



Amplify: A consumer voices bureau values statement

September 2020

We have learned a lot from speaking with consumers and partners about how organizations can employ authentic and empowering consumer engagement and storytelling practices.

Amplify, our consumer voices bureau, promotes the notion that **“organizations should be microphones for people to tell their own stories in ways that highlight their humanity and foster empathy”**. We borrow this phrasing from Kate Marple, whose **guide on empathetic social change storytelling** is an excellent resource for further reading.

We ask that all organizations who connect with consumers through *Amplify* consider the following principles for authentic, empowering consumer engagement, and commit to actualizing these principles in your work:

- Storytelling and sharing personal narratives is a critical component of complex care and changemaking more broadly. In addition to their lived experiences, many consumers have experience, skills, and expertise in other areas (e.g., leadership, policy, research, peer counseling, etc.). We encourage organizations to involve consumers not only by inviting them to share their stories, but also as participants in solution-oriented activities such as program design and planning, evaluation, and organizational governance.
- There are often disparities in the way organizations pay consumers compared to the way other experts are paid for their work. Consumers should be compensated fairly for their time and effort. At a minimum, consumers should not incur expenses for participating in an event. Systemic income inequality impacts many individuals' ability to pay for things up front and wait for reimbursement, so we recommend covering costs directly and paying stipends and honorariums in advance when possible.
- Individuals must be able to give informed consent about how, where, and for what purposes their story and other personal information is shared. To support this process, we ask that organizations provide detailed information in advance about the format and purpose of speaking engagements as well as information regarding how recordings, transcripts, and other materials containing personal information may be used.
- Authentic and empowering story sharing promotes a holistic and empathetic narrative that focuses on the person, not their “problem.” As owners of our own stories, everyone should be able make an informed decision about how, when, and why we share our experiences, and deserve the opportunity to share our stories in our own words and from our own perspectives. While coaching can help individuals to refine their stories and speaking style, consumers should not be asked or expected to alter the substantive content of their stories in order to better fit a narrative that may be convenient for the event.

- Complex care is team-based work. Because of this, it is critical that we respect, acknowledge, and value diverse perspectives, experience, and opinions. Additionally, organizations should ensure consumer participation by addressing common obstacles such as lack of access to transportation, technology, childcare, time, and accommodations for people living with disabilities and complex needs and those who speak languages other than English.
- The principles of respect and authenticity in relationships apply to us all. Organizations should foster authentic consumer engagement and avoid tokenization by:
 - Defining in advance the role consumers will play in your project and the level of engagement you hope to have;
 - Assessing the skills and experience--in addition to lived expertise--people will need in order to fully participate, and finding a balance between the training and support the organization can offer and what people need to come in knowing;
 - Practicing deep listening and being genuinely open to considering new and varied perspectives;
 - Only asking for feedback when there is the ability to respond to it;
 - Setting honest expectations, following through on promises, closing the loop regardless of the outcome, and being as transparent as possible.
- We recognize the impact trauma has had on many of our lives, and therefore promote a trauma-informed approach to our work and to the way we work with each other. **Trauma-informed** principles include promoting safety, choice, collaboration, trustworthiness, and empowerment. We all play a role in creating relationships and interactions that embody these principles.

The Camden Coalition welcomes any questions about these guiding principles of consumer engagement and is happy to work individually with your organization on employing these practices into your work.

About the Camden Coalition of Healthcare Providers

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.

For more information about the Camden Coalition, visit www.camdenhealth.org.