



## *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.

### **Amplify Value Statements**

Amplify holds the following values of consumer engagement:

- Storytelling and sharing personal narratives are critical components of complex care and change-making. Many people with lived experience also have experience, skills, and expertise in other areas (e.g. leadership, policy, research, peer counseling, etc.). We encourage organizations to engage people with lived experience not just by inviting them to share their stories, but also involving them as participants in solution-oriented activities such as program design and planning, evaluation, and organizational governance.
- 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 to make an informed decision about how, when, and why we share our experiences, and have the opportunity to share our stories in our own words and from our own perspectives.
- People with lived experience should be compensated fairly for their time and effort. There are often disparities in the way organizations pay people with lived experience compared to the way other experts are paid for their work. We recognize that systemic income inequality impacts many individuals’ ability to pay for things up front and wait for reimbursement, so we will seek to cover costs directly and pay stipends and honorariums in advance when possible.
- 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 support participation by people with lived experience by addressing common obstacles such as lack of access to transportation, technology, childcare, and time, as well as accommodations for people with disabilities and complex needs, different educational backgrounds, 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(s) that people with lived experience will play in the project and the level of engagement they will 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 that trauma has 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.

A note on language: We use the terms “consumer” and “person/people with lived experience” interchangeably to refer to individuals with lived experience as a person, or caregiver for a person, with complex health and social needs. We recognize that not everyone identifies with one or both of these terms and acknowledge that they can carry some limitations and potentially unwanted connotations. While we have decided that these terms are the most widely understood and acceptable options for general communication about this work, we also respect every person’s right to use different terminology to identify themselves. **Read more.**

## About the Camden Coalition of Healthcare Providers

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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](http://www.camdenhealth.org)