

# Welcome to the Community Engagement Learning Network!

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**Community engagement** refers to the different ways in which health (& social) care organizations can reach out to, engage, and partner with people with lived experience, with the goal of working together to improve healthcare and achieve positive health outcomes.

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Please join us for our next session on **July 22<sup>nd</sup>** from **3-4:30pm ET**

Featured presenter:  
Boston Children's Hospital  
Patient-Family Advisory  
Committee

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## Welcome to INSPIRE's Community Engagement Assessment & Practice Library

This self-assessment takes less than 10 minutes to complete and offers customized suggestions, including 'easy wins' for your organization and community!

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### Start Your Assessment

Start Now

Your responses will be used to provide recommendations about specific ways your organization can strengthen partnerships with PWLE.

We strongly recommend that you start with the self-assessment so we can help point you in the right direction, but you can choose to skip the self-assessment and explore our full Practice Library on your own.

What is this self-assessment? +

Who should take this self-assessment? +

How to take this self-assessment: +

Click to filter by practice category

Building authentic and impactful relationships with PWLE

Building organizational infrastructure for engaging PWLE

Creating strategies and goals for engaging PWLE

Measuring and evaluating your work with PWLE

Search resources...



Articulating A Clear Statement Of Purpose

Creating strategies and goals for engaging PWLE



Creating Engagement Opportunities

Building authentic and impactful relationships with PWLE



Engaging Executive Leaders

Building organizational infrastructure for engaging PWLE



Ensuring Representation

Creating strategies and goals for engaging PWLE



Establishing Feedback Loops That Support Action

Building organizational infrastructure for engaging PWLE



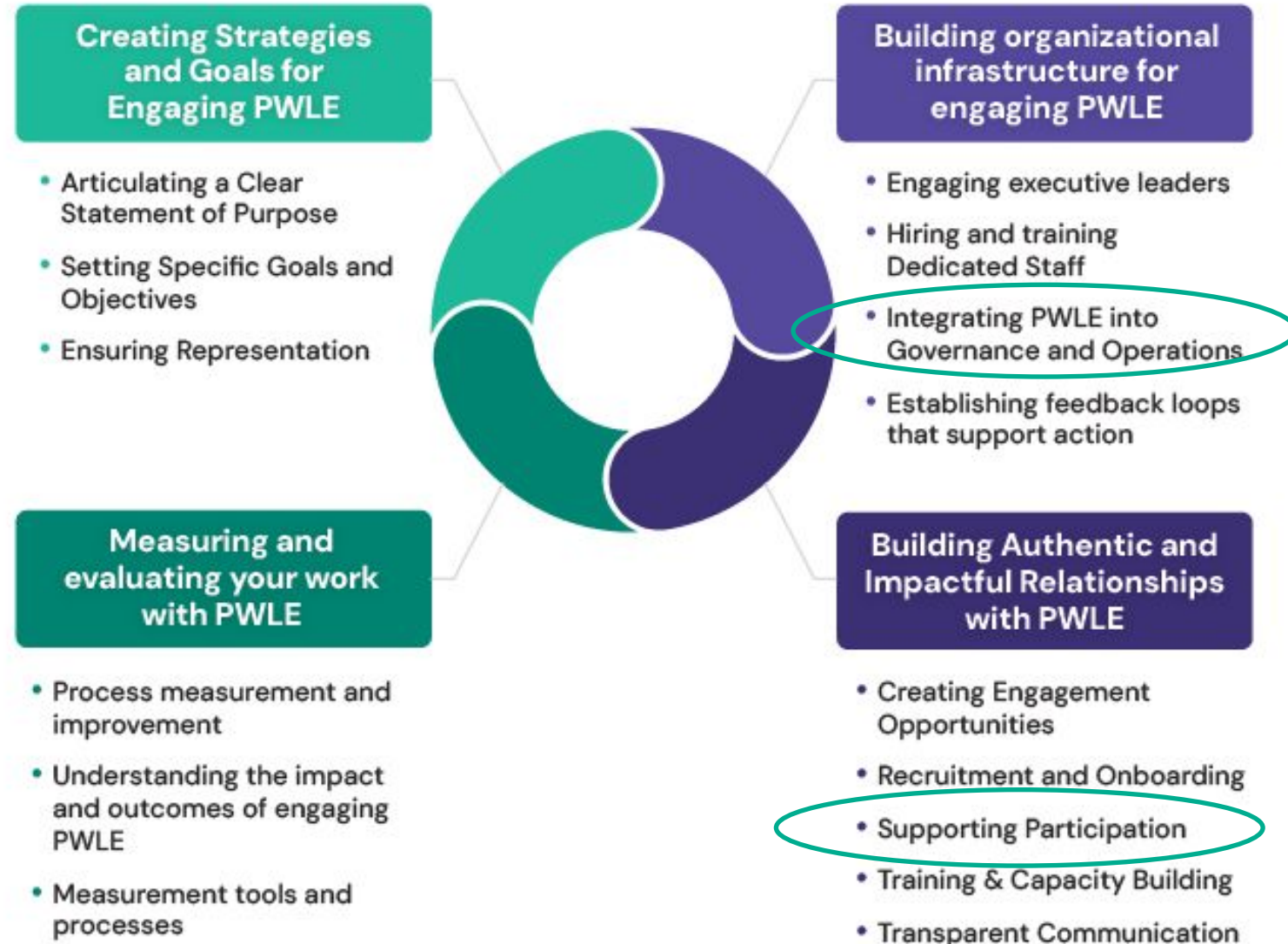
Hiring And Training Dedicated And Skilled Staff

Building organizational infrastructure for engaging PWLE



# The INSPIRE Framework for Engaging PWLE

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# Building Authentic Engagement Through Lived Experience Leadership in Governance

*Maritza Gomez and Morgan Steward*



**The National Center**  
for Complex Health & Social Needs  
*An initiative of the Camden Coalition*

# Agenda

- Governance Practices that Support PWLE Participation
- Building Sustainable Infrastructure for Lived Experience Leadership
- Addressing Barriers to Equitable Governance Engagement: A Conversation with Board Members with Lived Experience

# Who we are

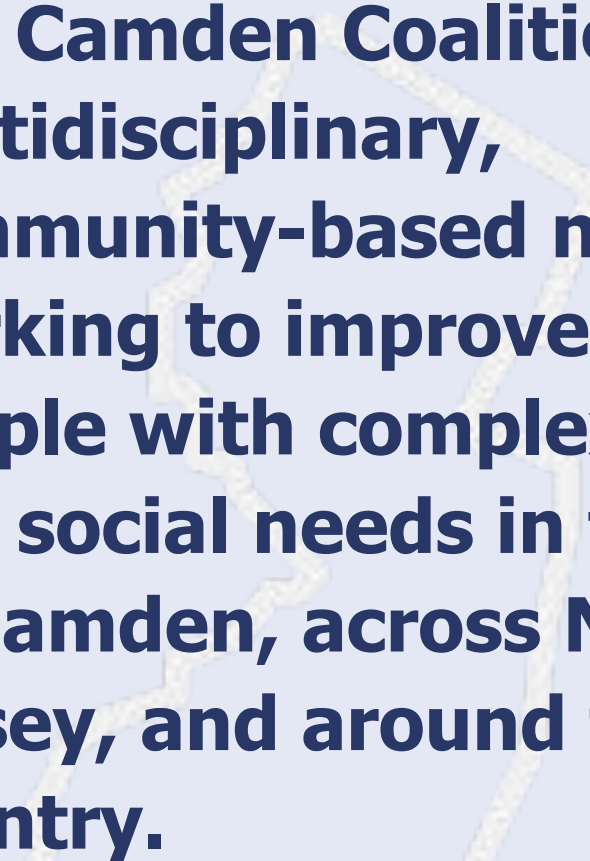
## Mission

To improve the health and well-being of people with complex needs by demonstrating and advancing equitable ecosystems of care.

## Vision

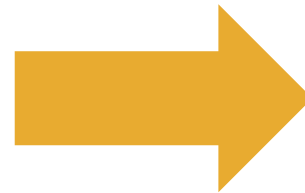
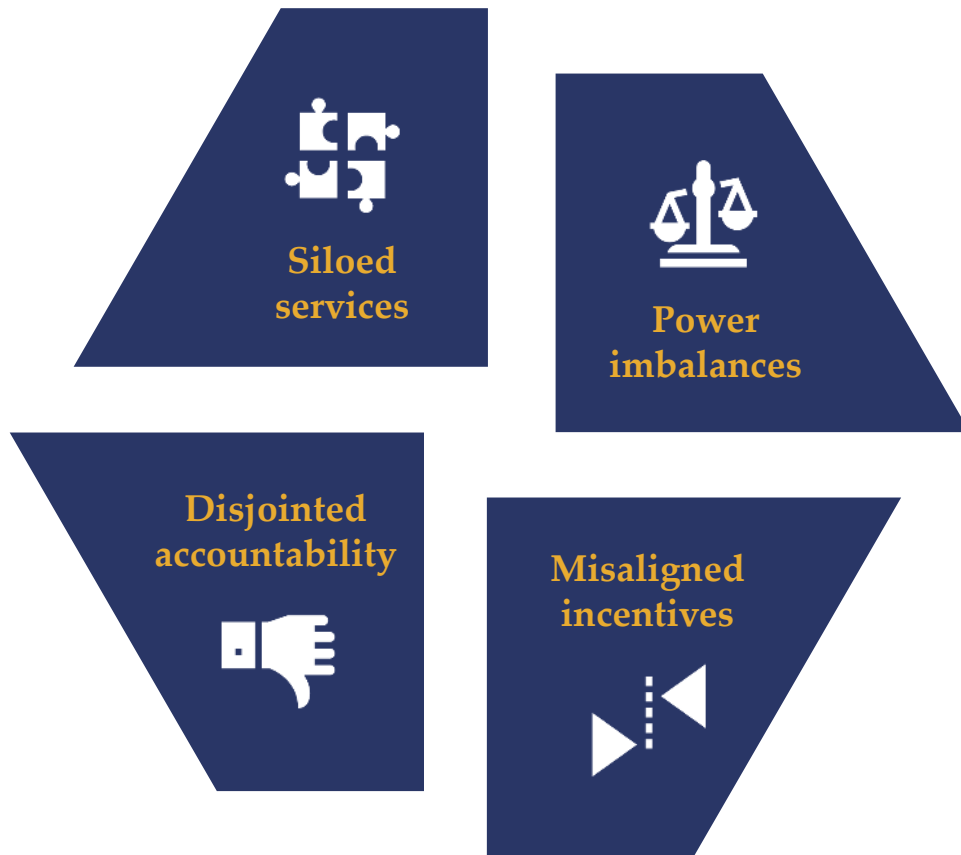
Transformed health and social systems that ensure every individual receives person-centered care rooted in authentic healing relationships.

**The Camden Coalition is a multidisciplinary, community-based nonprofit working to improve care for people with complex health and social needs in the city of Camden, across New Jersey, and around the country.**

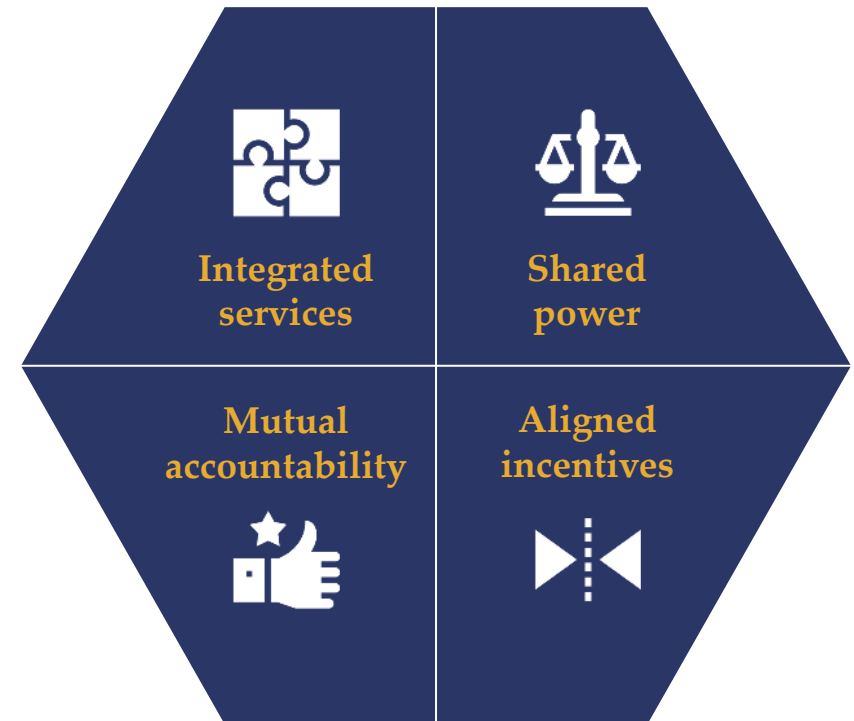


# Reimagining whole-person care

## Weak ecosystems



## Strong ecosystems





**Poll:**

**For those in professional roles within an organization, does your organization currently involve PWLE in formal governance roles?**

**For PWLE, have you served on an organizational board or committee?**



**Designing inclusive  
governance practices**

# Why integrate PWLE into organizational governance?

- Programs and services aligned with and responsive to community needs
- Advances diversity, equity, and inclusion in a tangible, structural way
- Creates and sustains equitable and improved health outcomes
- Surfaces blind spots - insights organizations would otherwise miss
- Builds community trust through demonstrated accountability



# Defining governance roles for PWLE

**Key shift: Moving from ad-hoc input to sustained engagement & leadership pathways**

<b>Transactional Engagement</b>	<b>Relationship-Centered Governance</b>
One-time listening sessions	Ongoing, formalized roles (e.g., board seats)
Feedback collected, rarely closed-loop	Two-way communication with visible follow-up
No defined level of influence	Decision-making authority clearly specified
PWLE as guests or storytellers	PWLE as partners and decision-makers

# Organizational commitment & buy in

- Articulate your "why" and consider updating mission statements and strategic plans to align with your plan
- Secure leadership commitment
- Allocate dedicated resources including staff time, facilitation, plain-language materials
- Acknowledge power dynamics to ensure transparent decision-making, equitable compensation, clearly defined roles
- Update bylaws — the Coalition amended its bylaws to require consumer seats

# Creating safe and trusting environments

## Diverse voices

Invite PWLE with diverse identities, lived experiences, and those most underrepresented

## Transparency

Promote trustworthiness in all communication and decision-making to build psychological safety

## Staff training

Ensure staff know how to make PWLE feel like meaningful contributors — not observers

## Intentional design

Design meetings to be low-barrier, accessible, and inclusive — not an afterthought

## Psychological safety

Create spaces where people feel secure, respected, and genuinely supported

# Representation & recruitment

## Nothing about us without Us!

- Build relationships before you have an ask. Attend community events, listen without an agenda
- Partner with trusted messengers: community leaders, grassroots orgs, faith-based networks
- Leverage PWLE networks like word-of-mouth referrals from people you already work with
- Remove barriers from the start - offer compensation, childcare, translation, transportation
- Hire staff who reflect the communities you wish to engage
- Treat lived experience as equally important as professional knowledge



# Onboarding PWLE for governance roles

*Governance meetings involve content PWLE may not be familiar with financial statements, strategic plans, bylaws. Orientation and support are not optional.*

- Hold dedicated onboarding sessions to establish trust, review expectations and, build relationships with committee staff
- Introduce fellow committee members so PWLE know who's in the room and why
- Level-set on content, explain key terms, processes, and what decisions they have influence over
- Provide ongoing context for board materials in plain language, pre-meeting briefings & post meeting debriefings

## **The "Board Buddy" System**

Pair each PWLE board member with someone already on the board.

Low-cost, high-impact. Gives PWLE a go-to person for questions they might not want to ask the full group.

Encourage them to connect between meetings.

# Compensation: Making participation accessible

## Compensation is a necessity, not a perk

- PWLE receive regular compensation for participation and preparation including meetings, reading materials, travel, follow-up
- Requires internal infrastructure: coordination with legal and finance to establish clear, equitable guidelines
- Engage PWLE in developing your compensation policy - be open to feedback
- The Camden Coalition's model: compensate consumer board members; review annually with a board sub-committee

# Compensation: Navigating barriers & flexibility

Barrier	Solution
Impact on public benefits (Medicaid, SNAP)	Have open conversations; connect to benefits counseling
One-size-fits-all payment	Offer flexible options: gift cards, smaller installments over time
Check-only payment	Explore direct deposit, pre-paid cards
Compensation doesn't fit everyone's needs	Alternatives: purchase an item, pay a bill, cover training costs, make a donation in their name
Limited budget	Have transparent conversations; consider mutual-benefit approaches

# Ongoing support and mutual benefits

- Offer leadership development, training, and networking. PWLE grow while the organization gains insight
- Provide transportation stipends, meals during meetings, and childcare support
- Consider technology access & hybrid participation: Virtual platform accessibility, computers, internet for remote participation
- Cover travel costs including hotels and meals for in-person meetings



Build organizational  
infrastructure  
to sustain meaningful  
involvement

# Building organizational infrastructure

**Amend bylaws:** Codify consumer seats so the commitment outlasts any individual leader

**Formal committees:** Create standing roles not just ad-hoc groups tied to grant cycles

**Define authority:** What can PWLE advise on or approve?

**Dedicate staff:** Facilitation and support roles, timely follow-up

**Cross-department buy-in:** What other departments (finance, legal, IT) should be part of the process?



Identify and address  
common barriers

# Addressing barriers: Practical solutions

Barrier	Practical Response
No dedicated budget	Making compensation a line item
Public benefits risk	Open conversations; flexible payment options; benefits counseling referrals
Burdensome payment processes	Streamline with Finance; consider partnering with a CBO to administer
Lack of trust	Show up consistently; close the loop; acknowledge past harms; build relationships first
Inaccessible materials	Plain-language board packets; pre-meeting briefings; "board buddy" system
Tokenism	Define decision-making authority explicitly; compensate equitably; elevate feedback visibly
Technology gaps	Provide devices, internet access or hybrid options, live translation

# How the Coalition embeds PWLE in governance

## Community Advisory Committee (CAC)

Patient graduates, community members & CBOs on a formal board committee. Provide feedback on programs, offer insights, raise issues, participate in story-sharing, advocacy & research.

## CAC Board Trustees

CAC elects chair & vice-chair; these officers + 2 members sit on the Board to advise and make independent recommendations on strategic direction.

## National Consumer Board Members

Consumers from across the country serve on our Board. Share broader expertise and diverse perspectives from beyond our immediate community.

Clear roles & expectations

Preparation & context

Compensation & respect

Two-way communication



Questions?

# Community building

- How are you fostering community in your own life or work?
- What else do you wish was there?