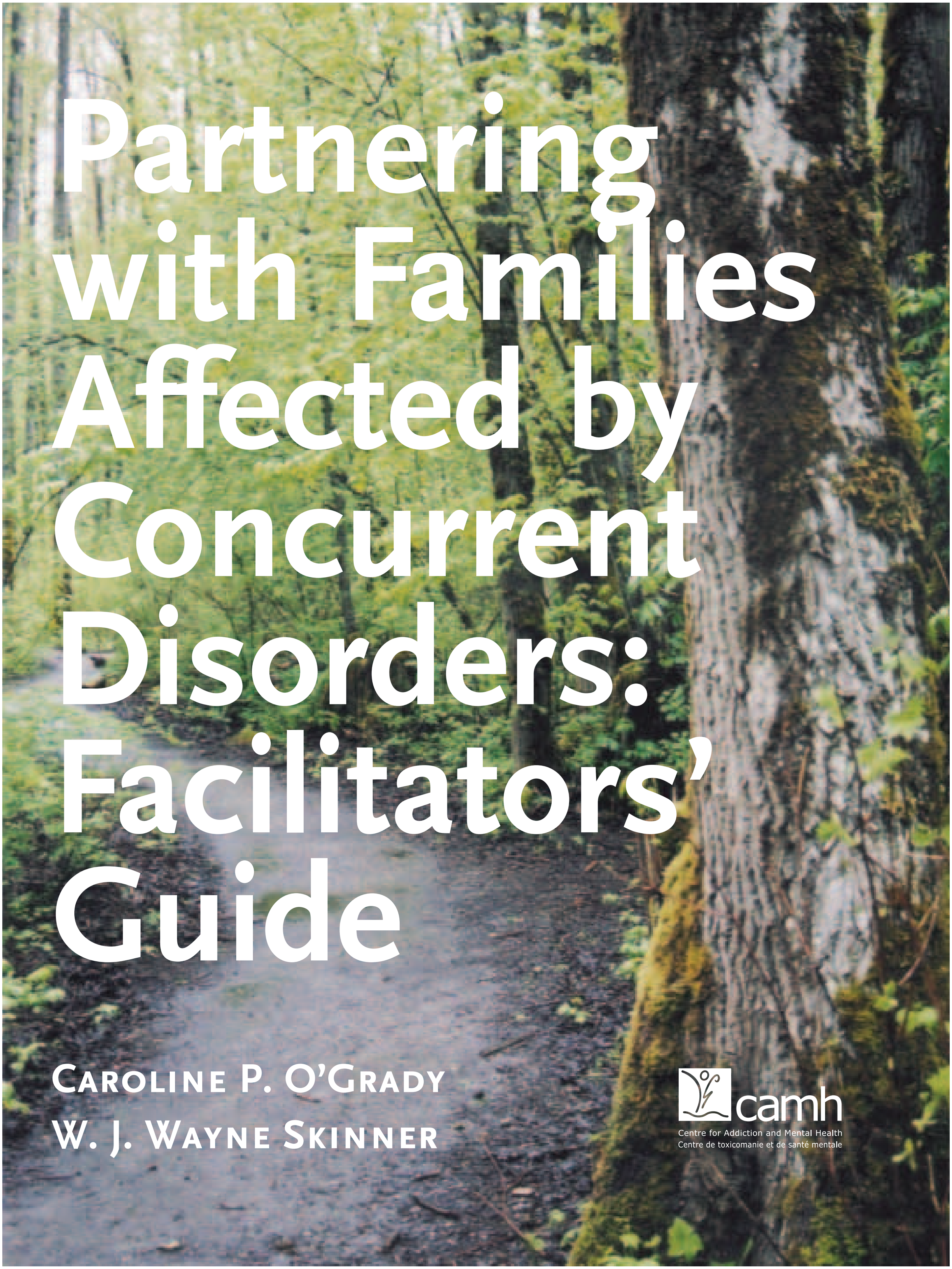

Partnering with Families Affected by Concurrent Disorders: Facilitators' Guide

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Part I: Overview

Family members are often the primary support for people who have substance use and/or mental health problems. We know that these caregivers are likely to experience significant physical, emotional, social and spiritual stress. Although there are a growing number of interventions designed to help and support family members, many agencies do not see this as their mandate, and—if they do—it is secondary to the job of working with the person diagnosed with substance use and/or mental health problems.

It can be said fairly that there are structural and conceptual limitations in the ways formal treatment services think about and put into practice responses to substance use and mental health problems. Those limitations make it difficult to see the importance and value of treatment services for family members. This is even more pronounced in the area of concurrent disorders, where people have co-occurring substance use and mental health problems.

Clinicians often lack training and tools that would allow them to feel confident and prepared to undertake the task of working with families. So, even when the level of willingness is high, there can be barriers that, if not addressed successfully, can undermine and interfere with starting and sustaining this work.

Our involvement in this area of work is a result of several factors.

- We share a belief in the value of including families in the helping process.
- We have been impressed by the growing evidence base in support of this view.
- Our contact with family members has led us to recognize that family members can be profoundly affected by having a family member with an illness.
- Family members often show a strong desire to understand addiction and mental health problems and have a high level of motivation to be part of the process of care, change and recovery.
- Families represent an amazingly underutilized resource in addressing substance use and mental health problems in our communities.

The work we share in this guide is part of a larger effort to provide evidence-based services for family members. The focus of our project has been education and peer group support for family members. But we see this as just one aspect of a much broader scope of services that will lead to better outcomes for people with concurrent disorders and their families. We do not see our work as the last word, but as an attempt to extend our work of supporting families. As such we invite you to join in the growing dialogue about this work, and to participate in the emerging community of practice that includes and actively engages family members to find effective responses to the impact of concurrent disorders on consumers and their families.

PARTNERING WITH FAMILIES AFFECTED BY CONCURRENT DISORDERS: AN EDUCATION AND SUPPORT PROGRAM

Program description

The education and support group is intended to help family members:
- learn about concurrent disorders
- develop skills that help them deal with the impact of concurrent disorders on their family life
- collaborate with their family member and treatment providers to find ways to manage substance use and mental health problems.

The primary objective of this education and support program is to increase the well-being of the family members (in contrast to psychoeducation intervention where the primary objectives are related to consumer outcomes—see p. 55).

The program consists of 12 weekly group sessions that combine presentations on topics related to concurrent disorders, interactive activities and opportunities for families to share their stories and to offer support to one another. The groups consist of 10 to 12 family members (this program does not include the consumer). The groups are not limited to a single mental health diagnosis (see Group composition, p. 13) and are independent of any treatment for the family member or person who has concurrent disorders.

Program resources

Partnering with Families Affected by Concurrent Disorders has two components.

The *Facilitators' Guide* is intended to be a supporting resource for family support group facilitators. In it we share observations and offer suggestions based on our own experience and feedback from family members who participated in the initial project. We provide an overview of and orientation to the overall goals of the support group, as well as specific comments, suggestions and tips for the content areas that are covered in the weekly sessions.

The accompanying resource for families (*A Family Guide to Concurrent Disorders*) [www.camh.net/About_Addiction_Mental_Health/Concurrent_Disorders/cd_family_guide0607.pdf] contains the content for each of the 12 sessions.

Audience for this guide

This guide is intended for health care and social service workers who are willing to make a commitment to convene and facilitate a group for family members affected by concurrent disorders. We expect that people working in addictions, mental health or concurrent disorders will be the ones most likely to be interested in offering formal programs. But we also hope that these resources will support the efforts of workers in a broader range of service environments (e.g., social service agencies, corrections) to support families affected by concurrent disorders

Facilitators of these groups will need to be comfortable and competent in facilitating group psychoeducational and peer support sessions. The importance of those skills in making this activity a success cannot be overemphasized.

It is not realistic to expect clinicians to have expertise in all topic areas. For example, if neither of the group co-facilitators has a background in psychopharmacology (covered in Session 8), we suggest inviting someone with expertise in this area (e.g., a pharmacist or doctor) to participate in this session.

Language

We have deliberately attempted to give a human—and hopefully humane—tone to the way we talk about substance use problems, mental health problems and concurrent disorders. For example, we use the terms substance use and substance use problems, mental health and mental health problems, and co-occurring mental health and addiction problems (concurrent disorders). We acknowledge that in many cases families need to understand diagnosis-based terminology (e.g., substance use disorder, mood disorder) that is used in some sectors of the substance use and mental health treatment systems. But we have found that, when working at the family level and the consumer level, being open to a language that refers to and comes from their experience helps make the empathetic, humane connection that is so important in this work. This is not meant to suggest patronizing either family members or consumers, but to recognize the deeply human elements that are involved not just when these problems occur but when people mobilize their considerable strengths and resources to work on solutions.

DEFINING “FAMILY”

By family, we mean anyone who supports and is concerned about someone who is struggling with concurrent substance use and mental health problems. We do not require that it be proven or formally established that the family member they're concerned about has concurrent disorders. We do not require that the family member they're concerned about be a consumer of our services or of any others. Instead, we work to validate and respect the concerns of the family members who want to participate in this process, and to create a welcoming environment. This includes being open to the ways family members experience the problems and challenges of living with someone struggling with substance use and mental health problems, of paying attention to the language they use, and to speaking about concurrent disorders in ways that show that we see these as human problems that deserve respect, concern and support.

Part II:
Working with families

Great movement has been made in the past decade in Canada toward integrated and collaborative treatment of addiction and mental health problems. This has been based on a growing awareness that integrated approaches produce better outcomes for consumers. The evidence also strongly suggests that social support is unequalled in its importance in producing effective long-term outcomes.

Complementing this has been a growing movement of family members who, while they know full well the problems related to concurrent disorders in family members, have felt that they were not included in finding effective solutions for these problems. They have become more mobilized and assertive about their need and right to understand, participate in and contribute to their loved ones' treatment.

Working with members of consumers' social networks can help them progress toward personal goals and prevent and reduce the severity of slips and relapses, regarding both substance use and symptoms of mental health problems. The significant advances made by consumers, families and professionals, working together, gives us hope that we can continue to improve the long-term outlook for people with concurrent disorders.

FAMILIES AND THE SUBSTANCE USE AND MENTAL HEALTH SYSTEM

Too often family members are not welcomed or included in the process of working with someone with mental health and substance use problems. Family members' stories about their experiences with the system often provide strong illustration of this fact. When the mental health system offers family members acceptance and support, it's an important step in helping them feel empowered to be more assertive about their needs.

At the same time that family members need to feel more empowered, treatment services need to be more inviting and open to family involvement. This starts with professionals openly exploring their attitudes, values and beliefs about family members, the ways current routines and procedures usually presume family members aren't to be included, and the policies and practices that need to be in place to ensure that the experience of family members is more positive. Family members have seen the difficult journey that has resulted in a loved one coming into care. Working to involve family members in ongoing, active support for consumers in recovery is a wise investment of resources, as is the provision of support to family members, even when the family member they are concerned about is not in care.

The consumer's consent is a necessary condition for involving family members in the direct care of someone with substance use and/or mental health problems (see *A Family Guide to Concurrent Disorders*, Chapter 7). But lack of consent does not preclude providing education and support to family members. The evidence strongly suggests that education and support has a positive impact on consumer outcomes as well as on his or her well-being (see p.54).

IMPORTANT PRINCIPLES FOR HEALTH CARE PROFESSIONALS WORKING WITH FAMILIES

The primary goals in working with families of persons with co-occurring mental health and substance abuse problems include the following:

- Providing support and respect for families.
- Listening to families' concerns and involving them as equal partners in the planning and delivery of treatment wherever possible.
- Acknowledging, valuing and respecting family members' special kind of expertise.
- Offering a variety of evidence-based interventions for families. This includes professional and peer support and education about concurrent disorders.
- Providing opportunities for family members to increase their feelings of personal mastery and self-efficacy.
- Acknowledging that family members also move through their own journey of recovery and that this journey into, through and out of illness often parallels that of the consumer.
- Addressing family members' experiences of grief and loss.
- Exploring family members' expectations of the treatment program and expectations for the consumer.
- Assessing the family's ability (strengths and limitations) to support the consumer.
- Providing ways for the family to build resilience in the presence of emotional pain, conflicts, difficult emotions, extreme stress and caregiver compassion fatigue.
- Encouraging family members to expand their social support networks—for example, to participate in family support organizations such as The Schizophrenia Society of Ontario or the Mood Disorders Association of Ontario; help the family gain access to support from other families affected by concurrent disorders.
- Helping resolve family conflict by responding sensitively to emotional distress.
- Providing relevant information for the consumer and his or her family at appropriate times.
- Emphasizing the importance of family member self-care.
- Providing an explicit crisis plan and professional response.
- Helping the family develop problem-solving skills.
- Facilitating access to another professional in the event that the current work with the family ceases.

Part III: Preparation

ADAPTING THE PROGRAM

The materials in this package were developed and tested in a specialized addiction and mental health organization in Toronto. The package was also used in a 12-session group in a community-based mental health agency in eastern Ontario. Researchers have argued that, when education and support programs are moved from research settings into community-based agencies, it is often necessary to adapt content in order to increase participation and maximize outcomes (Pollio et al., 2002). When presenting the educational component, facilitators should emphasize the material that reflects the concerns of the group members. For some populations, this might involve being attuned to ethno-cultural or linguistic issues. For others, it might mean focusing on specific mental health problems or specific substance use problems or both. Other group member characteristics that should be taken into consideration when looking at the content of the sessions include:

- the amount of time that has elapsed since the family member's diagnosis
- whether the relative is in treatment
- whether the family members have participated in support and/or advocacy groups (Solomon, 1996).

Group facilitators should also consider adapting the method of delivery of the program to fit the characteristics of the community in which they are working. For example, agencies that serve a wide geographical area might consider using Internet-based discussion groups rather than face-to-face meetings. Other strategies to consider include:

- alternating the location for sessions between two or more communities
- increasing the interval between sessions
- decreasing the number of sessions, and increasing the length of each session (McFarlane et al., 2003).

The basic principle that informs this approach to supporting families is continuing to check in with the participants from week to week to get feedback and to be open to "tweaking" the materials and the process of conducting the groups to ensure maximum benefit for group members.

CHOOSING A DELIVERY METHOD

This facilitator's guide describes a multi-family group education and support program. However, our interviews underlined the importance of offering a variety of approaches to family education and support. Each of the 38 family members involved in our study were randomly assigned to either an education and support group for family members affected by concurrent disorders or to an intervention in which they received only *A Family Guide to Concurrent Disorders*. (See p.61 for a detailed description of the study.)

The following comments illustrate the range of opinion among the participants in our study.

> *. . . you included all of the important areas and the material in all of the topics will help families to understand concurrent disorders. But I still think that you really need the process of meeting in a support group too—so it was all important.*
>
> *I found for myself that often when I left the CD family group, I felt a little bit down, and I think that's because I have a problem with guilt . . . and I would hear the other family members talk and some seemed to be doing more with their kids than I was doing with my son. So I was comparing a lot and I tend to do that—and sometimes I would come out at the end of the group feeling a little bit frustrated . . . if I had a choice, I would have preferred just having the manual and going through it on my own.*
>
> *For me, both the group support and the education were helpful. There was so much I didn't know—and every time there was a handout, I made sure that I took the time to read it . . . so that was very important for me. But then again, the interaction in the group was equally important. I couldn't give more weight to one or the other.*
>
> *One thing for me personally—I tend to like the educational material to read on my own instead of hearing from another person what they're going through. At the time when I entered the study, I was actually hoping that I would be randomized into the manual group. But I understand that it was a study and that we couldn't choose one intervention over the other, so I didn't say anything. But I really did like the information we were given. I sometimes found too that I didn't like talking in a group.*

Program format

Research indicates that both multi-family and single family approaches are effective. There is some evidence that there is a correspondence between the effectiveness of a particular approach and the family's circumstances. For example, families who have already had some experience with support groups often do better with a single family approach, while those whose relative has recently experienced a first episode of psychosis often find a multi-family group to be more effective (McFarlane et al., 2003). Ideally, substance use and mental health services would offer both types of approaches. In reality, practical considerations often determine the choice of format. In urban settings with constrained resources, multi-family groups are often the most practical option. On the other hand, agencies that serve a population spread over a large area may find it difficult to attract enough family members to support a group, and so may choose a single family format.

Group composition

Traditionally, service provider–led psychoeducation and education and support groups have focused on a single mental health diagnosis. However, requiring a single diagnosis often makes it more difficult to recruit enough family members to form a group. Fortunately, recent studies have suggested that groups consisting of families whose relatives have disparate primary psychiatric diagnoses have a number of issues in common and can reach a consensus on the content of the group program (Pollio, 2002). Pollio and his colleagues also found that parents, siblings and other family members identify a common set of core issues.

RELATIONSHIP OF PROGRAM TO OTHER FAMILY AND CONSUMER SERVICES

It is important to keep participants oriented to the mandate of this group, which is not therapy, but education and support. Often, participants feel that the education and support groups have "therapeutic" effects on the ways they feel about themselves or behave in the world. But the groups should not be perceived as or promoted by the group facilitators as offering therapy in any formal way.

Family members may also be involved in more formal professional clinical services, such as individual, couple, family or group therapy. They may also be receiving pharmacotherapy. These can be vitally important resources to them. Group facilitators or members should not referee issues arising from these other involvements. Keep the focus on the primary purpose of the group and maintain a boundary around other activities.

One of the objectives of this education and support program is to help families understand and work within the addiction and mental health systems (see Session 7: Navigating the Treatment System, p.37). Resources (e.g., websites, books) and services for family members with concerns about addiction and mental health problems in a loved one can be accessed in person, via the telephone, or via the Internet (see Session 12: Saying

Goodbye, p. 48. You will want to add services in your own community). Often group participants have already had contact with services, with mixed results: in many cases with positive experiences and a desire to stay connected; in some, not so positive, and there may be wariness for the facilitator to overcome.

Planning for follow-up

Our experience suggests that some of the people who complete the group may want to continue to meet. Before their first meeting with group members, facilitators need to have a clear understanding of how much they and their agencies can contribute to ongoing activities after the end of the formal group program. Group members also need to understand what they are being asked to contribute. It is important to clarify if the group wishes to have formal facilitation or will take responsibility for its own continuing contact. Our inclination is to support family members taking as much responsibilty as possible, with the facilitators taking as minimal a role as is feasible.

Part IV: Implementation

RECRUITMENT

One of the challenges of offering support groups for family members is how to support potential group members while you are waiting for a sufficient number to start the group. The optimal group size is 10 to 12 participants and it can take time to build that number. You can start with a smaller number (six or more), if participants have committed to participating in all 12 sessions. Allowing the group to be heterogeneous in terms of the mental health and addiction issues that members are specifically concerned about was an advantage in our project (see Group composition, p. 13).

CHECKLISTS AND GUIDELINES

"The proof is in the pudding." That's the test for cooking, but also for getting a support group up and running. You can have all the ingredients, but if they're not mixed properly, things might not turn out as well as you had anticipated. **The importance of carefully planning for implementation cannot be overstated.**

SETTING UP THE GROUP: A CHECKLIST

- Secure a space that is adequate and available for the duration of the group.
- Make sure that you have facilitators who are ready, able and willing.
- Recruit participants and keep in touch with prospective group members as you prepare to start the group.
- Ensure that participants are agreeable with the time and location, and can commit to attending at least 80 per cent of the sessions.
- Determine the operating guidelines for the group (open or closed, rules for bringing in new members, duration of group sessions, whether to have a planned break, tasks and goals for each session).
- Familiarize yourself with the group location. Make sure that the materials you need (flip chart, print materials, beverages and snacks, if these are being provided) will be available for each session.
- Keep in touch with each group participant. Encourage members to send RSVPs. Call members who miss a session and encourage them to come to the next one.

Being open to continuing review is the vital complement to thoughtful preparation. Preparing your own checklist and updating it as you go can help you to bring an organized approach to facilitating a family support group.

ROLE OF FACILITATORS

The role of facilitators in an education and support group is primarily one of guiding and trusting in a process where, based on our experience, remarkable individuals are motivated to come together to give and receive support. The motivation of group participants tends to come from:
- frustration related to a perceived lack of information and support in their experiences to date, particularly their dealings with service providers, as well as their involvement with the family member with concurrent disorders
- deep feelings of commitment and concern with finding solutions to the problems that have been affecting their families.

Successful facilitators will be guided by a continuing respect for these motivating forces, as well as by their understanding of group dynamics and interpersonal processes.

We encourage the use of two facilitators, but the group can be led successfully by one facilitator. Another option is to have a facilitator who is a service provider, and one who is not a helping professional. The two facilitators may agree to a clear division of roles where the professional is the leader of the group, and the lay facilitator is an assistant or resource to the group or they may choose to share the facilitator function in a fairly equal manner.

First meeting with the family member

We found it useful for at least one of us to meet and get to know the family member and their concerns as part of group preparation rather than delegating this task to another staff member. **A positive first meeting increases the probability that the person will attend the group** and enhances his or her comfort level in approaching a new situation.

This meeting can also be used to collect baseline information. Before-and-after data help to demonstrate the impact of the group in both qualitative and quantitative terms (see Evaluation, p.19). **However, if you decide to measure the impact, make sure you are aware of your agency's policies concerning collecting and retaining data about human subjects.**

During the session

In our weekly group sessions, it was helpful to be clear on roles—who would open the session, who would take the lead in exercises and other activities. When one person led the group tasks, the other was free to watch and guide process aspects of the group. This ensured that everyone was included in the dialogue, that the enthusiasm participants can easily feel for their own stories did not fill up all the time, and that others were drawn into the discussion.

KEY TASKS

Important functions that need to be covered include:

- Preparing for the session—room set-up, beverages and snacks (if part of the plan), materials distributed.
- Welcoming participants and helping them feel comfortable and at home.
- Starting the group on time and making sure that participants know one another.
- Negotiating the agenda for the session.
- Encouraging respectful dialogue by giving supportive feedback when possible and gently reminding people of the rules of respectful listening and speaking when necessary.
- Ensuring that everyone has the opportunity to participate.
- Wrapping up the session by summarizing key issues that emerged.
- Planning for the next session by reviewing times and agenda and any tasks that participants are expected to take care of in the meantime.

A key measure of an effective facilitator is that members leave the session feeling good about themselves, their co-participants and the experience.

CHALLENGES

Engaging family members

People who participate in family education and support groups are usually highly motivated. But we know that motivation can vary over time, and can be affected by experiences with others, including the group facilitators. We also know that some families come to the group with negative attitudes about service providers. Often these feelings have been shaped by previous experiences with service providers who, while they might have been kind, supportive and well-meaning, did not know what to do when a family member asked them for information or help.

We see every contact as an opportunity to connect and engage with the family member. This starts with the first telephone call, and continues during the preparation process for the group. Never let the need to get forms filled out outweigh the chance to attend to the concerns of the person you are seeing. Helping the person to feel welcomed and settled can go a long way to getting the information you need.

We usually start our first meeting with the family by asking them to give us an overview of their situation and to talk about how the group might help. When you first meet with families, you will often find that they have what may seem like an inexhaustible need to tell you their stories. You may find that you are the first service provider to give the family member a chance to express their concerns and worries and that by actively listening you begin to build a relationship. From a practical perspective, you will also get valuable insights into the family's situation. You can help them focus their story so that they don't feel that they need to share all the details in the first group meeting. We have found that it helps to remind family members that this meeting is not the only chance they will have to share their story and that one of the purposes of the education and support group is to give them an opportunity to give and receive help and support from other group members.

Drop-outs

Family members may drop out of the group because some life event has occurred that makes it impossible for the person to attend, because they have lost interest in the process, or because something happened in the group that offended or upset them. Whatever the case, we encourage proactive encouragement and outreach. A phone call, whether or not the person sent regrets, can help to keep the person in touch with what the group has been discussing and exploring. Keeping positive and encouraging contact can help the person who feels disconnected feel still welcome in the group. For example, we called one of our group members twice to let her know that we were thinking about her and wanted to know how things were going. We let her know that she could reconnect with us at any time and that she could join another family group later on. Of course, in the end, it is important to respect a group member's decision not to continue. **However, every group member should know that if they want to reconnect, the door is still open.** If the issue has to do with the group process or the group composition, or if the person is seeking support of a different nature, help them as best you can to find alternative resources.

Part V: Evaluation

FAMILY RESPONSE TO THE PROGRAM AND PROGRAM MATERIALS

Family education programs should include a component that measures the participants' degree of satisfaction with the program materials and the delivery. Any basic evaluation form should have brief questions that can be answered on a scale (quantitative) and questions that can be responded to in narrative form (qualitative). These forms can be handed out at the end of each session, or toward the end of the final group session.

Here are some examples of questions that can be answered using a scale:

- What is your overall rating of this session (or, if you choose to ask this question at the end of the program, the family group)?
- How satisfied were you with the material covered?
- How satisfied were you with the format of the group (the way it was run)?

Here are some examples of open-ended questions:

- What did you like about this week's group session? (or, what did you like about the group?)
- What did you dislike about this week's group session? (or, what did you dislike about the family concurrent disorders education and support group?)
- Which of the *A Family Guide to Concurrent Disorders* chapters were your favourites and why? (or, list the names of the chapters/sessions and ask people to place a check beside their favourites, or rate their top three favourite sessions.)
- Did you dislike any of the *A Family Guide to Concurrent Disorders* chapters? Were there any chapters that did not meet your personal needs/interests? Which ones and why?
- Would you recommend that we drop any of the material or chapters from the family guide?
- Is there any information that you think is missing from the family guide and really should be included?
- Do you have any other comments?

MEASURING OUTCOMES

The primary goal of family education and support programs is to increase the well-being of the family members who participate in the group. The outcomes to be evaluated should be related directly to this goal. The goals should be realistic. For example, the goal of a one- or two-session workshop may be an increase in knowledge about mental illness and substance use, while a program of 10 or more sessions can aim to increase coping skills as well (Solomon, 1996). If you decide to measure the impact, make sure you are aware of your agency's policies concerning collecting and retaining data about human subjects.

After an extensive review of a broad array of articles and books related to families, mental illness and substance use problems, as well as successful—and not so successful—interventions designed to improve family well-being and consumer outcome, we decided to evaluate the following areas for our study (see Appendix 2 for details):

- empowerment (personal mastery and self-efficacy)
- coping
- social support
- caregiver burden
- perception of stigma ("stigma by association")
- degree of hopelessness
- satisfaction with life / quality of life.

In future studies, we plan to add a measure of the overall health of caregivers and/or family members.

Part VI: Session outlines

A Family Guide to Concurrent Disorders [www.camh.net/About_Addiction_Mental_Health/Concurrent_Disorders/cd_family_guide0607.pdf] contains the content for each of the 12 sessions. It includes:

- information and educational material
- activities
- tip lists
- resources and contact information
- quotations from family members.

The 12 chapters in *A Family Guide to Concurrent Disorders* introduce topics in an ordered sequence. Inevitably, some participants will read ahead, or jump out of sequence. We are inclined to be flexible and to allow the needs and opportunities that arise over the life of the group to help determine the format and content of the sessions. This may mean changing the sequence in which material is presented. For example, one of our group members suggested that the recovery material should be discussed in the first session. Some of the clinicians who attended our workshops have asked about starting off with the self-care session. You may find that the group wants to spend more than one session on a particular topic and will agree to drop a topic that they feel is less relevant to their situations.

In the session outlines, we share suggestions for facilitating the sessions and presenting the content.

Some of the sessions include quizzes:

- Preoccupation and Impact Scale (Session 4)
- Assessing Resilience (Session 5)
- Family Concurrent Disorders Readiness to Change Ruler (Session 7)
- Recovery Attitudes Questionnaire (Session 11)

You may want to ask the group members to save their completed quizzes and to take one or more of the quizzes again in the final session, to see if their answers and scores have changed.

SESSION 1: INTRODUCTION

Session Goals

- Welcome and engage participants.
- Provide overview of support group process.
- Identify and address participants' concerns and issues.
- Start the discussion of how substance use and mental health problems interact.

Content Outline

- Understanding the terminology
- The relationship between substance use and mental health problems
- The impact of concurrent disorders
- The biopsychosocial approach to understanding concurrent disorders
- An introduction to treatment

Leaders' Notes

Most participants like the opportunity to check in at the beginning of each session. For the facilitator, this creates the challenge of working with participants' stories and connecting them with the key themes for the session. Participants are often anxious to share information about life events. We have found that allowing this to happen first is much more engaging for the participants than requiring that they wait until we have introduced our material.

INTRODUCING THE GROUP: A CHECKLIST OF TOPICS TO COVER

- Introductions (families and facilitators introduce themselves and give a five-minute overview of why they are here)
- Overview of purpose and process
- Weekly group—follow-up at intervals over the next 12 months
- Facilitators' goals
- Group members' goals
- Confidentiality
- Differences among participants—the principle of respect
- "Air time"—giving everyone a chance, making sure everyone is included, not being clock-watchers
- Facilitators' role
- Group members' role
- Housekeeping—breaks, bathrooms, refreshments, seating
- Group structure—readings, activities, attendance, checking in when absent
- Check-out at the end of the session—discuss concerns, suggestions, requests with the group

ICEBREAKERS

To help the group members get to know one another, consider using some activities where each group member responds to questions by moving to a place in the room that represents his or her answer. For example, line people up in a row and ask them to guess the percentage of people who will have—over their lifetime:
- a mental health problem
- a substance use problem
- both problems.

Move the participants into groups that represent the actual percentages (see *A Family Guide to Concurrent Disorders,* Chapter 1), and ask them how these facts match their assumptions or perceptions. The goal is to use the information to invite participants to comment, share their reactions and interact with one another. It is important to proceed carefully and respectfully, and to acknowledge that no one should feel coerced or obliged to participate.

Other easy icebreakers include:
- asking people to arrange themselves in a line that represents the distance that each member has travelled to attend the session—from the longest to shortest distance
- asking people to arrange themselves in a line that represents the length of time they have been dealing with the health problems of the family member they are concerned about. To figure out who has spent more or less time dealing with the issue, and where in the line they should be located, they will have to interact with one another.

Once the group members have started to feel comfortable with one another, you can ask them to group themselves in terms of their relationship to the family member with concurrent disorders. For example, have the parents (or mothers and fathers separately), group themselves, have siblings group, offspring, or spouse and partners, or friends. You could also ask the members to form groups based on the gender of the family member with concurrent disorders (male or female) or by mental health or substance use diagnosis.

A suggested order is:
- travel distance
- family member status (father, mother, offspring, spouse/partner, sibling, friend)
- mental health issues involved
- addiction issue involved
- length of time they have been dealing with mental health and addiction issues
- length of time involved with the health care system.

Stop and process participants' thoughts, observations and comments after each activity with some, of course, taking more time than others.

SESSION 2: SUBSTANCE USE PROBLEMS

Session Goals

- Provide an overview of substance use problems.
- Enhance concern and regard for people with substance use and other addiction problems.
- Help participants understand how substance use problems affect their families.
- Encourage identification of practical concerns and goals that participants have for their families.

Content Outline

- DSM criteria for substance-related disorders
- What is the risk of becoming substance dependent?
- Why do people become substance dependent?
- Types of substances

Activities

2-1: Identifying Substance Categories

Leaders' Notes

The most important thing to remember when planning for this session is to link the educational material to participants' real life situations. This is true of every group session, but it is especially important for this session (and Session 8: Medication, p.38). Information on drugs and medications and the interactions between the two can be overwhelming for family members already inundated with new information and consumed by worry and preoccupation. We learned this lesson the hard way when, after preparing a 75-slide PowerPoint presentation for this session on substance use problems, we only made it through two slides. We quickly realized that letting the group participants pave the way for the discussion by using their personal situations as a guide was a much more effective strategy. **Information that is meaningful and personal is far more relevant and much easier to absorb.**

EXPLORING REASONS FOR SUBSTANCE USE

Many family members have trouble understanding why their relatives continue to use substances despite obvious negative consequences. A *Family Guide to Concurrent Disorders* includes an activity that helps family members think about how their relatives might see the benefits and costs of substance use (see Activity 7-1: Exploring Ambivalence about Change). The activity is part of a discussion about motivation to change behaviour, but we have found it helpful to begin the benefit/cost discussion in Session 2, and then pick it up again in Session 7.

Ask the participants about problems that result from substance use or other behaviours such as gambling. Ask them to talk about their own family experience and write their responses on a flip chart. Examples participants have given include:
- lost jobs and income
- social rejection
- jail as a result of out-of-control behaviour
- hospitalization
- fear of loss (children, partner, family)
- embarrassment
- blackouts
- increased fear of psychiatric episodes.

Then ask the participants to suggest what people might see as benefits of using substances or engaging in other addictive behaviours, such as problem gambling. Examples participants have given include:
- excuses their behaviour
- makes them feel good, at ease, relaxed
- balanced him
- makes them think they are important
- makes them sound more intelligent
- helps them to stay awake, keep thoughts going
- needed for social acceptance, to deal with peer pressure
- helps reduce anxiety
- escape—makes troubles go away.

SESSION 3: MENTAL HEALTH PROBLEMS

Session Goals

- Provide an overview of mental health problems.
- Help participants understand mental health issues affecting their family.
- Develop a better awareness of what it is like to have mental health issues and why substance use and other addictive behaviours might be something to which that person is especially susceptible.
- Encourage identification of practical approaches to addressing the issues of daily living.

Content Outline

- Why do people develop mental health problems?
- Mental health disorders
- Personality disorders

Activities

3-1: Identifying Mental Health Problems

Leaders' Notes

Family members may have a lot of information about mental health problems, particularly the health issues of their own family member. However, this knowledge is often spotty and ill-formed. Consequently, it is important to offer participants an overview of these issues so that they begin to understand how mental health problems arise, and how to address them effectively.

DISCUSSING THE COMPLEXITY OF PROBLEMS

In this session mental health problems are organized along four dimensions—psychosis, anxiety, mood and impulsivity. For participants with family members with a severe and persistent mental illness, this may represent an expanded view of mental health problems. The presence of a powerful diagnosis such as schizophrenia or bipolar disorder may mask other problems, so that the complexity of symptoms are reduced to one overarching problem rather than a number of issues, each of which could be addressed in its own right. For example, someone who has schizophrenia could also have a social anxiety problem, which could be addressed using social skills training.

DISCUSSING DIAGNOSIS

We found that family members are often preoccupied with "the diagnosis." They may already feel frustrated and confused because of their previous experiences of seeking care for their family member. They want someone to tell them what is wrong and what needs to be done. They often have stories of misdiagnosis—and as a result misprescription of medication. They sometimes talk of multiple diagnoses, some of which compete with one another.

This is another instance where we found it useful to start discussing the issue in this early session and then pick up the discussion again in Session 7: Navigating the Treatment System. One point to reinforce is that these problems are complex. Because these issues often vary in their presentation, "what's up front at any point in time" (as one participant put it) will vary also. It is usually only over time that the service provider gets an accurate picture, so it is understandable that families may have had negative, unsatisfying experiences in their search for understanding and help.

Respect the frame of reference and belief system that participants may have. Some may have trouble accepting a particular diagnosis because it means their family member might need to take prescription medication; others might have trouble seeing that many people need an active, well-supported approach to psychosocial issues as well as medication. Facilitators need to anticipate that family members will share their beliefs and options and to develop a plan to deal with the issues constructively.

SESSION 4: HOW CONCURRENT DISORDERS AFFECT FAMILY LIFE

Session Goals

- Provide an overview of the ways families are affected by concurrent disorders.
- Help participants identify specific areas in which their lives have been affected by concurrent disorders.
- Highlight the importance of sharing experiences with peers and trusted health professionals.

Content Outline

- Behaviour changes
- Relationship changes
- Increased responsibility
- Impact on caregivers

Activities

4-1: Personal Impact Log
4-2: Preoccupation and Impact Scale
4-3: Family Concurrent Disorders Index of Concern Quiz

Leaders' Notes

BEGINNING THE SESSION

Families need an opportunity to tell their stories. It can be more difficult to experience illness in someone you love than it is to have an illness yourself. Family members find this idea to be accurate, powerful and compelling. They often need validation of how draining the experience of supporting someone with a mental health and substance use disorder can be. They also need people to understand how much they love their family member and want them to recover or go back to the way they once were.

Researchers often use the term "caregiver burden" to describe the physical, emotional, financial and social effects of caring for someone with substance use and mental health problems. **It is easy to use terms like caregiver burden without realizing the impact that this can have on caregivers, other family members and the family member with concurrent disorders.** Many family members feel that the concept of *burden* ignores or cancels out the positive and rewarding aspects of trying to help their loved one. We used terms such as compassion fatigue rather than burden during this session. In fact, we discussed with the group members our experiences in using the term caregiver burden with families, and explained that we now use other ways to describe this phenomenon.

There are a number of scales that can be used to measure caregiver burden. If you use a caregiver burden scale or measurement tool to assess whether people's perceptions and experiences improve over the course of the 12 sessions, you might also want to explain that, although you cannot ethically or legally change the name of an existing questionnaire or scale, you do acknowledge the implications of using this term.

A FINE BALANCE

Eastern philosophy thinks of health as balance. Energy is called "chi." One of the ways to help balance the chi/energy in this session is to take a few minutes to go around the circle of participants, asking each person to talk about his or her loved one's strengths. You can pose questions such as:

- What is the one thing you love most about your family member?
- What do you think is his or her greatest strength?

After you acknowledge how painful, exhausting and frustrating it can be to have a family member with concurrent disorders, you can ask:

- What is the most rewarding part of your experience?
- Has there been a positive aspect to caring for your family member?

We have found that group members deeply appreciate recognition of the rewarding side of the caregiving experience. This validation helps to set the stage for a discussion about the ways in which families are affected by concurrent disorders. Once group members begin opening up about the impact on the family, it can be a challenge to end the session after two hours. Because family members so often go unrecognized for their perseverance and courage and may even be blamed instead of rewarded for their efforts, they are often relieved to be given an opportunity to talk about their own pain and suffering and that of the other members of the family.

PERSONAL IMPACT LOG

We found that group members enjoyed completing the Personal Impact Log. However, some participants needed help with clarifying the objectives of this activity. Rather than having participants fill in the log on their own, you can ask them do the exercise as a group. For instance, go around the table asking each person to give an example of how they as a family member have been, or continue to be, affected by their loved one's substance use and mental health problems. Remind the group that "impacts" may be positive as well as negative. You may choose to begin with one category such as how their physical health has been affected and then go through each of the other three sections of the log. Or you may suggest that each person tells the group how he or she has been affected in all four areas. Group members can use their completed logs when they develop their self-care plans (see Session 5, p. 33).

PREOCCUPATION AND IMPACT QUIZ

We developed this tool after realizing how profoundly caregivers and other family members are affected by their experiences. We decided to include the quiz in *A Family Guide to Concurrent Disorders* to help family members think about the degree to which this preoccupation had permeated their lives. This quiz has not been tested for reliability and validity. It cannot be used in a formal evaluation or research study. However, you may find it helpful in your own efforts to examine whether or not preoccupation is changed by participation in a family concurrent disorders education and support group. We plan to test the psychometric properties of this quiz in the future, and to make that formally tested measurement tool available to family members and health professionals.

FAMILY INDEX OF CONCERNS QUIZ

Explain to participants that the items in this quiz may help them to identify areas that most concern them and to consider strategies that might help them resolve some of these concerns. Suggest that they think in terms of *small* steps that could help them make some changes in particular areas.

Ask them to circle the number that best corresponds with *how they are feeling right now*. Once they have completed all of the questions, suggest that they add them up to get their total score. The higher their total score, the more uneasy, worried or alarmed they are overall about their situation and the more they may need to focus on their own emotional, social and physical health and well-being.

This quiz can also help family members:
- identify any personal areas of concern over which they have little (if any) control
- consider how they might learn to accept what they cannot change.

Identifying areas over which one has little if any control and learning to accept these can be just as important as identifying areas of concern that are amenable to positive change. For example, family members may want their relative to stop using alcohol or other drugs, while the person may decide that he or she wants to *cut down* on their use, rather than stopping completely. This can be difficult for family members to accept. However, trying to force their relative to reach a goal that is of no interest to him or her can actually work in the opposite direction and result in an unwanted outcome. For example, he or she may resist being forced to act on a goal set by other people by using *more* drugs, turning to other sources of income to purchase those drugs, and withdrawing further from the family circle.

SESSION 5: SELF-CARE

Session Goals

- Explore the benefits of taking care of oneself.
- Explore self-care strategies across all domains of participants' lives (e.g., physical, emotional, social, spiritual, financial).
- Encourage and help participants as they develop their own self-care plans.

Content Outline

- Short-term self-care strategies
- Dealing with difficult feelings
- Long-term self-care goals
- Building a self-care plan

Activities

5-1: Assessing Resilience
5-2: Quick Wins
5-3: Stop-Start-Continue
5-4: Self-Care Plan

Leaders' Notes

In our group about one third of the participants approached the whole idea of caring for themselves with great enthusiasm. They agreed that caring for oneself should be a priority for family members and they had already taken steps toward creating, regaining or maintaining their physical, emotional, social and spiritual health and well-being. They were eager to convince their peers that maintaining a healthy balance in their lives would help make their situation a little easier to bear. They talked about how attending to their own needs had positively affected their lives, and were eager to share the specifics of their personal self-care plans and activities. For example, one of the mothers in the group talked about how much she looked forward to walking long distances every day and reading inspiring books. Another participant discussed the significance of spirituality in her life and described how her spiritual beliefs had comforted her and helped her keep going despite feelings of loss, grief, sadness and self-doubt. Another participant described how connected she felt after attending family focused self-help / mutual aid groups.

However, if there is one topic with which many family members become frustrated and impatient, this is it. Some family members are not yet able to break free from the anxiety, preoccupation and stress inherent in caring for a loved one. We found that family members newer to the experience of caregiving were more cynical about spending an entire group session talking about the benefits of taking good care of themselves.

> *I know intellectually that I should be taking better care of myself, but realistically, where am I supposed to find the time? I'm dealing with one crisis after another. It sounds really nice and all, but I'm afraid that relaxing with a good book or dragging my husband out to see Brad Pitt and Angelina Jolie on the big screen just aren't on the radar right now, you know? Spending time thinking about myself and worrying about whether I'm eating too many carbs or getting enough beauty sleep or working on those abs seems a little over the top, you know what I mean? They're luxuries some of us just can't afford—especially when your hypomanic 18-year-old kid has just been busted by undercover cops for buying drugs from the friendly neighbourhood crack dealer.*

If you validate the exhaustion and stress that caregivers experience, you can ease into the topic of self-care without appearing to be insensitive. Most family members experience a kind of journey of recovery that often parallels the ups and downs that their loved ones experience. They may be unable to focus on their own self-care needs or they may wrestle with feelings of guilt and shame when they think about doing so. Many participants commented that they would start to relax and feel happier once their family member received proper treatment and started to get better.

USING A SELF-CARE ACTIVITY

Beginning the group with a self-care activity just prior to the weekly check-in is an effective way to introduce the topic of caring for the caregiver. We used a meditative exercise from *Full Catastrophe Living* (Kabat-Zinn, 1990) in which raisins are used to facilitate the practice of mindfulness. Group participants were so delighted with this exercise that we ended up including it at the beginning of each of the remaining group sessions. You can also invite the participants to imagine that their past week was captured on tape. Ask them to review the tape from a self-care perspective. As they do this, can they identify a low point and a high point from the past week? Invite them to share a key point or two if they are comfortable doing so.

USING AN ANALOGY

Another way of introducing the participants to the idea of self-care in spite of—or perhaps because of—the challenges they face is to use a simple analogy to reinforce the fact that without their own physical, emotional, social and spiritual health, their attempts to help their family member with his or her concurrent disorders would likely be ineffective. You can ask the group to respond to the following:

> *You are travelling by airplane with your three-year-old child when the plane suddenly loses cabin pressure and altitude. Oxygen masks drop down in front of you and the rest of the passengers. Who do you put the oxygen mask on first—your child or yourself?*

And of course, the correct response is "yourself as the caregiver." Without ensuring that you will not lose consciousness because of a lack of oxygen, you put both yourself and your child at risk.

Once family members get past their concern about spending time focusing on themselves, they tend to become much more open to the idea of developing their own personalized self-care plan. As part of the check-in for the remainder of the group sessions, you can ask each participant to briefly discuss one way in which they took care of themselves the previous week. The idea is to help them become as attentive to themselves as they are to their family member.

ACTIVITIES

Since it can be difficult for some participants to jump into a discussion about their own personal "Self-Care Plan" (Activity 5.3) it might be wise to work on this activity as a group (similar to the way you would facilitate the discussion and activities during Session 4). We recommend that you start off with some of the other activities included in the chapter on self-care, rather than moving straight into the self-care plan activity. For example, "Quick Wins" (5.1) and "Stop-Start-Continue" (5.2) tend to be easier for participants to discuss and complete because they allow easy identification of the specific behaviours and perceptions with which they are satisfied and those that are a source of concern. These behaviours and perceptions can be associated with easily accomplished actions, which in turn can lead quickly to feelings of success and mastery.

We recently added another activity we call Assessing Resilience (5.4). This followed from a discussion we had in our group about family resilience and "hardiness" and from questions about whether caregivers and other family members could in fact strengthen their ability to be resilient under stressful circumstances. Facilitating a conversation about what "resilience" means to different group members, and perhaps about what factors seem to be most common in "resilient" people is helpful before giving participants time to complete the *Resiliency Quiz* (developed by Patricia Morgan) and discussing the items on the quiz and participants' scores (let each group member choose whether or not to share his or her score). This whole notion of the ability to "bounce back" after suffering extremely adverse circumstances is not only of great interest to family members, but is an area frequently discussed in the literature on families, mental health and substance use problems.

SESSION 6: STIGMA

Session Goals

- Enhance awareness of the impact of stigma on families affected by concurrent disorders.
- Help participants identify the ways in which their families have suffered the effects of stigma.
- Identify strategies to fight against stigma on a personal, family, community and broader social level.

Content Outline

- Understanding stigma
- Experiencing stigma
- Surviving stigma
- Combating stigma

Leaders' Notes

> *Your piece on stigma reminded me of the fact that everyone handles mental illness differently in terms of disclosure. We need to respect that some families are uncomfortable with disclosure and the added stresses that brings to the family to keep the illness a secret. I myself have no difficulty talking about my own situation, but I know that many find it difficult to expose the addiction on top of the mental illness, and often only after I have said my son has an addiction to alcohol do others reveal the same. Your report alludes to the ignorance of the general population about concurrent disorders and the fear about these illnesses and subsequent stigma. I think families can reduce stigma by being educated about the illness and in turn by educating others.*

We have found that discussing stigma with family members is much easier when facilitators begin with practical exercises.

STARTING THE DISCUSSION

Before actually getting into a discussion of personal experiences with stigma, it is generally helpful to ask the group what things come to mind when you say the word "stigma" (e.g., definitions of the term, mental images or words that people associate with stigma, or movies that have dealt with the subject of stigma and mental health and/or substance use problems). Some family members will have experienced feelings of shame and embarrassment, sadness and guilt, and anger and frustration due to stigma, while others will say that they have never been directly affected by stigma at all.

Another way to start a discussion is to ask the group to talk about the difference between the terms stigma, prejudice and discrimination. You can explain that "stigma" refers to a feature that is viewed by others as undesirably different. You can ask the group members for examples or you can provide examples (e.g., medical conditions such as obesity, hair loss, or physicial disabilities). Examples relevant to concurrent disorders include someone talking to themselves as a result of a psychotic disorder or hallucinogenic substance use. The idea here is to help the family members differentiate the visible or invisible traits themselves from people's attitudes toward such stigmatized traits (prejudice), and people's behaviours toward those who are stigmatized (discrimination).

STIGMA AND SUBSTANCE USE AND MENTAL HEALTH PROBLEMS

It is important to discuss reasons for stigmatizing particular conditions, traits, marks and behaviours. For example, ask the group to think about a number of stigmatized health care conditions and then have group members talk about the different reasons for stigmatizing people with these illnesses.

A general discussion about the reasons for stigma usually leads to talking about stigmatization of people who have substance use and mental health problems. This is a good opportunity to talk about common myths about mental health and substance use problems. For example, some people:

- Believe that individuals with personality disorders are seeking attention and are unwilling to take responsibility for their behaviour.
- Fear individuals who hear voices and talk to themselves because they mistakenly associate such behaviours with violence.
- Believe that individuals who have major depression are really just lazy.
- Believe that individuals who have substance use and mental health problems make the problems worse by refusing to take responsibility for their behaviour.

Talking about these, and other, examples is a comfortable way for many family members to begin relating the discussion of stigma to their own personal lives.

DISCUSSING PERSONAL EXPERIENCE OF STIGMA

You can ask participants to share their own experiences with the group. It is helpful if the facilitators begin the discussion with a non-threatening example of how they have experienced stigma themselves. I often talk about how I grew to six feet tall before I was 12 years old and was laughed at and discriminated against because everybody else in my class, including (and especially!) all of the boys, were so much shorter than I was. I often add that after suffering a terrible sunburn one summer as a pre-teen, I was known as "The Towering Inferno."

It can also really put group members at ease if one of the facilitators shares an experience with substance use or mental health problems in their own family. Some clinicians will not be comfortable and willing to do this, but being upfront about substance use and mental health issues and the associated experiences of stigma and discrimination is greatly appreciated by family members.

We have found that the module on stigma is often one of the group members' favourites. Although it can be a painful and uncomfortable topic for family members, once they become engaged in the discussion, they tend to experience a sense of satisfaction and gratitude for such an opportunity.

SESSION 7: NAVIGATING THE TREATMENT SYSTEM

Session Goals

- Review experiences family members have had with the treatment system.
- Highlight negative and postive aspects.
- Identify barriers to getting treatment and support services to work together and to include family members.
- Imagine what an ideal system of care and support would look like.
- Discuss ways that family members can be effective advocates for the needs of people with concurrent disorders and their families.

Content Outline

- Is there a treatment system?
- What should happen: integrated treatment
- Sequential or parallel treatment
- Finding treatment
- Screening and assessment
- Treatment planning
- Treatment

Activities

7-1: Exploring Ambivalence about Change
7-2: The Family Concurrent Disorders Readiness to Change Ruler

Leaders' Notes

Families are looking for a simple, direct answer on how to negotiate what they see as "the treatment system." Too often they have failed to get help and support. Our group members told us of appearing and reappearing for help for their family members, only to meet new professionals who did not know about the history. Often they had to tell the story over again and again. Their comments speak to the need for someone who knows their story who can be accessed on an as-needed basis. But without a consistent response capability in the "system," they found themselves taking on the role of case managers for their family members.

NAVIGATING THE TREATMENT SYSTEM

Because of the importance participants gave to this theme, we decided to organize this session around the concept of navigating the system. **We help participants understand how the components of the treatment system work and emphasize the importance of becoming proactive so they can make existing health care resources work better for them and their family member.** This can be a "grassroots" strategy for getting treatment resources to become more interrelated and collaborative: in other words, the "system" that consumers and family think it should be.

Chapter 7 in *A Family Guide to Concurrent Disorders* includes tools to help families work with service providers:
- a list of questions to ask a treatment agency
- a sample family information document
- a form for tracking treatment history
- questions to ask about transition or discharge plans.

We suggest using the treatment history form to help family members summarize the family's experience of trying to navigate the system. Ask them to share their stories and use their responses to make a list on a flip chart. Then ask participants to discuss ways to change the outcome, or share examples of when things have worked well and what made a difference.

MOTIVATION AND CHANGE

We also find it helpful to discuss motivation and stages of change as they relate to how ready and willing both the person with concurrent disorders and the family are to seek help. You can use Activity 7-1: Exploring Ambivalence about Change to pick up the discussion about benefits and cost of substance use that you started in Session 2. Activity 7-2: The Family Concurrent Disorders Readiness to Change Ruler gives family members a chance to evaluate how ready they are to make changes in their beliefs and behaviours.

SESSION 8: MEDICATION

Session Goals

- Provide an overview of the major classifications of psychiatric medications.
- Facilitate discussion about the ways that alcohol and other drugs may interact with prescribed medications.
- Raise awareness of the importance of keeping up-to-date records of prescribed medications.

Content Outline

- Drug therapy for mental health problems
- Drug therapy for substance use problems
- Medication management
- Medication abuse or dependence
- Drug interactions
- Ongoing treatment
- Stopping medication

Activities

8-1: Tracking Side-effects

Leaders' Notes

Concurrent disorders family education and support groups can be facilitated by clinicians from a variety of health care disciplines such as nursing, social work, psychology, occupational therapy and medicine. In this session it makes things easier if one of the two co-facilitators has *some* background expertise in psychopharmacology. If neither clinician has expertise or feels comfortable responding to family member's questions about their relative's medications, consider inviting a colleague such as a nurse or a pharmacist to join you for this session. You will probably be able to respond to most of the questions that come up, but it's a good idea to ensure that family members can access a health care professional with formal training in pharmacology.

As with Session 2: Substance Use Problems, the most important thing to remember when planning for this session is to link the educational material to participants' real life situations. If you do invite another health care professional to this session, mention this to him or her and ask that they keep this in mind when offering information about medications or the interactions between medications and alcohol and other drugs.

We recommend giving each family member time to discuss the medications currently being prescribed to their loved one. In fact, it is a good idea to cover this immediately after the check-in for this session (and meditation exercise if you have decided to do it in this session).

Take this session slowly and respond to questions using basic language and simple terminology that everyone can understand. Briefly review the categories and classifications of psychiatric medications. You may wish to remind participants that medications each have two different names—a generic and a trade name—and that health professionals may use these names interchangeably. Since many people use the Internet to find information about medications, remind them that the trade names for medications are sometimes country-specific and that they should check the origin of the material.

Often group members make comments such as, “Oh yes, my son was taking that medication two years ago, but he started having really bad side-effects. He gained so much weight that our family doctor was concerned about him” or “My husband just kept getting worse until they switched him to the medication your son might end up taking—and did it ever work for him!”

It is very important to consider what you will do if a participant makes a misleading comment about a medication or unintentionally gives the group inaccurate information. For example, someone might relate a story about a side-effect of a particular medication that happened to *their* family member but is in fact a very rare side-effect. You must comment on this, gently if necessary, so other participants don’t get inaccurate information.

Since this is a family concurrent disorders group, you will probably be asked how a specific substance that is being misused interacts with psychiatric medication. Spend time on these questions because they address a reality of everyday life for families. If a *general* question arises that you or your guest facilitator don’t feel comfortable answering, tell the group that you’ll find out the correct answer and get back to them at next session. If one of the family members asks advice about dealing with a *specific* medication or a combination of medications and other substances—we were asked whether excessive daily use of marijuana would interfere with the effectiveness of olanzapine (a popular antipsychotic medication) and whether or not it would be wise for the person to take a higher dosage of this medication until he or she was able to reduce their use of marijuana—you should recommend that participants check with their family member’s pharmacist or prescribing physician.

TRACKING SIDE-EFFECTS

This is an activity to be done, if at all possible, with the family member with concurrent disorders. Group facilitators can discuss any side-effects related to particular medications that they have noticed, but the actual tracking of side-effects is an at-home ongoing activity (so that family members can keep a log for future reference, for informing new health professionals working with their relative, ER staff or other workers, and to support medication changes).

SESSION 9: RELAPSE PREVENTION

Session Goals

- Orient participants to addiction and mental health problems as chronic relapsing conditions.
- Discuss some of the common features of relapse as a process.
- Explore the ways that relapses can be used as learning experiences that enhance the prospect of long-term recovery.
- Discuss practical issues that participants face and how relapse prevention approaches can (and perhaps already have) helped them deal with the relapsing nature of co-occurring addiction and mental health problems.

Content Outline

- Relapse prevention: substance use
- Relapse prevention: mental health

Activities

9-1: Identifying Risk Factors
9-2: Relapse Prevention Strategies
9-3: Caregiver Relapse Prevention Plan

Leaders' Notes

Relapse and relapse prevention are areas that we have learned a lot about in the past two decades. Now, what starts out being something that people are apprehensive about can sometimes be an important, constructive part of the process of change and recovery. One of the goals of this session is to help participants see these processes through a new lens, one that helps them see a relapse as something that can often be prevented or if it happens, can be minimized. Often family members can see things shaping up and can help their relatives either avoid a relapse or to deal with it effectively.

When we framed the discussion in this way, we found that family members took a more constructive view of relapse. Since we knew we would be using the metaphor of a journey to talk about recovery in the next session, we introduced the idea that on every long journey there will be periods of bad weather. By being prepared, by trying to move around—or if need be to work through—bad weather, the journey could still continue. One of the best tools in this process is to get participants to talk about the experiences they have already had with relapse:

- Were there events that indicated a relapse was coming?
- Do they have a better sense of what was helpful in averting, or minimizing, a relapse and what wasn't helpful at all?

Their past experiences can be the starting point for putting relapse and relapse prevention in a new perspective. Participants will have different "takes" on this. Some may be bruised and apprehensive about it happening again. Others might have stories about how they helped to make relapses better (or worse), or how awareness and good communication in the family might actually have prevented a relapse.

Ask the group to identify things they can do to keep things on course, and ways that if they are not careful they could make things worse. For example, sometimes people admit they saw warning signs, but let things go. Or, they reacted too impulsively, perhaps out of fear or frustration, only to find that they had escalated things in the wrong way.

RELAPSE PREVENTION PLANS

Writing a relapse prevention plan (see Activity 9-2: Relapse Prevention Strategies) helps family members think about more effective ways of responding to signs of a possible relapse. Suggest that, if possible, they work on this project with their relative.

As we discussed in Session 5, many family members have trouble justifying taking time to care for themselves. We suggest reinforcing the importance of self-care by asking them to create a plan that addresses the steps that they would take to prevent a "relapse" in their own physical, emotional, social and spiritual health.

SESSION 10: CRISIS AND EMERGENCY

Session Goals

- Help participants to identify potential crisis and emergency risks that might apply to their situation.
- Encourage the development of crisis and emergency plans that allow quick, effective action when needed.
- Increase confidence that if families are prepared, crises and emergencies can be better managed.

Content Outline

- Crisis
- When a crisis becomes an emergency
- Getting treatment in an emergency situation
- Creating an emergency plan
- The forensic mental health system

Activities

10-1: Reflecting on an Escalating Crisis
10-2: Creating a Crisis Card

Leaders’ Notes

The key objective of this session is to shift the focus from being reactive, fearful and waiting for the other shoe to drop, to being proactive, prepared and more confident about what to do in a crisis or emergency.

One of the great benefits of working with families who are affected by concurrent disorders is learning from experts. In this case, the experts were our group members. First of all, they highlighted this topic as an essential one for them when we did our needs assessment. That helped us identify key content to share with them. When they started sharing their practical experience, we realized that some of the tools and approaches they had developed deserved to be more widely known. An example of this was the participant who kept copies of key information—health card, social insurance number, home address, telephone numbers, family doctor’s name and address, diagnoses, prescription medications—at hand so that if there was a need to present for care, they were ready. Or, if vital information was lost, they had back-up copies. This interested other group members a great deal. As a result, we made it an integral ingredient in making a crisis/emergency plan (see Activity 10-2: Creating a Crisis Card).

By canvassing for ideas based on experience or on identified needs, we were able to access and draw on the expertise of the group participants. By discussing the ideas in detail, we could evaluate and validate the resourcefulness of the participants. By offering to pull materials together, we could help other participants add to the ways they dealt with potentially distressful events.

SESSION 11: RECOVERY

Session Goals

- Facilitate discussion about the "journey of recovery" metaphor and how it also applies to family members.
- Help participants describe their personal journeys of recovery and think about where they are on this journey.
- Help participants to identify factors that can help move them forward in a positive direction.

Content Outline

- The role of hope in recovery
- Establishing and sustaining recovery
- Family members' role in recovery

Activities

11-1: What does Recovery Mean to Me?
11-2: What does Recovery Mean to my Relative?
11-3: Wisdom Written in Shorthand
11-4: Your Recovery Journey
11-5: Recovery Attitudes Questionnaire

Leaders' Notes

> *. . . probably the one thing that resonated the most with me was the idea of . . . I mean, it was not necessarily a separate topic on its own—but it was the idea, or message, of hope. It's so easy to lose hope in this situation. Actually, it was in the Recovery section. It's easy to get discouraged and feel hopeless, and I'm sure everybody around the table has felt hopeless sometimes. And, again . . . it's not surprising when you think about it . . . but to get that message of hope and to hear it from the other family members . . . and to hear how they kind of—they still kind of can see their way out of the situation. Or, how did we word it? We talked about accepting the fact that things may not be the same as they were before—and about how that's a kind of progress, too. There's hope in that—like, not feeling discouraged because that's the best you can hope for. So, that was probably the thing that resonated the most for me . . . that I felt some hope—and not just for me, but for my son as well. Sometimes I think he sees it as hopeless—so it's*

> *important to try and find ways to give him hope, and for us to have hope—and those two things are obviously pretty closely tied together.*

The idea that when the person who has co-occurring mental health and substance use problems embarks on a process of recovery, family members also travel their own parallel journeys, strikes a chord with many family members and generates new ideas about what recovery means.

We must also add that not every family member found the whole idea of recovery easy to understand and accept. In fact, one person was actually very frustrated with the idea that people "recovered" from co-occurring mental health and substance use disorders. Give group members a chance to talk about their reactions to the idea of recovery. People may also have difficulty seeing recovery as something they also go through as caregivers and family members. Often, once the group members begin to understand that recovery means many different things to different people and does not necessarily mean a complete absence of all symptoms for the rest of a person's life, the notion of a journey or process of recovery becomes much easier to accept. It is then much easier for family members to think about themselves as travelling their own pathways of recovery, in which they may gain acceptance, begin taking better care of themselves, learn to set limits and expectations with their ill loved one and develop a newfound sense of hope and serenity.

PERSONAL STORIES

It can be helpful to ask participants to describe what their own view of recovery is. Most family members have no difficulty describing the unique ways in which their ill loved ones are on a journey of recovery. We found that several family members with a great deal of experience and many years caring for a loved one had little trouble distinguishing between an ongoing process of recovery and a "cure" for mental health and substance use problems. They could give detailed and specific examples of their family member's recovery.

Some participants even found value in their family member's relapses and felt that on the whole, in spite of (or perhaps because of) their ups and downs, their family members were changing and moving forward even if progress was slow at times.

As we suggested in Session 6, it can also be helpful for facilitators to talk about the journey of recovery in one of their own family members or even in themselves. Again, not every health professional will feel comfortable doing this.

WISDOM WRITTEN IN SHORTHAND

Consider presenting and discussing inspirational recovery sayings (or what many 12-step programs such as Alcoholics Anonymous (AA) call slogans or “wisdom written in shorthand”). Here are some examples (others can be found in *A Family Guide to Concurrent Disorders*, Chapter 11):

- Pain is necessary, suffering is optional!
- A journey of 1,000 miles begins with the first step.
- Be part of the solution, not the problem.
- There are two days in every week over which we have no control—yesterday and tomorrow. Today is the only day we can change (or: It is not the experience of today that drives people mad; it is the remorse of yesterday and the dread of what tomorrow may bring).
- If nothing changes, nothing changes (or: If you do what you always did, you’ll get what you always got).
- Feelings aren’t facts!
- Let go or get dragged.
- Expectations are preconceived resentments.
- Serenity isn’t freedom from the storm; it is peace within the storm.
- Intolerance = Contempt, prior to investigation.

Ask group members to choose a saying that speaks to their experience and talk about what it means to them.

SESSION 12: SAYING GOODBYE

Session Goals

- Formally end the group.
- Get feedback from participants on their experiences in the group.
- Obtain suggestions about things that participants valued most and things that would improve the experience.
- Encourage participants to think about ways they will continue to stay resilient and obtain support.
- Identify resources that could be of help to participants, the family member with concurrent disorders and other family members.
- Celebrate participants' contributions to making the family support group a positive experience.

Content Outline

- Taking care of the formal tasks related to the ending of the group.
- Allowing participants an adequate time for input and feedback about the experience.
- Taking time to celebrate and affirm the contributions participants made to the support group.
- Talking about the road ahead for each participant in the context of the journey of recovery—immediate issues, concerns on the horizon.
- If part of the plan, reminding participants of follow-up for individual contact for evaluation and feedback of the experience.
- Highlighting the ways that the door remains open for continuing support, formally and informally.
- Saying goodbye and expressing appreciation, respect and best wishes.

Leaders' Notes

As a way of formally acknowledging that the group is coming to an end, give participants time to reflect on their experiences in the group and to offer feedback about the content and the group process. Make sure that each member has an opportunity to make comments. Remind participants of any further contact that is part of the program—such as a follow-up meeting for evaluation.

If you have asked the group to keep their answers to one or more of the quizzes—Preoccupation and Impact (Session 4), Assessing Resilience (Session 5), The Family Concurrent Disorders Readiness to Change Ruler (Session 7), Recovery Attitudes Questionnaire (Session 11)—you may want to ask the group to take one of the quizzes again, and to see if their answers and scores have changed. This will help each person focus on the positive changes in his or her own life. Some people may also find that this activity highlights problems or areas that they need to work on.

RESOURCES FOR ONGOING EDUCATION AND SUPPORT

Introduce the issue of looking ahead and talk about the resources that are available in the agency hosting the group and in the community, as well as online and in books.

Be prepared to answer questions about follow-up services. For example:

- Will this group be meeting for any follow-up sessions in the future?
- Does your program/agency offer any *other* support educational groups for families or any other kinds of family services?
- Does your agency provide family therapy interventions or concurrent disorders consultations for families in crisis?

If your agency does have family programs, be prepared to talk about details such as:

- the number of families on wait lists
- the specific inclusion/exclusion criteria or other requirements (if any) for other available family services.

If possible, hand out flyers or brochures about your agency's family services and other services available in your community (e.g., family therapists, the local chapter of The Schizophrenia Society of Ontario or the Mood Disorders Association of Ontario).

A *Family Guide to Concurrent Disorders* contains a list of resources (websites, online publications and books and booklets). You will probably want to add other resources that you have found useful.

CELEBRATING THE WORK OF THE GROUP

Consider ending this session with a ceremony or celebration that affirms the work of the support group as an important and valued accomplishment. This can be as simple as having a cake or giving out certificates. Often the group will come up with suggestions. Whatever you choose to do should feel like a natural part of the group process rather than an artificial ritual that is being imposed on the group.

SAYING GOODBYE

Share you own perspective on the experience of the past 11 weeks, and let the group members know that you recognize and appreciate their contributions to the group and their efforts to support their own families.

It is also extremely important to give participants room to grieve the closing of the group, to establish ongoing connections with each other where desired, and to say goodbye.

References

Kabat-Zinn, J. (1990). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness.* New York: Delta.

McFarlane, W.R., Downing, D., Lapin, M.B., Jacobson, L.H., Perry, K. & Amenson, C.S. (2003). *Family Psychoeducation Workbook.* Washington, D.C.: Center for Mental Health Services.

Pollio, D.E., North, C.S. & Osborne, V.A. (2002). Family-responsive psychoeducation groups for families with an adult member with mental illness: Pilot results. *Community Mental Health Journal, 38,* (5), pp. 413–421.

Solomon, P. (1996). Moving from psychoeducation to education for families of adults with serious mental illness. *Psychiatric Services, 47,* pp. 1364–1370.

Resources

WORKING WITH FAMILIES

Family Mental Health Alliance. (2006). *Caring Together: Families as Partners in the Mental Health and Addiction System*. Toronto: author. Available: http://ofcmhap.on.ca/files/Family_stn1.pdf. Accessed 24 April, 2007.

Fischer, E.P., Shumway, M. & Owen, R.R. (2002). Priorities of consumers, providers, and family members in the treatment of schizophrenia. *Psychiatric Services, 53* (6), pp. 724–729.

Glyn, S.M., Cohen, A.N., Dixon, L.B. & Niv, N. (2006). The potential impact of the recovery movement on family interventions for schizophrenia: Opportunities and obstacles. *Schizophrenia Bulletin, 32* (3), pp. 451–463.

Jensen, L. E. (2004). Mental health care experiences: listening to families. *Journal of the American Psychiatric Nurses Association, 10* (1), pp. 33–41.

Marshall, T., Solomon, P., Steber, S. & Mannion, E. (2003). Provider and family beliefs regarding the causes of severe mental illness. *Psychiatric Quarterly, 74* (3), pp. 223–236.

Sherman, M.D. & Carothers, R.A. (2005). Applying the readiness to change model to implementation of family intervention for serious mental illness. *Community Mental Health Journal, 41* (2), pp. 115–127.

FAMILY PSYCHOEDUCATION AND FAMILY SUPPORT AND EDUCATION

Dixon, L., McFarlane, W.R., Lefley, H., Lucksted, A., Cohen, M., Fallon, I. et al. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services, 52,* pp. 903–910.

McFarlane, W.R., Dixon, L., Lukens, E. & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy, 29* (2), pp. 223–45.

McFarlane, W.R., Downing, D., Lapin, M.B., Jacobson, L.H., Perry, K. & Amenson, C.S. (2003). *Family Psychoeducation Workbook*. Washington, D.C.: Center for Mental Health Services. Available: http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/family/. Accessed 6 June, 2007.

Mueser, K.T. & Gingrich, S. (2006). *The Complete Family Guide to Schizophrenia*. New York, Guilford Press.

Murray-Swank, A.B. & Dixon, L. (2004). Family psychoeducation as an evidence-based practice. *CNS Spectrums, 9,* pp. 905–912.

Solomon, P. (1996). Moving from psychoeducation to education for families of adults with serious mental illness. *Psychiatric Services, 47,* pp. 1364–1370.

CONCURRENT DISORDERS

Center for Substance Abuse Treatment. (2005). *Substance Abuse Treatment for Persons with Co-occurring Disorders. Treatment Improvement Protocol (TIP)* Series 42. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Drake, R.E., Mueser, K.T., Brunette, M.F. & McHugo, G.J. (2004). A review of treatments for people with severe mental illnesses and co-occurring substance use disorders. *Psychiatric Rehabilitation Journal, 27* (4), pp. 360–374.

Health Canada. (2002). *Best Practices: Concurrent Mental Health and Substance Use Disorders.* Ottawa: Minister of Public Works and Government Services Canada, Cat. #H39–599/2001–2E.

Mueser, K.T., Noorday, D.L., Drake, R.E. & Fox, L. (2003). *Integrated Treatment for Dual Disorders.* New York: Guilford Press.

Skinner, W.J.W. (ed). (2005). *Treating Concurrent Disorders.* Toronto: Centre for Addiction and Mental Health.

Torrey, W.C., Drake, R.E., Cohen, M., Fox, L., Lynde, D., Gorman, P. & Wyzik, P. (2002). The challenge of implementing and sustaining integrated dual disorders treatment programs. *Community Mental Health Journal, 38,* pp. 507–521.

WEBSITES

COCE: SAMHSA's Co-occurring Center for Excellence. Available: www.coce.samhsa.gov. Accessed 6 June, 2007

Appendix 1: An overview of the research

NEED FOR FAMILY SERVICES: HIGHLIGHTING THE EVIDENCE

Families play an important role in the lives of people who have substance use and mental health problems.

- Most people who have concurrent disorders have regular contact with at least some of their family members (Clark, 1996).
- Approximately two per cent of Canadians over the age of 17 are caring for a family member, friend or neighbour who has been diagnosed with a mental health problem (Decima Research Inc., 2004).
- Forty-seven per cent of people who are caring for someone who has a mental health problem have been providing care for at least five years (Decima Research Inc., 2004).

The majority of families are providing care because they feel it's a family responsibility, but more than half of the respondents in the Decima study said that a lack of mental health services was a contributing factor in their decision (Decima Research Inc., 2004). Many families who take on the primary caregiving responsibility report some level of frustration with their interactions with the treatment system (Lucksted & Dixon, 1999).

Many caregivers have found information about substance use and mental health problems through support groups, publications and the Internet. But few have been given any formal training in problem solving, communication skills and symptom and medication management by the treatment system (Pickett-Schenk et al., 2006).

What are families looking for?

Mueser (2002) provides an overview of families' needs based on several studies. He identifies the following areas:

- information about concurrent disorders
- strategies to decrease stress in the family
- help with problem solving

- collaboration with the treatment team
- increased social support.

POTENTIAL FOR PARTNERSHIPS BETWEEN FAMILIES AND SERVICE PROVIDERS

When given access, information and support, family members can become allies of the treatment provider (Torrey et al., 2002). Family members can:
- educate and motivate professionals by sharing first-hand experiences
- advocate for effective services
- provide training to clinicians
- help family members with concurrent disorders
- help other families
- monitor and support services through involvement on boards and planning committees.

APPROACHES TO WORKING WITH FAMILIES

The Schizophrenia Patient Outcomes Research Team (PORT) recommended that all families who have contact with a relative with a mental health problem be offered a family psychosocial intervention. This intervention would span several months and include education about mental illness, family support, crisis intervention and problem solving (Lehman et al., 1998, Lehman et al., 2004). Other best-practice standards have also recommended that families participate in education and support programs.

- *Clinical Practice Guidelines: Treatment of Schizophrenia* (Canadian Psychiatric Association, 2005)
- *Practice Guideline for the Treatment of Patients with Schizophrenia, 2nd edition* (Lehman et al., 2004)
- *Canadian Network for Mood and Anxiety Treatments (CANMAT) Guidelines for the Management of Patients with Bipolar Disorder: Consensus and Controversies* (Yatham et al., 2005)

Service provider–led approaches that have been developed to address the needs of families include:
- multi-family group psychoeducation conducted by a mental health or addictions professional
- individual psychoeducation
- short-term multi-family education and support programs
- individual family consultation
- various forms of more traditional family therapy.

In addition, many families find support from peer-led information and support classes or groups, such as those provided by The Schizophrenia Society of Ontario (SSO), the Mood Disorders Association of Ontario (MDAO) and the National Alliance for the Mentally Ill (NAMI) (McFarlane, 2003).

The next section discusses the evidence base for the two group-based programs:
- multi-family psychoeducation
- short-term muliti-family education and support.

Multi-family group psychoeducation

DESCRIPTION

The primary goal of family psychoeducation groups is to improve outcomes for the family member with concurrent disorders (e.g., reduced time in and admission to hospitals, reduced relapse rates, improved overall level of functioning). In contrast to family therapy where the family is receiving treatment, family psychoeducation sees the family (and the consumer, where possible) as part of the treatment team (McFarlane et al., (2003b).

Family psychoeducation interventions seek to provide families with professional and peer support; information they need about mental health and/or substance use problems; and the coping skills they need to work with their loved one.

Most family psychoeducation programs:
- are led by health care professionals
- are offered as part of a treatment program for the consumer
- are diagnosis-specific
- extend over a period of nine to 36 months (Dixon et al., 2004).

RESEARCH

Research has shown that family psychoeducation programs lead to positive outcomes for consumers and families. See McFarlane et al. (2003a) for the specific studies that support each of the following.

Positive outcomes for consumers:
- reduction in relapses
- reduction in hospitalization rates
- increase in consumer participation in vocational rehabilitation
- decrease in the cost of care
- increased consumer involvement in family life and social activities

- reduced psychiatric symptoms
- reduced relapse rates
- reduced consumer depression
- improved consumer energy and motivation.

Positive outcomes for families:
- increased well-being of family members
- better health and fewer medical problems for all family members
- increased hopefulness
- development of effective emotional, behavioural and cognitive coping strategies
- increased perception of personal mastery and self-efficacy.

Family psychoeducation was originally developed as a component of treatment programs for people who had schizophrenia or other psychotic disorders (McFarlane et al., 2003a) and research now supports family psychoeducation as an evidence-based treatment for schizophrenia (Lukens & McFarlane, 2004).

Recently reports of studies of groups that focus on bipolar disorder, depression, eating disorders, borderline personality disorder and ADHD have appeared in the literature (Lukens & McFarlane, 2004, Murray-Swank & Dixon, 2004). A program for people with severe mental illness and substance use disorders and their families that combines single-family and multi-family group formats is being evaluated in a study supported by the National Institute of Mental Health (Mueser & Fox, 2002).

BARRIERS TO IMPLEMENTATION

Although the benefits of family psychoeducation have been documented, many family members do not have access to psychoeducation programs (Dixon et al., 2001). One of the most frequently cited explanations for the lack of programming is the time commitment for clinicians, family members and other resources for programs that run for at least nine months (Dixon et al., 2001).

When groups are available, drop-out rates for consumers and family members are substantial. Studies report rates ranging between 28 per cent and 70 per cent (Pollio et al., 2002).

Family support and education programs

Family education and support programs were developed in part because of a shortage of family psychoeducation programming. Many of these programs originated as grassroots initiatives by family members to offer programs that focused on their own needs. Family support and education now includes family-led programs, service provider–led programs, and programs led by family-service partnerships (Dixon et al., 2003).

DESCRIPTION

Family support and education programming is based on research that shows helping family members develop coping skills is likely to increase their "confidence or self-efficacy in managing their relatives' illness and in reducing their own stress and burden" (Solomon, 1996).

Family support and education differs from family psychoeducation in that:

- It is shorter—usually a maximum of 12 sessions.
- Sessions can be facilitated by a service provider or a family member.
- It is open to all family members, regardless of consumer's diagnosis.
- It does not require that the consumer is in treatment.
- Consumers do not attend sessions with the family members.

RESEARCH

In contrast to family psychoeducation, family support and education programming does not yet have a large enough body of research to be considered an evidence-based practice.

However, researchers have started to investigate the outcomes of both service provider–led and family-led programs. Early evidence suggests that "families who participated in the interventions gained knowledge and felt greater satisfaction with mental health treatment, experienced a reduction in burden, distress and anxiety, and improved self-efficacy, and coping behaviors" (Solomon, 1996).

THE SUPPORT AND FAMILY EDUCATION (SAFE) PROGRAM

The SAFE program is 14-session service provider–led program developed at the Department of Veterans Affairs (VA) in the United States. The program is designed to:

- teach caregivers about mental illness
- provide an opportunity for families to ask questions about treatment options
- reduce stigma by providing a forum for families to discuss concerns and get support from peers
- publicize the availability of mental health services at the VA centre
- help families understand the importance of early intervention and of open communication with treatment providers
- link families with treatment resources and community resources, including support groups (Sherman, 2003).

Sessions are not diagnosis-specific and families can choose to attend some, or all of the sessions.

Preliminary five-year program evaluation data have shown high levels of participant satisfaction and that participation is associated with an increased understanding of mental illness, awareness of treatment resources, and ability to engage in self-care activities as well as decreased caregiver distress (Sherman, 2006).

FAMILY-TO-FAMILY EDUCATION PROGRAM (FFEP)

The FFEP is a family-led 12-week program that provides families with:
- information about mental illness, treatments and rehabilitation
- help with developing self-care, mutual assistance, communication, problem-solving and advocacy strategies
- help with developing insight into their responses to mental illness (Dixon et al., 2004).

A controlled evaluation of the FFEP concluded that the program:
- reduced subjective burden
- increased empowerment
- increased knowledge of mental illness and the mental health system
- increased self-care.

When the participants were reassessed six months after the end of the program, the results indicated that the gains had been sustained (Dixon et al., 2004). These results confirmed the finding of earlier studies of the FFEP and its predecessor the Journey of Hope program (Pickett-Schenk, 2006).

The CAMH Partnering with Families Affected by Concurrent Disorders project builds on these studies. We intend to add to the evidence base for family support and education programs and to extend its reach to include programs that address the concerns of families whose relatives have both mental health and substance use problems. We describe our work to date in Appendix 2.

REFERENCES

Canadian Psychiatric Association (2005). Clinical Practice Guidelines: Treatment of Schizophrenia. *Canadian Journal of Psychiatry, 50* (Suppl. 1), pp. 29S–36S.

Clarke, R.E. (1996). Family support for persons with dual disorders. In R.E. Drake & K.T. Mueser (Eds), *Dual Diagnosis of Major Mental Illness and Substance Use Disorder II: Recent Research and Clinical Implications: New Directions for Mental Health Services* (Vol. 7, pp. 65–77). San Francisco: Jossey-Bass.

Decima Research Inc. (2004). *Informal/Family Caregivers in Canada: Caring for Someone with a Mental Illness.* Ottawa: Health Canada.

Dixon, L., Lucksted, A., Stewart, B., Burland, J., Brown, C.H., Postrado, L., McGuire, C., & Hoffman, M. (2004). Outcomes of the peer-taught 12-week family-to-family education program for severe mental illness. *Acta Psychiatrica Scandinavica, 109,* pp. 207–215.

Dixon, L., McFarlane, W.R., Lefley, H., Lucksted, A., Cohen, M., Fallon, I., et al.. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services, 52,* pp. 903–910.

Lehman, A.F., Kreyenbuhl, J., Buchanan, R.W., Dickerson, F.B., Dixon, L., Goldberg, R. et al. (2004). The Schizophrenia Patient Outcomes Research Team (PORT): Updated treatment recommendations 2003. *Schizophrenia Bulletin, 30,* pp. 193–217.

Lehman, A.F., Lieberman, J.F., Dixon, L. B., McGlashan, T.H., Miller, A.L., Perkins, D.O. et al. (2004). *Practice Guideline for the Treatment of Patients with Schizophrenia, second edition.* Washington, D.C.: American Psychiatric Association.

Lehman, A.F., Steinwachs, D.M., & the Co-Investigators of the PORT Project. (1998). At issue: Translating research into practice: The Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations. *Schizophrenia Bulletin, 24,* pp. 1–10.

Lucksted, A. & Dixon, L. (1999). Quality of care in services in family members of people with serious mental illnesses. *Mental Health Services Research, 1,* pp. 223–230.

Lukens, E.P. & McFarlane, W.R. (2004). Psychoeducation as evidence-based practice: considerations for practice, research and policy. *Brief Treatment and Crisis Intervention, 4,* pp. 205–225.

Mairs, M. & Bradshawe, T. (2005). Implementing family intervention following training: What can the matter be? *Journal of Psychiatric and Mental Health Nursing, 12,* pp. 488–494.

McFarlane, W.R., Dixon, L., Lukens, E. & Lucksted, A. (2003a). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy, 29* (2), pp. 223–45.

McFarlane, W.R., Downing, D., Lapin, M.B., Jacobson, L.H., Perry, K. & Amenson, C.S. (2003b). *Family Psychoeducation Workbook.* Washington, D.C.: Center for Mental Health Services.

Mueser, K.T. & Fox, L. (2002). A Family Intervention Program for Dual Diagnosis. *Community Mental Health Journal, 38,* pp. 253–270.

Murray-Swank, A.B. & Dixon, L. (2004). Family psychoeducation as an evidence-based practice. *CNS Spectrums, 9,* pp. 905–912.

Pickett-Schenk, S.A., Cook, J.A., Steigman, P., Lippincott, R., Bennett, C. & Grey, D.D. (2006). Psychological well-being and relationship outcomes in a randomized study of family-led education. *Archives of General Psychiatry, 63,* pp. 1043–1050.

Pollio, D.E., North, C.S. & Osborne, V.A. (2002). Family-responsive psychoeducation groups for families with an adult member with mental illness: Pilot results. *Community Mental Health Journal, 38,* pp. 413–421.

Sherman, M.D. (2006). Updates and five-year evaluation of the S.A.F.E. program: A family psychoeducational program for serious mental illness. *Community Mental Health Journal, 42,* pp. 213–219.

Sherman, M.D. (2003). The support and family education (SAFE) program: Mental health facts for families. *Psychiatric Services, 54,* pp. 35–37.

Solomon, P. (1996). Moving from psychoeducation to education for families of adults with serious mental illness. *Psychiatric Services, 47,* pp. 1364–1370.

Torrey, W.C., Drake, R.E., Cohen, M., Fox, L., Lynde, D., Gorman, P. & Wyzik, P. (2002). The challenge of implementing and sustaining integrated dual disorders treatment programs. *Community Mental Health Journal, 38,* pp. 507–521.

Yatham, Y.N., Kennedy, S.H., O'Donovan, C., Parikh, S., MacQueen, G., McIntyre, R. et al. (2005). Canadian Network for Mood and Anxiety Treatments (CANMAT) guidelines for the management of patients with bipolar disorders: Consensus and controversies. *Bipolar Disorder, 7* (Suppl. 3), pp. 5–69.

Appendix 2: The Project

Partnering with Families Affected by Concurrent Disorders compared two family interventions, a concurrent disorders family education and support group and an educational manual/workbook for family members of individuals with concurrent mental illness and substance use.

Although most sources recommend that in order to achieve improvements in the ill person's status (such as increased functionality, decreased hospitalization, better substance use outcomes and fewer relapses), family group interventions should run for no less than nine months, we had as our overarching goal the improved well-being of the family members and caregivers. Family members did provide us with anecdotal evidence in favour of improved consumer outcomes associated with family interventions, but our study revealed positive and significantly improved outcomes for family members themselves after a period of only three months. Results revealed significant positive changes, particularly in terms of mastery and self-efficacy, satisfaction with life, coping, and reduced caregiver burden.

PHASE 1

During Phase 1 of the project, we conducted a focus group to find out what families needed. Needs that emerged included:

- information about various psychiatric diagnoses and associated treatments, especially psychotropic medication
- information about alcohol and other drug use and dependence and how problematic substance use interacts with mental illness and with prescribed medication
- information about community resources for consumers and families
- effective family communication techniques
- self-care and coping with stress
- crisis management.

Results also suggested that family members preferred a structure that included both peer support and facilitator-led educational components.

PHASE 2

Using the results from the Phase 1 focus group, we began Phase 2: to design and pilot a support group intervention. The purpose of this phase was to evaluate the group content and format.

Ten family members participated in a 90-minute weekly support group for six weeks. The group provided educational material about concurrent disorders and allowed participants to share their personal stories, challenges and coping strategies.

At the end of the pilot phase, we completed open-ended qualitative interviews with family member participants, evaluating overall satisfaction with the group content and format. The principal investigator administered a series of quantitative instrument tools to participating family members during a one-to-one meeting before beginning the group intervention; these tools were administered again at the completion of the pilot study. These tools were designed to measure changes in:
- perceptions of social support
- feelings of personal mastery and empowerment
- sense of caregiver burden
- level of hopefulness
- degree of stigma.

PHASE 3

Phase 3 employed a randomized controlled trial to determine the effectiveness of a 12-week group intervention. This intervention consists of a one-hour peer support open discussion, followed by a 30-minute educational session led by the group co-facilitators. The educational content is based on primary areas of interest identified by family participants from Phases 1 and 2 of the study.

Family members at both the CAMH site and a community-based agency in Brockville, Ontario, were randomly assigned to either an experimental intervention group or the control condition. Each of the two sites recruited up to 10 participants for each of the experimental and the control conditions, for a total sample size of 20 study participants per site. The control condition participants did not take part in a support group; they received a comprehensive educational manual designed for family members, which they worked on independently.

Quantitative data analysis demonstrated significant improvements from baseline assessment to completion of the Family CD Education and Support intervention. Results from analysis of the manual-only intervention did not show as much improvement across the variables studied, although when the two interventions were compared, there were no significant differences between them. Although the support group intervention showed significant positive changes across a greater number of variables than the manual-only intervention, the extent of the changes between the two interventions was not statistically significant. In other words, the results showed that both interventions—manual only and group support—produced positive effects for participants. We were not able to conclude that one was better than the other, in spite of the trend data in favour of the support group.

Limitations in the study include a short follow-up period and a small number of study subjects. The findings do justify, we believe, further work in this area, with a larger study cohort and a more extended follow-up period. Nonetheless, we can say that both these interventions did produce positive effects in a number of life areas: empowerment, social support, coping, hopefulness, perceived stigma, satisfaction with life and reduced caregiver burden.

Feedback from consumers participating in pilot support groups, from the group facilitators and data, both qualitative and quantitative, all endorse the merit and value of offering this service to family members affected by concurrent disorders.

> *I was really amazed because I've never heard of any group like this, where both the mental health and substance use problems are dealt with. I didn't think anything like this was available at all. I didn't realize there was nothing for families of someone with concurrent disorders until I started reading more about it and before we started the group.*
>
> *—Family CD group participant*

> *Thank you for the opportunity to review this information. I found it very informative. . . . I have had some personal experience attempting to navigate the treatment system (my husband was diagnosed with mental illness about 11 years ago) and this information would have been very useful to me at that time. I am certain it will reduce anxiety/fear around mental illness and addiction by giving families the information they need and steps to follow if they have no previous experience with this devastating disease. This resource gave me a sense of hope that individuals with concurrent disorders can recover and lead productive lives.*
>
> *—Clinician / Case Worker*

DEVELOPMENT OF THE FACILITATOR'S GUIDE AND FAMILY RESOURCE

Development of the facilitators' guide and family resource was an integral part of the study. The first set of participant materials was developed based on information from the Phase 1 focus group. This material was used in the pilot group. We used this material and the feedback from the pilot group participants to create Version 1 of the family resource.

Version 1 of the family resource was used as the psychoeducation component of the intervention group and was the manual given to the control group. We then revised Version 1 based on the input from the participants. The revised manual—called *Concurrent Disorders: A Resource for Families*—was reviewed by family members and service providers across Ontario. Their comments and suggestions informed the final revision. The result is *A Family Guide to Concurrent Disorders*.

The facilitators' guide is based on the facilitators' notes from the pilot and the trial and an analysis of the qualitative interviews with family member participants.

We hope that this process will be one of continuing iteration, so that suggestions and recommendations from facilitators and participants will allow us to update and improve this resource.

Having concurrent substance use and mental health problems obviously affects the person experiencing the problems directly, but they also have powerful effects on family members and friends. Families need help to deal with the impact of concurrent disorders, but families are also a key to finding effective solutions.

A Family Guide to Concurrent Disorders is based on the collection of materials that was developed for a family support and education group at the Centre for Addiction and Mental Health.

Part I is an overview of concurrent disorders, an introduction to treatment options and information about substance use problems, mental health problems and how they interact.

Part II focuses on the impact of concurrent disorders on family life. It includes information on self-care strategies for family members and understanding and coping with the effects of stigma.

Part III explores treatment and support for people affected by concurrent disorders. It includes strategies for navigating the mental health and substance use treatment systems, information about psychosocial and medication treatment options, recognizing and planning for relapses, and anticipating and coping with crisis situations.

Part IV talks about the journey to recovery.

Also available from CAMH:
Addiction: An Information Guide
Anxiety Disorders: An Information Guide
Bipolar Disorder: An Information Guide
Concurrent Substance Use and Mental Health Disorders: An Information Guide
Couple Therapy: An Information Guide
Depressive Illness: An Information Guide
The Forensic Mental Health System in Ontario: An Information Guide
Obsessive-Compulsive Disorder: An Information Guide
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Women, Abuse and Trauma Therapy: An Information Guide
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