Beyond Stigma: Public Education and Awareness Campaigns

NAMI Strategies

Bob Carolla
Director of Media Relations
NAMI (National Alliance on Mental Illness)
bobc@nami.org

Institute of Medicine Epilepsies Committee’s Workshop on Health Care Quality, Access and Education
Washington, D.C.
June 29, 2011
Stigma is imposed by others

“Deriving from a condition which the target of the stigma either did not cause or over which he has little control.” – Gerhard Falk, *Stigma: How We Treat Outsiders* (2001)

**Structural**

- Laws and regulations
- Policies or practices

**Cultural**

- News
- Entertainment (television, movies, attractions)
- Advertising
- Retail products (costumes, toys, t-shirts)
Surgeon General’s Report on Mental Health

Chapter One, “The Roots of Stigma”

http://www.surgeongeneral.gov/library/mentalhealth/home.html

In 1999, the report is a landmark. A widely recognized, official authority identifies stigma as a public health concern, providing leverage for advocacy.

In 2003, the President’s New Freedom Commission on Mental Health calls for “a national campaign to reduce the stigma of seeking care.”

“Stigmatization of people with mental disorders has persisted throughout history…Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders.”

“It reduces patients’ access to resources and opportunities…and leads to low self-esteem, isolation and hopelessness. It deters the public from seeking and wanting to pay for care”.

“In its most overt and egregious form, stigma results in outright discrimination and abuse… It derives people of their dignity and interferes with their full participation in society.”
Strategies
Each one can reinforce others

Praise
Protest
Personal Contact
Partnerships
Advocacy

*Protest and advocacy include education and raising awareness*
Protest

NAMI StigmaBusters program

- Specific target
- Private contacts or through the news media
- Public teaching moment
- Pressure points: bad publicity
- Seeks remedial action
- May change behavior, but not attitudes
- Can lead to partnerships

List serves, Facebook, Twitter are effective for mobilizing individual actions

Traditional media for broad protest and public education

Works best locally for achieving remedial action and building partnerships
Protest Case Study: Who Won?

Crazy for You Bear
Valentine’s Day 2005

Local controversy became national
Teaching moment in national media
Apology and promise to “make no more”
Rejects call to stop selling existing inventory
Governor speaks out
Bear sells out
CEO forced off hospital board
Now a $500+ collector’s item on E-Bay
Personal Contact
The Face of Mental Illness

Civic Presentations by Individuals
Living with Mental Illness

www.nami.org/ioov
Personal Contact
The Face of Mental Illness

www.nami.org/namiwalks

Energizes grassroots
Raises community awareness
Builds partnerships
Uses traditional and social media
Raises local funds
Measurements
Output, Circulation, Engagement vs. Effectiveness
Still Evolving

Protests

Case by case results: responses from target
Media coverage: amount and content
Social media: engagement; comments

Personal contact

Before and after audience surveys
Television and movies: audience figures; surveys
Recommendations

*These are personal ideas only. They do not necessarily represent NAMI positions or proposals.*

- Publish an official major report on stigma as a public health concern: for epilepsy alone, brain disorders in general or all illnesses.

- Broaden the campaign to a “one brain, one mind” perspective based on science. Use an overarching logo, tag-line, etc. in which disease-specific content can be inserted.

- Outreach: include social media for news, discussion, action

- Develop more and better baselines, monitoring and measurements, including surveys around “stigma events” (movies, etc.)

- Include grassroots strategies.