* while another explained, *"I facilitate you in developing your goals and assist you in achieving them. So they're not my goals."*
- Incremental. All of the care managers acknowledged the incremental nature of goal setting. In some cases, they encouraged individuals to take on a goal in pieces. *"We never tell them that it's not realistic, because you never know... We go back to the small steps, and we say, 'OK, great. You know, this is what your goal is.' But, help them with, 'What do I have to do to get there? Where do I start?'"* An incremental approach was also valued as a way to encourage individuals to embrace more substantial goals. *"You know, if somebody's isolated at home, 'I don't want to do this and that and the other thing' and you don't really know him very well, or her, and the member doesn't know you very well, then you do baby steps."*
- Individualized. All but one of the care managers described how goal setting is necessarily an individualized process. One care manager said, *"I kind of customize the approach, depending on what member I have in front of me."* Another explained that an individualized approach is necessary because, *"there's no normal, OK, this is the way it goes and it's going to be smooth."* Another described the importance of being flexible in

how they approach the individual, *"I think the first thing I do is feel out their personality and once I walk in, where they're willing to meet me."* In one setting, however, some goals were standardized, although the care manager directed the interviewer to the member preference section of the care plan, noting "*they're all different, and they're specific to that member."*

- Include Family or Others. Inclusion of family in the goal-setting process was both beneficial and challenging in the three sites. One care manager summarized the balancing act: *"You're going to hit some bumps in the way where you don't really agree [with the family] maybe, but they're the people that are involved with the client so at the end of the day you have to treat it as sensitive as possible and manage it the best way you can."*

  In a residential setting where individuals suffer from dementia, a care manager said, *"I usually include the families either in that conversation, or I have a separate conversation with them to fill in the gaps. And a lot of times, the families will tell me what was important to them in the past, what were their guiding values..."* She explained further, *"So, we work with families to identify, you know, 'If your mom could say what her goal was, what do you think she'd say?'"* Another care manager in a program serving individuals in a community setting emphasized the need to include families *"because that is their support network. That's the people they see every day. They don't see us every day."*

  But in each setting, care managers provided examples of family goals that are misaligned with the individual's goals. One family wanted the individual to move to a different room in a residential setting, but the individual did not want to move. *"We had to respect her choice to not move."* In some cases, *"the family becomes too involved and almost speaks more than the member. So you don't really get to hear their voice anymore ..."* One care manager described the need to get the individual away from a dominant family member. *"Sometimes it's a conflict but you have to keep insisting that I need to speak to her, I need to speak to the client and listen to the client."*

4.B.4. Goal Setting Challenges

Goal setting challenges articulated by care managers included the following:

- A Complicated Activity and Construct. Goal setting can be challenging. Many people have never engaged in goal setting. Some people who work toward goals in life do not use the term, "goals." Other people are not goal-directed. For some the concept of goals does not resonate, particularly in health care settings. Members of one care team observed that some individuals, *"don't even understand the idea of a goal,"* explaining further, *"a lot of times people don't always think about goals,"* and *"sometimes they just run out of ideas and they don't even know where to start."* Another care manager similarly observed, *"Some people aren't very forthcoming with what they want. And some people don't even know."*
- Resistance to Goal Setting. In the interviews specifically in the CCRC, where the individuals were generally independent and had significant financial resources, some older adults were resistant to goal setting. *"I've been there, I've done that, leave me alone. I don't have any goals. I'm too old,"* was a response that a care manager described as not uncommon in that setting. Another characterized the resistance to goal setting as, *"I just want to do what I'm doing now. And I don't want to do any more than that."* An individual

joked, *"Goals. At my age?"* While some older adults were enthusiastic about goal setting, the reluctant reactions were not observed in the interviews with younger adults.

- Unrealistic Goals (See "Negotiating"). In some instances, individuals wanted to set goals that were unachievable due to external circumstances, such as the desire to move when funds were not available to support a move. One individual's goal was to continue to live with her parents, "*But the member, of course, thinks that she can live with her parents forever and ever. She doesn't have a concept that parents are aging; she doesn't know what that means, and that they develop health problems of their own and that they won't be able to physically help her out anymore at one point."* In these cases, the care managers said they would not dismiss the goal, but would instead work with the individual to identify preliminary steps. In other cases, they would reframe the goal, so an individual's goal of buying a car was shifted to getting a job to fund the purchase of a car.
- Conflicts. In addition to the family conflicts described above, other conflicts arose between the individual's goals and the goals of care managers or programs. Some individuals with serious mental illness did not want to set the goals the care managers needed them to pursue, such as continuing therapy or medications. Care managers noted that many of these individuals did not see the need to have a goal of continuing medications or therapy once their illness was under control. A care manager described the process of setting an interdisciplinary team goal, even though it was not the individual's goal, for an individual who was not addressing medical needs. *"Say we have somebody that is—and this is going to be medical, because I'm medical—that's very out of control that doesn't want to work on stuff. We still have the option to put it in their care plan as an IDT goal for them, and just say that they don't agree to it."* Organizations also addressed conflicts between individual's goals and program goals with risk agreements. A care team that viewed the individual's goals as a threat to safety or well-being could put a risk agreement in place.

  "But we can still put it in and just say that, you know, we realize that, you know, their A1C of 17 is going to kill them. But they're not willing to work on it, so here's what we're going to do. We're going to continue to call every two weeks and provide education. We're going to continue to make the referrals. We're going to continue to do this, and we're going to try to get them to understand at some point that it is important, and keep working with them to find what their trigger is to get them to—I don't want to say 'buy in,' but really it's buy-in."

4.B.5. Negotiating and Prioritizing Goals

Negotiation is a central part of eliciting and defining goals, particularly in the context of programs offering benefits to individuals. Negotiation was an important element of prioritizing goals and determining where to start.

Care managers described processes they use to fine-tune, focus, and reframe goals. The negotiation process appeared to come naturally to the care managers. One described how she would negotiate goals with an individual: *"'Oh, so you want to do this? Let's talk about the steps.' And that's where you usually catch someone to say, 'OK, so in order to run that marathon, you're going to have to do this, this, this. Are you willing to do that?' And most people would say, 'Oh, no, I couldn't do that.' You know, 'Are you willing to run every day three miles?' Because you look at the formula to get there, and they're, 'Oh, no, I couldn't.' 'So, let's look at your first goal, and let's modify it so you can do what you think you can do.'"*

Other descriptions of negotiating were offered when discussing two situations that gave rise to the need to prioritize multiple goals. In the first situation, the individual had multiple goals that would be difficult to pursue at the same time. In the second situation, the care manager and/or organization had goals for the individual, but the individual had different goals. This situation appeared to be more difficult for care managers than the process of prioritizing among an individual's goals.

- <u>Prioritizing Multiple Individual Goals.</u> Care managers expressed comfort in helping individuals to prioritize multiple goals. Two care managers focused the discussion on feasibility, with the first emphasizing what is achievable in the short-term, with the reflecting the program's six-month goal structure: *"We kind of look at what's realistic. What do you want to do within the next six months?"* The second measured feasibility in the context of desired outcomes: *"Which one is more feasible at this point? Which one is going to create less conflict and chaos in your life?"* This care manager also emphasized the individual's ownership of the goal and the long-term implications, *"At this point, this is your goal. How is it going to affect you immediately? What are your long term plans?"*
- <u>Prioritizing Care Manager/Organizational Goals and Individual Goals.</u> Tension between the need to manage health and behavioral health outcomes and respect for the individual's preferences emerged in discussions about how to prioritize the goals of the care manager and the individual.

  In some cases, care managers emphasized health goals over individual preferences. One care manager described how the team *"provide[s] guidance in the prioritizing of the goals" using as an example, "Well no, you have to look at your blood pressure and understand that this is not OK."* The care manager continued to explain, acknowledging the emphasis on health status over individual preference: *"It's our job to get them to understand that it should be a preference, and I hate to use the word, 'should,' but I mean diabetes is kind of like—it's a health danger."* Another care manager described the process of focusing goals on breaking destructive cycles for people with serious mental illness: *"The clients that we get are ... in the hospital a lot or it may be their first break. So I try to break that cycle and ... t take care of the immediate goals,"* but, *"Sometimes the client ... they don't want to hear that sometimes, but you have to try to focus. It's not always easy because ... everyone wants to do what they want to do and in their mind they think they can do it. 'I don't need this now, I can do this.' But sometimes it's not always like that."*

  This tension was evident in an interview with an individual who was served by that care manager. She had articulated two goals: to open a coffee shop and return to school. The care manager's goal was for the individual to restore her Medicaid eligibility. When asked about the care manager's goal, the individual replied, *"For me, is OK; is not important. But [care manager] said that it would be better, so if he say so, why not?"* She acknowledged that she had not told the care manager about her goal to start a business.

  Though care managers often prioritized goals addressing health and safety over individuals' goals, they described other instances where individual preferences were honored over health status. *"That reminds me of that case where that woman lived by herself and didn't take good care of herself, and didn't let her staff members in. She ended up getting very sick ... and died, because she didn't let the nurse look at her legs.... That was hard. But it was her choice. And she lived the life she wanted to live."* Acknowledging the individual's central role, another care manager said, *"You may say 'Well, this is the* *most important and this is the reason why you're coming to the hospital,' but you really have to listen to the client."*

At two sites, organizational policies influenced care plan goal prioritization. Care plan goals had to be achievable within six months, which may not have permitted care plan goals that aligned with what was most important to the individual. In the Medicaid MCO (site 8), certain goals (e.g., for preventive care) were standardized and assigned to all individuals in the program, without regard to individual's preferences. Similarly, there was some standardization in the Health Homes program: *"There are certain goals that must be achieved because they're participating in Health Homes Program, which is they must adhere to medication compliance which is necessary. They must be following up with their doctors and achieving way of life."*

4.B.6. Documenting Goals

Even though care managers involved individuals, except those with dementia, in goal-setting most did not involve the individual in the documentation process. Overwhelmingly, care managers used their own words, not the individual's, to document goals in the care plan. *"Up here [a skilled nursing facility], the way it would work is that I would have a conversation with the person and then fill out the form. So, they don't have to know about the paper ... [but] they get to have the meaningful conversation."*

At another site, the care team described the following process: *"So we really write it in the home, and then we come back, and we'll type it up, and then we'll sit down as a team of three.... We'll put it into this format, then we go back out to the house."* Another care manager emphasized the need for individuals to write down their goals in their own words, *"I really think it's important that, for me anyways, that the resident actually writes the goals themselves. They're going to more likely do it if they're the ones writing it. It's not just us talking about it and me jotting it down and handing them a piece of paper."* In the two sites where we reviewed the care plans for concordance (sites 4 and 8), the goals were in the words of the care manager, except in one case, where the individual's goal was written in quotes in the care plan.

4.B.7. Monitoring, Updating, and Identifying Barriers

Care managers described the process of monitoring goals over time. All of the organizations check in with individuals on their goals at least quarterly, with some checking as frequently as weekly. Care managers used care plans to record and track progress toward goals, eliciting information about progress in conversations with the individual, but none used a tool or formal process for tracking progress toward goals.

- <u>Updating Goals in Care Plans.</u> Care managers referenced regulations when asked about how often they are required to update care plans. Care plans were reviewed and updated at least quarterly, but plans could be updated whenever necessary. *"Like if they sign it today, and then they call tomorrow and say, 'You know what, I don't want to do that anymore. I don't want to go to the senior center, because it's winter. So can you take that off?' Then we'll revamp the care plan, and we'll take that off as an outcome for them."* Some individuals were very engaged in the updating process: *"Some members, actually it's funny, because when we go in the house, they'll have their care plans out. Like, 'I didn't do that yet.' I'm like, 'You're right; you didn't.' (laughter) You know. Or, 'I don't really like that anymore.'"*

- Barriers to Goal Attainment. When monitoring progress toward goals, barriers to goal attainment became evident, with both care managers and individuals highlighting barriers to goal attainment. Two categories of barriers were described by care managers and individuals. The first category was external barriers: loss of a family member, family interference, lack of housing options and inadequate financial resources. The second category of barriers originated in the illness: the limits imposed by physical conditions and pain. For individuals with serious mental illness, care mangers focused on a cycle where an individual is hospitalized and then stabilized with medications and therapy. The recovering individual feels better and perceives no need to maintain the treatment plan, which can start a slide back to illness and hospitalization. Individuals described some barriers to goal attainment as originating in depression and a feeling of inadequacy. One described her reaction to trying to pursue several goals at once: *"For a little while, I started doing the GED, and looking for a job, and I was doing everything at the same time, and it just became so overwhelming to me that, you know, and then when I don't see no success, or nothing is happening, you know, I feel like—I feel like I'm a failure and I just can't get anything done."*

4.B.8. Classification and Quantitative Description of Care Plan and Interview Goals

We reviewed the documented goals in care plans for 42 people (8 interviewed individuals and 34 non-interviewed individuals). We also reviewed the goals that were elicited from the 8 individuals interviewed. Figure 2 and Table 7 show the different domains found in all documented goals compared to elicited goals.

Documented Goals: The review of documented goals for 42 people yielded 124 goals; on average individuals had 3 documented goals with a range from 1–14 goals per person. Goals fell into 4 large categories (Figure 2) -- health and wellness, service/care oriented, lifestyle and independent living -- and 26 more specific domains (Table 7). Four goals could not be classified into any of the 26 domains. The most common domains of documented goals were maintaining medical appointments (43%), maintaining or obtaining housing (29%), safety in their home or community (29%), ability to complete ADL/IADL tasks, improving physical activity (21%), and financial and benefits management (21%). Goals tended to be similar within organizations. Unlike the other two sites, which provided medical care and LTSS or behavioral health care to people with complex needs, the continuing care retirement community, which focused on a more independent, older adult population, tended to have care plan goals focused on hobbies, physical activity, and volunteering. For example: "Maintaining and improving my health and fitness so I can travel and participate in outdoor activities, such as hiking." The CCRC care plans included an overall individual goal in the person's own words, the specific goals and the outcomes individuals hoped to achieve.

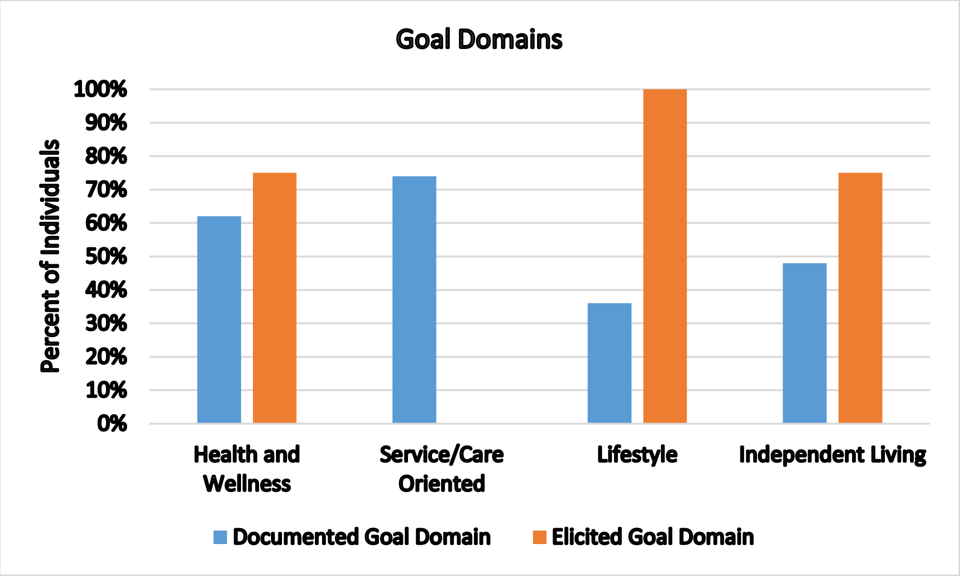
In the health home that served individuals with behavioral health needs, care plan goals often focus on maintaining appointments with medical and behavioral health providers, managing medication, obtaining housing, and financial and benefits management. For example, "Goal is to make submit request for an appeal and go to appointment to have her Medicaid case reviewed and explore spend down options." The health home goals are written by the care manager.

The special needs plan that serves adults with disability living in the community uses two template goals that are repeated in many of the care plans: "Member will be able to safely and effectively complete his ADLs/IADLs in his home and community" and "Member will maintain health with maintenance exams and preventive screens." Care plans also include more individualized goals. “Member will have decreased pain with a score of 5 or below on a scale from 0–10, for the next 6 months.” The special needs plan goals are also written by the care manager and include “member approach to meeting goal” and “interdisciplinary care team approach to meeting goal” fields. These additional fields add detail to the care plan goals that often draw a connection between the services and care provided and the overall outcome the individual hopes to achieve.

Elicited Goals: Interviews yielded 44 elicited goals for 8 individuals, an average of 6 goals per individual. Researchers classified goals into 14 of the domains identified from the record review; 2 domains were added for goals elicited in the interviews (“Religion” and “Improving relationships with family members”). Five of the 44 goals (at least 1 goal for 3 individuals) could not be classified into any domain (e.g., “make the best of circumstances”). The most common goals elicited during interviews were improving physical activity (50%), maintaining or obtaining housing (50%), spending time with family and friends (63%), improving mental health (28%), religion (38%), improving relationships with family members (38%), obtaining employment (38%) and obtaining education (38%).

No goals elicited during the interview fell into the service/care oriented category, although care managers suggested that individuals might have goals around obtaining particular services or equipment. Individual goals tended to focus on outcomes, whereas care plan goals tended to focus on services and appointments needed to achieve outcomes. It is also likely the interviewed individuals felt their care and services were sufficient and did not identify continuing those services as a goal.

Figure 2: Goal Categories



Documented Goals: Obtained from review of 42 records
Elicited Goals: Obtained from interviews with 8 individuals
Note: *Total >100% because most individuals had more than one documented or elicited goal.*

Table 7: Domains of Documented Goals in Care Plans vs. Elicited Goals From Interviews

		Percent of People with Documented Goal (N=42)	Percent of People with Elicited goal from Interview (N=8)
		%(N)	**%(N)**
Health and Wellness	*Overall*	*62% (26)*	*75% (6)*
	Generic	14% (6)	
	Physical activity	21% (9)	50% (4)
	Specific clinical markers (e.g., LDL, HbA1c)	10% (4)	
	Condition specific symptoms (e.g., allergies, UTI)	10% (4)	13% (1)
	Pain	17% (7)	13% (1)
	Weight loss	5% (2)	25% (2)
	No hospitalization/ED visits	7% (3)	15% (1)
	Mental health	14% (6)	38% (3)
Service/Care Oriented	*Overall*	*74% (31)*	*0%*
	Continue services/See providers/Attend Apts.	43% (18)	
	Education about health condition	5% (2)	
	Medication management	14% (6)	
	Transportation	7% (3)	
	Financial/benefits management	21% (9)	
Lifestyle	*Overall*	*36% (15)*	*100% (8)*
	Social activities: Volunteering	7% (3)	25% (2)
	Social activities: Hobbies	17% (7)	13% (1)
	Social activities: Family/friends	12% (5)	63% (5)
	Social activities: Travel	2% (1)	
	Social activities: Religion		38% (3)
	Improve relationships with family members		38% (3)
	Employment	2% (1)	38% (3)
	Education	2% (1)	38% (3)
Independent Living	*Overall*	*48% (20)*	*75% (6)*
	Generic	7% (3)	13% (1)
	Housing (e.g., remaining in home, finding new home)	29% (12)	50% (4)
	ADL/IADL	21% (9)	
	Reducing Falls	5% (2)	
	Safety (e.g., living safely in the community)	29% (12)	13% (1)
Other		*10% (4)*	*38% (3)*

4.B.9. Individual Level Concordance Between Documented Goal and Elicited Goal

One aim of this study was to determine whether there was concordance between the documented goal in the care plan and goals articulated by individuals during an interview designed to elicit their goals (i.e. elicited goals). For the eight individuals interviewed, we obtained 44 elicited goals and compared those goals to 39 documented goals abstracted from individual's care plan record.

Overall there was substantial alignment between documented and elicited goals (see Table 8). Eight of the 39 documented goals in the care plan were offered spontaneously by the individual during the interview. Twenty-six of the documented goals were classified by the researchers as aligned with elicited goals, that is to say the goals reflected similar domains and/or were logically related (e.g. care plan goal flowed from elicited goal). Twenty-nine of the documented goals did not match the elicited goals but were affirmed by the individual as being important to them. One documented goal in the care plan, which concerned weight loss, was rejected by an individual—though he agreed that he might lose some weight, he rejected the target amount documented in the care plan. Two affirmed documented goals were out of date.

Eighteen of the 44 elicited goals, or "what mattered most" to the individual, did not align with any documented goals in the care plan (Appendix B). Missing from the documented goals were goals related to employment, family (spending time with family and repairing or managing relationships), spirituality and education. Interviews did not explore the reason for the absence of themes from documented goals, although one individual stated that she had not shared an elicited goal with her care manager.

Table 8: Care Plan Goal Concordance with Individual Goals (sample of interviewed participants only)

Individual spontaneously offered care plan goal (N=39)		**Care plan goal (N=39) aligned with one or more individual goals**		**Care plan goals (N=39) affirmed by individual during interview as relevant (current or former)**			**Individual goal/what matters most (N=44) reflected in care plan**	
Yes	No	Yes	No	Yes	No	Unknown*	Yes	No
8	31	26	13	30	1	8	26	18

*In some cases, individuals were not asked about specific goals, in others, the individual did not answer the question.

Table 9 describes the goals found in the documented goals of the 8 interviewed individuals compared to the domains found in the elicited goals. These findings mirror those found in the analysis described above and displayed in Table 7 comparing a larger sample of documented goals to the elicited goals of the 8 interviewed individuals. Documented goals that focused on service/care oriented domains and specific clinical conditions (e.g., provider visits, lab values, avoiding specific conditions, taking medications, applying for Medicaid) were not offered spontaneously by people. When affirming care plan goals with regard to their care, a number of individuals noted that they do those things (e.g., HIV monitoring, daily glucose monitoring), but do not view them as "goals." Treatment and treatment outcomes were not considered to be most important by interviewees.

Table 9. Domains of Documented Goals in Care Plans vs. Elicited Goals From Interviews (sample of interviewed participants only)

		Percent of Interviewed Individuals with:	
		Documented Goal Domain (N=8)	**Elicited Goal Domain (N=8)**
		%(N)	**%(N)**
Health and Wellness	*Overall*	*88% (7)*	*75% (6)*
	Generic	25% (2)	
	Physical activity		50% (4)
	Specific clinical markers (e.g., LDL, HbA1c)	25% (2)	
	Condition specific symptoms (e.g., allergies, UTI)	13% (1)	13% (1)
	Pain	25% (2)	13% (1)
	Weight loss	25% (2)	25% (2)
	No hospitalization/ED visits		15% (1)
	Mental health	25% (2)	38% (3)
Service/Care Oriented	*Overall*	*88% (7)*	*0%*
	Continue services/See providers/Attend Apts.	75% (6)	
	Education about health condition		
	Medication management	25% (2)	
	Transportation		
	Financial/benefits management	38% (3)	
Lifestyle	*Overall*	*25% (2)*	*100% (8)*
	Social activities: Volunteering	13% (1)	25% (2)
	Social activities: Hobbies		13% (1)
	Social activities: Family/friends	13% (1)	63% (5)
	Social activities: Travel		
	Social activities: Religion		38% (3)
	Improve relationships with family members		38% (3)
	Employment	13% (1)	38% (3)
	Education	13% (1)	38% (3)
Independent Living	*Overall*	*75% (6)*	*75% (6)*
	Generic	13% (1)	13% (1)
	Housing (e.g., remaining in home, finding new home)	50% (4)	50% (4)
	ADL/IADL	38% (3)	
	Reducing Falls		
	Safety (e.g., living safely in the community)	38% (3)	13% (1)
Other		*13% (1)*	*38% (3)*

4.B.10. Acceptability of Quality-of-Life Instruments

As noted above, interviews with individuals were conducted after the individual had completed the PROMIS-29. Care managers reviewed the PROMIS-29 and the Collage Lifestyle Survey before responding to the interview questions.

Across the interview one theme dominated: Both care managers and individuals viewed an interactive conversation as superior to instruments.

Insight Into How the Person Is Doing. Most participants and care managers affirmed that instruments could provide insight into how the individual is doing. Both acknowledged that the responses or a score could be helpful in providing insight about their condition to themselves and their care manager. For example, one individual said her responses could alert the care manager to issues that she chose not to tell the care manager.

One care manager and two individuals who were interviewed at Site 1, the CCRC, were unenthusiastic about the ability of the PROMIS-29 instrument to be useful to individuals or care managers. One individual described the form as *"too superficial."* Another said, *"It didn't tell me anything new about what I already know."* Although a care manager acknowledged that responses to some questions could be useful, she said, *"I don't like this tool at all for [a skilled nursing unit]"* explaining that too many of the questions were irrelevant in the lives of the people in that unit.

Identifying Goal-Setting Targets. When asked whether instruments could help to identify goal-setting targets, most care managers and a majority of individuals agreed that that instruments could be useful for that purpose. Care managers focused on the benefit that instruments may bring to their attention individuals' concerns they were unaware of; individuals agreed with the concept when asked, but they did not explain their responses. The same two individuals at Site 1 who did not think the instruments could provide information about how people are doing also saw no value in using the instruments to identify targets for goal setting.

Identifying Goal Setting Targets. Most individuals and care managers affirmed the value of using instruments to track progress toward goals over time. One individual explained, *"I would want to see if I'm progressing or not."* Another described how the care manager could use the information, *"maybe in six months if you gave me another questionnaire, and it got better or worse, it would be in there, and she would see that, and maybe be able to, you know, help me."* Two individuals were skeptical about this use for instruments. One said, *"I don't know if I'd go to a survey for that."* The other said, *"I don't think that's the direct way to go about it."*

A care manager emphasized the value of tracking change over time as the basis for a conversation. *"You could say your score last year was this, your score this year is this and the sections that we've noticed your biggest changes are here and could open up some good conversation."* Another focused on the value of tracking as a way to prompt consideration about what is happening with the individual. *"I think a standardized tool like this would actually be very useful in that, because you're asking the same exact questions the same exact way, and if the answer's different, then there's a change. What's happening? Is this a positive change, or a not positive change?"* Two care managers said that using PROMs for measurement could help prove the success of their interventions.

Care managers voiced some concerns about comparing two numbers. One pointed out that, while there is value to documenting progress, when there is not progress, *"then are you making* *the resident feel even worse about themselves by saying, you know, ‘you actually didn’t improve and you put all this effort in and you tried.’”* Another cited a limitation of comparing two numbers without context and background: *“You can’t just go by the number because you don’t know what’s going on.”*

<u>Measuring Progress Toward Goals Across the Population.</u> Care managers were asked about whether instruments could be used to measure progress toward goals across their organizations. Four of the five who responded to the question supported this use, but they said little to explain their answers. One care manager expressed uncertainty. *“I don’t know. Tentatively—well, if half the building is depressed it might be a good question to find out like why, what’s going on. It might be too individualized to ... for these kind of forms here for that. I’m not sure.”*

<u>Relevance of the Instruments.</u> Relevance was a theme that occurred in the context of several questions. Those who affirmed the efficacy of instruments across different uses did not explicitly assert their relevance, but those who questioned efficacy did question the relevance of the instruments. One care manager, referring to the Lifestyle survey, commented as she read survey questions: *“‘Do you do Sudoku? Do you do crossword puzzles? Do you like bird watching? Do you like genealogy?’ In some ways, who cares? I don’t care.”* Another said *“‘Are you interested in acupuncture? Aromatherapy?’ I mean, nobody here is interested in that.”* When asked about the relevance of questions about sleep, anxiety, or the ability to run, walk, or dance, one individual replied, *“No, no, no, no, no. That’s not applicable to me.”* Another said the questions were not helpful, *“Because my thinking goes beyond in each of these categories. It’s too superficial.”*

<u>Missing Domains in the Instruments.</u> Individuals and care managers were asked if there were domains that were not addressed in the PROMIS-29 that should be addressed in the context of integrated care settings. Recommended topics and areas are shown in Table 10.

Table 10: Recommended Additions to PROMIS-29

Relationships
Available support
Financial Stability
Ability to do errands without assistance
Aspirations/life goals
Source of happiness
Interests
Substance use (alcohol, tobacco, marijuana)
Benefits
Education
Language and culture
Receiving regular medical care
Living environment
Stress
Spirituality
Autonomy and choice

In addition to topics, participants made additional suggestions. One recommended that individuals should be able to rate the importance of each question: *"Maybe they're scoring low because they could care less about that and they're scoring higher on something else because that's what they've been focusing on, so it could be an interesting component to add."* Several perceived a negative tone, including one who said *"it's not exactly strength-based."* One offered the following alternative: "*'What are you happy about? What's sparking your interest these days?' So that you can capture the good stuff as well as the not-so-good stuff."*

Level of Difficulty of Instruments. All participants were asked about the level of difficulty of the PROMIS-29; care managers were also asked about the Collage Lifestyle Survey. Overall, participants viewed the PROMIS-29 as being an instrument that individuals could answer. Some individuals expressed a dislike of questionnaires that use Likert scales. Care managers noted that individuals with impaired cognitive function might have difficulty completing the written form. A number of participants who critiqued the difficulty level attributed difficulty to the lack of relevance.

Duplication and Survey Burden. Although some suggested that the PROMIS-29 or Lifestyle survey could fill a gap, a number of care managers (even those who saw value in quality-of-life tools) felt than an additional instrument would result in duplicate information and effort.

5. Summary

5.A. Phase 1 Summary

Promising Practices in Goal-Oriented Integrated Care: Across the eight sites in Phase 1, we observed a strong commitment to supporting individuals' independence. Some specific promising practices observed were:

- Each site uses in-home assessments to understand the individual's situation and identify the supports and services necessary to help the individual live as independently as possible.
- Sites engage both social and medical disciplines in care planning, often pairing a nurse and social worker to conduct assessments and develop care plans.
- Care managers value their relationships with the individuals they served and often have skill sets that matched the needs of the individual they served (e.g. pairing a behavioral health care manager with individuals who have serious and persistent mental illness).
- Although information technology barriers hinder communication, sites use creative approaches to engage individuals, providers and the community such as having care managers attend medical appointments with individuals and using interpreters in the community to community health workers. The one sites that uses an integrated EHR system connects its electronic care management system to external community systems, including local emergency departments and the prison system.

Remaining Gaps in Integrated Care: Our Phase 1 findings highlight several important gaps.

- Assessments tend to focus on an individuals' medical and services needs but paid little attention to their goals and priorities. Similarly, care plan reflect program priorities, but not always individuals' priorities.
- Most organizations lack of effective technological solutions for communicating within the team and between the team and individuals served. Full care plans are too often not

accessible to other providers and individuals. Often care managers summarize care plans into a succinct summary and/or “to-do” list for PCPs and other providers. This practice can promote efficiencies by focusing busy physicians’ attention on immediate needs or on most urgent problems that only medical doctors can address. However, this may cause one party to not understand how the other could use the additional information to inform their decisions.

- The redundancy in assessment and care planning efforts, and lack of a shared care plan, may result in different goals of care. The multiple assessments and care plans often reflect the different skills, responsibilities and biases of those conducting the assessments. While the MCO may develop a comprehensive care plan, individual providers may also develop plans of care whose goals may or may not match those of the comprehensive care plan. Care team members risk working at cross-purposes, each aiming to achieve different goals, at best creating inefficiency and at worst, potential harm. The vision of a comprehensive, shared care plan guiding care across providers and settings is still be largely aspirational, and there are regulatory and operational challenges to engaging care team members efficiently and in a way that capitalizes on each member’s unique expertise. Yet, the potential to deliver accountable, person-centered care that respects and addresses individual needs, preferences and goals depends on realization of this vision.

5.B. Phase 2 Summary

Characteristics Needed for Successfully Eliciting Goals: Across the three sites included in Phase 2, four major themes emerged related to successful goal-setting encounters: (1) Goal setting is a conversation, (2) Listen and be present, (3) Respect the individual, and (4) Trust between the individual and care manager. Successful approaches to eliciting goals were sometimes conflicting. Some care managers stressed the importance of nudging or pushing the individual to set more ambitious goals, while others noted the importance of trusting the individual as an expert in their own goal setting. Other successful approaches included using incremental goal setting, individualizing the goal setting process and including the family or others were appropriate.

Goal Setting Challenges: Care managers also described goal-setting challenges, including individual who may have difficulty or disinterest in setting goals or set unambitious goals for themselves. Other challenges included the tension between individual goals and the goals that families may want to set or the care managers or program’s goals for the individual.

Goal Domains: Documented goals tended to fall into four broad categories -- health and wellness, service/care oriented, lifestyle and independent living. In contrast elicited goals fell into only three of the above categories (health and wellness, lifestyle and independent living. We found that 74% of individuals had a documented care plan goal focused on provision of services and care whereas no individuals identified goals related to obtaining or maintaining a particular services or care management. Goals elicited from individuals tended to focus more on lifestyle, with 100% of interviewed individuals identifying a lifestyle goal, but only 36% of individual care plans included a documented goal related to lifestyle.

Concordance between Documented and Elicited Goals: Goals elicited from individuals in interviews were generally aligned with the documented goals found in their care plans. Although individuals did not use the same words to describe their goals and often identified goals beyond those in the care plan, individuals affirmed the importance of all most all documented care plan goals to their overall life goals. Documented goals tended to reflect domains like obtaining and maintaining services, medication management and maintaining appointments with health providers that individuals affirmed as important to helping them achieve their lifestyle goals. Only once did an individual reject a portion of a care plan goal, and two thirds of the care plan goals were aligned with, if not identical to, what matters to the individual or individual goals.

Usability of Quality of Life PROMs: Care managers endorsed use of quality-of-life PROMs to identify areas of concern that might not otherwise emerge in conversation, to measure an individual's progress toward goals, and to measure population-wide goal attainment. Individuals were less enthusiastic about using PROMs for goal setting, with older adults more negative about their use than younger adults. However, individuals were more receptive to the idea of using PROMs to track progress over time.

6. Conclusion

Our aim for this project was to understand the current state of practice and identify promising approaches for providing goal-oriented, integrated care. Some organizations elicit and document goals that are substantially concordant with those identified by individuals as most important; other organizations do not use a person-centered approach to goal-oriented care planning. Given the varying interpretations of "integrated" care, how care teams are defined, how information is shared among care team members and how care plan goals are developed and documented, there is a clear need for quality standards and performance measures. Quality standards could help organizations implement practices and systems that support effective, timely, interdisciplinary collaboration in the delivery of care and services that address individuals' priorities.

There is also a need for performance measures that can assess how well organizations help people achieve the outcomes that matter most to them; however, we must balance the need for structure, from a quality measurement perspective, with the need for individualized of outcomes from an individual and provider perspective. Additional research is necessary to develop approaches for identifying, documenting and measuring the outcomes individuals identify as most important that can be used for both individual care plan development and organization-level quality measurement.

Integrated care is an emerging system. Research will be needed to identify ways to decrease redundancy in assessments; to include the goals of the individual in care plans; to improve communication within interdisciplinary teams and with the individual; and to share care plans among care managers, other team members, and individuals. One specific area that would benefit from further study is the effect of the filtering that occurs when care managers provide limited information to PCPs. These current barriers to integrated care need to be overcome if the vision of truly integrated care is to be achieved.

The creation of standards for assessment, care planning and care plans, and communication of assessments and care plans would provide guidance to integrated care delivery organizations within this still developing care delivery framework.

Our concordance analysis demonstrated that, although documented care plan goals do not match the goals expressed by individuals word-for-word, both individuals and care managers agree that documented goals reflect or address many of the individuals' priorities. Goals tend to identify outcomes that are important to individuals, whereas care plan goals tend to focus on services and appointments needed to achieve outcomes.

Quality-of-life PROMs were not promising for goal-setting, but have potential for targeted use in evaluating outcomes related to patient goals. More research is necessary to identify the best approach for integrating outcome measurement into a goal setting and monitoring process to ensure that an approach is relevant to individuals and not overly burdensome for care managers

Appendix A. Interview Guides

***Phase** 1: Organization Leaders and Staff Interview Guide*

Participants: Organization Leaders, Quality Oversight, Data Management Staff

Objectives: By the end of this conversation, we want to understand:

- how you help to integrate a person's medical, behavioral, social and functional needs across providers and settings;
- how the patient/members needs are assessed, goals set and care plans developed;
- how changes in condition are addressed and how information about the event and changing needs are shared; and
- your thoughts on measurement related to patient/member goals.

1. What benefits/services are covered by the health plan? What is carved out?
2. What does your organization do to facilitate the integration of all of a person's needs (medical, behavioral, social, functional) across providers and settings?

   Probe as Necessary:

   a. How does your organization conduct assessments and develop care plans for different types of individuals *(e.g. different risk groups, different age groups, different for individuals with behavioral health needs)*?
      i) How are the assessment and care/service plan documented?
      ii) How care/service plan is integrated with authorization process?
   b. Disciplines of care managers/case managers.
   c. Case load for care managers
   d. How are care teams formed? How do they interact and collaborate?
   e. Can you tell us about how information from the assessment is documented, stored and shared with other providers? Walk us through the process from start to finish.
   f. How is this process integrated with the assessment conducted by state or county as part of an eligibility or level of care determination?
   g. Do you have high-volume PCPs that see many of your patients? If so, who in the PCP office do you communicate and coordinate most closely with? Do you have other types of high-volume providers?
3. SPECIFIC to data management staff: Who has access to different parts of the EHR/EMR if one exists?
4. What is your organization doing to support goal setting among individuals/patients?

   Probe as Necessary:

   a. Staff/provider training in eliciting goals
   b. Documentation of goals
   c. Sharing goals with other providers
   d. How does your organization track individuals' progress on achieving goals?
5. What is the organization's role in monitoring individuals between assessments and making sure providers have information about status between assessments?

Probe as Necessary:

  a. Information flow between providers
  b. Information flow from organization to providers

6. We are particularly interested in how your organization identifies and responds to significant changes in condition or major changes in an individual's situation that could require a change in the care plan.

   For each of the events below can you tell me about:

   a. How you know if the event/change in condition has occurred?
   b. How do you respond to the event?

      Events:
      i. Loss of caregiver
      ii. Hospitalization
      iii. ED visit
      iv. Loss of housing or change in housing
      v. Substantial change in functional status
      vi. Loss of significant provider

7. What are barriers to your being able to support integrated care, goal setting, monitoring individuals, or responding to significant changes in condition?
8. How does your organization measure the impact of its efforts supporting integrated care?

   Probe as Necessary:
   a. Quality measures
   b. Monitoring goal attainment
   c. Monitoring provider care team performance
   d. How is the information fed back to the providers and individuals/patients
   e. If there are providers or care teams not meeting organizational or performance goals, how do you handle that?
   f. Does your organization offer any training to providers or staff on collaborative team-based care? Please describe the training.

9. Quality measures have long been used to evaluate hospitals and health plans in delivering evidence-based care to patients. Examples include % of diabetics whose HbA1c is under control. What type of measures would be useful to understand how organizations like yours are doing at providing integrated, person-centered care for people with complex needs?
10. What do you think about a measure or set of measures based on (beneficiaries'/patients'/clients'/members') progress towards achieving their self-defined goals?
11. What sort of change, if any, would be required in your organization to make this type of measurement feasible? For example, implementing a system for tracking goals.

Appendix A. Interview Guides

***Phase** 1: Provider Interview Guide*

<u>Participants</u>: Primary care, personal care/support, care coordinators, case management, behavioral health, specialty care, therapy, vocational therapy

Screening Question:
How would you describe your role in the assessment and care planning process?

Section 1A:
- a. Primary responsibility for assessment and care planning
- b. Part of a team that is responsible for assessment and care planning

Section 1B:
- c. Provide input, but not responsible
- d. Have access to assessment and care plan information, but do not contribute
- e. No role

<u>Objectives</u>: By the end of this conversation, we want to understand:
- how the assessment process works;
- how goals are set;
- how the care plan is developed; and
- how information is shared across providers, payers and other appropriate parties.

Section 1A: Role in Assessment and Care Planning Process
*Providers **<u>directly</u>** responsible for conducting assessment or developing care plan with recipient

1. How do you identify what kinds of services your (beneficiary/patient/client/member) population needs? For example, do you use an assessment tool? Tell me about the process from start to finish.

   Probe as necessary:
   - a. Provider’s role in assessment
   - b. Other providers' roles in assessment
   - c. Information shared with other providers. Who do you typically share information with? Do you communicate with the PCP directly, or with a care manager?
   - d. Additional assessments conducted by other providers/organizations: People/patients may receive several assessments from other providers or from the county or state. Are you aware of these assessments and do you try to integrate them into your assessment? If yes, how?
2. How do you develop a plan of care and services to address assessed needs? For example, do you work with the (beneficiary/patient/client/member) to develop a care or service plan? Do you work with other providers? Tell me about the process from start to finish. ***Only necessary if not addressed in previous question on assessment.**

   Probe as necessary:
   - a. Provider’s role in care planning
   - b. Provider’s role in delivering care/services in plan
   - c. Other providers’ roles in care planning
   - d. Information shared with other providers. Who do you typically share information with? Do you communicate with the PCP directly, or with a care manager?
   - e. Additional care plans developed by other providers/organizations
3. Do you talk to (beneficiary/patient/client/member)s about their goals? Tell me about that process? ***Only necessary if not addressed in previous questions on care planning or assessment.**

   Probe as necessary:
   - a. How provider elicits/negotiates goals
   - b. Documenting goals

   c. How information about goals is shared with other providers
   d. Tracking progress on goals

4. What do you think is the most valuable aspect of the assessment and care planning process?
5. Please tell me about some of the barriers you face in the care planning and assessment process.

   Probe as necessary:

   a. Collaborating with other providers
   b. Engaging the (beneficiary/patient/client/member)
   c. Engaging other providers
   d. Developing the care plan
   e. Sharing or receiving the information
   f. If there are multiple assessments or care plans, what are the challenges integrating the assessment and care plans into a single plan.

Section 1B: Role in Assessment and Care Planning Process
*Providers ***not* directly** responsible for conducting assessment or developing care plan with recipient

1. How is [use term that org uses for assessment] and [use term that org uses for care planning] done in [name of organization]?
   Probe as necessary:
   a. Provider's role, if any, in organization's assessment/care planning
   b. Do you do or are you aware of additional assessments or care planning?
2. Is this information from the organization's assessment and care planning shared with you? How is it shared? How do you use the information?
   Probe as necessary:
   a. Information that is most helpful
   b. Information that is not received but would be helpful
   c. Information that is not read or used
3. Are you aware of (beneficiary/patient/client/member) goals in the care plan? Tell me more about how you get and use that information. ***Only ask if not addressed in previous question.**
   Probe as necessary:
   a. Talking to patient about goals and progress on goals

Section 2. Information sharing (All providers)

1. Next we'd like to know more about how you receive and share information with other members of the care team about the (beneficiary/patient/client/member)? Can you tell me about that?

   Probe as necessary:

   a. What types of information are you receiving?
   b. What types of information do you share? Who do you typically share information with? Do you communicate with the PCP directly, or with a care manager?
   c. How information is received/looked-up/requested/automatically sent to you
   d. How you send information (phone, fax, portal, direct secure messaging, other)
   e. How information is shared with (beneficiary/patient/client/member)
2. We are particularly interested in how you find out about and respond to significant changes in (beneficiary/patient/client/member) condition or situation that could require a change in the care plan. Describe the process of identifying and responding to such changes when it works well?
   a. For each of the events below can you tell me about:
      i. How do you find out if an event has occurred?
      ii. What is the process to respond to the event?

iii. How is information about the event and any subsequent changes to the care plan shared with you?
iv. How do you share information about changes to the care plan with other providers?
v. Events:
    1. Loss of caregiver
    2. Hospitalization
    3. ED visit
    4. Loss of housing or change in housing
    5. Substantial change in functional status
    6. Substantial change in care or service provider

Appendix A. Interview Guides

***Phase** 2: Provider Interview Guide (Goals & QoL)*

Linked Care Manager/Recipient Identifier: ______________________

General Process Questions:

1) What works best for eliciting goals from different clients?

   Probe as necessary:
   a. Do you have any tools or templates that you use to help you elicit or document goals?

2) How do you have to modify your approach with different people?

3) What are some of the most frequent challenges you encounter in addressing peoples' goals, and how do you overcome them? If not addressed, ask: How do you handle it when:

   a. The individual's goals are not achievable in your opinion (within their current resources or abilities).
   b. There are conflicts between individual and their family
   c. There are conflicts between the individual's goals and best clinical practice for managing their health
   d. Trade-offs are needed (e.g. longevity, symptom management, functional capability or quality of life)
   e. There are multiple goals, which can't all be addressed at once
   f. The individual's goals are outside the scope of the organization's control (e.g. require support or resources the organization is not responsible for).
   g. There are other barriers to eliciting goals?

Patient Specific Questions:

4) **Share [Patient's Care Plan].** Can you describe the goals that [Patient's Name]'s is working on? How important do you think these goals are to [Patient's name]?

   Probe as necessary:
   a. How engaged do you think [Patient's name] is with these goals? Why do you think so?

   b. What goals do you think are most important to [Patient's name]?

   c. Whose words are reflected in the care plan?)

5) How did you and [insert patient's name] decide on the goal(s) that is documented here? Please describe the process of eliciting and negotiating the goals from start to finish. Probe as necessary on any potential challenges (per 4 a-g).

6) We just interviewed [Patient Name], and she/he told us what was most important to her/him was [Goal from Interview]. What are your thoughts about the relationship between what [Patient Name] told us was most important and the goals documented in the care plan?

   (1) **If related** or a part of, can you describe how it relates, how will meeting the goal in the [care plan] get [Patient Name] closer to achieving [Goal from Interview]?

(2) **If different/unrelated**: Knowing [Patient name], what do you think might account for the differences?

Probe as necessary:

a. Do [Patient Name]'s goals and preferences change often, or might they have they changed since you discussed [care plan] with her/him?
b. Were the discussions used elicit goals focused differently?
c. Are you expected to document goals in a certain way?

Section 2: Quality of Life Tools

One of the areas we are interested in is how standardized measures of quality of life could be used in the care planning process. I'd like to show you a few examples of standardized quality of life measures that have been used in research and evaluation to understand how well people are doing.

1) How well do you think tools like these would work at capturing how well your [recipient] population is doing?

    Probe as necessary:

    a. What additional topics or areas do you think are important to include in this tool?

2) How hard to you think it would be for the individuals you care for to fill out this questionnaire? Why? Do you think a family member or close friend could help someone fill it out if they had difficulty?

3) If the people you cared for filled this out as part of their assessment, how do you think you could use the information gathered from this tool?

4) These tools are designed so you can calculate a "score" based on people's responses and compare an individual's quality of life "score" to other people or to their own scores over time. How might you use information on how someone's quality of life changed over time or compared to other people?

5) I'd like to share a potential use for the tool, and get your reaction to it. A tool like this could help individuals identify the most important areas that they feel impact their quality of life. These are areas where they would like to either improve or maintain their status in order to have the best possible quality of life. For example, an individual could fill out the questionnaire and then identify "satisfaction with social activities" as an area that is very important to them that they would like to improve. You could work with the individual to set a goal for how much improvement, over what time frame you might expect to see improvement, and what you and the individual can do to help achieve this goal. In six months you could come back and see whether the individual achieved the goal by using the same questions to see if the individual is more "satisfied with social activities."

    What do you think about this example? Do you think this would be valuable for the recipient? Why or why not?
    Probe as necessary:

    a. Do you think using the tool this way could help you develop a care plan for the individual? Why or why not?
    b. If this tool was used in the way I just described, an organization like yours could track how many people were improving or maintaining their quality of life and achieving their goals. How do you think your organization could use this information?
    c. Do you think the percentage of individuals who meet or make progress towards their goals would be a good measure of how well an organization is serving individuals? Why/why not?

Section 3: Tracking Success (Optional, if time permits)

1) I'd like to talk now about how you currently track "success." In other words, how do you know things are on track for [insert patient's name]?

   Probe as necessary:
   a) When was the last time you checked in with [insert patient's name] about his/her progress in meeting his/her goals?
   b) How often to you usually assess progress?
   c) Is this a formal process? How do you do this?
   d) How do you document progress?

Appendix A. Interview Guides

***Phase** 2: Recipient Interview Guide (Goals)*

Linked Care Manager/Recipient Identifier: _____________________

We are doing research about how [organization] provides care, services and support. Before we talk about what [organization] does for you, I'd like to learn a bit about what is important to you in your life and health and find out more about your health and wellness.

1) I would like to hear a little bit about who you are and what your everyday life is like. So tell me a little bit about yourself…

   Probe as necessary:
   For example: Are you married, single, have children; where did you grow up? Did you work?

2) What would you say are some things that are very important to you in your life now?

Note to interviewer: Reflect individual's responses back, and prompt for agreement or correction.

3) So, I heard you say that xxx matters most to you. Does this sound right?
   a) If yes, great.
   b) If not, what other things really matter to you that I didn't hear you say?

4) What does it mean to you, to say you're "doing well?" When in did you last feel this way?

5) Is there anything in your life you'd like to change, that could help you get closer to doing well? In terms of your health, socially, or in other ways?

6) I am interested if you have any goals for either your life or health? Can you describe what you'd like to accomplish in the next 3-4 months?
   Probe as necessary:
   a) Are there things going well in your life or with your health that you want to make sure continue?
   b) Do you have any new or recent problems that you would like to solve? Medical problems? Social concerns?
   c) For example, I heard you say (reference response to Q5 or other dissatisfaction individual expressed). Is this something you would be interested in trying to improve?

7) Have you made progress in the past year on any of these things? Describe what you have accomplished to me. What helped you?

   Probe as necessary:
   a) Support services?
   b) Medical care?
   c) Support from family/friends/community
   d) Behavioral health care/counseling?
   e) Other important people?
   f) Financial resources?

Concordance

Note to interviewer: Identify from first half of interview what the individual identifies as "most important to them." This will become the "interview identified goal" referenced throughout the rest of the interview.

8) Ok, now I'd like to talk about the goals that are listed in your [term used by organization to describe care or services plan] that you and [insert name of interviewed provider] developed
    a) How long ago did you last talk with [Name of interviewed provider] about your goals? Let's look at the goals that are written here.
    b) [Read goals]. Which of these goals are related to [interview identified goal]? Can you describe how they are related?

Note to interviewer: Use first goal identified by recipient as "selected care plan goal" throughout rest of interview"

If recipient identifies a care plan goal as "related" to interview identified goal.

c) Tell me more about how you think [selected care plan goal] is related to [interview identified goal] we were just talking about.
d) How will meeting the [selected care plan goal] get you closer to achieving [interview identified goal]?
e) Can you explain how you came to [selected care plan goal]? Did [care manager] ask you questions like we just asked you?
f) How important to you is [selected care plan goal]?
g) What about the other goals in your care plan, how are these goals related to [interview identified goal]?

If recipient cannot identify a care plan goal as "related" to interview identified goal.
Select a care plan goal that appears to be related to the interview identified goal, and probe: What about [selected care plan goal]? Could this be related to [interview identified goal]?

h) Ok, so you don't think any of these goals are related to [interview identified goal], are any of these goals important to you? Tell me about why they are important (or unimportant to you).
i) How did these goals become part of your [name of care plan]?
j) Has what is important to you changed since you discussed [name of care plan] with [care manager]? How so?

Review of Consent to Provider Interview

Note to interviewer: Reserve time to ask this question last.

We have talked about what is most important to you, and how well your care plan reflects what is most important to you. We are scheduled to talk with [care manager] about how well [care manager] understands what matters most to you. We will also ask about how she/he uses this information to plan for your care and services. Is it still ok with you if we tell [care manager] what you told us was most important to you?

Note to interviewer: If recipient says no, ask:
Ok, that's fine. We won't share what you told us. Is it still ok if we talk with [care manager] about how she/he understands your goals, and how the goals in your care plan were decided on?

Additional questions, only if time permits:

9) I can see here that you set this goal [x months/days] ago. Do you think you've made any progress towards this goal? ***Ask only if goal in record is different from goal identified at beginning of interview**

    Probe as necessary:
    a) Has your goal changed at all? Maybe scaled back or made your goal bigger?
    b) Does anyone ever ask you about how you feel about your progress on your goal?
    c) [if progress is documented in record] It says here that you've make [x] progress on your goal. Do you think this is accurate?

10) Do you ever talk with your other providers about your goals? [List providers]. Who in the care team besides [provider name] seems to be most interested in your goals?

    Probe as necessary:

    a) How often did you and that provider talk about your goals?
    b) Does [name of care manager] ask you about progress you are making on your goals?

11) Do you think your [term used by organization to describe care or services plan] is designed to help you achieve your goals? Can you tell me more about how your care plan has helped or hindered you from achieving your goals?

    Probe as necessary:

    a) Examples of when care/services were delivered that helped you meet your goals.
    b) Examples where care/services were not helping you meet your goals.
    c) Examples of care/services needed to meet goals, but not received

Appendix A. Interview Guides

***Phase** 2: Recipient Quality of Life Questionnaire Interview Guide*

Introduction.

Note to interviewer: Hand the Quality of Life Questionnaire to the recipient, and ask the individual to complete it, explaining that you will discuss the questionnaire after it has been completed. If the individual has difficulty reading or writing, you may read the questions and response options aloud, and mark the individual's responses.

Section 1: Individual context.

Objective: To understand the type of care and services being provided to the individual and the person/team the person works with the most to determine what care and services will be provided.

1) Tell me a little about what [insert name of organization] does to help you?
2) Is there one person or team of people you work with the most frequently? When did you talk with him/her/them last? (*Identify name of care manager and use throughout rest of interview*)

Section 2: Quality of Life Questionnaire

Objective: To understand whether the quality of life questionnaire is meaningful to individuals, what additional domains they would want to see reflected, and how they would like to see the questionnaire used.

The form you completed at the start of this interview includes questions about how your health and symptoms affect your ability to do things in your daily life.

3) Do you think your answers to the questionnaire you just filled out could help [care manager] understand how you are doing in your daily life?

   Probe as necessary:

   a) Why or why not?
   b) What other information do you feel would help [care manager] understand how well you are doing?
   c) What would you change about these questions? How did you feel about filling out the form? (*Probe on whether questionnaire is too long, confusing or difficult to answer*)

4) Let's pretend [care manager] asked you to answer these questions to help him/her understand what about your care and services is working. Your answers to the questionnaire can be used to find out how you are doing over time. Would you like to be able to talk to your doctor [or care manager] more about your answers to the questions?

   a) If yes: What would you most like to talk about or most want to know about your answers on the questionnaire? (*Probe on whether people would want their doctor to explain the assessment, present a score from the assessment, or just talk more generally about the results.)*
   b) If no: Why not?

5) By answering the questionnaire, do you think it helped you identify something you could improve about your health or how you're doing in your life?

Section 3: Vignette

Objective: To elicit reactions to vignette focused on goal setting with quality of life questionnaire. Select the vignette and accompanying goals that are most relevant to the individual being interviewed (elderly, younger with disability, mental illness)

I will be sharing a situation with you that is an example of how an individual and their care manager might work together to establish and meet goals. As you respond to this example, I'd like to understand how YOU would want this situation to go and how you would feel during the process. Basically, I need you to pretend that you are the person in this situation.

Elderly Vignette: Mary is a 70-year-old woman with multiple health problems that make it difficult for her to do the things that she wants. She is often short of breath, has some pain in her hands from arthritis, and usually gets hospitalized two or three times each year. Mary doesn't like being in the hospital and wants to avoid being hospitalized again, but it's hard. After her last hospitalization, she had to move in with her daughter and son-in-law. Their house is in a different neighborhood that's farther away from her friends and church. She worries that she'll get lost if she tries to go for walks by herself. Mary also had to leave behind her garden where she used to do a lot of work and the pain in her hands makes her think she wouldn't be able to start a new one. Mary has an appointment coming up and decides to ask her care manager about her worries.

At the visit, Mary fills out a form like the one you just filled out asking about her health and how her health affects her life. Mary answers the questions, and it gets her thinking more about her health and the things she wants to do in her life. Based on Mary's answers to the questions, Mary's care manager notices that Mary is having difficulty doing the types of things she most wants to do, like visiting friends, working with her church or gardening. After they talk about the results of the questions, Mary's care manager asks her if she wants to work together to set a goal toward feeling better that they can check up on during her next visit. For example, she may want to set a goal of having less pain in her hands or being able to do more of the activities she wants.

Younger Disabled Vignette: Mary is a 36-year-old woman who uses a wheelchair and has multiple health problems that make it difficult for her to do all the things she enjoys. Mary recently moved to a more accessible home, where she's able to complete many tasks on her own. She receives some supportive services such as assistance with meal prep and showers and has someone coming in weekly to clean. Unfortunately, the place she is living in now is in a different neighborhood that's farther away from her family, friends and work. Friends visit occasionally, but not as frequently as Mary would like. Her sister visits every weekend to see how she's doing and also helps with grocery shopping. Mary is able to use a van service to get to and from her worksite, but this service is not available in the evening. As a result, she has difficulty getting around the community once she gets home from work. Mary is an avid sports fan and would like to be able to attend local sports games. She is starting to feel isolated and would like to get out more, but she is unsure how. She has an appointment coming up and decides to talk to her care manager about her worries.

At the visit, Mary fills out a form like the one you just filled out asking about her health and how her health affects her life. Mary answers the questions, and it gets her thinking more about her health and the things she wants to do. Based on Mary's answers to the questions, her care manager notices that Mary is having difficulty doing the types of things she wants, like visiting friends or attending sporting events. After they talk about the results of the questions, Mary's care manager asks her if she wants to work together to set goals to help her do more of the things that are important to her; goals that they can check up on during her next visit. For example, she may want to set a goal of connecting with friends or getting out more.

Mental Illness Vignette: Mary is a 40-year-old woman with bipolar disorder and other health problems that make it difficult for her to do the things she enjoys. She was recently hospitalized for her bipolar condition and cannot go back to living on her own until she is able to consistently follow her doctor's orders, including using prescribed medications. She has temporarily moved into a group home. The group home is in a different neighborhood that's farther away from her friends and church, and she worries that she'll get lost if she tries to go for walks by herself. She also lost her job after her hospitalization and would like to find a new job. She wants to get back to living on her own. She's worried about money, but is also worried that she won't get along with people at a new job. Mary has an appointment coming up and decides to talk to her care manager about her worries.

At the visit, Mary fills out a form like the one you just filled out asking about her health and how her health affects her life. Mary answers the questions, and it gets her thinking more about her health and the things she wants to do in her life. Based on Mary's answers to the questions, Mary's care manager notices that Mary is having difficulty doing the types of things that are important to her like working and getting out on her own. After they talk about the results of the questions, Mary's care manager asks her if she wants to work together to set goals to help her do more of the things that are important to her; goals that they can check up on during her next visit. For example, she may want to set a goal of finding a place to work where she feels comfortable, or following a system to make it easier for her to take medications on her own.

6) If you were Mary, how would you like to set goals with your care manager?
    a) How involved would you like [care manager] to be in helping you choose a goal?
    b) What would the goal look like?

Now, I will show you a few example goals that other people have set:

- Feel less worried
- Sleep through the night more often
- Be able to do more work around the house and yard
- Be able to run, walk or dance without symptoms
- Be able to climb stairs
- Go to urgent care or the emergency room less
- Have fewer hospitalizations
- Have more energy
- Engage in more social activities

7) How are these goals different or similar to the kind of goals that are important to you?
8) If you had one of these goals, what sorts of care and services would help you to meet these goals? (Probe on access to healthcare providers, medication, behavior change, environmental changes, social support, etc.)

At Mary's next check-in (six months later), her care manager asks her the same questions she answered at the start of her last visit. The care manager compares Mary's answers and reviews how she's done on her goal since they last met.

9) If you were Mary, how would use information about how your current answers compare to previous answers?
10) Would you be interested in seeing if you are making progress towards your goal?

(Probe on information related to how to improve if you're not meeting your goals, what contributed to improvement and how to keep it up, etc.)

Section 4: Alignment with Quality

Objective: To understand views on goal setting, whether they view goal setting as valuable and important to health and quality of life, and the circumstances under which participants would like or would not like to engage in goal setting with their care managers.

Appendix A. Interview Guides

11) Thinking back to Mary’s story, would you want your care manager to help you by using a questionnaire like the one you completed? Why or why not?

12) [OPTIONAL AS TIME ALLOWS] When a person sets goals with their care manager, in what ways can the care manager help the person meet the goal?

    a) How helpful do you believe setting a goal with a care manager is toward achieving better health and being able to do the things that you want to do with your life?

    b) Are there times when setting a goal with a care manager would not be helpful? Can you tell me more about when these times are, and why?

13) [OPTIONAL AS TIME ALLOWS] For what problems would setting goals be most helpful?

    a) Are there certain problems related to your health and well-being where you *really* want the care manager’s help? *(Probe on health risks, medication adherence, managing condition/pain.)*

    b) Are there any problems related to your health and well-being where you *don’t* want the care manger to get involved?

Appendix B. Interview Goals Missing from Care Plans

Interview Goals Missing from Care Plans
Work at Walmart
Family & friends
Religion
Being with family, especially her grandson
Be active in church
Spirituality
Having a safe and large enough apartment
Improve relationship with mother while he lives with her
Take less pain medication
Make the best of circumstances
Get assistance from family
Go to college to study psychoanalysis
Open a coffee shop
Go to law school
Work with at-risk youth
Writing poetry and writing in journal
Family
Address immigration status