



## Psychiatric Patient Advocate Office

### Developing a Research Agenda for Mental Health Advocacy

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## Considerations

- What is mental health advocacy?
- What is its role in a comprehensive mental health system?
- What contribution does advocacy make to positive health care outcomes and what are its underlying mechanisms?
- What can be learned from further study?

## Advocacy Defined

- No single definition
- A multidimensional concept
- Includes a broad range of roles, functions, activities and goals
- Many different models
- Many different proponents

## Advocacy – A Broad Range of Activities

- Provision of education and information
- Consciousness-raising
- Mediation
- Negotiation
- Peer support and mutual aid
- Legal redress
- Political engagement and activism

## Types of Advocacy

- Family
- Legal
- Peer
- Political
- Professional
- Self
- Volunteer

## “Advocate”

- “to plead or raise one’s voice in favour of”
- “to defend or recommend publicly”

*Oxford English Dictionary (2<sup>nd</sup> ed., 1989)*

## Goals of Advocacy

- Restoration of decision-making authority
  - Autonomy
  - Personal effectiveness
- Mitigation of vulnerability
- Rights protection and realization
  - Human
  - Civil
- Reduction and elimination
  - Stigma
  - Discrimination
- Promotion of social inclusion

## A Social Constructionist Model of Mental Illness

- Takes into account the experience of disease or dysfunction
- Includes personal, family and cultural values and belief systems
- Experiences may lead to differing explanatory models, consumer choices and satisfaction with proposed treatment regimens

## A Social Constructionist Model of Mental Illness (cont'd)

- Has heuristic value
- Provides clues to our understanding of the genesis of stigma, discrimination and social marginalization
- Examines the complex interplay of social and biological factors contributing to individual vulnerability
- Assists in developing more effective approaches to symptom and illness management

## Individual Autonomy vs. the Authority of the State

- Advocacy serves as a counterweight within the mental health system
- Supports autonomous decision-making in the least restrictive care environments
- Consonant with emerging best practices
- Consistent with the principles and protections of a democratic society

## Enhancing Personal Control Through Empowerment

- The ability to take charge of one's life may be a key determinant of mental health and continued well-being
- Biological or genetic characteristics may not be readily modifiable, but it is possible to address an individual's personal and environmental resources

## Models of Empowerment and Some Empirical Findings

- Establishing equality between clients and professionals
- Personal power may be augmented through treatment partnerships and community accommodations
- Trust, empowerment and choice may positively impact consumer engagement with health care services
- Making one's own choices may improve personal effectiveness, self-esteem and social competence
- Collaboration between doctors and patients may support adherence to treatment regimens

### Models of Empowerment and Some Empirical Findings (cont'd)

- Education and empowerment programs may foster improved consumer outcomes while reducing the use of traditional services
- Quality of life, increased employment and community involvement may be positively associated with consumer empowerment
- Empowerment may be fundamental to both recovery and advocacy

### Advocacy and Grassroots Recovery Share Common Elements

- Consumer driven
- Empower consumers to make their own choices
- Strive to reduce barriers to personal needs and wants
- Preserve consumer rights and entitlements

### Stigma and Discrimination

- Pervade society
- Endemic to health and mental health care systems
- Consumers may stigmatize themselves by incorporating negative social values
- Self-stigma may negatively impact service usage

### Stigma and Discrimination (cont'd)

- Cultural beliefs and attitudes may engender stigma and lead to discriminatory access to medical services
- Recent findings demonstrated inequitable access to preventative interventions for cardiovascular disease was associated with status as a psychiatric patient – Kisely, et al., (2007) Inequitable access for mentally ill patients to some medically necessary procedures. *Canadian Medical Association Journal*, 176 (6), 779-784
- Continuing medical education may help to reduce stigmatizing beliefs held by physicians and medical students

### Mental Health Advocacy Studies

- Limited body of literature
- A randomized controlled study used an advocacy model to support community tenure – Freddolino, P. Moxley, D & Fleishman, J. (1989) An advocacy model for people with long-term psychiatric disabilities. *Hospital and Community Psychiatry*, 40, 1169-1174
- Individuals who received advocacy services were hospitalized significantly fewer days than a control group, after controlling for demographic and clinical variables

### Fundamental Assumptions

- Advocacy is integral to a comprehensive mental health system
- Advocacy strikes a balance between the authority of the state and individual self-determination
- Empowerment may be central to all advocacy models
- A consumer-driven, grassroots recovery model and advocacy share common elements
- There have been very few studies of advocacy and its impact on health care outcomes for individuals with mental illness

### Conclusions: Further Explorations and Linkages

- Consumer empowerment and self-identified goals for recovery
- Interrelationship of self-esteem, personal power and personal effectiveness and their impact on individual health and well being
- How do advocacy interventions (e.g., negotiation, facilitation, provision of information, collaboration and self-advocacy) positively affect quality of life, care and personal satisfaction?
- How does advocacy mitigate individual vulnerability and the stress engendered by feelings of powerlessness?

### Conclusions: Further Explorations and Linkages (cont'd)

- How does the provision of advocacy reconcile best interest and rights protection and consumer autonomy perspectives, which are often viewed as diametric opposites?
- How can advocacy positively inform the development of public policy?
- How does advocacy impact consumer service access, engagement and utilization?
- What are the points of intersection between clinical best practices and the protection and realization of consumers' civil and human rights?

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