

*Putting Family-Centered Care
Philosophy into Practice*

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In Spring, 2004, as part of its overall family initiative, CAMH began a process of strengthening supports it offers to family members of persons with mental health and/or substance use concerns and the ways in which it involves families in client care. To this end, family members, the Family Council, clinical staff representatives and the Community Support and Research Unit collaborated on a consultative process to develop Action Plan templates that clinical program staff could use to review their programs and identify strengths and weaknesses in how they work with families. This report synthesizes the literature on evidence-based best practices for involving families in client care and supporting them more generally. As such, this report constitutes a companion document to the templates. It is intended to assist staff with identifying strategies for protecting strengths and strategies for addressing weaknesses in the involvement of families in treatment care planning and decision-making and in the planning, monitoring and evaluating of services for families.

The literature review was guided by four key questions: 1) What are best practices for a family philosophy?; 2) What are best practices for involving families in client care?; 3) What are best practices for designing and delivering professional mental health and addiction support services to families?; and 4) What are best practices for facilitating families helping families? We discuss some general considerations in undertaking the literature review and then summarize literature in regard to each question in turn. We finish with concluding remarks about the ways in which these four questions are linked.

General Considerations

Two issues need to be addressed before proceeding further. First, throughout this report “family” is used in an inclusive way to include kin and significant others, that is, family can be anyone a client views as important because of a strong enduring connection with that person [1, 2]. Second, because it is generally accepted that interventions should be consistent with evidence-based best practices [3, 4, 5], assumptions underlying “evidence-based best practices” need to be clarified. Evidence-based best practices are health care practices for which there is sound empirical evidence supporting their use [4, 5, 6].

Experimental and quasi-experimental designs are typically viewed as the gold standard or best form of evidence [6, 7]. Yet qualitative research, particularly as it relates to increasing our understanding of social impacts of living with mental illness and/or addictions, has much to offer. Qualitative research may be

particularly helpful in shedding light on wellness [6] from intrapersonal and interpersonal perspectives because identities of clients and of family allies are socially constructed, that is, grounded in everyday interactions [8] with each other and with service providers. If we want to promote wellness of clients and support their families then we need to think about what we say and do in social interactions with them. Thus, the ensuing literature review includes both quantitative and qualitative research findings.

1) What are best practices for a family philosophy?

There are two main philosophies for working with families. The first, family-focused care is centered on meeting clients' needs within the context of the family [9]. By contrast, the second philosophy, family-centered care focuses on meeting the needs of both clients and families. It emphasizes relationships [10], and recognizes and builds on the strengths and interconnectedness of families [11]. A family-centered care philosophy starts from the premise that families have a critical role to play in supporting people with mental health and/or substance use concerns and in promoting their wellness [12]. Involving families, then, becomes a key strategy for early intervention in psychosis [3]. In addition, a family-centered care philosophy acknowledges the potentially harmful effects of caregiving on family members and thus, that they, in their own right, require the attention of health care professionals [12].

Adopting a family-centered care philosophy requires a shift in organizational practices and in the attitudes and behaviours of individual providers from a model in which professionals are seen as the only people in possession of expert knowledge to a model that is based on *knowledge exchange* and *partnership* [13, 14, 15]. Studies repeatedly demonstrate limited solicitation of family members' insights in health care decision-making. One study [16] involving 12 families of inpatients found that none of the caregivers had been asked by staff for information regarding the impact of medications on clients. Similarly, a survey [17] of 36 therapists at a community mental health centre revealed that in 52 % of cases in which family members were not contacted, the therapist believed that such contact would not benefit the client, yet clients' refusal to give consent to share information with family occurred in only 10 % of cases.

Achieving family-centered care is a process that involves a shift in organizational culture, structures and systems [15, 18, 19] from one of diagnosis and treatment only to one that promotes learning as well [1, 14]. It is most easily accomplished in organizations that value families [1] and incorporate this into strategic planning [10,

19], facilities design, human resource policies and practices, and fiscal planning [19]. It requires that clinical decision-making power is shifted to middle level management and front line staff to enable them to be flexible in supporting families [18]. Putting family-centered care into practice also entails developing and maintaining mechanisms to monitor and reward family input [14].

Family-centered care is an evidence-based best practice [11]. Research demonstrates that involving families hastens client recovery from mental illness [1, 2] and addiction [20], lowers the risk of mortality [2], reduces reliance on health care services [2], reduces the rate of rehospitalization and relapse [2, 21], enhances medication compliance [2, 21] and bolsters client interpersonal functioning and family relationships [2, 21]. Family-centered care improves health care quality and cost effectiveness [22, 23] and both health care professionals and clients have found that this collaborative approach results in greater satisfaction with health care [24].

The core tenets of family-centered care are:

- Treat clients and their families with dignity and respect [1, 19, 24, 25, 26];
- Openly communicate with clients and families [20, 24, 25];
- Build on the strengths of clients and families [1, 15, 24, 25, 26, 27] and foster partnership between them [11];
- Collaborate with clients and families in making treatment, policy and programming decisions [7, 15, 19, 24, 25, 28], including involving families in designing, monitoring and evaluating services [15];
- View clients and family members as individuals and as members of a family and a community [1, 15, 19, 27];
- Regard families as a key source of information about their relative's and their own needs [1, 27]; and
- Tailor services to fit families needs and preferences [15, 26, 27], including ensuring that services are appropriate for a family's culture and traditions [15, 27, 29, 30, 31] and recognizing that conceptualizations of illness and substance use may vary within and across families [29].

A key advantage to adopting a family-centered care philosophy is that it has a high degree of congruence with an empowerment ideology. Empowerment, for example, assumes that all people have strengths and capabilities as well as the capacity to become more competent and that by building on strengths rather than correcting weaknesses, the likelihood that people will become empowered is optimized [32]. Service delivery practices mirroring a family-centered care philosophy can empower families [32].

2) What are best practices for involving families in client care?

In identifying best practices for involving families we need first to consider barriers to their participation in client care. Families are frustrated by aspects of the health care system including: problems in communicating with professionals, including receiving inconsistent information; failure to involve families in treatment planning; the enduring nature of the need for services and financial strain in conjunction with an inability to predict which services will be most beneficial; and challenges in locating appropriate support services [33]. One study [34] found that the three most frequently cited aggravations of family members were: being unable to obtain pertinent information regarding their relative and being excluded from care planning, being financially unsupported because of funding and reimbursement issues, and having to be in crisis to get prompt attention/service. A study [35] of 228 family members revealed that only 31 % thought they were sufficiently involved in treatment planning. Similarly, a project [36] involving 19 family members residing in Northern Ontario found, as an emergent theme in qualitative data, that they were rarely involved in treatment planning. Research also suggests that families may, in general, be more frustrated by interactions with specific subgroups of health professionals. A study [37] of 274 family members found statistically significant differences in satisfaction with interactions with various groups of professionals, with interactions with psychologists being the most satisfying and interactions with psychiatrists being the least satisfying for families.

In keeping with the principles of family-centered care, the ideal family-provider relationship recognizes the expertise that families have to offer [13] and the importance of working collaboratively to achieve the main outcome goals for working with families, which are to achieve the best possible outcomes for the client and to ameliorate the distress of the family [7]. Collaboration may be viewed as the extent to which family and provider work together and the extent of reciprocity in their working relationship [38]. Collaboration is thought to be critical to client outcomes in that family involvement in the treatment planning process is associated with better client functioning and high family satisfaction with the care process [38]. Findings suggest that the best predictor of collaboration is provider attitudes toward family participation in client treatment [38], which underscores the importance of the need to alter organizational practices at the system and individual levels to achieve the vision of family-centered care.

Strategies that can be used by health care agencies and professionals to engage families in client care in a collaborative manner include:

- Listening to families' concerns, needs and questions, and understanding the unique issues facing family members as a function of their relationship to the care recipient (e.g., spouse, parent) [28];
- Soliciting their input and feedback particularly because they have intimate knowledge of the client and can shed light on the strengths, interests and competencies of the client [13, 28] as well as the rate and severity of decompensation [39] and substance use;
- Acknowledging strengths, expertise and contributions of family members [28];
- Exploring families' expectations of the intervention and the client [7];
- Assessing the capacity of the family to support the client [7];
- Facilitating the resolution of family conflict by responding thoughtfully to emotional distress [7];
- Acknowledging and dealing with feelings of loss [7];
- Working with families to develop a crisis plan [7];
- Helping improve communication between family members [7];
- Providing education and training for the family, including structured problem-solving techniques, at suitable times [7];
- Encouraging family members to expand their support networks [7];
- Being flexible in meeting the needs of the family [7];
- Providing resources to facilitate involvement (e.g., childcare) [28];
- Providing the family with easy access to another professional in case current work with the family ceases [7]; and
- Developing strategies for resolving problems related to confidentiality [28].

Legal restrictions regarding confidentiality are often viewed as an obstacle to involving families in client care [17, 38, 40]. If construed, however, as parameters guiding information sharing then the way is paved for sharing information. Specific strategies that can be used to facilitate the timely and appropriate sharing of information include: having a clear procedure for obtaining consent to share information, having reasonable time limits that specify the nature of the information that the client is agreeing to share and with whom, providing written information to the family about what type of information can be shared with them, providing staff training so that staff are clear about what information can be shared and under what circumstances, and answering questions of families in a general way so as not to violate confidentiality [41].

Because family-centered care assumes that families can provide important insights that improve the quality of health care services [10], organizations that adhere to a family-centered care philosophy involve families in a myriad of other ways beyond having input into an ill relative's care. Additional roles for families include:

participating on steering and advisory committees that design, monitor and evaluate organizational policies, programs and practices [10, 19, 22, 42]; offering paid staff positions for consumers and family members [22]; creating and maintaining a family resource center [22]; and participating in the training of mental health professionals [19, 24].

3) What are best practices for designing and delivering professional mental health and addiction support services to families?

Stress process theory [43, 44] is the dominant conceptual framework for understanding the impact that mental illness and addictions have on families. Put simply, stress process theory assumes that a stressor is comprised of both objective and subjective dimensions and that the impact a stressor has on an individual depends on the coping resources available to respond to the stressor. Social support constitutes a major resource, of which there are three types: informational, emotional/validational and instrumental (i.e., tangible assistance with tasks).

Stress process theory assumes that chronic stress has predictable negative consequences that must be mitigated to promote the wellbeing of families, most if not all of whom experience subjective burden and psychological distress [34]. Subjective burden is best predicted by two components of objective burden – the ability to cope with problem behaviours of the client and the strain on family relationships [45]. Sustaining a high level of subjective burden frequently results in depressive symptomology and worsening of a family member’s emotional health [46]. In consequence, family members’ ability to continue to provide a supportive role may be negatively impacted [46].

Work conducted within a stress process framework is typically enhanced through the application of one or more additional theories, most notably family systems theory [27], ecological systems theory [27], and lifespan development theory [26, 47]. When taken together, these four theories highlight the multidimensional and contextual nature of an individual’s response to stress by focusing our attention on the interconnectedness of people as family systems and highlighting that families can adapt and may have varied support needs over time.

Models for intervening with families that are rooted in stress process theory and complementary contextualist theories serve to focus intervention efforts on enhancing the capacity of families to cope with the situation. Desirable strategies that they may undertake to deal with mental illness and/or addiction can include: eliminating or reducing the amount and intensity of demands; attaining additional

resources; learning and engaging in behaviours to help manage stress and ongoing strains; and making situations more constructive, manageable and acceptable for the entire family [46]. Providing social support to families is a key way in which these may be achieved. Empirical evidence suggests that social support has both direct and buffering effects on mental health outcomes, in that it functions as a protective factor that facilitates coping and family functioning thereby reducing the harmful effects of stressors [46]. Thus, interventions that focus on helping families cope with problem behaviours of clients and relationship strain may be particularly beneficial [45] in that they may ameliorate family subjective burden.

Psychoeducational programs are a form of social support for families in that such programs provide both informational and emotional/validational support. Psychoeducational programs are led by professionals and aim to improve the ability of families to deal with difficult behaviours through improved problem solving [48, 49] and to reduce their distress [49]. As a result, families' capacity to interact with clients in ways that mitigate the impact of environmental stressors on clients is improved [27].

Research demonstrates that there is a need for these forms of support regardless of the unique characteristics of each case. For example, a survey [50] of 197 families in Indiana found similar information needs were identified regardless of whether the client was an inpatient or outpatient or which region of the state the family resided in. Most frequently cited information needs were in regard to: future course of illness (78 %), medication benefits and side effects (74 %), and crisis situation management (74 %).

Family psychoeducation constitutes evidence-based best practice for professional services for families [4, 7, 51, 52] as participation in such groups has been associated with a reduction in subjective burden and distress [16, 26, 53, 54], increased knowledge about mental illness, better coping strategies, and improvements in family relationships [48]. Such programs involve education about illness symptoms, causes, treatments and prognosis and provide emotional support, crisis intervention and problem-solving skills training [13, 23, 55, 56].

Evidence-based best practices guidelines suggest that psychoeducation programs should: be at least nine months in duration to achieve improvements in caregiver outcomes [23, 55, 56], not be restricted to families scoring high on expressed emotion (a construct comprised of three factors: criticism, hostility and over-involvement), be delivered in multiple rather than single family formats to provide cost-effective services that foster families accruing the benefits of mutual peer

support [23, 57], and assume a biological rather than a family-based etiology [23, 55].

Part of being flexible in designing and delivering services to families entails tailoring interventions to meet the unique needs of particular subgroups of family members and offering a range of service options and components [13, 58]. For example, to support minor children of a person with a mental health and/or substance use concern, health care agencies should develop strong links with community agencies and other systems that will be supporting the family [59, 60]. Similarly, parents who have provided longstanding assistance to a person with a mental health and/or substance use concern may be particularly interested in estate planning and other information related to establishing supportive mechanisms for when they can no longer provide support. One study [61] found that more than two thirds of a sample of mothers who lived with and provided care to adult children with a mental illness expressed a need for services to help with such planning.

4) What are best practices for facilitating families helping families?

Professionally led and family-led groups typically have similar content including: housing, medication management, family relations, dealing with professionals, financial concerns, and service and treatment concerns [48]. Thus, it is not surprising that many of the benefits of participating in professionally-led psychoeducation groups also accrue from participating in family-led initiatives [54]. Research shows that benefits to families of involvement in family-led programs include: greater knowledge about mental illness, better coping skills, lowered caregiver burden, strengthened identity, greater emotional support, and enhanced relationships with clients and capacity to support clients [42, 54, 62]. In fact one study [48] found no difference between coping ability, illness knowledge, and changes in relationship with client and social support amongst families who participated in a psychoeducational program as compared to those who participated in a family-led program.

Where family-led groups differ from professionally-led groups is in the extent to which different types of social support are emphasized and the function such programs have on a systemic level. Professionally-led groups highlight dealing with relatives' problem behaviours and coping with emotions whereas family-led groups emphasize advocacy [48]. Moreover, psychoeducational programs are usually presented within a specified timeframe and have a predetermined formalized content and structure [63]. By contrast, information provision within

family-led groups is typically more variable and ad hoc and is provided through a greater variety of modalities [63].

Health professionals are well positioned to foster the development of family-led groups [63]. One of the key roles of service providers is to provide families with information about existing family-led supports. Research shows that families expect to receive this information from providers yet often do not receive it. For example, a study [64] of a sample of Quebec families who participated in a family-led support group found that only 39 % had been informed of the group by service providers. The majority had heard about the group from friends or advertisements. Similarly, another study conducted in Chicago found that only 35 % of families attending family-led groups had heard about these groups from mental health care providers or agencies [65]. Professionals need to increase their awareness of existing family-led groups so that they can better serve families [66].

In addition to referring families to groups [13, 63], professionals can bolster the capacity of family-led supports by: helping to establish new groups where none exist proximately [13, 66]; providing leadership/facilitation training to newly forming groups [13]; supplying information, including clarifying mental health system practices or policies [63]; liaising with other professionals to increase their awareness of and support for such groups [63]; helping to assess the information and other support needs of a particular group so that the content of group sessions is tailored to participants' needs; and assisting groups in garnering funding and other resources (e.g. meeting space) to support their continuance. Because structure and focus are important factors impacting on the success of family-led groups [63], professionals can also serve as a resource to group leaders in helping to clarify a group's focus.

Conclusion

We began by asking what constitutes best practice for a family philosophy and found that a family-centered care approach constitutes evidence-based best practice for the delivery of health care services. We then asked about best practices for involving families in client care, best practices for designing and delivering professional services for families, and best practices for supporting families in supporting each other. Arguably, answering the latter three questions served to illuminate the strategies for operationalizing a family-centered care perspective. Many of the mechanisms by which the vision of family-centered care can be achieved have already been implemented at CAMH, such as: incorporating the valuing of families into strategic planning; creating a Family Council; and having

families participate in designing, monitoring and evaluating services through involvement on program advisory committees. With these building blocks, CAMH is well positioned to make family-centered care a reality.

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