the Playbook
Better Care for People with Complex Needs

BETTER CARE PLAY

Building Authentic and Mutually Beneficial Partnerships with Complex Care Consumers

Collaborating with consumers and better understanding their communities can strengthen different facets of complex care programs, including program design and planning, research and evaluation, care delivery, and quality improvement. Partnering with complex care consumers can also assist health care systems in delivering care and services that is more responsive to patients' experiences, preferences, and values. While many health care organizations recognize the importance of meaningful consumer engagement, there are often challenges and uncertainties about how to build authentic and mutually beneficial partnerships with individuals and their communities.

What is a Play?

If you are not a sports fan, then the concept of a "play" may be unfamiliar. Yet the idea is simple: a play is a plan designed to help deliver a win through highly coordinated teamwork. This idea can be applied to help redesign systems to better serve individuals with complex health and social needs. Explore additional plays on the *Better Care Playbook* at **bettercareplaybook.org**.

The goal of this play developed by the Camden Coalition of Healthcare Providers is to help you consider practices that build meaningful partnerships with consumers.

Building Authentic and Mutually Beneficial Partnerships with Complex Care Consumers

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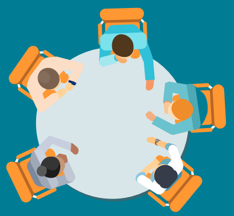

Define the specific role and level of engagement consumers will have.

2

Support participation of consumers with varied backgrounds and experiences.

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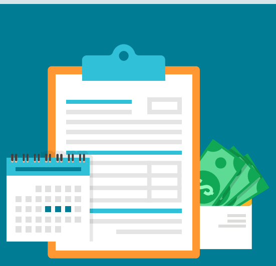
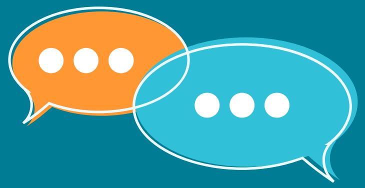


Compensate consumers fairly for their time and efforts.

4



Let consumers know the outcome of their participation.

How to Run the Play

1. **Define the specific role and level of engagement consumers will have.**
    - Consider how and why people who have received complex care services can provide necessary insight to help your organization meet its goals, and keep that knowledge at the forefront while working with consumers.
    - Understand consumers' interests and ask them how they would like to be involved. Communicate with them about what your organization would like them to contribute, and set clear, transparent expectations about involvement and time commitment so consumers can make an informed decision about whether they can participate.
    - Structure and frame questions to tap into a consumer's point of view. For example, consumers likely have useful information about how to best improve clinical workflows, but may not think of themselves as experienced in clinical redesign. Instead, frame the conversation to elicit how changes would affect the overall patient experience so that consumers can share their insights more readily.
2. **Support participation of consumers with varied backgrounds and experiences.**
    - Recruit consumer participants by outreaching to individuals who have received care or services from your organization, or by connecting with community leaders (e.g., faith leaders, block captains, neighborhood associations, etc.) and other community-based organizations.
    - Reduce barriers to engagement by providing assistance with potential complicating factors like transportation, technology hardware and software, and child care. Ask consumers in advance about the types of support or accommodations they need to participate, and do everything possible to meet those needs.
    - Dedicate staff resources to ensure consumers receive necessary support in preparing for, participating in, and debriefing after meetings and events.
    - Employ a flexible approach to working with consumers who may be living with complex medical issues, behavioral health needs, trauma histories, functional limitations, and/or social needs.
3. **Compensate consumers fairly for their time and efforts.**
    - Tailor compensation for individuals based on their personal situations. In particular, people who receive public assistance can have their benefits negatively impacted by accepting a large lump sum of money. Alternatives to cash payment could include covering the cost of attending a conference or professional development course.
    - Cover costs directly and pay stipends and honorariums in advance whenever possible. Income inequality impacts many individuals' ability to pay for things up front and wait for reimbursement.
4. **Let consumers know the outcome of their participation.**
    - Understand and address sources of community mistrust or hesitancy to become involved, such as past experiences where participants felt their input was not utilized, or the sense that "nothing ever changes."
    - Share outcomes with consumers regardless of whether you are able to act on their insights. Being responsive to consumers does not mean your organization must do exactly what they advise. Rather, it is important to clearly communicate why their input was not integrated, or clearly communicate in advance if feedback is being sought for purely informational purposes.

  - Develop mechanisms to report back to consumers. For instance, share outcomes by sending a final report to all participants or hosting a community meeting to share updates.

Tips and Tricks

- After making some initial connections with consumers, partnering with them to design and implement a consumer recruitment strategy can tap into their deep understanding of how to connect to and engage with other members of their communities. This can create a sustainable model of continuing your organization's bi-directional relationships with consumers.
- Building authentic relationships and understanding intrinsic motivation is an important aspect of consumer recruitment and retention. Take the time to get to know them as people, understand what motivates them to be a part of this work, and what value they take from it.
- Consumer engagement is a way that organizations can begin to acknowledge and dismantle systemic inequalities, such as access to education, the impact of poverty, and the impact of trauma that affords some groups more privileges and opportunities than others. Organizations can help mitigate these negative impacts by devoting resources to support training, professional development, mentorship, capacity building, and employment opportunities for consumers.
- Recognize the impact that trauma has had on many of our lives, and employ a trauma-informed approach to your work with consumers — and with all people. Trauma-informed principles include promoting safety, choice, collaboration, trustworthiness, and empowerment.
- Promote empathetic and empowering story sharing practices whenever consumers are asked to share their personal stories or lived experiences publicly. Consumers should be able to give informed consent about how, why, and for what purposes their stories are shared and must be allowed final approval of any content developed using their personal stories. Consumers should not be asked to change their story to fit a particular narrative, and stories should paint a portrait of a whole person rather than just highlighting their "problems."
- Maintain relationships so that your network of consumers grows more diverse and your invitations can be more tailored to their interests and experiences.
- Tap into consumer speakers bureaus, such as Amplify: A consumer voices bureau, to support your efforts to foster authentic and mutually beneficial partnerships with consumers.

Additional Resources

- **Tokenism in Patient Engagement** – This resource provides examples of genuine versus token consumer engagement.
- **Tips for Recruiting Patients and Families to Serve In Advisory Roles** – This tip sheet includes strategies for recruitment of patients and caregivers for advisory roles.
- **Person-Centered Engagement at the Organizational Level Change Package** – This comprehensive toolkit covers activities for planning, implementing, and scaling consumer engagement at the organizational level.
- **Build Trust with Your Community** – This blog post highlights suggestions for building trust with community members.
- **Consumer Engagement Resources - Including Several Case Studies** – This guide contains tips, stories, and other resources for engaging people with lived/living experience in poverty reduction work.
- **Trauma-Informed Approach and Trauma-Specific Interventions** – This resource presents the six key principles of trauma-informed approaches.
- **Who Tells the Story?** – This guide describes strategies for employing authentic and empowering storytelling practices within organizations.

This Better Care Play was developed by Evelyne Kane and Whitney Buchmann of the Camden Coalition of Healthcare Providers. It is part of a series developed in partnership with the Camden Coalition to share practical lessons in serving complex populations.

About the Better Care Playbook

The Better Care Playbook is an online resource center designed to help health care stakeholders find the best in evidence-based practices and promising approaches to improving care for people with complex health and social needs. It is made possible by seven leading health care foundations — Arnold Ventures, The Commonwealth Fund, The John A. Hartford Foundation, Milbank Memorial Fund, Peterson Center on Healthcare, the Robert Wood Johnson Foundation, and The SCAN Foundation — that are working together to accelerate health system transformation. To learn more, visit **bettercareplaybook.org**.