Talking About Complex Care:
A Guide for Clear and Effective Communications

February 2022

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The views expressed here do not necessarily reflect the views of the funders.
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- Camden Coalition of Healthcare Providers’ National Center for Complex Health and Social Needs
- Center for Health Care Strategies (CHCS)
- Community Catalyst
- Institute for Healthcare Improvement
- Social Current (formerly the Alliance for Strong Families and Communities/Council on Accreditation)

The messages and guidance contained in this document reflect the experience and expertise of a diverse community of frontline providers, advocates, consumers, systems leaders, and policymakers who are actively working to improve the health and well-being of individuals with complex health and social needs. We are grateful for their generous contributions through surveys, focus groups, and conference working sessions. A special thank you to our partners at the American Hospital Association, Rush University Medical Center, and Kaiser Permanente for their thorough review and thoughtful feedback.

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ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a policy design and implementation partner devoted to improving outcomes for people enrolled in Medicaid. We support partners across sectors and disciplines to make more effective, efficient, and equitable care possible for millions of people across the nation. For more information, visit chcs.org.

ABOUT THE NATIONAL CENTER FOR COMPLEX HEALTH AND SOCIAL NEEDS

The National Center for Complex Health and Social Needs (the National Center) connects complex care practitioners with each other and supports the field with tools and resources that move complex care forward. The National Center is an initiative of the Camden Coalition of Healthcare Providers, a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, New Jersey, and across the country. To learn more, visit camdenhealth.org and nationalcomplex.care.

ABOUT THE FUNDERS

The SCAN Foundation is advancing a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence. For more information, visit TheSCANFoundation.org.

The Robert Wood Johnson Foundation is committed to improving health and health equity in the United States. In partnership with others, the Foundation is working to develop a Culture of Health rooted in equity that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have. For more information, visit rwjf.org.
# Contents

1. Introduction ......................................................................................................................... 4  
2. About this Guide .................................................................................................................. 5  
3. About Complex Care ........................................................................................................... 7  
4. Messaging ............................................................................................................................ 9  
5. Communication Challenges ............................................................................................... 21  
6. Language ........................................................................................................................... 22

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*By Rachel Davis and Lorie F. Martin, Center for Health Care Strategies; and Lisa Miller and Carter Wilson, National Center for Complex Health and Social Needs*

1. Introduction

The language and messages used to describe complex care have evolved continuously over the last decade. This is a good thing. It means that the field is collectively listening and taking into account the expanding evidence base; the changing political and social environment; and, importantly, the inclusion of more voices — in particular, individuals with complex needs and organizations outside of traditional healthcare (e.g., public health departments, social safety net agencies and institutions). As the field evolves, a remaining challenge is that the language used to talk about complex care is not always consistent across organizations, sectors, and geographies. These disparate ways of communicating about what complex care is and aims to achieve limits opportunities for the field’s growth. The Blueprint for Complex Care, released in 2018, noted the importance of aligned messaging to strengthen the field. Using consistent messages and language will help fortify the field at large as well as expand and deepen commitment to the adoption of complex care programs and strategies.

To improve health and well-being for individuals with complex needs, those in the field need to influence key audiences, including policymakers, executives, care delivery partners, and the public. Fortunately, the growth and development of complex care has contributed to a growing awareness of the interplay of physical and behavioral health, structural and social conditions, racism, stigma, and bias. Policymakers and healthcare leaders increasingly recognize the critical role the human service sector plays in addressing individual- and community-level drivers of health, and in advancing health equity. In response, complex care models are increasingly focused on cross-sector efforts to address and coordinate a broad array of health and social services, both at the individual and community level.

There is an opportunity to capitalize on this momentum to support the scale and spread of complex care efforts, ensure investments reflect the best practices of the field, and address the system failures that drive complexity. Doing so requires common messages that can more fully articulate what complex care is and the value it can offer to individuals, communities, and institutions. The goal of this guide is to communicate the value of complex care to various audiences to advance the field.
2. About this Guide

Consistent and clear language is essential for anyone working to build support for complex care approaches, including complex care providers, program leaders, consumer advocates, and communications professionals. This guide can help complex care stakeholders more effectively frame messages to:

- Communicate program goals and priorities to patients, families, and the community at-large
- Coordinate more effectively with patients, families, providers, and community partners to meet patient needs
- Engage institutional leaders and payers to invest in new complex care programs
- Recruit community partners to participate in existing complex care programs
- Demonstrate that existing programs are complex care programs
- Advocate for policy change
- Develop promotional or social media materials or speak to the media

The guide presents core and audience-specific messages and practical guidance for communicating what complex care is and the value it provides. The language outlined in the guide reflects the shared priorities and perspectives of a diverse array of stakeholders, including people with lived experience of complex needs.

Developing this Guide

The following activities informed the contents of this guide:

- **Literature review** - Reviewed publications and web content related to complex care or care for high-needs populations for existing language as well as related messaging guides.
- **Online survey** - Fielded a national survey with more than 100 responses including individuals with complex needs, health and social care providers, payers, researchers, academics, advocates, and state government officials.
- **Focus groups** - Convened six focus groups, with 4-6 participants each, to discuss core messages and how to best use them. Focus group members, selected to achieve diversity in race, gender, sector, role, and geography, included individuals with complex needs and representatives from the social sector.
- **Conference working group** - Held two sessions at the Putting Care at the Center 2021 conference where participants provided feedback on the need for messaging consistency and clarity and on language challenges.
Using the Guide

The guide provides broad messages for communicating the value of complex care as well as core language that can be modified based on the audience. It organizes key messages within three levels:

<table>
<thead>
<tr>
<th>LEVEL</th>
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<tbody>
<tr>
<td>Individual</td>
<td>Specific individuals or defined populations</td>
</tr>
<tr>
<td>Community</td>
<td>Organizations or defined communities/regions</td>
</tr>
<tr>
<td>System</td>
<td>Healthcare systems, managed care organizations, state or local agencies, etc.</td>
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Each level contains messages to help stakeholders talk about:

- The problems complex care addresses
- The solutions complex care offers
- The impacts complex care achieves
- The ways complex care advances health equity

The messages in each level can be used as is or tailored for the audience based on their opportunities to influence care for individuals with complex health and social needs.

And finally, the last section of the guide focuses on the critical importance of human-centered destigmatizing language. The words we use are powerful. Language used to describe complex care and the people it serves should respectfully refer to people and their unique experiences to empower individuals.

*Consistent and clear language can help amplify the purpose and value of complex care.* It can bring together a disparate array of stakeholders involved in the complex care ecosystem at the individual, community, and system level to better align communications and present a clearer vision of the current and future state of complex care. Doing so will help support a stronger foundation to improve opportunities for better health and well-being for millions of people in communities across the nation.
3. About Complex Care

Complex care is a growing field that seeks to improve health and well-being for people with complex health and social needs. This includes individuals with multiple chronic physical and behavioral health conditions who often face many barriers such as homelessness and unstable housing, food insecurity, lack of transportation, as well as frail older adults and people with serious illness. Both the chronic health conditions and social barriers are often, but not always, exacerbated by systemic inequities such as racism, ableism, ageism, and poverty. Complex care seeks to help people with complex needs, many of whom are members of marginalized groups, identify and meet their own health and well-being goals by coordinating access to a wide range of services and supports and building individual self-efficacy.

Complex care works at individual, community, and system levels to address the root causes of poor health that cross existing boundaries among sectors, fields, and professions. Complex care is at the forefront of efforts within healthcare to address social and economic drivers of health as a strategy to improve health equity. Programs may be housed in many settings, ranging from healthcare clinics, hospitals, and health plans to community-based organizations and social service agencies.

Complex care initiatives often focus on specific groups, or subpopulations, of individuals that share a major medical, behavioral, and/or social driver, such as children with complex needs, individuals experiencing chronic homelessness, or frail older adults. These subpopulations differ from one another in meaningful ways that need to be accounted for in intervention design, ecosystem development, and policy initiatives.

Collectively, these overlapping subpopulations are connected by the fact that the current systems of health are failing to meet their needs. Their diverse, and at times profound needs, requires a holistic understanding of the drivers of health, delivery by multidisciplinary teams, and care that includes coordination across settings, services, and sectors. Ultimately, efforts to reshape our approach to health using these principles and approaches can benefit everyone, not just individuals with complex needs, through a more humane, holistic, and person-centered system.

Complex care brings together entities across the health ecosystem to address barriers at the [individual, community, and system] levels. Through these efforts, there is a greater ability to address barriers to care for the population in need.

- Director of Integrated Care Management for a clinically integrated network
Key Complex Care Terms

Following are definitions of core terms that are integral to the field and are used throughout this messaging guide:

- **Complex health and social needs** - Multiple and intersecting medical, behavioral health (including both mental health and substance use disorders), and social needs that intersect to drive poor health and well-being outcomes.

- **Complex care** - A person-centered approach to care that brings together patients and their families, the community, and the health care system to collaboratively improve health outcomes and well-being for people with complex health and social needs.

- **Complex care ecosystem** - A local network consisting of different organizations, sectors, fields, and/or professions working collectively to improve services, systems, and policies that impact the health and wellness of individuals with complex health and social needs.

- **Health equity** - Everyone has a fair and just opportunity to be as healthy as possible (see *What is Health Equity? And What Difference Does a Definition Make?*, Robert Wood Johnson Foundation).

- **Person-centered care** - Individuals’ values and preferences guide all aspects of their healthcare, supporting their realistic health and life goals (see *Person-Centered Care: A Definition and Essential Elements*, American Geriatrics Society).

- **Drivers of health** - The social, economic, and environmental factors that contribute to health outcomes.

For more on complex care language — including a discussion on the use of the word “complex,” terms to use and avoid, person-first language, and more — see section 6 of this guide.
4. Messaging

When crafting messages, it is important to be clear and concise. Doing so may require you to focus on what matters to your audience and de-emphasize some points that may be important to you. The messages that resonate will depend on the audience’s role, priorities, and personal beliefs, experiences, and preferences. Use your judgment and knowledge of the specific stakeholder you are addressing when choosing which messages to emphasize.

Elements of Effective Messaging

While there is no one right way to use this guide, the following recommendations may be helpful when communicating about complex care services.

1. **Be aware of your audience.** Successful communication, including storytelling, relies on resonating with target audiences. Whenever possible, know exactly who they are and what they care about most. Tailor your messages to ensure that you’re not speaking to everyone in the exact same way. Avoid jargon!

2. **Be relevant.** Respect your audience by speaking to points that are most important to them and adapting stories with their priorities in mind.

3. **Be focused.** Prioritize your primary intention and edit your message into intuitive, easily digestible pieces. You should be able to get your point across in less than 30 seconds.

4. **Be authentic.** It’s not just what you say, it’s how you say it. Inject your personality, experience, and point of view in order to resonate and be relatable. Show your passion!

5. **Be consistent.** Use common and consistent language to build continuity with your audience and establish trust and reliability.

6. **Be visual.** When relevant, consider using images of specific people (with consent!), charts, and graphics.

7. **Be both literal and visceral.** Combine facts and figures with personal stories and conceptual metaphors.

8. **Be open to other influences.** Show content to others, request honest feedback, and consider all comments. Complex care requires collaboration.
What Makes Complex Care Challenging to Communicate?

• **Different meanings.** The term ‘complex care’ has different meanings for different people. Examples include using it to refer to care for complex medical conditions, as shorthand for “children with complex needs,” or to group all individuals that are high cost to the system.

• **Broad and narrow definitions.** It is used to mean both a narrow form of care delivery (e.g., care coordination), as well as a broader field organized around shared principles and a common goal of transformed systems of health that are coordinated, person-centered, and equity driven.

• **Diverse populations.** There is no clear-cut consensus around who this population consists of, meaning that the term *complex care* is often used as a “catch-all” and can encompass subpopulations with a vast array of conditions, including people with multiple medical diagnoses, people with medical and behavioral health conditions, people with serious and persistent mental health conditions, frail older adults, and people with serious illness.

• **Multiple causes of complexity.** There are many forces that contribute to complexity, including environmental and social ones. It is challenging to succinctly present how these interconnected dynamics can drive poor health outcomes.

• **Broad audience.** Complex care stakeholders encompass a diverse audience, including providers and organizations operating in different roles, systems, and geographies, each with their own pressures, opportunities, perspectives, rules, and payment structures. There is no “one size fits all” messaging that speaks effectively to all of these audiences.
Key Complex Care Messages

Complex care is a person-centered approach to care that brings together patients and their families, the community, and the healthcare system to collaboratively improve health outcomes and well-being for people with complex health and social needs. Below is a broad set of underlying messages that can be used to describe complex care’s purpose and value.

CORE MESSAGES

Our health and social systems typically focus narrowly on an individual’s single need and are not designed to work together to address multiple needs, often leading to costly and avoidable care.

Many causes of poor health are best addressed through non-medical interventions that require cross-sector and community collaboration.

Complex care provides person-centered, whole-person care that addresses the multiple drivers of health and uses a multidisciplinary team to coordinate care across settings, services, and sectors.

Complex care seeks to improve health and well-being for patients, ensure access to the right services at the right time, reduce costly avoidable healthcare use, and advance health equity.

These core statements can be used together as an “elevator speech” pointing to the value of complex care or used separately and tailored for specific needs. While the above messages provide a consistent “big picture” foundation about the value and goals of complex care, it is important to adapt messages to address the needs and perspectives of specific audiences. The remainder of this section provides tailored messages that can be modified as needed to reach intended audiences.

TAILORED MESSAGES

This section outlines broad messaging goals and core messages customized for three key levels relevant to complex care: individual, community, and system. Depending on the context of your conversation and the perspectives of the individual(s) you are speaking with, one or all of these levels may be relevant.
Barriers Confronting People with Complex Needs

When communicating the value of complex care programs, it may be helpful to articulate the experience of individuals receiving care in the existing system to highlight why person-centered care is essential. Consider asking the audience to reflect on a time when they or a member of their family had a healthcare-related issue or barrier that was frustrating. Then use a story of an individual with complex needs to explore the barriers that they face. Ideally, these would include real-life examples from your community or system. General examples can also be effective at emphasizing the barriers individuals face.

Individuals with complex needs often encounter:

- Impacts of trauma;
- Providers who dismiss or demean their experiences and perspectives;
- Providers who do not look like them, speak their preferred language, or have adequate training in providing culturally appropriate care;
- Social networks that are unable to provide the necessary physical and emotional support;
- Complex and difficult-to-navigate systems (e.g., public benefits);
- Systems that lack accountability for poor health outcomes;
- Neighborhoods that are not supportive of health due to lack of grocery stores, pharmacies, parks, sidewalks, etc.
- Limited services from under-resourced community-based organizations and government agencies meant to address the social and economic drivers of health, including food, housing, and financial support; and/or
- Structural, institutional, and interpersonal racism, bias, and other forms of discrimination.

"We are the epicenter for rehabilitative and medical care for the world . . . but the systems just suck. If they are not demeaning us, they are hard to access or there are gatekeepers."

- Olivia Richard, individual with complex health and social needs
### Individual-Level Messages

Following are core messages for talking about the goals and impact of complex care at the individual level, including for individuals and their families, providers, and other stakeholders who interact with this population. Modify these messages based on your audience and specific context.

| **Complex care addresses...** | **A lack of person-centered care:** The existing healthcare system and workforce are not equipped to meet the needs and preferences of people dealing with multiple health challenges.  
**The drivers of health:** Current care delivery often focuses on patients’ immediate medical issues and fails to address the social and economic causes of poor health. |
|---|---|
| **Complex care provides...** | **Person-centered care:** Complex care providers have a complete view of the whole person and are able to support patients in achieving their goals.  
**Team-based care:** Complex care is delivered by a collaborative, multidisciplinary care team, often including members from the community. |
| **Complex care improves...** | **Health and well-being:** Complex care addresses challenges that interfere with a patient’s ability to achieve optimal health, well-being, and quality of life.  
**Patient and provider satisfaction:** Complex care provides a better experience for patients, families, and providers, offering the opportunity to co-design care approaches. |
| **Complex care advances health equity by...** | **Identifying health disparities within populations:** Complex care focuses on individuals and populations with poor health outcomes, many of whom are members of marginalized groups.  
**Centering the patient:** Care planning and delivery is centered around the voice of the individual receiving care. |
Why Complex Care Takes an Ecosystem

While many complex care programs begin as a single care management program, the principles of care are best realized in a complex care ecosystem. But why do organizations need to closely collaborate with one another to achieve improvements in patient care? Because doing so improves effectiveness, efficiency, experience, and quality of care delivery by:

- **Sharing information.** Sharing real-time, detailed information on the individual's conditions, circumstances, and goals means all providers have a holistic view of the individual and can tailor care accordingly. Bringing together the perspectives of community-based organizations, public health, and health system perspectives creates a comprehensive picture of the needs of an individual.

- **Leveraging existing trust and relationships.** Community-based organizations may operate closer to where people live and have a deep understanding of the population and community they serve. As a result, they are well-positioned to leverage strong, trusting relationships that allow for better care.

- **Specializing competencies in focused services.** Knowing that the holistic needs of the individual are being met by partner organizations allows for specialization and efficiency in delivery. Rather than reinventing a service that already exists, paying attention to existing assets and potential partnerships in delivery creates a more integrated system of care.

Unlike the human body, which is made of many separate parts, the care system for that complex body is not integrated or coordinated. Imagine if your heart told your hand ‘It’s not my job to pump blood all the way to you; you need to get your own transportation.’ Yet we allow the taxpayer supported health system to give messages like that to our most frail and vulnerable individuals and their families.

- Molly Markert, Liaison, Colorado Access
Community-Level Messages

Following are core messages for talking about the goals and impact of complex care at the community level. Modify these messages based on your audience and specific context.

**Complex care addresses...**

**Rigid and fragmented care delivery systems:** Our health and social systems (e.g., healthcare, public health, social care, housing, education, etc.) typically focus narrowly on a single need and are not designed to work together to address multiple needs.

**High costs due to preventable utilization:** Lack of access to necessary physical health, behavioral health, and social services often results in poor health outcomes and avoidable and, often expensive, use of services.

**Complex care provides...**

**Cross-sector collaboration:** Complex care brings organizations across sectors together to share information, increase access to services, co-design solutions, and improve the quality and efficiency of care.

**Opportunities to meaningfully address community needs:** Complex care seeks to understand the community and identify and prioritize populations experiencing health disparities.

**Complex care improves...**

**Access to quality care:** Complex care helps patients get access to the right services at the right times from the right providers.

**Cost and utilization:** Complex care improves services for a population that despite frequent, and often costly, use of healthcare and social services, still has poor health outcomes.

**Complex care advances health equity by...**

**Creating sustainable systems of care:** Complex care seeks to redesign existing delivery systems that fail to meet the needs of the population they serve.

**Building the ecosystem of care:** Complex care builds cross-sector partnerships and encourages health systems to share power with members of the community.
The Relationship Between Populations with Complex Needs and Marginalization

Members of historically marginalized groups (e.g., people of color, people with disabilities, queer and trans people) are more likely to experience health disparities due to racism, ableism, homo/transphobia, and other forms of bias and discrimination. While not all members of marginalized populations develop complex needs, they are overrepresented due to the damaging impacts of discrimination and systemic oppression. Marginalization can cause some members of these groups to develop complex needs by:

- **Causing trauma:** Social marginalization that results from the intersection of multiple factors including race and ethnicity, gender, sexual orientation, gender expression, disability, immigration status, and socioeconomic status is associated with disproportionate risk of exposure to chronic stress and trauma, and increased vulnerability to its impact. Starting from a young age, the more trauma a person encounters, the more their risk for chronic health conditions, social gaps (e.g., homelessness, incarceration), and health-risk behaviors increases.

- **Limiting opportunities:** Systemic racism and geographic segregation has produced underinvestment in communities of color with corresponding inequities in housing, education, economic opportunities, wealth and income, and access to healthcare, healthy food, recreation, and other opportunities. Higher rates of incarceration lead to disruption in social networks. All of these factors put individuals at higher risk for illnesses and social needs, resulting in complex needs.

- **Creating distrust:** Prejudice based on race, disability, sexual orientation, or other factors creates alienation and reinforces barriers to accessing necessary services and supports. As one individual with complex needs shared, “you have to trust the person . . . to be able to tell my doctor things that they may use against me.”

"Getting to the root cause of well-being is what complex care is all about . . . if you are only addressing the medical issue you are missing a lot. And even if we talk about efficiencies in terms of the economics of healthcare, if you are not looking at these other factors you have the potential of spending more than necessary.

- Christian Kulak, Strategic Planning Director, Excellus Health Plan
Systems-Level Messages

The following are core messages for talking about the goals and impact of complex care at the systems level, such as healthcare systems, managed care organizations, or state or local agencies. Modify these messages based on your audience and specific context.

**Complex care addresses...**

- **Systemic racism and implicit bias:** Members of marginalized groups (e.g., people of color, people with disabilities) face racism, ableism, and other systemic forms of bias and oppression. These forces are also present within our systems and impact the quality of care.

- **Chronic underfunding of essential systems:** For decades, the United States has under-resourced public health institutions, behavioral health services, and community-based organizations necessary for maintaining the health and well-being of populations and communities.

**Complex care provides...**

- **Policy and systems change solutions:** Complex care prioritizes where investments should be made, financial incentives aligned, and partnerships created to address the root causes of poor health outcomes.

- **Cross-sector solutions to address non-medical needs:** With its holistic approach, complex care provides an opportunity to improve and support non-medical services to address social needs, including through value-based payment.

**Complex care improves...**

- **Collaboration by reducing fragmentation:** Complex care strengthens opportunities for collaboration – within the healthcare system and across sectors and the community – to better meet patient, provider, and organizational needs.

- **Systems for all:** Complex care infuses a focus on person-centered and equitable care delivery into our health and social systems, and supports integrated care delivery to align with the needs of the individual.

**Complex care advances health equity by...**

- **Expanding how value is assessed:** Complex care focuses on outcomes that matter to the individuals served and the communities they live in, including equity, well-being, and community integration, in addition to traditional financial measures.

- **Implementing policy and structural changes:** Complex care targets the underlying causes of health inequities, including redistributing power from the health sector to individuals receiving care and community-based organizations.
## Deploying Your Messages

### STAKEHOLDER-SPECIFIC CONSIDERATIONS

Following is general guidance on how to tailor your message to the priorities of key stakeholders. It is important to understand your audience’s perspective to effectively refine your messages.

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<thead>
<tr>
<th>AUDIENCE</th>
<th>LEVEL OF FOCUS</th>
<th>EMPHASIZE</th>
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</table>
| Individual     | Individual     | • The individual’s strengths, assets, and resilience that can be used in achieving their self-identified goals
• The individual’s barriers to health and well-being
• Past harm that providers and institutions may have caused
• What can be achieved by engaging in care
• The individual’s autonomy and effort in engaging with care
• Opportunities to share power with the community and codesign care |
| Providers      | Individual     | • Access for patients to essential supports and services, including non-medical resources
• New resources for care delivery, including from non-medical providers
• Opportunity to focus on clinical care through team-based approach and working at the top of one’s license
• Improved patient/participant experience and health
• Improved provider satisfaction and reduced burnout by ensuring they have the necessary resources to address needs
• How complex care advances equity |
| Social sector leaders | Individual + Community | • Co-design and co-leadership of complex care programs
• Healthcare isn’t looking to medicalize social services but instead partner with community-based organizations to address social needs
• Improved individual and community experience and health outcomes by holistically addressing needs
• Investments in capacity building to better integrate social and health services
• New financial opportunities to pay for expanded services
• Access to the health outcomes data to better understand and articulate the impact of their work
• Improved health equity and community health |

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<th>AUDIENCE</th>
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<tr>
<td>Health system leaders</td>
<td>Community</td>
<td>• More efficient clinical operations</td>
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<tr>
<td></td>
<td></td>
<td>• Expanded information on patient complexity for use in negotiations with payers</td>
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<td></td>
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<td>• Cross-sector collaboration among organizations with different funding streams</td>
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<td>• Improved provider satisfaction and reduced burnout by ensuring they have the necessary resources to address needs</td>
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<td>• How complex care advances equity</td>
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<td>Managed Care Organizations</td>
<td>Systems</td>
<td>• Opportunities to better predict costs</td>
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<td>• Improved member engagement and monitoring</td>
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<td>• Greater understanding of member’s clinical, behavioral, and social needs</td>
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<td>Government Systems</td>
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<td>• Aligning incentives/payments with needed services</td>
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<td>• Improved patient experience and health outcomes</td>
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You have to start marrying the clinical rationale with the financial imperative. It’s really about communicating that in a way that stays true to the mission and is savvy enough to generate the resources to actually address the problem. Let’s rededicate ourselves to that approach.

- Dave A. Chokshi, MD, MSc, FACP, Health Commissioner of New York City
QUICK MESSAGING TIPS

Following are tips to enhance use of the messages in this guide.

✓ Know your audience. The stakeholder-specific guidance above is high-level and needs to be tailored for your specific audience(s). The individuals in these stakeholder groups have perspectives and pressures that are unique to their state, local geographies, institution, and individual experience. Prior to making a full pitch, work to understand their needs and goals.

✓ Feature participant stories. Stories help create an emotional connection. Use stories that highlight the areas your stakeholders care about. For example, stories that show how relatively simple efforts can result in avoided hospital admissions appeals to health system leaders. Stories that highlight respectful and compassionate care will resonate with those receiving care.

✓ Highlight the community voice. Sourcing and incorporating the perspective of the community into messaging can demonstrate how complex care centers the goals and needs of those it serves.

✓ Incorporate local data. When possible, use your community’s or system’s data to highlight the need or health outcomes of your work.

Useful Graphics to Help Tell the Story

Pictures are worth a thousand words. Following is a list of select graphics that can be used to support you in communicating what complex care is and its value:

- Challenges of Evaluating Complex Care Programs – Outlines the challenges of evaluating complex care programs solely focused on cost and utilization. Source: Center for Health Care Strategies, 2018.
5. Communication Challenges

Following are common challenges individuals face when communicating what complex care is and the value it creates. This information can help you frame a response if the concern is raised by your audience.

What is the return on investment (ROI)?

Talking points:

- “There are some studies that have shown an ROI, others that have not, and more research is needed. But we do know that the current healthcare system does not meet this populations’ needs effectively or adequately support providers in treating them. Complex care is a more holistic way to support patients, clinicians, and systems in addressing these complex challenges.”
- “The potential to reduce costs is just one benefit of complex care programs. Other potential benefits include improved quality of life, improved patient satisfaction, and more coordination between providers.”
- “Complex health and social needs drive poor health outcomes and service utilization.”
- “Complex care uses cross-sector resources and funding streams to address these underlying drivers.”

For more: The Building the Value Case for Complex Care Toolkit helps users articulate how complex care programs can align mission and margin.

What is the evidence that this works?

Talking points:

- “Complex care targets locally defined populations and uses the unique combination of medical, behavioral, and social resources available in a community.”
- “The local nature of complex care programs makes robust, cross-sector studies difficult to perform.”
- “Studies have shown that the intentional integration of healthcare and social services leads to improved health and lower costs.”

For more: CHCS’ Better Care Playbook and The Commonwealth Fund’s Return on Investment (ROI) Calculator for Partnerships to Address the Social Determinants of Health contain evidence-based and promising practices for complex care.
How is success measured?

Talking points:

- “The impact of complex care can be measured across multiple domains including effectiveness/quality of services, equity, health and well-being, service delivery, and cost/utilization.”

- “Complex care generates efficiencies through enhanced partnerships (leveraging their resources), new data/information, and more effective community engagement.”

For more: Measuring Complexity: Moving Toward Standardized Quality Measures for the Field of Complex Care summarizes the existing quality measures that might be applied to complex care programs.

To me, even as a finance person, the term ROI is almost too simplistic. Other things are just as important to the holistic picture.

- Rick Wagers, Senior Vice President and CFO, Regional One Health
6. Language

The words we use matter. While we cannot align all terms across the complex care community, the culture of complex care is one of respect for the experience and autonomy of individuals with complex needs, and optimism that we can improve health and well-being.

Use of the Word ‘Complex’

Using the term ‘complex’ to describe a population (individuals with complex health and social needs) or care delivery (complex care practice) can be a point of contention. The term is used to define: (1) the interconnected and compounding effects of needs in an individual’s life; and (2) our overly simplistic and rigid systems that fail to account for this interplay. However, some interpret the word as implying that the individual is difficult or complicated. The term can have racial connotations when used by someone operating in a system that is biased or discriminatory.

Stakeholders in the field agree that having a term to describe both the work and those it serves is helpful for clear and consistent communications. It is important to note that individuals with complex health and social needs interviewed for this guide voiced support of the term when used to acknowledge the barriers they face and the care they need.

While imperfect, ‘complex care’ is an established and helpful term for describing the array of services required by people with multiple physical and behavioral health issues and social needs. When describing people served by complex care, the following guidance can help inform person-centered framing (e.g., avoid referring to someone as a ‘complex patient’).
Ways to Talk About the Individual’s Role in Improving Health and Well-Being Outcomes

While an individual’s behaviors can impact their health and well-being outcomes, it is important not to blame the individual for the failures of health and social service systems. Be careful, however, not to portray the individual as a helpless victim or having no opportunity to improve their own health and well-being outcomes. As outlined in Core Competencies for Frontline Complex Care Providers, it is the responsibility of complex care providers to “meet people where they are, create safety, and explore behavior change” in order to “cultivate (an) individuals’ resilience, ability, and self-efficacy.” It is our collective responsibility to ensure that healthy choices are universally available and that individuals are protected from discrimination and trauma.

**Emphasize:**

- Those with complex care needs are neither the sole source of the problem nor solely responsible for the solution.

- Finding and realizing the solution will require the participant’s active involvement in goal setting and care delivery and management.

- Complex care providers must promote self-efficacy in individuals so they can navigate fragmented systems and direct their own care.

- The individual receiving care defines what success looks like.
## Language Usage

Following are recommendations for language that accurately and respectfully presents individuals and their experience.

### TERMS TO USE AND AVOID

<table>
<thead>
<tr>
<th>PHRASE TO AVOID</th>
<th>WHY?</th>
<th>USE INSTEAD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequent flyer</strong></td>
<td>• Dismissive and derogatory toward people who are seeking help in often overwhelming situations</td>
<td>• Person/people with patterns of frequent (emergency department, hospital, etc.) utilization</td>
</tr>
<tr>
<td><strong>Superutilizer, high utilizer, high-utilizing, over-utilizer</strong></td>
<td>• Dehumanizing, reduces personhood to utilization patterns</td>
<td></td>
</tr>
<tr>
<td><strong>Complex patient(s)</strong></td>
<td>• Can be viewed as derogatory, also imprecise</td>
<td>• Person/individual/patient/ consumer (see below) with complex health and social needs</td>
</tr>
<tr>
<td></td>
<td>• All people are complex; at issue are the complex circumstances experienced by the individual</td>
<td>• Person/people living with complex needs</td>
</tr>
<tr>
<td><strong>Patient(s) experiencing complexity</strong></td>
<td>• Imprecise and confusing</td>
<td></td>
</tr>
<tr>
<td><strong>High-cost, high-need patient(s)</strong></td>
<td>• Overemphasis on cost, muddies the messaging</td>
<td></td>
</tr>
<tr>
<td><strong>Noncompliant</strong></td>
<td>• Blames participants instead of the systems</td>
<td>• Explain/explore why the individual is not taking their prescribed medications, going to appointments, etc.</td>
</tr>
<tr>
<td></td>
<td>• Antagonistic toward participants instead of viewing them as partners (see this video)</td>
<td></td>
</tr>
<tr>
<td><strong>Overuse or overutilization</strong></td>
<td>• Blames participants instead of the systems, compares them to “ideal” patients who use healthcare services less than they do</td>
<td>• Patterns of high/frequent utilization of… (e.g., emergency department)</td>
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<tr>
<td></td>
<td>• Repeatedly using services without deriving lasting benefit</td>
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</tbody>
</table>

People often think multimorbidity is having two diseases... that [a person with complex needs] could have their needs addressed by being in both diabetes and mental health disease management programs. They don’t understand that 1+1 = 3.

- Director of Population Health Analytics for a health system
PERSON-FIRST LANGUAGE

**Person-first** language is generally preferable because it recognizes that a person’s condition is not their identity and respects their full humanity. Some people, however, particularly those in the disability justice community, prefer **identity-first** language in select circumstances, following the **social model of disability**, which says that people are disabled by barriers in society rather than by their own impairments or differences. They may prefer “disabled” to “person with a disability” and “autistic” to “person with autism.” When deciding between person-first and identity-first language, consider the context as well as the condition in question. When possible, ask about and respect the preferences of the person(s) being referenced.

<table>
<thead>
<tr>
<th>INSTEAD OF</th>
<th>USE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic</td>
<td>Person with diabetes</td>
</tr>
<tr>
<td>Schizophrenic</td>
<td>Person with schizophrenia; person with a schizophrenia</td>
</tr>
<tr>
<td></td>
<td>diagnosis</td>
</tr>
<tr>
<td>Homeless person</td>
<td>Person experiencing homelessness; person without stable</td>
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<tr>
<td></td>
<td>housing; unhoused or houseless person</td>
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<tr>
<td>Addict</td>
<td>Person with a substance use disorder; person with</td>
</tr>
<tr>
<td></td>
<td>addiction; person who uses drugs</td>
</tr>
<tr>
<td>Alcoholic</td>
<td>Person with an alcohol use disorder</td>
</tr>
</tbody>
</table>
PATIENT, CONSUMER, INDIVIDUAL?

Because complex care bridges sectors that each have different culture and language, there are a number of words used to refer to people served by complex care programs. In choosing which words to use, think about what makes the most sense given the context and audience. When speaking to the individual, simply ask how they would like to be referenced.

- **Individual** — always appropriate.
- **Person/people** — always appropriate.
- **Individual with lived experience/expertise** — when you are referring to their role or perspective in a complex care program or initiative. Be specific about what areas they have lived experience or expertise in.
- **Individual and their families** — when referring to individuals with family caregivers.
- **Patient** — when you need to contrast the individual with a provider or professional (i.e., patient-provider relationship) or emphasize that they are receiving care.
- **Consumer** — when you are taking a systems view or talking about consumer leadership.
- **Participant** — when you are communicating about a program that an individual is actively participating in.
- **Client** — when you are communicating about a social services or mental healthcare context.
- **Member** — when you are communicating about a managed care context.
ENDNOTES


7 Stories involving real people should be shared with consent or blinded to protect the individual's identity.