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Engaging Community - Paths to Patient Involvement

"Alone we can do so little; together we can do so much." Helen Keller



CATRINS HEPC FREE BY 2020

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Empowering patients to be lobbyists and change agents









Asset based community development ABCD (Kretzmann, 2010)

We value the unique skills and contributions of members

focus on assets and strengths rather than problems and needs



Our vision of resilience influences our communications with the public whereby we encourage and value the strength of community members

be relationship driven

We value the things that contribute to resilience such as story telling, art, and music

identify and mobilise individual and community assets, skills and passions

Asset Based Community Development (Kretzmann, 2010)





- recognises social capital and relationship building as an asset
- values empowerment and ownership of the development process
- makes efforts to strengthen civil society. These efforts have focused on how to engage people as citizens (rather than clients)

Key elements to a successful community reference group

- 1. Staff facilitator
- 2. Shoulder tap
- 3. Shared vision
- 4. Be curious
- 5. Remunerate
- 6. Give back
- 7. Reduce pressure, increase fun









Anchorage, August 2017



Resilience



Two core concepts:

- adversity
- adaptation

Capacity for resilience depends on

- individual personality traits
- · resilience building processes

(Fletcher & Sarkar (2013). Psychological resilience. European Psychologist, 18(1), 12-23)



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CONNECTING Finding allies Resilience = Rebuilding of the Self Socializing with others Talking to others Participating in counseling Connecting to a Higher Power Repairing relationships REFOCUSING Shifting priorities Working on self-improvement Clearing away negativity Focusing on action SELF **ACCEPTING** Accepting the situation SELF Facing one's feelings Expressing one's feelings Shame UNDERSTANDING Understanding external factors Developing insight into oneself Separating from the shame Creating meaning RESISTING Rejecting negative judgments Asserting oneself Challenging others Source: Shame and resilience in adult-hood: A Grounded Theory study (Van Vliet, 2008)

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Group membership

Social-cognitive learning theory (Bandura, 1998):

- Increased individual self-efficacy through vicarious learning
 "Wow, she says she feels great after doing that talk, maybe I could try it too..."
- Increased team self-efficacy after successful community action → "Hey, that went better than we thought, lets go even bigger next year!"





Building strength and influence

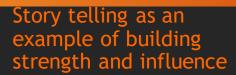
Peer support (Dennis, 2003)

- → assistance provided by a created social network with similar characteristics as the target population, as well as experiential knowledge of a specific stressor
- → Facilitator selects suitable team members

Critical public health approach (Greenhalgh, 2009)

- → patients challenge barriers to good health, such as discrimination and social exclusion
- → oppose prevailing norms and values (if necessary)
- → seek social justice





We speak for ourselves, and on behalf of the group in general, and on behalf of the community

Sometimes we may not want to use our full names

We might prefer to be "out" in smaller settings, rather than in the media

We encourage members to protect their privacy around questions from media or public that feel intrusive or stigmatising

Sometimes we may wish to hold back aspects of our story

With higher self-efficacy, CHAT members feel empowered to be active in health promotion and advocacy, encouraged to try new things such as public speaking, and confident in treatment choices

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Self-efficacy and empowerment

People with strong self-efficacy believe they can accomplish even difficult tasks and see them as challenges rather than threats to be avoided (Bandura, 1994)

accomplishments, proud we are a loud voice for hepatitis, and even prouder of the kinship and caring support network we have created JAYE CHAT has been a wonderful boost to my self esteem and self confidence Little did we know what a profound effect this would have, let alone the psychological benefits that would flow on from this on a CHAT has taught me the meaning of resilience: the ability to accept and adapt to challenges, to gain strength and accept support from those around us and to speak out and take action on issues that matter

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