Patient & Family Engagement: Definition, Framework, and Shared Outcomes

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NCQC North Carolina Quality Center

Changes In Healthcare Driving PFE As A Priority

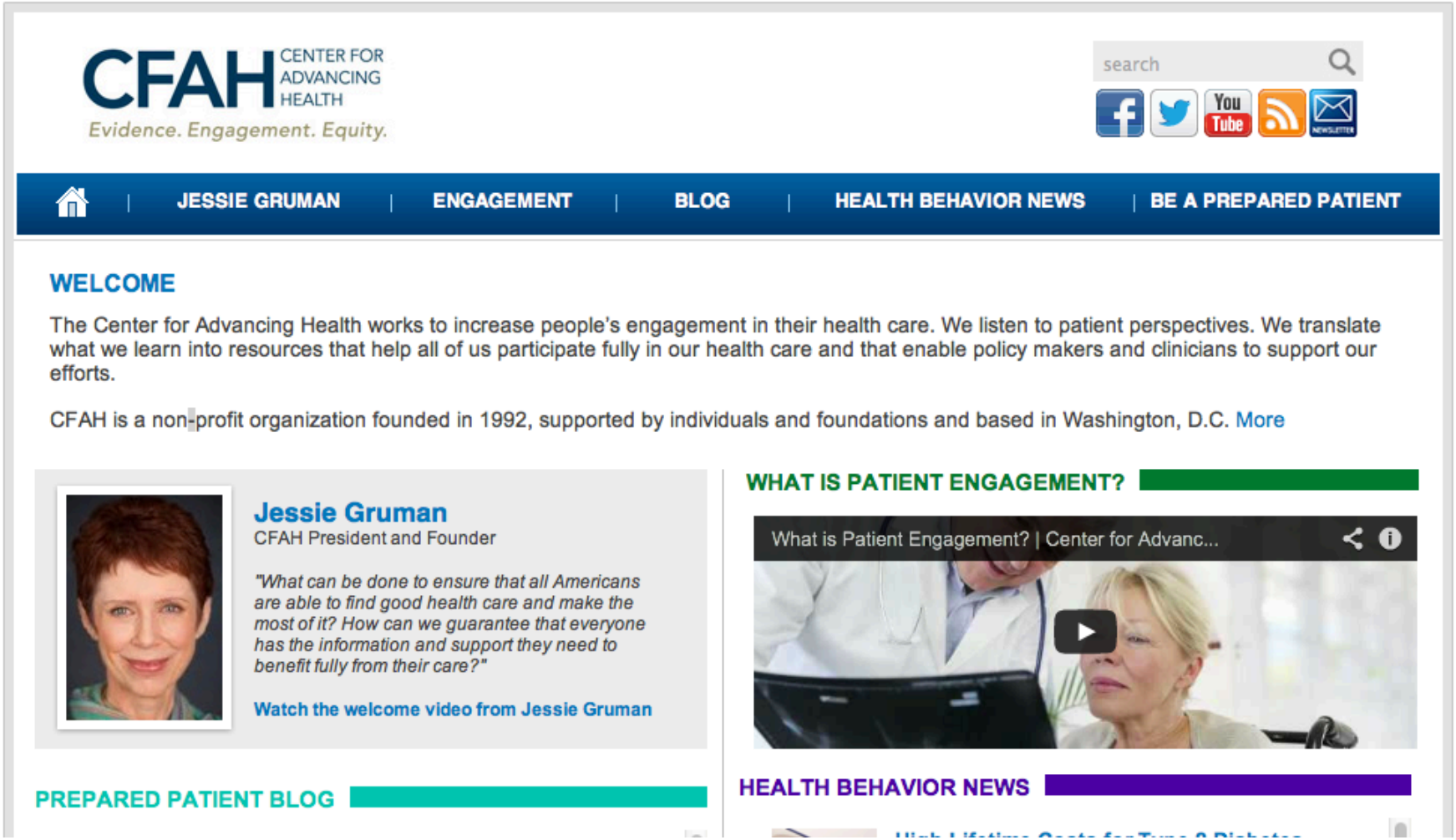
TODAY	FUTURE
Fragmented Care	Coordinated Care
Provider Centered	Patient Centered
Payment for Volume	Payment for Value
Facilities Focused	Care Systems Focused
Physician Accountability	Care Team Accountability
Paper	Electronic
Episodic, Hospital-Based Care Models	Longitudinal, Multi-Site Care Models
Inconsistent, Variable Methods	Efficient, Evidence Based Care
Cost Reduction	Cost Restructuring

PFE: The National Landscape

- Institute of Medicine (2000): Patient centered care one of six aims
- Affordable Care Act (2010): PFE essential part of health care delivery
- Patient Centered Outcomes Research Institute (PCORI): Meaningful engagement of patients in research
- Partnership for Patients 40/20 Campaign: Reduce harm, safety across the board, develop PFE advisor networks
- Health Infor. Tech. for Economic & Clinical Health (HITECH): meaningful use, patient access to medical records
- American Institutes of Research and GBMF: PFE Roadmap and Framework
- Health Research & Educational Trust, AHA: National PFE Survey
- Health plan changes and options: Expanded consumer responsibility

Definitions of Patient Engagement

- "The actions we take to benefit from the health care available to us." (Center for Advancing Health)
- "The 'holy grail' of health care" (KevinMD.com)
- "The next 'blockbuster drug" of the century (Forbes.com blog)
- "Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care." (American Institutes of Research)



Jessie Gruman
Center for Advancing Health
Patient Engagement
http://www.youtube.com/watch?v=AO-YwwISruI

Words Matter – And So Do Definitions

Patient-centered

"While patient-centered is a buzzword right now, providers need to reflect on what it actually means. At a minimum, providers will need to develop specific care plans that support patients' holistic health needs. ***Progressive organizations will go further and reorganize around patient needs, instead of specialties or academic disciplines."***

Inclusive

"It begins with the partnerships that will make care more collaborative, but does not stop with formal providers or community organizations. In the future, ***patients, family members, and lay caregivers will be more directly involved in both care planning and delivery.***

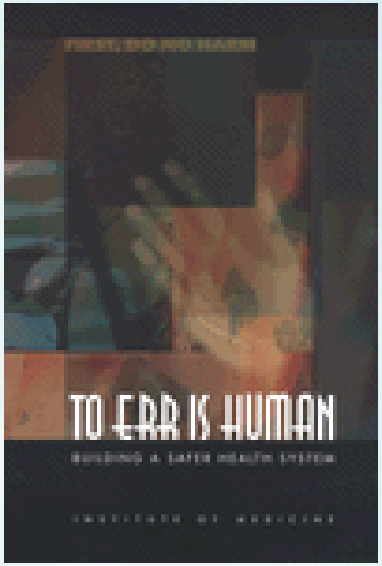
Rob Lazerow, Practice Manager
Health Care Advisory Board

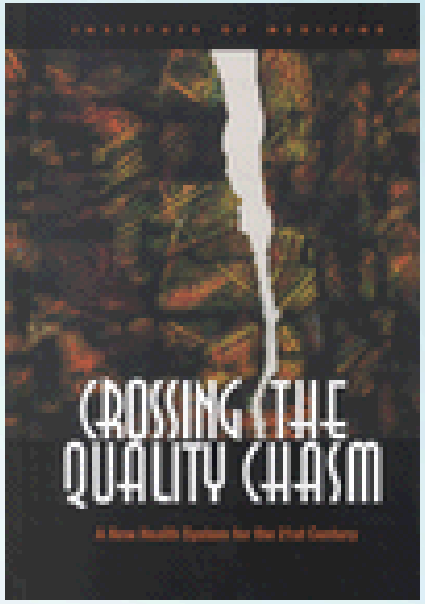
Definition of Quality

Care that is…

- ✓ **Safe**
- ✓ **Timely**
- ✓ **Efficient**
- ✓ **Effective**
- ✓ **Equitable**
- ✓ ***Patient Centered***

Institute of Medicine, 2000





Foundation for Engagement: Patient –Family Centered Care

"An approach to the planning, delivery, and evaluation of health care that is grounded in ***mutually beneficial partnerships*** among health care providers, patients, and families."

Source: Institute for Patient and Family Centered Care

"A ***partnership*** among practitioners, patients, and their families to ensure that decisions respect patient's wants, needs, and preferences and that **patients have the education and support they need** to make decisions and participate in their own care."

Source: IOM, 2001

The Foundation for Patient-Family Engagement: Patient-Family Centered Care (PFCC)

Dignity and Respect – *listen and honor choices*

Information Sharing – *communicate and share accurate, unbiased and timely knowledge with patients and families at all levels*

Participation – *encourage shared decision making in all planning, delivery, and evaluation of health care services and programs*

Collaboration – *partners in all aspects of care at all levels*

A Working Definition of Patient Advisors

Patient & family advisors *work in a variety of healthcare settings sharing their personal stories to represent all patients & families in providing an educated perspective of care by bringing authenticity, empowerment, respect and inspiration to the design and delivery of healthcare systems. Patient & Family Advisor roles include partner, educator, speaker, listener, advocate, collaborator and leader, ensuring the focus of healthcare is centered on the patient & the family. **

**Collaboratively written by the patient & family advisors in attendance at the IHI Forum, 2012*

Experience vs. Engagement

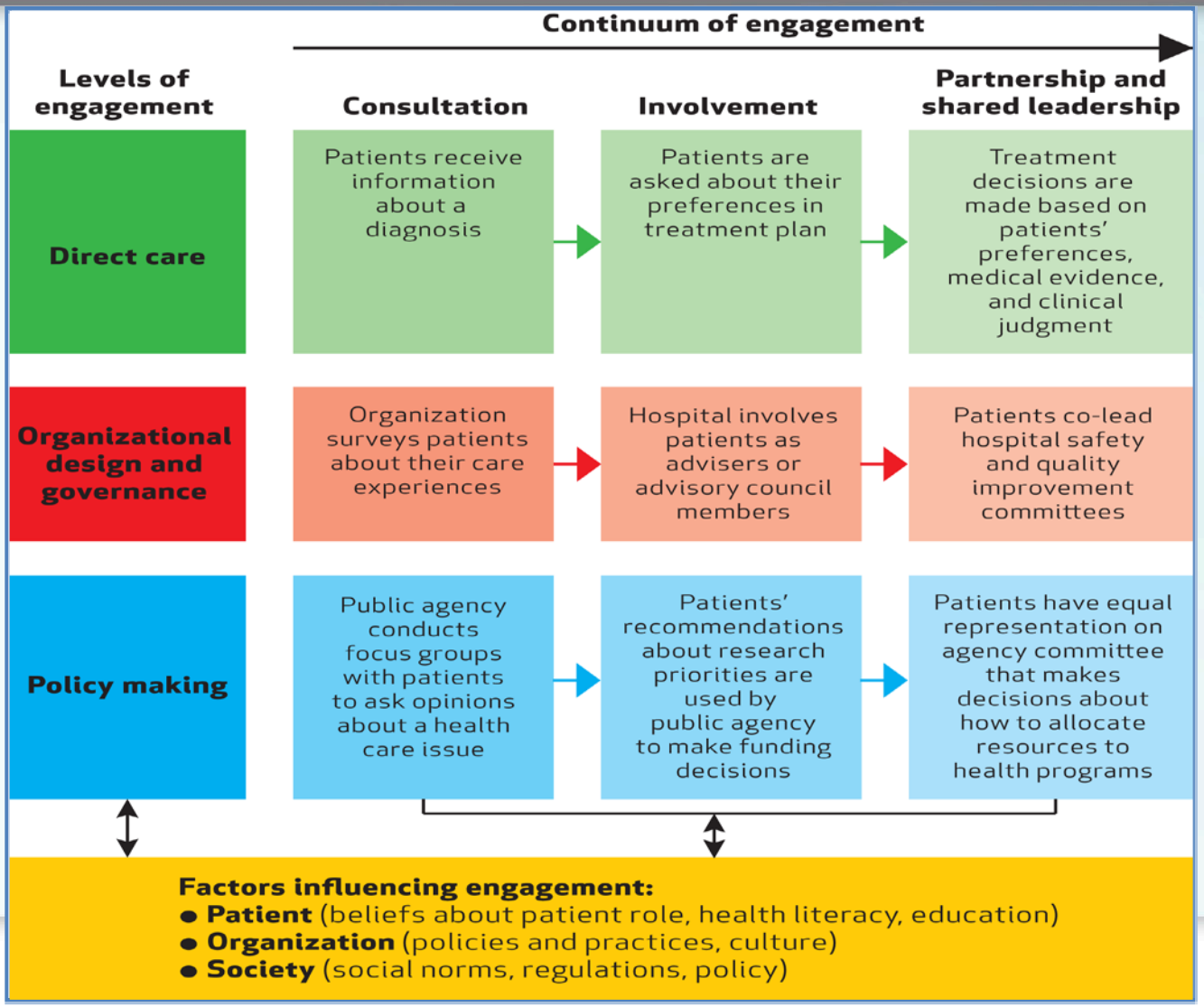
"To differentiate Patient & Experience and Patient Engagement, I think it's important to look at the goals of each. The goals of Patient Experience are to increase patient loyalty, increase market share and exceed the Patient's expectations. The goals of Patient Engagement are to get folks invested in their own care by providing opportunities and structures for patients and their families to become active participants in healthcare. The relationship is dynamic and reciprocal in nature, where as the Patient Experience work is more linear in terms of the healthcare organization making efforts to provide a positive patient experience. Although many patient experience efforts rely on patient input, engagement relies on an on going partnering relationship."

Libby Hoy, Patient Advocate

Patient & Family Engagement "Best Practices" Menu

- Handover reports (with patient & family engagement!)
- Family presence
- Interdisciplinary rounds with active involvement of patient
- Patient stories in all meetings (told by patients!)
- Safety rounds with patient advisors
- Shared decision-making tools and teach back
- Patient communication boards and care plans
- Patient & Family Advisor roles and councils
- Advisors on boards, leadership and performance improvement teams
- Patients & Family members as faculty
- Education material development with patients
- PFE priorities reflected in strategic plan, HR policies, leader expectations, performance contracts, etc.

Framework for Patient & Family Engagement
Karman KL et al, *Health Affairs* v. 32 no. 2 223-231 (2013)



Key Themes:

- *Continuum*
- *Levels*
- *Influencers*

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Levels of Patient Engagement

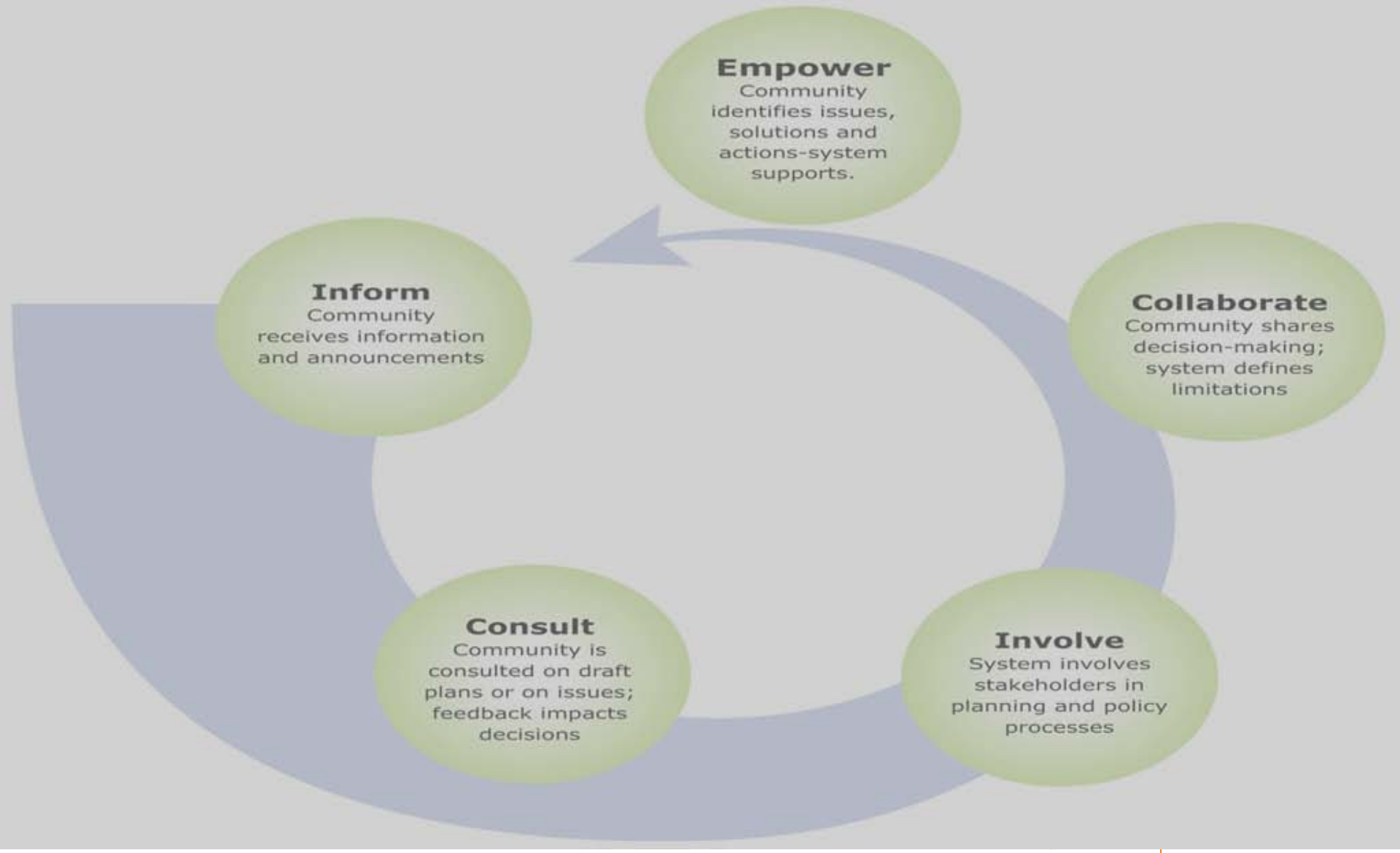
Individual (skills & knowledge)
Mutually agreed upon treatment plan

Healthcare Team (shared understanding)
"Handover" reports
Teach-back & access to medical records

Organization (integrate perspectives)
Patient-family advisors and advisor councils
Family presence

Community (population health)
Health education and literacy programs
Local, state, and national policy development

Engagement Model for Patients, Families, and Communities



Spectrum of Participation - International Association of Public Participation

What matters to patients…

Treat me with compassion and respect.
Ask me what I need. Get to know me.
Provide me with the best care possible.
Listen to and understand me.
Don’t judge me.
Respect my differences.
Let me define my family.
Involve me as a partner.
Give me information that is useful.

“ONE OF THE MOST IMPORTANT LEADERSHIP LESSONS IS REALIZING YOU ARE NOT THE MOST IMPORTANT OR THE MOST INTELLIGENT PERSON IN THE ROOM AT ALL TIMES.”

A GOOD LEADER INSPIRES PEOPLE TO HAVE CONFIDENCE IN THE LEADER.

A GREAT LEADER INSPIRES PEOPLE TO HAVE CONFIDENCE IN THEMSELVES.

For more information contact

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