

EMPOWERMENT THROUGH CLIENT AND FAMILY COUNCILS: CRITICAL ISSUES IN IMPLEMENTATION

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- **ABSTRACT:** The Empowerment Initiative at the Centre for Addiction and Mental Health (CAMH) in Toronto, Canada involved the creation of client and family councils and the increased participation of clients in organizational governance. A review of this initiative was conducted in collaboration with the coordinators of the Empowerment and Family Councils. The primary intent of this review was to identify the progress that had been made to date and identify some of the factors that have facilitated or impeded the implementation of this initiative. The methods employed for gathering information included document review, key informant interviews, focus group meetings with a wide variety of stakeholders, membership feedback sheets and data mining from a range of sources. A number of implementation issues were identified that are instructive to any organization undertaking similar empowerment initiatives.
- **KEYWORDS:** empowerment. client & family councils. organizational change. advocacy.

In recent years we have seen an increasing movement in the ideology underlying the provision of mental health services from a focus on serving patients to developing partnerships with users of service. Much of this refocusing has, however, been characterized by using different language rather than making significant changes in the way we work with those who experience mental illness. Many of the opportunities provided for client involvement are artificial and tend to be token means of reaching out to service users. Not only must “real” and “significant” opportunities be created for client involvement, but structural changes must take place in the mental health system to allow this practice to develop more fully. Two of Britain’s most outspoken advocates in this area are Peter Beresford and Suzy Croft (1993) who have developed a checklist of factors that can facilitate or impede genuine client

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involvement. These factors, which can be used to evaluate an agency's current practice, with clients include:

- the organization's commitment to, and policies regarding, client involvement;
- the nature of access provided;
- the extent of client involvement;
- support provided for involvement;
- the nature of that involvement;
- agency practices which facilitate or impede involvement; and
- the effectiveness of user involvement.

Genuine empowerment of clients must permeate all levels of the organization from working together as partners in the creation of a service plan to working on interdisciplinary task groups to recommend new models for community outreach or to develop new policies in support of these initiatives (Linhorst, 2006, Shera & Wells, 1999). There is a best practice literature in this area of client and family involvement in mental health organizations, and much of that knowledge comes from our colleagues in Britain (CRAWFORD, M.; RUTTER, D.; THELWALL, S.; September, 2003; ROSE, D. et. al., November, 2003).

THE CENTRE FOR ADDICTION AND MENTAL HEALTH

The Centre for Addiction and Mental Health (CAMH) is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centers in the area of addiction and mental health. CAMH is fully affiliated with the University of Toronto, and is a Pan American /World Health Organization Collaborating Centre. CAMH has approximately 330 status appointed physicians, 700 nurses, and 600 allied health professionals serving over 21,000 clients. During the divestment of provincial psychiatric hospitals in the 1990's CAMH was the only new organization that, right from the beginning, committed to provide funding for independent family and client councils.

In 2000 the CAMH commissioned consultants to explore how they might best implement client empowerment within their

organization. Four major strategies were developed including: member-run client and family self-advocacy councils; a fiscally and administratively independent advocacy service available to all clients; increased involvement of clients and families in the governance of CAMH; and the increased employment of clients by CAMH (Reville & Associates, 2000). CAMH endorsed all four strategies and supported the Councils' independence by supporting them in their efforts to become separately incorporated entities.

OBJECTIVES OF THE REVIEW

Most of these strategies had been underway for several years and it was felt that it was an appropriate time to carry out a review of the overall initiative. More specifically the objectives of this review were:

1. To determine the degree to which each of the strategies had been implemented relative to its initial plan.
2. To identify some of the factors which have impeded or facilitated the implementation of these strategies.
3. To make recommendations regarding changes needed to more fully implement each of the strategies.
4. To identify performance standards and measures that can be used to monitor the outcomes of the various strategies of the empowerment initiative.

The review focused on the Empowerment Council, the Family Council, and efforts to involve clients in governance activities. The employment initiative was an initiative that was already underway and a separate consultant assessment had been completed in this area (Western Management Consultants, May 27, 2005).

METHODOLOGY

This review was designed in collaboration with the Coordinators of the two Councils and clients involved in each of these organizations. Existing documentation (meeting minutes, reports, strategic plans, staff/consumer satisfaction surveys) was

examined prior to implementing other aspects of the review. The specific strategy for the review of each component emerged from discussions with the Coordinators and the methodologies employed included: key informant interviews; focus group meetings with clients and staff; membership feedback sheets; and data mining from a variety of sources. The consultants observed and worked with the Empowerment and Family Councils for a full year, attending many of their regular Board meetings, their Annual General Meetings and their strategic planning sessions.

In addition to our work with each of the Councils we conducted focus groups with front line staff and interviewed members of senior management. We also conducted key informant interviews with the Client Relations Coordinator, and the corporate leaders for diversity and the family-centered care initiative.

THE EMPOWERMENT COUNCIL

The Empowerment Council was initiated in 2001 and its mission is to act as a voice for clients/survivors and ex-clients of mental health and addiction services. It is run by a volunteer Board of Directors and has a membership of approximately 150. The Empowerment Council's terms of reference state that it is designed to:

- Advocate on a systemic level on behalf of addiction and mental health clients.
- Ensure client access to information, and educate clients in regard to choices, self-advocacy, critical thinking, leadership training, and political awareness.
- Educate, sensitize, and provide training to mental health professionals, addiction workers, and other members of the community.
- Ensure the representation of the client perspective at C.A.M.H. through participation on relevant committees and working groups.
- Increase client involvement in decision-making and accountability structures.

- Liaison with C.A.M.H and groups that share Empowerment Council goals.
- Conduct outreach and community development with mental health and addiction clients of C.A.M.H.

ACTIVITIES OF THE COUNCIL

Since its inception the Empowerment Council has engaged in a wide variety of activities. They have put major emphasis on expressing the client voice at CAMH in such areas as: the Bill of Client Rights; advocating for client issues with managers of units within CAMH; developing empowerment indicators for reports by CAMH programs; advocating for greater consultation of the Empowerment Council on public policy issues; and advocating for a client perspective on CAMH policies and publications. The Council is also very involved in expressing the client voice nationally and internationally, facilitating client involvement in governance at all levels of CAMH and providing education on client-related issues at CAMH, for other client organizations and at local, provincial and national conferences.

MEMBERSHIP FEEDBACK

Membership feedback sheets were distributed at site meetings hosted by the Empowerment Council. Members were asked for their feedback on the Council's performance and the nature of their service encounters with staff at CAMH. Members were almost unanimous in their feeling that the Empowerment Council was an important mechanism for the representation of clients. In terms of specific areas of activity the majority (73%) of members felt that the Empowerment Council did well or very well at: consulting with clients; expressing the client voice at CAMH; advocating for client rights at CAMH; advocating on matters outside CAMH that affect clients; and educating people about clients.

They were also asked to comment on the nature of their service encounters with staff at CAMH. A majority indicated that staff were respectful (60%), listened to them (70%) and supported them in their recovery (68%). On the other hand members were

much more mixed in terms of how they felt they were treated as clients in the development and implementation of service plans. Only half felt that they were: assisted in meeting their goals; provided with enough information about resources; offered meaningful choice in types of supports and services; sufficiently in charge of their treatment plan; and provided with information about their rights. These findings echo the comments in a client satisfaction survey (Client Satisfaction Survey, August, 2005) that indicated that many did not know how to submit feedback or complaints to CAMH (56%), and some (24%) did not feel they could refuse treatment such as medication or counseling. As we will discuss later in the article, a number of strategies have been implemented to respond to these concerns.

THE FAMILY COUNCIL

The Family Council was established in 2002. It was legally incorporated as a not-for-profit organization in September 2003, and is structurally separate from CAMH. It is run by a volunteer Board of Directors, and has a membership of approximately 120. The general membership and the members of the Board comprise people who are in a significant relationship with someone who has, or has had, a mental health or addiction issue.

The Council's Mission states that: "The Family Council is a voice for families at the Centre for Addiction and Mental Health." The Family Council's more specific terms of reference indicate that it is designed to:

1. Represent the interests of families at CAMH through the participation of families in governance, committees, work groups & other appropriate groups.
2. Provide and promote systemic advocacy for families at CAMH.
3. Ensure the provision of support and services for families.
4. Develop and support information and learning for families.

The Council has developed its activities, in accordance with its mandate. The Council does not have the resources to participate in all of the CAMH committees on which it is invited to sit.

The Family Council reviews CAMH information materials and policies and provides feedback from the perspective of families. The Council organizes information sessions at CAMH for families and for the public, and participates in sessions organized by others. The Family Council's volunteers run a Family Resource Centre. The Family Council gives priority to advocacy within CAMH, but also provides consultation services and advocates for families outside the organization.

MEMBERSHIP FEEDBACK

Much of the Council's mandate involves advocating to ensure that CAMH is meeting the needs of families. Currently, there is no system set up at CAMH to survey family members in a comprehensive and consistent way in order to measure how well CAMH is meeting their needs. The Family Council has sought feedback on its own effectiveness in a variety of ways since its inception.

The Council obtained some limited feedback on how well it was performing and how families perceive that their needs are being met by CAMH. Two-thirds of the families who responded felt that the Council was doing well or very well in terms of:

- consulting with families,
- expressing the family voice at CAMH,
- advocating in relation to CAMH policies and programs, and
- conducting advocacy and education with governments and the community.

In relation to CAMH, a large majority (78%) felt, at that time, that the Centre needed to improve its treatment of families in terms of:

- recognition of the strengths of families,
- involving families in care planning,
- providing information about services and programs,
- providing more options for services,
- providing information on the rights of family members,

- providing opportunities for family members to be heard by service providers,
- encouraging the involvement of families, and
- supporting active involvement of families on CAMH committees.

The Family Council's Annual General Meetings also provided an opportunity for families to give both the Council and the Centre feedback. Issues raised by those attending these events focused on medication, clients' rights versus families' rights, and the availability of information and support for families.

Overall, the information reviewed indicates that the Council is perceived as doing well in its work for families. The feedback also indicated that the Council has much more to accomplish in terms of assisting CAMH in meeting the needs of families. The feedback indicated that the services that CAMH is currently providing to families are perceived as excellent, but more services are needed. Families particularly want information of all kinds – information about existing programs, services, and supports – both for the primary client and themselves. They also want the opportunity to be heard more, and included more in the care of their family members.

CLIENT INVOLVEMENT IN GOVERNANCE

In an effort to obtain feedback regarding client involvement on committees at CAMH, a focus group was organized for those clients who were on committees. Sixteen people attended the meeting. The Empowerment Council chooses client representatives for Centre-wide committees and encourages elections of client representatives by other clients for program level committees.

The group did feel that they had made an impact on CAMH policies; some changes in how programs report to the Board; and some progress in getting client concerns investigated. They did, however, indicate that their impact could be greater. Some of the barriers they identified included:

- too few clients on committees

- suggestions from clients not listened to, dismissed or explained away unless change suggested is very minor
- language and literacy (professional language both spoken and written) often makes information inaccessible; need for translation when English is not a person's first language
- there should be reimbursement when extensive reading or other meeting preparation is required
- clients still excluded from important decisions (hiring, electing, etc.)

CLIENT RECOMMENDATIONS

Clients made a number of recommendations to assist clients in improving the degree to which their voice is heard in meetings. Some of the major ones were:

- know how committees work (terms of reference, rules of order for meetings)
- lobby for more clients on committees
- be fully aware of client rights
- carefully consider, consult, and prepare for what you want to accomplish for clients on a particular committee
- access a client database of information to support arguments
- speak up, propose agenda items and make motions that matter to clients
- openly state when you are being excluded, ignored, shut down, or prevented from participating fully in the committee process
- quit those committees on which you are not allowed or able to provide more than token input
- meet with other committee members for peer support and information sharing

STAFF PERSPECTIVES

To obtain the perspectives of the direct service staff regarding the Empowerment Initiative the review team hosted

several focus group discussions. These meetings were held with occupational therapists, recreational therapists, advanced practice nurses and clinicians, and social workers. A total of 30 staff participated in these discussions. Participants were asked to respond to a one- page feedback sheet prior to having open discussion about the empowerment initiative. They were asked to: rate their level of awareness of the activities of the initiative; identify its major accomplishments; describe difficulties and barriers in implementation; and make recommendations for changes or new activities in the area of empowerment. Several major themes emerged from these discussions including:

- While most staff were aware of the Empowerment Council's work to create the Bill of Client Rights and the Family Council's involvement in the Family Initiative, most were unaware of the other ongoing activities of the Councils.
- Staff did feel that the Councils served to highlight the importance of client and family empowerment at CAMH.
- There is a need to do a better job of communicating with line staff – they are willing to provide assistance to clients but need ongoing information.
- There is an immediate need to facilitate client, family and staff knowledge about, and engagement with, the Bill of Client Rights.
- Staff are feeling the pressure of a large number of new initiatives and it is a challenge to juggle them and give them sufficient priority.
- Staff need more training in the best practices of contacting and engaging clients and families in program initiatives.
- Need to clarify the confusion and overlapping of objectives of the Empowerment Council, Psychiatric Patient Advocacy Office, and the Client Relations Office.
- Staff noted the limited resources of the Councils relative to the population served and needs across CAMH and the province.
- Many staff prefer to work with clients in an empowering manner but some felt that high clinical caseloads don't allow enough time to work in a truly collaborative manner.

Some of the major recommendations made by those attending the focus groups included:

- Incorporate discussions of empowerment issues and objectives into client rounds, clinical sessions and groups.
- Develop a list of clients and family members that are available and willing to participate to the decision-making and educational activities of programs.
- Have clients and family members attend weekly community meetings.
- Develop peer support initiatives, including hiring peer support workers in all programs (SOLOMON, 2004)
- Develop more employment opportunities for clients.
- Assign specific program staff members to act as liaisons to the Empowerment and Family Councils.
- Have client and family representatives of the Councils on all Program Advisory Committees

CHALLENGING THE BARRIERS

This review identified several areas that appeared, at the time, to be impediments to the full achievement of the goals of the Empowerment Initiative. The following is a list of those critical implementation issues and includes a brief discussion of some of the actions that have been taken to respond to the identified barrier. *Many of these responses will be of interest to other organizations attempting similar empowerment initiatives.*

- *Financial Independence:* The goal in setting up the Councils was to create independent bodies to advocate for clients and families and serve their interests. Currently, CAMH is the sole funder of the Councils, which can affect their ability to advocate on controversial issues. Both Councils need to explore opportunities to increase and diversify their resource bases. A recently revised memorandum of agreement has clarified the independent nature of the Councils. This was achieved by using an extensive process of negotiation with legal representation on both sides. The agreement makes it clear that it is not a “service contract” but funding to support activities that are

central to the objectives of the Council. Both Councils are actively seeking alternative sources of support

- *Objectives:* The Empowerment Council's objectives are very broad given its current resource base. While this allows flexibility and breadth in its activities it can lead to staff spreading themselves too thin. It is critical for the Council to prioritize its objectives on an annual basis. There are many opportunities and a need for more consultation between CAMH and the Council. (Canadian Council on Health Services Accreditation, 2005). This increased, but selective, involvement in policy and program design, in fact, may prevent the need for systemic advocacy in some areas and allow a more focused advocacy effort in other important areas. Annual objectives, targeted activities and participation on identified committees are now prioritized on a year-by-year basis.
- *Overlap of Objectives & Lack of Information:* Many clients and staff commented on their confusion regarding the objectives of the various advocacy units at CAMH (Empowerment Council, Family Council, Client Relations Office, Psychiatric Patient Advocacy Office) and suggested that clear information must be provided regarding the alternatives available to clients and families to voice their concerns. Both Councils needed to develop strategies for information dissemination including greater use of CAMH's website. To address these issues CAMH developed a Client Information Package (including a DVD); undertook a staff training (co-led by clients) on the Client Bill of Rights; developed mandatory training for new staff; and included information related to the Councils and alternative complaint mechanisms in the annual physician re-appointment package. Most of this new information is available via E learning modules.
- *Administrative/Staff Capacity:* Both Councils are achieving a lot in spite of their limited resource base. Both coordinators experience a high level of stress in meeting their responsibilities. While staffing levels do fluctuate with project funding, it is essential that both Councils have an absolute minimum level of core staff. The budget of the

councils has been increased slightly and, relative to other institutional cutbacks, has been protected. Limiting annual objectives, membership development and flexible use of unspent monies has allowed the Councils to undertake special initiatives

- *Membership Development*: The potential membership and volunteer resource base for both the Empowerment and Family Council is significant. This potential has not been fully explored, due, in part, to the lack of resources for the Councils to do this work. This is an issue that many small non-profit organizations struggle with (The Canadian Center for Philanthropy, 2003). Supporting this focus on systematic membership recruitment and development is critical to the overall capacity and the long-term functioning and impact of the Councils. The Family Council, for example, hired a consultant to assist them with membership development. This will, hopefully, provide more human resources to undertake a variety of initiatives both with CAMH and the larger community. CAMH also pays for Council members time when they are involved in major new initiatives such as the Family-Centered Care Project.
- *Perceptions of Service*: Families who provided their views via surveys and at public forums felt that, while things were moving in the right direction at CAMH, there was still a significant need for further improvement. Clients reported that they felt they were listened to and respected but not really regarded as partners in the treatment planning process. Strategies of empowerment are only beginning to permeate the provision of clinical services at CAMH (LINHORST; HAMILTON; YOUNG; ECKERT. 2002). There have been a number of recent developments in this area, the most visible of which is the Family-Centered Care Initiative that has been implemented in a number of program areas. Learning modules that focus on how empowerment (SHERA, 2006) and recovery (TORREY, 2005) can be incorporated into clinical practice have been developed. A newly developed electronic care plan also provides a structure and process that emphasizes

partnership with clients and families. A Quality Assurance and Patient Care Committee, a subcommittee of the CAMH Board of Trustees, monitors the implementation of this new approach. Other initiatives like the use of best practices in working with families, peer support workers, supported employment and partnerships with community agencies have been developed to provide further support.

- *Participation in Governance & Committee Work:* Members of both Councils participate effectively on a number of CAMH committees and in working groups. The Councils do not have enough staff time or volunteer resources to serve on the wide range of committees available, or to the extent envisioned by the original Empowerment Framework. Clients who participated on committees identified a significant number of areas to be addressed to more fully achieve the objective of meaningful client involvement in decision-making. Facilitating meaningful participation requires special efforts to orient, prepare and involve clients in decision-making opportunities (LINHORST; ECKERS; HAMILTON; 2005; RESTALL; STRUTT, 2008).
- *Self-evaluation:* Both Councils could benefit from stronger internal evaluation mechanisms that measure processes, outcomes and the impact of their activities. Given the resource intensive nature of these activities the Council may wish to apply for further financial or in-kind assistance for these endeavors. Some of the evaluation measures typically used by mental health organizations such as the client satisfaction surveys need to incorporate some of the more established measures of empowerment (PARSONS, 1999) and service standards for client involvement (DIAMOND; et. al., 2003). CAMH has recently made some modifications in its data gathering surveys to reflect these important dimensions of service.
- *Champions at the Program Level:* There is significant variation in the degree to which programs had implemented client-centered care and empowerment opportunities for clients and their families. CAMH has found that champions are needed at the program level to provide leadership for these changes and ensure they are

implemented into day-to-day practice. This strategy for promoting client and family-centered practice and program delivery has now been more fully operationalized. Senior advanced clinical practitioners have been identified in each program area and they provide leadership in: client/family centered practice; promoting adherence to the Client Bill of Rights (including being knowledgeable about alternative complaint mechanisms); and ensuring that all staff are aware of the activities of the Empowerment and Family Councils. They meet regularly as a group and provide updates on activities and problem solve issues that have emerged in their respective programs.

MOVING THE EMPOWERMENT AGENDA FORWARD

The Empowerment Initiative has made significant progress in providing opportunities for client involvement through the work of the Empowerment and Family Councils and efforts to enhance client participation in governance at CAMH. While these efforts are important and have made a significant impact, there is always more to be done. Linhorst (2006) argues that there are several conditions that must be in place to empower people with severe mental illness including: managed psychiatric symptoms; participation skills; psychological readiness; mutual trust and respect; reciprocal concrete incentives; availability of choices; participative structures and processes; access to resources; and a supportive culture. Appropriate organizational structures and policies are needed to foster an organizational culture that promotes empowerment and participation in decision-making for both clients and staff (HARDINA, 2005).

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- *RESUMO: A Iniciativa de Autorização no Centro de Vícios e Saúde Mental (CAMH) em Toronto, Canadá envolveu a criação de cliente e conselhos de família e a crescente participação de clientes na administração organizacional. Uma checagem desta iniciativa foi conduzida com a colaboração de coordenadores da Autorização e*

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Conselhos de Família. A intenção primária deste exame era identificar o progresso que tinha sido feito para datar e identificar alguns dos fatores que facilitaram ou impediram a implementação desta iniciativa. Os métodos empregados para colher informação incluíram exame de documento, entrevistas de informantes fundamentais, reuniões de grupo de foco com uma grande variedade de apoiadores, avaliação dos membros do conselho e dados de uma gama de fontes. Foram identificadas várias questões de implementação que são instrutivas a qualquer organização que empreende iniciativas de autorização semelhantes.

- PALAVRAS CHAVE: autorização. cliente & conselhos de família. mudança organizacional. advocacia.

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