



BRIEF

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Lessons on consumer engagement from *Amplify*

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Introduction

Over the past several years, consumer engagement* has moved from a fringe consideration to a burgeoning commitment across the health and social care sectors. This change of heart also necessitates a change of practice to ensure that consumer partnerships are mutually beneficial — strengthening the work of organizations as well as providing genuine benefit to consumers and their communities. Through our work in Camden and with our partners across the country, we have found this change in practice to be well worth it. Authentic consumer partnerships have the potential to build trust, foster equity and inclusion, support community health and well-being, and improve health outcomes.

At the Camden Coalition, we endeavor to center lived experience across our work, and to support our partners in doing the same. To this end, in October 2020, we launched Amplify: A consumer voices bureau to create a pathway for complex care organizations to connect to consumer experts. Long before the program's launch, the Camden Coalition helped organizations around the country connect with complex care consumers and ensure that partnerships — from speaking at events or participating in projects — felt meaningful. Creating *Amplify* allowed us to formalize and strengthen this work.

At the outset, we imagined that *Amplify* would function much like a traditional speakers bureau, and primarily act as a matchmaker between client organizations interested in partnering with people with lived experience and our network of complex care consumers. We also imagined that the work would include providing support to our consumer participants in preparing for projects and events.

What we didn't expect was how much we would be able to help organizations think through and actualize the structures and practices necessary to build authentic and mutually beneficial consumer partnerships. Since its launch, *Amplify* has supported many exciting projects, which you can read about here and on our blog. We've also learned some important lessons about how complex care organizations can strengthen their consumer engagement work.

**We use the terms "consumer" and "person with lived experience" interchangeably to refer to individuals who identify as having first-hand experience as a person (or caregiver of a person) with complex health and social needs. These terms are often used synonymously with "patient," "client," or "community member." We recognize that all of these terms can be limiting, lacking in specificity, and/or carry potentially negative connotations. In speaking with consumers in our networks about this, we have heard that most feel less concerned with the use of this terminology than they are with other ways in which they hope to be authentically included in the work. Because of this, we hope that our use of these terms will not detract from the other ideas about consumer engagement contained in this brief.*

1. Break out of the story-sharing box

One thing we heard repeatedly from our [National Consumer Scholars](#) during the planning and design phase of *Amplify* is that they are most often asked by organizations to participate by sharing their story — specifically a story about the difficult things they have lived through. While story-sharing can be an essential aspect of change-making, consumers felt that too often organizations overlook that they have other skills and interests, and their desire to participate in an ongoing capacity and in solution-oriented activities. This insight shaped how we talk about *Amplify* as not just a speakers bureau, but as a resource to encourage organizations to include people with

lived experience in a wide range of activities.

Consumers can add immense value to complex care programs and events by:

- ▶ *Participating in working groups and planning committees*
- ▶ *Serving on advisory boards*
- ▶ *Speaking at conferences, panel presentations, and webinars*
- ▶ *Consulting on programs and initiatives*
- ▶ *Training and educating staff*
- ▶ *And much more*

Amplify-supported projects, 2020-2022

- [Jamal Brown](#) co-led a presentation to the staff of [Virtua Health's Community Health Institute](#).
- [Quiana Womack](#) served as a member of the planning committee for a [regional convening](#) organized by the [Pennsylvania Department of Health's Office of Health Equity](#).
- [LaKeesha Dumas](#) was selected as the consumer engagement representative on an expert panel convened as part of the [Quality Improvement Program- New Jersey](#)
- [Mia Matthews](#) co-led a roundtable learning session for participants of the [National Center's Student Hotspotting program](#).
- [Sara Reid](#), co-facilitated an interactive roundtable session at the 2021 [American Hospital Association's Advancing Health Equity virtual conference](#)
- [Stephanie Burdick](#) presented at the sunset session for the first cohort of the [Advancing Health Equity Program's grantees](#).
- [Janice Tufte](#) was selected to present the keynote speech at a grantee convening of California's [Local Indigent Care Needs \(LICN\) Program](#).
- [Cisily Brown](#) presented on a panel at the 2021 [Nexus Summit](#)
- [Rebecca Esparza](#) was featured as a plenary session panelist at our 2021 [Putting Care at the Center](#) conference.
- [Cynthia Gibbs-Daniels](#) presented on a social determinants of health panel organized by the [Society of Health Policy Young Professionals](#)
- [Dennis Heaphy, LaKeesha Dumas, and Naomi Williams](#) (2021-2022 National Consumer Scholar) were selected to serve on the [National Advisory Committee for the Advancing Health Equity Learning Collaborative](#)
- [Connie Montgomery](#) (2021-2022 National Consumer Scholar) was a featured presenter in a [Health Affairs Briefing: Caring for Those with Complex Needs](#)
- [Stephanie Burdick and LaRae Cantley](#) (2021-2022 National Consumer Scholar) were panelists on a webinar on patient engagement practices organized by the [National Nurse-Led Care Consortium](#)
- [Jonathon Harp](#) co-led a session on consumer engagement during a [QIP-NJ behavioral health learning collaborative](#)

Amplify: Co-created with consumers

Leading up to the launch of *Amplify*, the Camden Coalition partnered with three consumer experts — [Cynthia Gibbs Daniels](#) and [Cisily Brown](#) (members of the 2019-2020 National Consumer Scholars cohort), and [LaKeesha Dumas](#) (who is a longstanding member of the Coalition’s National Advisory Committee) — to support the planning and design phase of *Amplify*. Cynthia, Cisily, and LaKeesha helped design a semi-structured interview guide and led a series of interviews with other members of the 2019-2020 National Consumer Scholar cohort to understand their perspectives and preferences for how *Amplify* should operate. Their input shaped our practices on things such as compensation, the importance of including consumers in ways that go beyond story sharing, and informed the creation of our [Amplify value statements](#).

Much like our work with our Consumer Scholars research team that led to the creation of [this brief exploring consumer engagement experiences](#), our work with the consumer design team for *Amplify* was both an opportunity to strengthen our work through consumer partnerships as well as a replicable model for how other organizations can partner with consumers in their own planning and design initiatives.

We have been glad to see that many of *Amplify*’s clients have conceptualized roles for consumer advisors that go beyond story-sharing. Others, who came to *Amplify* looking for someone to share their story, have embraced an expanded consumer role after conversations with our consumers and staff. In one instance, a consumer shared a story of their lived experience to kick-off a learning collaborative session, but was then also featured on the session panel, discussing the ways in which their lived experiences can (and should) inform the work. Other projects have tapped into both the lived and professional experience of our *Amplify* consumers by inviting them to contribute through their lens of lived experience, as well as their relevant experiences working as a community health worker, policy analyst, or researcher.

“[Through working with *Amplify*], I was able to effectively share the importance of including individuals who live with complex care (medical and social needs) in all aspects of care improvement, from research to evaluation.”

— *Janice Tufte, consumer expert with Amplify*

The opportunities, models, and formats for community engagement work are vast, and organizations should continue to embrace consumer participation in ways that go beyond story sharing.

2. Inclusive spaces are accessible spaces

A common challenge faced by our *Amplify* clients has been how to meaningfully engage consumers in highly technical conversations on topics such as value-based payment reform or clinical workflow design. Some clients have talked about past consumer engagement endeavors that have fallen short of their desired impact because consumer participants did not fully engage in the conversation or brought up issues that organizers felt were “off topic.”

One common approach organizations take to address these challenges is by asking “how can we better prepare consumers to participate in these spaces?” We’ve found that a better question is “how can we as organizations intentionally create more inclusive and accessible spaces?”

Creating more inclusive and accessible spaces can mean:

- ▶ *Providing context, background information, and definitions for common terms to all participants in advance of meetings.*
- ▶ *Including a consumer on the planning team to help create meeting agendas and conversation topics that are relevant and accessible to consumer participants.*
- ▶ *Creating defined spaces for people with certain sets of expertise to discuss specific topics – considering critically the desired outcomes for the work and how the format and structure of a project can best support these outcomes.*
- ▶ *Acknowledging and working to overcome implicit and explicit power imbalances that may be present within diverse groups of stakeholders.*

3. A commitment to consumer engagement means committing resources

While there is certainly a growing interest in consumer engagement, this interest is (generally speaking) outpacing the willingness to dedicate resources to support the work. Often, consumer engagement is an afterthought in a process that has already been planned out. This limits the potential for meaningful consumer participation, particularly when engaging individuals with complex health and social needs and those from communities impacted by health disparities, socio-economic injustices, and systemic racism.

From our experience with *Amplify*, many organizations are increasingly committed to paying consumers fairly for their work, but there are still other resources that should be dedicated to support consumer partnerships.

For instance, while a trauma-informed and person-centered approach to healthcare delivery is increasingly becoming the norm, these practices are not always carried over to the ways organizations treat their staff members or the consumer experts they partner with.



Tight project timelines, rigid deadlines, and fast-paced communication can be especially challenging for consumers (and people in general) who have competing priorities, recurring health challenges, or face barriers due to literacy, language, technology, transportation, or educational access. Assumptions — such as access to a computer and/or printer that would enable someone to read a lengthy document, or the ability to pay up front for travel costs if they are reimbursed — do not reflect the reality of many consumers' circumstances.

Dedication of resources for consumer engagement should always include providing fair compensation for time and effort, but there are other ways resources should be dedicated as well.

First and foremost, creating meaningful consumer partnerships takes time. Building relationships with people, understanding their skills, interests, and intrinsic motivation to work as consumer experts is not something that can happen overnight. A popular proverb tells us “The best time to plant a tree was 20 years ago. The second best time is now.” The same is true for building authentic relationships with consumers.

Flexibility is another resource needed when working with consumers — particularly those who live with complex health and social needs. Illness, hospitalizations, and competing life priorities are often unavoidable for complex care consumers. In acknowledgement of this, partnership work requires flexibility. The ability to reschedule meetings, the willingness to communicate through texts or mail exchanges when the standard email and electronic calendar invites present barriers to participation, and an ability to change direction in response to consumer feedback are vital and often overlooked aspects of consumer partnership building.

In addition to time and flexibility, organizations should provide consumer partners with access to supportive and engaged staff members who are committed to building and maintaining relationships and have the skills and experience to provide trauma-informed support. Dedicated and experienced staff support is a necessary resource to meet people where they are.

4. Clarify the what, the why, and the how

Another important resource that should be dedicated to consumer engagement work is thoughtful and deliberate consideration of what, why, and how. Interest in engaging consumers is a great starting point, but on its own, interest is not sufficient to build meaningful partnerships and avoid token participation that merely “checks the box.”

The “what”

Organizations should spend time considering the specific role they imagine consumers playing in their project or event, as well as considering what skills and experience — in addition to lived experience — consumers will need to fill this role.

Consumers' roles in a project can be considered on a spectrum of engagement, with informing and consulting roles requiring a lower level of engagement, and partnership and leadership roles requiring a higher level of engagement, and therefore a higher level of resources and support.

Organizations should match the level of engagement required with the needs of the project or initiative at hand, as well as the availability of resources and support for consumer participants. Partnership and leadership roles are increasingly seen as the gold standard for engagement, but there is nothing wrong with engaging consumers in informing or consulting capacities if done meaningfully and intentionally. We have found that it is better for organizations to thoughtfully undertake lower levels of consumer engagement — acknowledging the strengths and limitations of that approach — than to rush to integrate consumers at a leadership level before the necessary resources, structures, and expertise are in place to do so.

The “why”

While there is growing agreement that community engagement is an important and worthwhile endeavor, it is still valuable for organizations to clearly articulate their “why” for doing this work. Is there a specific problem the organization is trying to solve where consumer input can clarify the challenges that need to be addressed, or identify overlooked solutions? Is the organization hoping to improve practices such as cultural humility or use of inclusive language? These

are only a couple of examples of the many specific “why’s” for consumer engagement work, and each organization and initiative should define their own.

Having — and being able to articulate — the specific reason consumer partnership is necessary can clarify purpose and help garner support from individuals who may be skeptical about the utility or impact of consumer partnerships. Organizations can take this a step further by considering not just why they are engaging consumers in this particular project or event, but also defining what specific impact and outcomes they hope to achieve by partnering with consumers in the work. These outcomes could include things like:

building trust with their service population and/or the larger community an organization is serving through partnerships that improve care and services and provide benefits to consumer participants,

identifying community-aligned solutions by directing resources to address the issues most salient to the community and ensuring that services are delivered in a way that is aligned with community values and preferences, and

increasing diversity across project partners by ensuring that teams responsible for designing and implementing care interventions are reflective of and include members of the community.

How Amplify can support your work

Whether you have an upcoming event or project that could benefit from participation from consumers, or you want to talk more about the potential for *Amplify* to support initiatives that are still in a planning phase, we welcome the opportunity to speak with you about your work and how we may be able to support it. *Amplify* was created to ensure that people with lived experience are engaged early and often in complex care work. There is no opportunity too small, or time frame that is too soon to begin the conversation.

Submit a request through the [Amplify request form](#) or [learn more](#).

“Having a consumer expert and advocate comfortable with speaking up on behalf of the consumer experience on a panel with many clinicians was valuable in planning a program meant to serve the needs of the patients while following clinical recommendations. Getting a meaningful perspective of the patient experience is so important.” — *Amplify client*

The “how”

Once organizations are clear on what role they hope consumers will play and what impact they hope consumer involvement will have, it is important to think about how to get there. This can include considering how to identify and recruit people who bring the necessary types of skills, experience, and/or diversity factors, and, as mentioned above, what resources the organization can commit to provide supportive practices and structures that allow authentic and impactful work with consumers.

Partnering with consumers in this planning phase is an excellent practice. For example, consumers can play a crucial role in advising on outreach and recruitment strategies for community engagement initiatives and bring an important perspective into what structures and supports will be

necessary to support representative participation from the community. As mentioned above, the Camden Coalition benefited greatly from the consumer experts who worked with us on the planning and design process for *Amplify*. We encourage other organizations to begin their consumer engagement as early on in a process as possible.

Toward better consumer partnerships in complex care

Building authentic and meaningful consumer partnerships is an ethical imperative for complex care. Consumer partnerships ensure that services and programs are aligned with and responsive to community needs and goals. They are a strategy for advancing diversity, equity, and inclusion work, and are instrumental in ensuring that complex care initiatives

are able to create and sustain improved health and well-being outcomes for the individuals and populations they serve.

Through our *Amplify* work, we have learned so many valuable lessons about what it means to build authentic and mutually beneficial partnerships between health and social care organizations and consumer experts. To move from token consumer engagement to meaningful and robust consumer partnerships, it is essential for organizations to conceptualize initiatives that go beyond story sharing, create inclusive and accessible spaces for the work to take place, commit time to clarify the what, why and how of their consumer engagement work, and dedicate sufficient resources to move the work from commitment to reality.



About the Camden Coalition

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of complex care by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals in Camden and regionally.

Through our National Center for Complex Health and Social Needs (National Center), the Camden Coalition works to build the field of complex care by inspiring people to join the complex care community, connecting complex care practitioners with each other, and supporting the field with tools and resources that move the field of complex care forward. The National Center's founding sponsors are the Atlantic Philanthropies, the Robert Wood Johnson Foundation, and AARP.



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