

# **Inclusion: Consumers as Equal Partners**

**Aligning Forces for Quality Annual Meeting**

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# National Partnership for Women & Families

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## “Americans for Quality Health Care” Project

**WE CAN HELP!**

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# The Role of Consumers

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- For consumers to be equal partners—a “culture shift” is needed.
- First step—getting all stakeholders to believe consumers should be equal partners.

# Why should consumers be equal partners?

- ***Project Goals—Consumer Engagement***
  - Use information to make better choices/decisions
  - Better self-management
- ***It works***
  - Improved knowledge about options
  - Better decisions for their needs
  - Greater satisfaction, more realistic expectations
  - More active role in their own care
- ***Consumers are the end-users/why we're all here***
  - Can't serve customers if don't know their needs
- ***Can't keep doing the same thing and expecting different results!***

# How do we get there?

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*Two dimensions to consumer engagement:*

- **Patients/General Public**
  - End-users
- **Consumer Advocates**
  - Dedicated to representing the interests and perspective of patients.
  - “Trusted intermediaries”

***Need Both!***

# Consumer Advocates

- **Key to:**
  - Ensuring project output is meaningful to consumers
  - Reaching and engaging end-users
- **Knowledge of constituents**  
*(needs, perspective, "barometer," cultural issues)*
- **Represent "population" vs. individual needs**
- **Intermediary— "Trusted source and messenger"**  
*(can help expand your communications capabilities)*
- **Moral imperative**  
*(Urgency! What's at stake)*
- **Skilled at "advocacy"**  
*(can balance diverse interests & perspectives)*

# Engaging Consumer Advocates

- **Who does the outreach matters**
  - Trust & respect are critical
  - Use person-to-person & peer relationships
  
- **“True” advocates**
  - Not everyone is!
  
- **Making the case for quality**
  - Link to access
  - Be sensitive to limited resources
  - “Right-to-know” can be compelling
  
- **Ongoing support and technical assistance**
  - This is new terrain & new language for most advocates

# Engaging Consumer Advocates

- **“More than one”**
  - Avoid “tokenism”
  - Most stakeholders travel in groups
  
- **Impact**
  - If they can’t “make a difference,” it’s not worth their time
  
- **Delivering to constituents**
  - “What’s in it for them”
  
- **Sustainability**
  - Must be more than a time-limited grant project

# For consumer advocates...

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- “Engagement” must be the “real deal”—
  - Involvement from the beginning
  - Leadership and decision-making

# Engaging Patients

## *Key Challenges*

- **Lack of public awareness**
- **Myths and misconceptions**
  - More is better
  - Health care is too confusing
  - Quest for Marcus Welby
- **Are we willing to tell the real story?**
  - i.e. “Evaluability”  
“Negative Framing”

# Other Challenges and Considerations

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- Make the information “actionable”
- Know your audience
- Use the right messengers and venues
- Test and improve
- Align benefit design

# Recruiting “Patient Advisors”

- Work through advocates, community organizations, providers
  
- **What to look for:**
  - Able to use personal experience constructively
  - Able to see beyond personal experience
  - Good people skills
  - Good communication skills
  - Can participate effectively in multi-stakeholder group

# Successful Patient Participation

- Orientation
- Ongoing support
- Genuine effort to include
  - Logistics
  - Welcoming environment
  - Language
  - Real listening
  - Regular debriefing
  - Consider “mentors”

# Conclusion

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- Engaging consumers as *equal partners* will require a “culture shift”
- May take us out of our comfort zone— but will drive quality improvement and patient engagement
- Can’t get there by doing “more of the same”