



Consensus Development Conference on IMPROVING MENTAL HEALTH TRANSITIONS

November 4 – 6, 2014

Edmonton, Alberta

Institute of Health Economics

Question 3:

What is the evidence for the role of other support systems, including primary care in effective interventions?

The role of nongovernment organizations (in effective support systems).

Presentation by:

Orrin Lyseng

Executive Director

Alberta Alliance on Mental Illness and Mental Health (AAMIMH)



Conflict of Interests

No conflict of interests to disclose

What is the AAMIMH?

- A consortium of six professional organizations and eight non-profit organizations which have come together to speak collectively on issues of common concern around addiction and mental illness and mental health
- Its mandate has three key points:
 - Work to ensure the mental health system reflects best practices and is responsive to the mental health needs of Albertans.
 - Unify and strengthen the voices of the mental health communities.
 - Advocate for mental health issues to be prominent on health and social policy agendas.

Non-government Organizations

A **non-governmental organization (NGO)** is any **non-profit**, voluntary citizens' group which is **organized** on a local, national or international level.

Google

AAMIMH NGOs that provide service and support to persons living with a mental illness and their families and are provincial in scope would include ...

- The Canadian Mental Health Association (CMHA)
- Schizophrenia Society of Alberta (SSA) and its Branches
- OBAD (Organization for Bipolar and Affective Disorder)
- The Alberta Network for Mental Health

NGO's Continued:

- Regional NGO's provide services within a geographic area such as the Regional offices of CMHA and Branch offices of SSA
- Some NGO's may provide a selected range of services
 - The Support Network (Edmonton) – crisis support, 211
 - The Distress Centre (Calgary) – crisis support, 211 & supportive counselling
 - Prosper Place Clubhouse – which follow a model of psychosocial rehabilitation and provide support to their membership
 - John Howard Society of Alberta (& Elizabeth Fry Society)

Three types of NGOs serving those with SPMI

- NGO's that provide a broad range of services and often beyond just services to persons living with SPMI.
Such as: CMHA, The Support Network, Distress Centre, Food Banks, others like Boyle Street Community Services in Edmonton.
- Those that are diagnostic specific or service specific - such as SSA, OBAD, Clubhouse, etc. Their boards may or may not be 100% consumer driven.
- Peer driven, not diagnostic specific, peer support organizations completely directed, staffed and run by people with lived experience of mental illness such as ANMH and in the case of addictions – the 12 step programs

Other organizations serving those with SPMI

Often overlooked when viewing the services provided to SPMI are organizations that provide a range of services to a broad cross-section of the population such as:

- Salvation Army
- Other church based organizations - like Catholic Social Services
- Other community organizations funded through United Way and other philanthropic support

What makes NGO's important?

Persons with severe and persistent mental illness (SPMI) should be able to expect that they have a range of services that they can choose from and access in order to be effectively maintained and thrive in the community.

- NGOs provide a range of services that is complementary to the formal clinical system
- The demand for services on the clinical system is high and the costs of a clinical system using treating professionals is high
- Often services delivered by NGOs can be at less cost than the clinical system due to salary differences and the strength of NGOs volunteer base. This can make NGOs an attractive alternative or complement to the clinical system in providing supportive services.

Examples of NGO services

- Peer support programs
- Social / Recreation programs
- Supportive career programs – job mentoring
- Basic life skills– cooking,
- Supportive housing
- Supportive counselling

NGO's provide a sympathetic, non-threatening environment that can result in a sense of community and belonging for the person with SPMI.

Observations

- Supportive housing services provided by NGOs are an important strategy in ensuring effective transition of the person with SPMI from institution to the community and for maintaining them in the community.
- Effectively maintaining the person in the community through provision of supportive services reduces the use of the more costly clinical system.

Observations (cont'd)

Prosper Place Clubhouse (Edmonton) recently produced a video of quotes and comments from the members and their families on the value that they saw of the clubhouse relevant to their health.

In the video:

- they acknowledged having a sense of belonging
- they had a sense of comfort that they did not have when attending the formal clinical setting
- they felt that they were mentally more healthy because of their belonging to the clubhouse
- they felt they had a sense of future
- family members saw their loved ones experience personal growth and felt their mental state had improved



Observations (cont'd)

A noted psychiatrist stated he once used to go to a peer support program through SSA called Unsung Heroes. He commented that, “I used to go and talk to them about mental health and mental illness and also about their medications. Now I go and listen to them talk and hear them share their experiences. One of the things that they talk about is the value of their job or their volunteer work. While some may discount the small hours that this may entail, for them this job provides them with meaning.”


Observations (cont'd)

The Partnership Education Program (SSA)

- provides presentations upon request to inform the public about schizophrenia which ideally are provided by a mental health professional, a family member and a person living with schizophrenia
- provides an understanding of the illness and an appreciation of the impact on the family and the individual

During my time as the Executive Director of the SSA, I had opportunity to review the feedback on the presentations. Several themes I noted:

- it helped people to understand the illness, thereby reduce the negative stigma,
- they felt empathy to the families
- they appreciated and admired the person living with schizophrenia who so willingly shared their experience



But what was significant for me was the pride and meaning these people felt in speaking of their life and their experience.

They were Advocates.

Advocacy is a strength of NGOs that is often not recognized and acknowledged.

Person's with a lived mental illness experience, and their families, are uniquely positioned to put a human face on an illness that carries a negative stigma and is often hidden. And NGOs can play a powerful role in that delivery.




Notable Alberta advocates:

Jim Hunter – Order of Canada

Austin Mardon – Order of Canada

Dennis Anderson – Governor General's Caring Canadian Award

No less important are the awards given out by the NGO organizations that recognize the significant contributions of individuals who speak out and advocate for support and understanding for those who experience a mental illness.



Just as it is important to recognize the value of these individual advocates, it is also important to recognize that NGOs themselves need to take a strong advocate role as well.

It can involve some discomfort.

How do you state to an organization that “You need to do your job better to ensure that persons with SPMI receive the services”, when the organization that you are speaking to is the very organization that provides you with the funding to operate?

How? You do so as an advocate. Speaking on behalf of the person that is receiving the service, not the organization delivering the service.

Nevertheless, NGOs are faced with challenges.

NGO challenges

These challenges were recognized by two organizations;

- the AAMIMH
- the Albert Disabilities Forum, a coalition of over 40 non-profit Alberta-based disability organizations

They jointly released a position paper document in 2014 entitled:

Valuing and Supporting Alberta's Non-Profit Disability Organizations (NPDO): Challenges and Solutions

Copies can be downloaded from either the AAMIMH or ADF websites

www.adforum.ca

www.aamimh.ca



Six Overarching Strategies

1. Develop strategies that will attract and keep required NPDO skill sets (both staff and volunteers)
2. Develop funding models that will enable NPDOs to do long range planning, meet administrative needs, eliminate cash flow problems and focus on service provision
3. Reduce administrative expense and time by simplifying and standardizing grant, contract, evaluation and reporting tools and processes

Over arching strategies cont'd

4. Support self advocacy and other programs that give persons with disabilities meaningful input and involvement in their own care and support, and streamline access to appropriate services in the least difficult way
5. Develop agreements and common policies/procedures on the sharing of information so that regional service availability, gaps and opportunities can be identified and decision making is based on accurate information
6. Vet policies and procedures through members of the disability community and their families to ensure they are workable and practical and meet the needs of the person with the disability



Summation:

NGOs play a critical role in the delivery of a range of needed support services to persons with SPMI. These services can:

- involve direct services such as supportive counselling / supportive housing, recreation and social support.
- involve advocacy efforts on behalf of the person with SPMI and their families, including public education and awareness activities with the intent to create a more informed, understanding and supportive community



But challenges exist

NGOs need to be considered a partner in the long term planning of services to persons with SPMI

NGOs need funding models that will enable long range planning and better resource allocation

NGOs and the people they serve need to be consulted on the possible impact of changes on their ability to provide service and ultimately the impact on the person that receives the service when changes to policy and funding models by government and large health care providers are being considered