

# Driving Equity through Consumer Partnership: Engaging Experts by Experience to Create Sustainable Change

2023 HCBS Conference: Managed Long-Term Services and Supports Intensive

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Monday, August 28th, 2023





*...Working with innovative health care and human services leaders across the country to develop capabilities, build infrastructure, and cultivate relationships that ensure consumers become enduring organizational partners, invaluable to shaping strategy and action.*

# At CACP, We envision a healthcare system where...

- The lived experiences of individuals with complex health and social needs are recognized as **indispensable** ingredients in designing equitable care and services that best meet those needs.



- Broad and deep collaboration between consumers as experts by experience and professionals as experts by training is woven into the cultural fabric of every organization serving people with complex needs.



- Together as partners, leaders and consumers are inspired to build trust, share power, and co-design solutions that improve outcomes, enhance experiences, and manage cost.

We know organizations walk a tightrope - Balancing resources with the needs of the people they serve

Consumers as “**experts by experience**” are a key complement to “**experts by training**” in driving the best decisions

Consumers are an important source for **critical insights** and **practical solutions** that lead to **better outcomes**

Understanding disparities and improving equity requires ongoing partnership with consumers and communities



# The Current Landscape around Consumers as Partners



## Current State

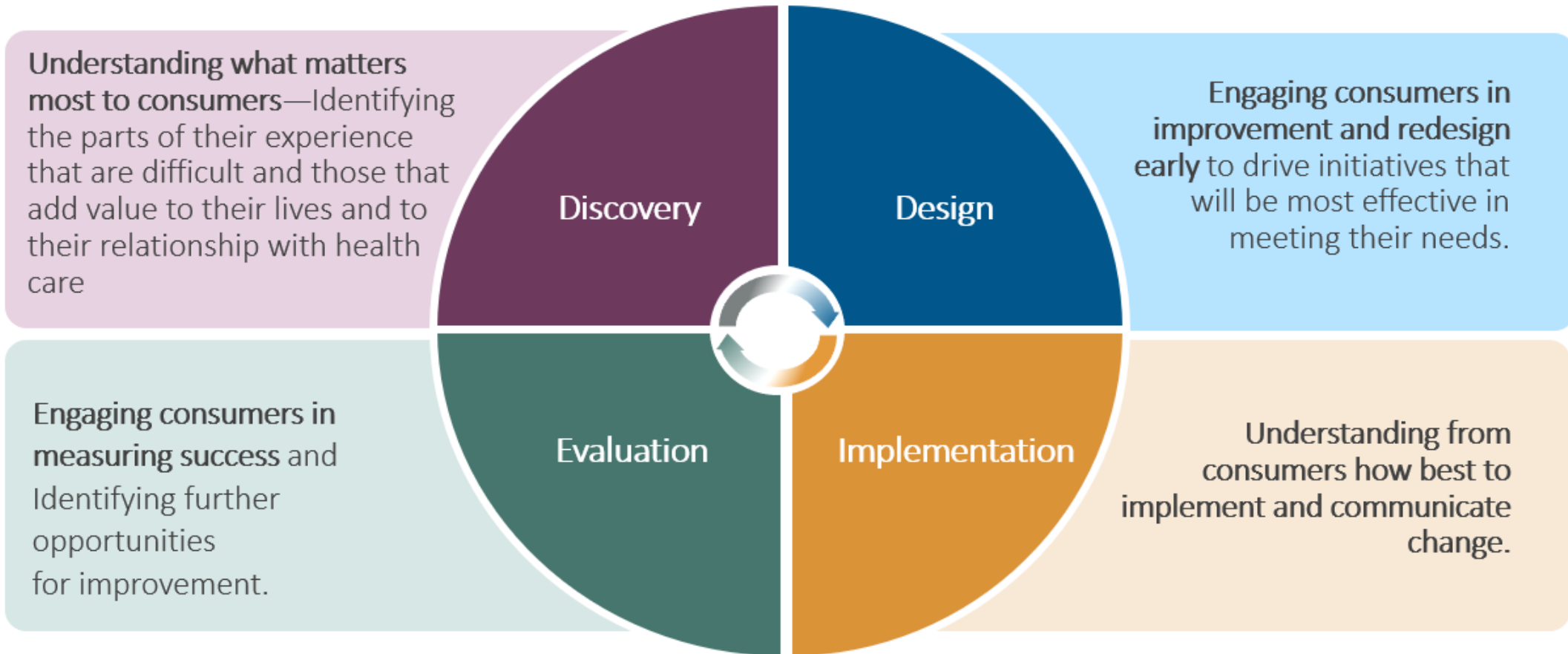
- Consultative “engagement” is still dominant within health care
- Engagement is largely around issues that “we” find important or think patients/community should care about
- Emerging information about ROI or proof of value



## Innovators are Sharing Decision Making Authority / Co-Governance

- Organizational processes and structures have shifted regarding how decisions are made
- Organizations **prospectively** determine the level of authority, influence and autonomy held by patients/consumers. “Not an afterthought”
- Transparently communicate and adhere to their decisions.





# How do we Achieve Authentic Partnership?



# How Do We Bring Consumer Voices to the Work?



# Levels of Consumer Engagement: From Participation to Partnership

 <b>Feedback</b>	 <b>Consultation</b>	 <b>Collaboration</b>	 <b>Co-Ownership</b>
<ul style="list-style-type: none"> <li>• Asynchronous interactions</li> <li>• Usually in the form of member surveys, questionnaires or electronically based user testing/reviews.</li> <li>• Typically, a single connection with consumers on various topics, often around satisfaction or experience.</li> <li>• Most commonly used in the area of evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Real-time, two-way interactions</li> <li>• Usually in the form of focus groups or interviews to gain consumer perspectives and insights at a single point in time about a topic or issue.</li> <li>• Typically, situational and shorter term.</li> <li>• Used across discovery, design, implementation and evaluation.</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing engagement and interaction with consumers requiring stronger, more trusting relationships.</li> <li>• Usually in the form of workgroups, advisory panels or workshops</li> <li>• Typically, longer term over the lifecycle of an effort from discovery and design through implementation and evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Complex, longer term, high trust relationships where consumers are embedded in governance, strategic planning oversight, and operations.</li> <li>• Usually in the form of Board and ongoing committee structures</li> </ul>

Levels of Engagement



# Organizational Roles in Consumer Partnership



## INFLUENCER

Ability to leverage relationships to ensure consumer engagement is part of the life cycle of activities you are supporting.



## FACILITATOR

To actively engage with partners to support consumers engagement activities. Provide guidance, support, etc.



## PRIMARY CONVENOR

To work directly with consumers throughout the lifecycle of activities.



“A person who has *experienced* something is almost always far more expert on it than are the experts.

A corollary is that any process including *only* experts, with *no* contribution from those with personal experience, will probably go wrong.”

*Gloria Steinem*