Brief to the Canadian Mental Health Association (CMHA) National Board of Directors

Submitted by the National Consumer Advisory Council (NCAC)

The farther backward you can look the farther forward you can see.

Winston Churchill

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Changing the process, expanding the actions, but not the intent

Background
Increasing participation and involvement of people living with mental illness within the CMHA has been a priority for over 20 years. In 1983 a resolution was passed that CMHA intensify its historically strong advocacy stance, ensure action is taken to improve quality of life, combat stigma, foster community involvement, foster development of consumer self-help groups, and recruit qualified persons who have been mentally ill as members of national committees and for other leadership roles. At the same time, the Framework for Support approach was being developed, and the first document, by John Trainor and Kathryn Church, was published in 1984. This was followed over the next two decades by policy and program initiatives throughout CMHA, and several revised versions of the Framework document by Trainor, J., Pomeroy, E. and Pape, B. Since its inception in the early 1980’s, the Framework policy project has called for the full involvement of consumers and families in mental health systems that are community focused and recovery oriented. In support of this, the Framework identified four key interest groups with the potential to integrate and support people with mental illness. The Community Resource Base, as these four groups are collectively called, reflected a shift in thinking by including consumers and families as full partners, along with mental health service providers and representatives of generic community groups and agencies, in the process of planning and operating the mental health system. These ideas of partnership, and the redefinition of consumers and families as key players and change agents with a wealth of practical and experiential knowledge, have proven to be enduring components of the Framework model. They are the foundation for a policy approach that is centred on the lives of people with mental health problems, not just the professional service system that is designed to help them.

The Framework for Support model is compatible with the best practices approach and was recognized in 1997 as a best practice in mental health policy.

In 1986, as part of the Framework project, a national Consumer Participation Task Group (CPTG) was formed for the purpose of increasing the involvement of consumers in planning and decision-making in mental health services and within society, and to look at consumer participation within the CMHA. The Task Group’s efforts had two immediate and concrete results. First, a resolution was passed that CMHA develop a plan to operationalize its commitment to increased consumer participation at all levels of the Association. Secondly, the National Board of Directors passed a motion in 1987 to establish a consumer advisory committee as a parallel to its existing professional advisory committee, with the goal of providing a consumer perspective to the Canadian Mental Health Association. . The CPTG evolved into the Consumer Participation Advisory Committee in 1991 and eventually became the National Consumer Advisory Council (NCAC). The original members of the committee decided that its membership should reflect the Framework’s Community Resource Base by including Consumers, Families, Mental Health Service Providers, Generic Community Groups
and Organizations, with a majority of consumers. In 1998, the NCAC returned to the original spirit of autonomy and self-direction behind its mandate by determining that its membership would be all-consumer, and it has remained that way to the present.

Since that time many Branches/Divisions/Regions have included consumers on their Boards and Committees, and government bodies have recruited consumers onto advisory committees.

In November of 1995 the following recommendations were put forward to the National Board of Directors:

1. That the Canadian Mental Health Association advocate, in full partnership with consumers, for consumers’ right to total participation in society. This includes advocating for provision of consumers’ basic needs, their special needs related to the disability, the recognition of their abilities, and their right to participate in decisions about their own lives.
2. Participating meaningfully includes taking an active role in the policy-making of the organization. Meaningful participation of consumers in the activities and leadership of the Association will be beneficial and must be supported by CMHA. Nominating committees shall seek consumers with expertise from their experiences inside and outside the mental health system. The Association shall ensure that opportunities for involvement, training and support are available to all consumer and non-consumer board members regarding issues of consumer participation.
3. That the Canadian Mental Health Association recognizes the essential value of consumers’ life experience as a key qualification for employment at all levels of the Association. It is strongly recommended that consumers be proactively sought to compete for employment opportunities within the Association.
4. That the Canadian Mental Health Association encourages and support consumer groups and networks in ways that respect their autonomy.

Revitalizing the Consumer Participation Base

The need for consumer input and participation in all CMHA activities, including staffing, governance, and evaluation, has been strongly acknowledged as a priority by the Association, and formalized in policy statements for many years. From time to time, CMHA members have identified the need to refresh this commitment, perhaps because of personnel changes over the years, changing perspectives, or simply a need for renewal of patterns that can become routine. In 2006 the Public Health Agency of Canada provided funds to the CMHA to mount a project to revitalize consumer involvement and maximize meaningful participation within CMHA. The project, Back to Basics: Enhancing our capacity to promote consumer participation and inclusion had the following objectives:

- To enhance the capacity of CMHA at all levels to involve consumers of mental health services in their activities and governance
• To enhance the capacity of CMHA at all levels to promote community inclusion of people with mental illness
• To create tools, resources and mechanisms for enhancing CMHA’s capacity to implement internal measures to ensure meaningful involvement of consumers in the organization’s policies, programs, and services
• To create tools and resources for enhancing CMHA’s capacity to implement external measures to promote inclusion of consumers in community life

This project developed consumer involvement tools during its one-year run. They were as follows:

**Consumer Involvement tools (development guided by the National Consumer Advisory Council)**

1. *Guideline for analysis*: In consultation with CMHA Divisions, Branches, and Regions, a set of guidelines for analyzing current barriers and opportunities for consumer engagement was produced.
2. *Tips for good practice*: Building on tips and strategies from CMHA affiliates, a set of good practices, tips and ideas for promoting consumer involvement in governance, staffing, and volunteering within the Association was produced.

**Inclusion in Community tools (development guided by the Mental Health Services Work Group)**

3. *Discussion Guide on Recovery*: Building on the Framework for Support document, a discussion guide for CMHA was created to use internally or with external partners on understanding the consumer-centred approach, the pillars of recovery and their implications for policy and practice.
4. *Workshop outline on best practices for promoting inclusion*: A workshop outline was developed based on Framework for Support concepts, directed toward staff and volunteers within CMHA affiliates. It would help them discover strategies for connecting with a variety of community resources to promote resilience, recovery, and community inclusion of consumers, and can serve as a template for training and education of others in their networks.

**Analysis of Current Role of the National Consumer Advisory Council (NCAC)**

Over the years, the NCAC has been instrumental in providing policy leadership regarding consumer participation within the Association. It has brought the consumer perspective to all of the issues and concerns on the CMHA’s agenda. Some of the accomplishments of the NCAC are:

- Developed the discussion paper Power, Paternalism and Partnerships, 2006
• Lead in the development of three resource packages on consumer participation for information sharing on strategies across CMHA
• Lead a survey of consumer participation within CMHA 1998
• Provided input on policy statements on Consumer Involvement, 1992, and Consumer Volunteers, 1998
• Assisted with encouraging nominations of consumers to the National Board
• Produced the Consumer Participation Celebration Package, a history of consumer participation within CMHA in honour of CMHA’s 75th anniversary, 1992
• Established the Consumer Participation Award in 1990

The current responsibilities as stated in the NCAC terms of reference are:

1. To provide advice to the CMHA National Board of Directors related to emerging issues as identified by the board or as identified by NCAC members.
2. To provide a consumer perspective in the Canadian Mental Health Association’s development of plans, programs, initiatives and policies.
3. To provide consultation and advice to the National Board of Directors and Committees on current issues, or to provide access to such consultation and advice and/or have representation on said committees.
4. In the performance of its function, to liaise with any and all work groups that has been assigned by the board president.
5. To monitor, encourage and support implementation of consumer participation initiatives at all levels of the Canadian Mental Health Association.
6. Members of the NCAC will make themselves available as much as possible to branches/regions/divisions to provide the consumer perspective.
7. To recommend an NCAC member to assist the work of CMHA and its committees/work groups.
8. An NCAC representative will serve on the CMHA National Office’s Awards Committee annually, and the NCAC will have sole voting privileges on the Consumer Involvement Award (Consumer) and the Consumer Promotion and Inclusion Award (Non-Consumer). To avoid any conflict of interest, the NCAC will not nominate any active NCAC member for an award, until their term of office as a voting member has ended.
9. To monitor, support and encourage increased consumer participation in the mental health field.
10. To promote mechanisms within CMHA that enhances communication and collaboration among the various consumer groups across Canada.
11. Each member will be responsible for carrying out the duties of a member and if need be, step down if unable to perform duties.
12. Each member will connect with consumers in their region as much as possible in order to bring their views to the Council.
The NCAC has held a seat on the National Executive Committee for the past fifteen years.

The NCAC has met in conjunction with the National Board of Directors every year (sometimes twice a year) for the past 22 years to carry out business such as making recommendations to the National Board of Directors, sharing items of interests concerning consumers in the various provinces and territory and to assist with the national awards ceremony.

**Advantages to involving consumers**

It has been recognized for years that consumers have a rich experiential knowledge to tap into. Organizations involving consumers in a meaningful way gain credibility and legitimacy with government funding bodies, services providers, families etc.

Other advantages to organizations that involve consumers are the:

- Benefit of consumer expertise
- Development of effective policies, programs and directions that is relevant to the constituency’s needs.
- Strengthened consumer voice and identification with organization
- Diversity of perspectives that contribute to organization decision making
- Reducing stigma both within and outside the organization

The rationale for consumer participation in mental health is twofold. First, it is an important value. Consumers have the right, as citizens, to participate fully in decisions that affect their lives and to be included in community life (Lord and Hutchison 2007). Second, active consumer participation benefits consumers (through increased social support, self-respect, and dignity), the mental health system (through enhanced relevance, realism, effectiveness, and sensitivity on the part of professionals), and the community (through the inclusion of people with diverse backgrounds and talents) (Hutchison et al. 1986).

**Proposed Change in Model and Role for the National Consumer Advisory Council (NCAC)**

**Future Role**

Changing times require examination of the structure and mandate of the NCAC. In conjunction with the CMHA’s strategic plan, the NCAC has examined its mission and proposes a shift in its mandate. “The National Consumer Engagement and Action Committee” (NCEAC) would carry on with the work of the former National Consumer Advisory Council, but will enhance the role and work in a different way. The NCEAC proposes to work in three major areas.
The model being proposed is outlined below. The three points of function for the NCEAC is to **advise** (CEO, Senior Management Team, Consumers, Consumer Organizations – internally and externally) **collaborate** (with Consumers, Consumer Organizations – internally and externally) and **engage** (Consumers – internally and externally).

1. **Advise**
The Canadian Mental Health Association continues to support and recognize the importance of consumer input and involvement throughout the Association. The need for a consumer body to provide advice and counsel on issues of importance to the consumer sector across the Association remains pivotal.

The CMHA also requires a national body of people with lived experience to connect with proposed “consumer reference groups” (consumers identified through the divisions/branches/regions) to bring issues of critical importance to consumers by consumers. Branches, Regions or Divisions would be asked to support the consumer reference groups in their provinces/territory by providing access to a telephone, computer and temporary space for conference calls. This would be a reciprocal relationship whereby input will be funnelled from the consumer reference groups to the National Consumer Engagement and Action Committee and reported on to the National Chief Executive Officer and the CMHA Senior Management Team.

2. **Collaborate**
It is important at this time that consumers within the Association make stronger connections internally and externally in order to work in a unified fashion.

**Collaboration with the Senior Management Team**

The proposed new working relationship with the Senior Management Team will help to bring a new working dimension and vitality to the work of this new model.

**Collaboration with National Mental Health Organizations**

The NCEAC will partner with other organizations for input on consumer values, empowerment, and meaningful engagement. Examples of organizations to partner with are the National Network for Mental Health (NNMH), Mental Health Commission of Canada’s Peer Support Project (MHCC), the Patients’ Association of Canada, and Centre for Addiction and Mental Health. The NCAC has worked in partnership in a very piece-meal fashion over the years. With this new model these partnerships will be solidified and used to build community on pertinent issues.
Collaboration with Consumers within the Association

It is very important that CMHA has a formal connection with consumers belonging to the Association. The NCEAC would formalize this relationship by organizing “consumer reference groups” through the divisions/branches/regions. Where CMHA offices have their own existing consumer advisory groups, formal linkages will be made with these groups. Where no such groups exist, the NCEAC would work directly with the division, branch or region office to identify interested and appropriate individuals who could constitute a reference group. In some cases, the numbers may be small, but the goal would be to start with at least two individuals. The responsibilities of the reference groups would include identifying local issues of interest or concern, monitoring the progress of consumer participation within CMHA at various levels, identifying potential new members of the reference group, and suggesting external groups at all levels for possible liaison by the NCEAC. The NCEAC would liaise with each group to share information, receive information, and to provide important information to the National Chief Executive Officer (NCEO).

These various routes of collaboration will serve to enhance and strengthen communications internally and externally as never before.

3. Engage

Stronger Consumer Voice

The CMHA is a very large organization comprised of 11 division offices, over 140 branch or regional offices, and a national office. It is the only organization of its kind in Canada dealing exclusively with mental health and mental illness. CMHA boasts over 10,000 staff and volunteers and it is vital that a body of its constituents, consumers of mental health services, play an important role in ensuring their meaningful participation in the Association.

The National Consumer Advisory Council (NCAC) has learned over time from the consumer population in the provinces and territories that the once strong consumer voice has diminished within the Association. This means that the consumer voice in a broader sense, with other organizations externally, has also dwindled. As a national body of people with lived experience, the “National Consumer Engagement and Action Committee” (NCEAC) will connect with the consumer reference groups across the country, described in point 2 above, to bring issues of critical importance to consumers by consumers e.g. stigma, recovery, peer support. The input of these reference groups will be funneled to the “National Consumer Engagement and Action Committee” (NCEAC), which will not only provide reports to the Senior Management Team, but will also report back to the consumer reference groups in an ongoing reciprocal communication process.
Consumers outside of CMHA will be reached through new partnerships with external consumer-oriented organizations thereby providing much needed growth of the Canadian consumer movement.

Process

In revisiting the NCAC’s role and structure the council consulted with various colleagues and partner Organizations to gain feedback on the proposed change in mandate. For example discussions took place with representatives of the National Network for Mental Health, Neasa Martin and Associates, Bonnie Pape, Consultant (and former Director of Programs, CMHA National), and Joan Edwards Karmazyn (representative of the Consumer Council of the Mental Health Commission of Canada).

The council researched collaborative models for consumer participation and partnerships, including models from Canada, Australia, United States, United Kingdom, and New Zealand.

Present NCAC Executive Board Seat

The NCAC has been successful over the past two decades in the development and increase of consumer involvement on boards and committees at all levels of the Association. In 2004 a bylaw was put in place to allow for the NCAC to have a seat on the CMHA National Executive. In the proposed new model the NCAC sees its role and mandate becoming more operational through involvement with the CMHA Senior Management Team and the National Chief Executive Officer while also increasing its external partnerships. The NCAC proposes that it maintain its present seat on the CMHA National Board and that its role with the Board be considered within the CMHA wide organizational model review that is being planned in keeping with the draft Strategic plan. Further discussion will take place should a change in the model of the national board occur.

A formal bylaw change will be required if there is an alteration in the NCAC’s role on the national executive.
**National Consumer Engagement and Action Committee Model**

**Advises** NCEO/CMHA SMT; external consumer organizations; internal consumer base

**Engages** Encourages a strong consumer voice to the Association and beyond; revitalizes consumer involvement within CMHA

**Collaborates** Develops “Consumer References Groups” within CMHA; collaborates e.g. NNMH, MHCC etc. to strengthen external links with sister organizations
Structure

The National Consumer Engagement and Action Group would continue to be comprised of consumers of mental health services representative of all ten provinces and one from the northern territories. Partnerships with other stakeholders in the mental community will be sewn into the model in advisory capacities as required.

Reporting to

The National Consumer Engagement and Action Committee would report to the CMHA Senior Management Team via the National Chief Executive Officer.

Conclusion

This proposed model has resulted from a review and thoughtful consideration of the role and relevance of a decades been developed as fodder for discussion at this point. The NCAC submits this outline as a means to stimulate conversation. Further work will need to be done by way of consultation with peers and other stakeholders to clearly determine the work plan for the next phase in the development of this new model if approved.

In its past, the NCAC has been a revered body of the CMHA and credited with contributing to the momentum of consumer involvement, participation, and employment of persons with lived experience in the Association. Its example has also created a ripple effect throughout Canada among stakeholders and government. The NCAC and the birth of a consumer movement is a by product of the Association’s Framework for Support model which has long been recognized as a catalyst for inclusion and challenged the mental health system to become more focused on the needs of the “person in the middle” the consumer of mental health services. Without this council consumers would most likely have continued in a paternalized and untapped state. This new model will ensure that the proliferation of the consumer voice will be continued within the Association, and expand and strengthen the consumer movement across Canada.
Reference List


Report of the Mental Health Transformation Workgroup to the Senate of Texas Committee on Health and Human Services, November 2006


