

# **SUPPORTING FAMILIES WITH PARENTAL MENTAL ILLNESS**

**A Community Education and Development Workshop**

**A Training Tool for Communities  
to Organize Services to Support Families**

**November 2002**



“This workshop was incredibly helpful. It provided an opportunity for our community to get to know one another better and begin to work together more effectively.”

- Workshop Participant

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- Ministry of Children and Family Development
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**This manual may be photocopied,  
but not resold.**

# TABLE OF CONTENTS

## INTRODUCTION

What is the Purpose of this Manual? .....	2
How did this Manual Come to be? .....	3
To Whom do we Owe Special Thanks? .....	6

## GETTING ORGANIZED FOR YOUR COMMUNITY EVENT

A. Setting the Tone.....	8
B. Location, Location, Location.....	9
C. Timing is Everything.....	9
D. Recommended Invitation List.....	10
E. Potential Community Trainers.....	14
F. Potential Sources of Money.....	14
G. Sample Budget .....	15
H. Sample Menu.....	17
I. Materials Needed for the Day. ....	18
J. Sample Invitation Letter.....	18
K. Sample Overview of the Day.....	20
L. Helpful Hints in Preparing for your Community Event.....	21
M. Overheads and Handouts.....	25
N. Request for Feedback.....	26

## THE WORKSHOP CONTENT

### A. Overview of Mental Illnesses

i. Lesson Plan.....	30
ii. Overheads.....	33
iii. Background Information.....	49
iv. References.....	62

### B. Experiences of Parent(s) with a Mental Illness

i. Lesson Plan.....	66
ii. Overheads.....	69
iii. Background Information.....	77
iv. References.....	86

### C. Experiences of Children Whose Parent(s) Have a Mental Illness

i. Lesson Plan.....	90
ii. Overheads.....	96
iii. Background Information.....	112
iv. References.....	139
v. Glossary for Children.....	142

**D. Experiences of Adult Children Whose Parent(s) Had A Mental Illness:**

The Legacy

i.	Lesson Plan.....	146
ii.	Overheads.....	155
iii.	References.....	164

**E. The Advance Planning Process**

i.	Lesson Plan.....	166
iv.	Background Information.....	168
v.	Overheads.....	174

**F. Community Best Practice: Self-Assessment Checklist**

i.	Lesson Plan.....	182
ii.	Overheads.....	185
iii.	Background Information.....	191
vi.	References.....	210

**III. ANNOTATED BIBLIOGRAPHY..... 218**

**IV. EXAMPLES OF PROGRAMS CURRENTLY OPERATING**

Current Programs - Specific Examples .....	224
In British Columbia .....	228
In Canada.....	231
In the United States .....	232
In Australia .....	235

# Introduction



# INTRODUCTION

## WHAT IS THE PURPOSE OF THIS MANUAL?

This manual, “*Supporting Families with Parental Mental Illness*” contains what is needed for anyone with some experience in adult education to hold a **community event that will inform audiences as to the issues involved in supporting families with parental mental illness**. This manual is meant as a “stand-alone” self-explanatory document that contains all the information needed to hold a successful workshop. This manual will support four functions.

### THE PURPOSE

1. To educate the community in understanding mental illness and its effects on parenting and child development.
2. To assist communities in critically assessing existing services.
3. To bring service providers together in an effort to encourage collaboration in working with families where there is parental mental illness.
4. To help communities answer the question: “What are we as a community doing to support families with parental mental illness?”

This manual is not a guide that outlines a variety of interventions that can be used in working with families with mental illness. You will not find a list of answers to the tough questions about how best to work with your clients. Instead, this is an opportunity to see the broader picture, to envision the community where these families reside and the services they can possibly access.

Sharon, a family therapist, reached across her desk for this manual during a session with a young girl whose father suffered from obsessive compulsive disorder.

“See this book? This is a book to help people learn about families like yours,” Sharon said.

“A whole book written about families like mine?” she asked incredulously.



The manual includes six sections, which will be the six major parts of the day. There are three sections that are intended to educate the community and the final section that is focused on community planning. Each section contains: a) a lesson plan for the workshop, b) overheads and handouts for participants, c) background information for trainers, and d) references for further information. This manual also offers a wealth of suggestions for how to set up the day to make it a success.

## **HOW DID THIS MANUAL COME TO BE?**

Parents who have serious and persistent mental illness are often not provided with the necessary services and support that will assist them in caring for their children.

Families with parental mental illness are caught in the gap between the mental health and child welfare systems. Mental illness is viewed as an individual problem that is the responsibility of the local mental health system. Parenting is not typically considered an issue; indeed, many mental health workers rarely go beyond asking if the person has any children. The safety and welfare of the children is seen as the responsibility of the child welfare system. Concerns about possible detrimental effects of parental mental illness on children often result in children being removed from the home and placed in foster care or adopted into other families. There is limited support to enable these families to stay together, or, during times when staying together is not possible, to maintain contact. By professionals in the community increasing their understanding of the challenges of parenting with a mental illness, families will be more likely to receive the necessary support that will keep them strong and healthy.

The importance of looking at the need to support families with a mental illness arose, in part, out of the Gove Inquiry, which identified issues relating to child protection and the relationship of custody and parental mental illness. In 1998, a small group of people gathered who were interested in the needs of children growing up with parents who had a mental illness. This group of people, the *Supporting Families with Parental Mental Illness Provincial Working Group*, decided to hold a community forum to talk about parental mental illness and the effect on children. This forum, the first of two, was held at the Vancouver Public Library in September 1998. The group wondered if there were

many people interested in this topic and it turned out there were as over 150 people arrived at the library that day, interested and willing to talk.

This led to support from the Ministry of Health Services and the Ministry of Children and Family Development and a second forum, this time provincial. Approximately three hundred people from all regions of the Province met at the Roundhouse Community Centre in September 1999. Everyone spent time discussing what worked and what did not work for families where there is parental mental illness. The comments were carefully recorded, grouped by general themes, and later presented to participants as a record of proceedings. This information was used to prepare the first draft of the “Community Best Practice: Self-Assessment Checklist” (Section F).

The aim became the promotion of integrated community planning to support families where there is parental mental illness. To this end, the planning committee developed the vision of a “Best Practices Document” as a guide for any community in the province wanting to consider the needs of these families. It was thought that a community education guidebook, along with steps needed to hold a community workshop, could be published for use by any person or group in the province who wanted to replicate this event.

In November 2000 and February 2001, two workshops were held to pilot the process and materials developed by the committee. Two different formats of the session were piloted and feedback was obtained from the participants, professionals who provide services to families with parental mental illness. From the information gathered and by going through the experience, the materials have been reworked and are presented to you in this manual, “*Supporting Families with Parental Mental Illness.*”

“It is always interesting to hear from others and gain a new perspective. I respected the wisdom in the room. This kind of workshop is very much needed in our community.”

- Workshop Participant

The scope of this project is to focus on the families with serious and persistent mental illness. We realize there are other medical conditions such as post-partum depression,

brain injury and developmental disability which often parallel and complicate the lives of children and families. Considerations of time and space dictate that this manual be restricted to its current parameters. We acknowledge the differences in parenting experiences of men and women. In preparing this document, the research available to us predominately focused on women's experiences. As well, this manual is not able to address the problems of undiagnosed mental illness, which is a significant issue in its own right. We also recognize that different communities have different needs. We believe that it is always good practice to address the specific cultural issues and practices of each community.

“The issue of racism for both the clients and their children can exacerbate the sense of isolation, hopelessness, and helplessness that people with mental health issues may experience.”

Honourable Lynn Stephens  
Minister of State for Women's Equality

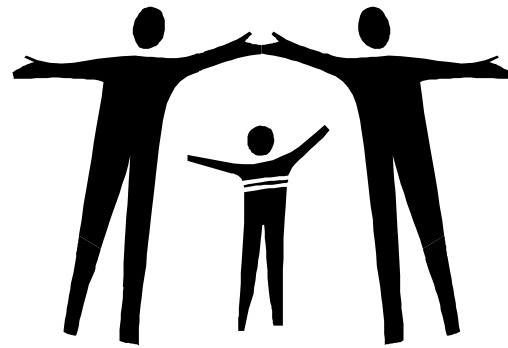
## **TO WHOM DO WE OWE SPECIAL THANKS?**

This manual is the result of the efforts of a group of people, most of whom have worked “off the corner of their desks” on this project. The initial group started with Lyne Brindamour, MSW, Dr. Rob Lees, Hylda Gryba, RN, BN, MA (Candidate), Sharon Van Volkingburgh, MSW, and Frances Levine, MA (Candidate). Dr. Nicole Chovil and Eric Macnaughton, MA soon joined the team, and Désirée Blume, MA, MEd, became involved during the pilot sessions.

We would like to thank all participants of the two forums, two pilot workshops, and the teleconference of organizations providing services to families with parental mental illness for their input and feedback. Special thanks go to Victoria Schuckel, Christine Davis, Dr. John Gray, Dr. Clem Meunier, Cinder Woods, Dr. Carol Matusicky, Virginia Ross, Theresa Duggin, André Faucher, Anne Butcher, Hannah Anderson, and Liz Clandenning. We would also like to thank the following people for reviewing our draft document and providing valuable feedback: Joan Duncan, David Maxwell, Cinder Woods, Victoria Schuckel, Susan Barnard, Doris Bodner, Larry Branswell, Cheryl Conant, Dr. Elliot Goldner, Marg Fraser, Elaine Jameson, Ruth Hess-Dolgin, Grace Kramer, Rick Kubo, Mitch Loreth, Kim Marshall, Linda Schmidt, Mark Sieben, Dr. Derryck H. Smith, Russ Spilsbury, Patrick Storey, Lynn Stephens, Ros Salvador, and the Supporting Families with Parental Mental Illness Working Group from Vancouver Community Mental Health. We also thank Zac Belado for the cover design and Donna Costello for Overhead F-1.

This project could not have been done without the support, financial and otherwise, from the Ministry of Children and Family Development, Child & Youth Mental Health Provincial Education and Training Strategy Committee, and Mental Health and Addictions, Ministry of Health Services. We also gratefully acknowledge donations from British Columbia Schizophrenia Society, Canadian Mental Health Association -- British Columbia Division, and Family Services of the North Shore.

# Getting Organized For Your Community Event



# GETTING ORGANIZED FOR YOUR COMMUNITY EVENT

This section contains all the information needed for you to prepare for a community event on “Supporting Families with Parental Mental Illness”. We have held these community events several times and through feedback and experience, feel that these helpful suggestions will set you up for a successful day.

**“It was a lot of work but well worth it for the benefits in our community afterwards.”**

- Lyne Brindamour

## A. SETTING THE TONE

Our intent for this day is to honour the diversity of the families we serve who are diverse in structure and composition. We also want to honour the services that are provided for families with parental mental illness, services that are also diverse. Our hope is that this event will affirm the differential strengths of a broad range of service providers. We believe that it is possible to utilize the strengths of service providers and connect them with the rest of the community. Together, one can begin where another leaves off, and by so doing, provide the best services possible to the families in need.

Another aspect of setting the tone is to remember to use inclusive language during the workshop. For example, instead of using “mother” or “father”, use “parents”, or instead of “marriage counselling” refer to it as “couple counselling.”

## **B. LOCATION, LOCATION, LOCATION**

First of all, you will need to find a suitable location for the community event. Your agency may have a boardroom or suitable large space to accommodate between twenty and fifty people (preferably a room with windows and fresh air). It is also important to ensure the location is accessible for the disabled and is on a bus route for those without personal transportation. There may be a local community centre that is willing to donate space for a day. Ask your Community Trainers for ideas as they may have access to suitable places. For our second session we inquired at the School District to determine the next Professional Development Day. A local school was empty on that day and willing to allow us to use their facilities. An added advantage of planning the event on a Professional Development Day is the greater possibility of principals, counsellors and teachers being able to attend.

## **C. TIMING IS EVERYTHING**

Our two pilot sessions were each held on one day and we were able to cover the information presented in this manual. You may want to have a two-day workshop, although you may have difficulty finding people able to commit to two days. One idea is to hold two or more sessions and have a period of time between each session.

You may also want to consider your audience and their level of understanding of the various topics covered in this resource. For example, you could hold a session entirely on the educational content and another on the Advance Planning Process.

Ultimately the decision is up to you, the presenter and host of your community event. Feel free to use any part or all of this manual to best design the workshop that will be beneficial to your community.

## **D. NOW, WHOM SHOULD WE INVITE?**

In order to optimize the benefits from this community event, it is important to convene the right mix of individuals and agencies. If the goal is to “make things happen”, then you likely require participants who represent a diversity of agencies, services and perspectives touching on the topic. Experience has shown that agencies highly sensitized and aware of the issues may want to send a large number of delegates, whereas others, whose input is central to the process, may not realize its importance. In order to avoid a process that only “preaches to the converted” it is necessary to seek a balance. Here are a few criteria to consider:

Who is in a position in the agencies involved to effect change administratively?

Who is in a position to influence attitudinal changes in agencies?

Who could make a difference with the knowledge gained from the workshop?

Whose voice most needs to be heard?

Who are the future decision-makers on policy and resources?

It is important to know that you may have to make several attempts to convene the participation of some (use follow-up phone calls, reminder faxes and letters), whereas others will be more than eager to attend.

Generate a master list of participants; send out your first invitation letter and then two weeks later follow-up with a phone call to confirm those who have responded and to inquire about those who did not reply. Some agencies may have questions regarding which employee would be best to send. A general guideline is to begin with the most responsible position in an agency and then work with them to determine representation. In some cases it will be helpful to have participation from several levels in one agency. For example, in dealing with a school district, attempt to have someone from the School Board office level as well as at the service delivery level, such as a counsellor.

Invite your MLA, Mayor and School Board Chair as dignitaries. Usually these people are not able to stay for the whole conference but are pleased, if the timing suits, to come and bring greetings and good wishes at the beginning or close of a conference. It



is a courtesy to send these people a letter. We have found that, because of their busy schedules, it is not as useful to attempt to speak to these VIPs directly. Build a relationship with their administrative support staff instead.

It is also helpful to invite and encourage participation of people with mental illness, people who grew up in homes with mentally ill parents (adult children) and older teens who are currently going through the experience. It is valuable to have more than one person from a family attend for support. Consider what barriers (such as childcare or transportation) might prevent their attendance. Contact Community Mental Health and any consumer groups if your community has them, such as a Mood Disorders Group. It might be a good idea to have a professional person (such as a counsellor) assigned for debriefing, should it be necessary.

Consider the following list when planning your session:

<b>RECOMMENDED INVITATION LIST</b>	
<p>1. Health Authority Representatives:</p> <ul style="list-style-type: none"> <li>• Member of the Health Authority Board</li> <li>• Member of the administration of the Health Authority (e.g. Director of Mental Health and Addiction Services)</li> <li>• Direct service hospital worker dealing with the mentally ill (e.g. psychiatric nurse)</li> <li>• Direct service hospital worker dealing with emergency room (e.g. R.N.)</li> <li>• Mental Health After Hours Emergency Services worker</li> <li>• Community Mental Health Clinician</li> <li>• Public Health Nursing</li> </ul>	<p>2. Ministry of Children and Family Development</p> <ul style="list-style-type: none"> <li>• Intake and Investigation Unit staff member</li> <li>• Family Services Social Worker</li> <li>• Child &amp; Youth Mental Health Clinician</li> <li>• Community Manager</li> </ul>
<p>3. Local Community Services Agency</p> <ul style="list-style-type: none"> <li>• Agency Board Member and Administrator</li> <li>• Family Services Workers</li> <li>• Early Childhood Support, workers or administrators</li> <li>• Neighbourhood Houses, Family Places</li> <li>• Boys' and Girls' Clubs</li> </ul>	<p>4. Consumer Representatives</p> <ul style="list-style-type: none"> <li>• British Columbia Schizophrenia Society</li> <li>• Adult Children</li> <li>• Teens currently living in a home with a parent with mental illness.</li> <li>• Family members with experience</li> </ul>
<p>5. Local Ambulance Service</p>	<p>6. Local Association of Physicians</p>
<p>7. Income Assistance Workers (Human Resources)</p>	<p>8. Local Police Force</p>
<p>9. Addiction Services</p>	<p>10. Local Transition House</p>
<p>11. Mental Health Contracted Services Providers / Rehabilitation Agencies</p>	<p>12. Local Foster Parents Association</p>
<p>13. Schools</p> <ul style="list-style-type: none"> <li>• Counsellors</li> <li>• Principals</li> <li>• Teachers</li> </ul>	<p>14. Self-Help Groups</p> <p>Support Groups AA, Al Anon, NA</p>

<p>15. Local Ministerial Association</p> <ul style="list-style-type: none"> <li>• Church Counselling Services</li> </ul>	<p>16. Military Services</p> <ul style="list-style-type: none"> <li>• Social Workers and Chaplains</li> </ul>
<p>17. Immigrant Support Agencies</p> <ul style="list-style-type: none"> <li>• Cultural Groups &amp; Organizations</li> </ul>	<p>18. First Nations Representatives</p> <ul style="list-style-type: none"> <li>• First Nations Child Welfare and First Nations Health Services</li> </ul>
<p>19. Special Populations</p> <ul style="list-style-type: none"> <li>• Women’s Centres</li> <li>• Organizations for People with Mental Disabilities</li> <li>• Organizations for People with Physical Disabilities</li> <li>• Organizations for gays, lesbians and bisexuals</li> </ul>	<p>20. Multicultural Organizations</p>
<p>21. Housing</p> <ul style="list-style-type: none"> <li>• BC Housing</li> <li>• Local non-profit housing society</li> </ul>	

## **E. POTENTIAL COMMUNITY TRAINERS**

Involve other individuals and sectors by calling on them to present each of the six sections of the community event. Remember to keep in mind issues of diversity. There are likely many qualified people to call. Here are some possibilities:

### **COMMUNITY TRAINERS**

- Community Psychologist
- School Counsellor
- Psychiatrists
- Agencies that support families
- Adult Mental Health
- British Columbia Schizophrenia Society
- Family Services
- Local Support Groups
- Public Health
- University or College Faculty and Interns

## **F. POTENTIAL SOURCES OF MONEY**

An important thing to consider is where you will find the money to host a community event. We have made every attempt to cut the costs of this community event so that it can be accomplished within a realistic budget.

Below is a list of places where you may potentially find money to support your community event:

#### **POTENTIAL SOURCES OF MONEY**

- Government Offices (e.g., British Columbia Ministry of Children and Family Development, Federal Government)
- Health Authorities
- Local Foundations (Counselling Agencies, Parenting Groups)
- Service Clubs (Rotary Club, Lions, Kinsmen)
- Local Businesses
- Nonprofit Organizations that support families may be able to donate food
- Corporate Sponsorship
- Pharmaceutical Companies

#### **G. SAMPLE BUDGET**

**The best things in life are FREE!**

At the community events we incurred a number of expenses itemized below. We decided to provide food for the participants for a number of reasons. First of all, they were assisting in the development of this manual and we wanted to thank them for their time and input. Secondly, our locations were a significant distance from any restaurants. We felt that if we had a lunch break there would be a higher rate of attrition and if we provided food there was a better likelihood that people would stay for the afternoon.

ITEM	COST
1) Catering (20-50 people)	\$300 and up (Optional)
2) Honorariums	\$100 and up per person (Optional)
3) Photocopying (all the photocopying was done and donated by committee members)	\$40 and up - 100 pages for 40 participants at \$0.10 per copy
4) Office supplies, stamps	\$50 and up
5) Prizes	\$30 and up (Optional)
6) Publications included in the handouts	\$100 - \$400 and up (Optional)
7) Child Care for Speakers & Consumers	\$70 and up
8) Replacement wage for Speakers	Varies

**The community event could potentially be held for free.** It would be possible to provide food if you charged a small fee per person to offset the catering costs. You may also see if the photocopying and office supplies could be donated. The video included would take the place of a guest speaker. It would also be possible to direct participants to the web sites where all the information that would be included in a handout can be found on-line: ([www.cmha-bc.org](http://www.cmha-bc.org)) and ([www.bcscs.org](http://www.bcscs.org)) and ([www.healthservices.gov.bc.ca/mhd/](http://www.healthservices.gov.bc.ca/mhd/))

Speakers may also come for free. If they are in a similar field, it could be part of their workday. In this case, provided you were able to find a location to meet for free, the only expenses would be prizes for one of the sessions, and these are also optional.

## H. SAMPLE MENU

It is important to feed people adequately and to provide for a variety of tastes and special diets (e.g. vegetarian). This is not as difficult as it may seem. When people have plenty to drink and snack on, they often feel well fed and their needs met. Here is a menu that we used for the pilot studies. As stated in the sample budget, there are always ways of providing for a minimal cost. Food is something that organizations and agencies could provide.

### SAMPLE MENU

#### Morning Coffee

- Muffins and fresh fruit
- Regular coffee, decaffeinated coffee, black and herbal teas
- Milk, cream, juice, and water
- Cups, glasses, napkins, stir sticks, and small plates
- Pitcher for juice, thermoses for coffee and hot water
- Platters for food

#### Morning Break

- Same snacks as in the morning with fresh coffee and hot water added

#### Lunch

- Variety of sandwiches and vegetables with dip
- Squares for dessert
- Plates, napkins, cutlery

#### Afternoon Break

- Fresh coffee, hot water, and cookies.

## **I. MATERIALS NEEDED FOR THE DAY**

There are always a number of items that are needed throughout the day. By going through this list, it is less likely that you will forget something on the day of the community event.

### **MATERIALS NEEDED**

- Nametags
- Participant folders
- TV and VCR
- Overhead projector
- Flip chart paper
- Pens and paper for all participants
- Sticky notes
- A poster to place questions and comments
- Prizes
- CD player
- Duotangs or folders for participants

## **J. SAMPLE INVITATION LETTER**

The letter to the participants should be sent out a month before the event to allow adequate time for response. We found that direct contact is the best way to ensure attendance. A phone call before the letter is mailed or faxed will prepare the recipient for your invitation and they will have an idea of who is sending it and the purpose of the community event. You will also be able to obtain a contact name over the phone. It is important that there be one person who collects all the names and contact information of all the participants. We also faxed a map of the location to the participants, which was greatly appreciated.



## SAMPLE INVITATION LETTER

March 00, 20??

Dear \_\_\_\_\_:

**Re: Community Event: Supporting Families with Parental Mental  
Illness**  
**Mountain Elementary School, 1234 Mountain Drive, North Vancouver**  
**Thursday, April 1, 2001 – 8:30 a.m. – 4:00 p.m.**

Parents who have serious mental illness are often not provided with the necessary services and support that will assist them in caring for their children. Families with parental mental illness may be caught in the gap between the mental health and child welfare systems. Concerns about possible detrimental effects of parental mental illness on children often result in children being removed from the home and placed in foster care or adopted into other families. Support to enable these families to stay together or maintain contact is limited. By professionals in the community increasing their understanding of the challenges of parenting with a mental illness, families will likely receive the necessary support that will keep them strong and healthy.

Family Services of the North Shore with support from the Ministry of Children and Family Development and the Health Authority are sponsoring a one-day information and community-planning event regarding the needs of families where there is a serious parental mental illness. Our aim is to promote integrated community planning to support families where there is parental mental illness.

Since the issues cut across many agencies, it is hoped that we can assemble a diverse group for an event on the North Shore on Thursday, April 1, 2001, 8:30 a.m. – 4:00 p.m. at Mountain Elementary School. Enclosed is an invitation/event overview flyer as well as a map for how to get to the school. Two seats are reserved for your agency/organization. There is no fee for this event.

It would be very much appreciated if you would canvas your agency to identify the person, or persons most likely to educate others within the agency on these issues. Also, this person may be someone who would facilitate inter-agency planning and protocols with respect to the needs of these families. Please call \_\_\_\_\_ at 988-1234 by March 15, 2001 to let us know who will be attending.

Sincerely,

Jane Smith  
Family Counsellor

## K. SAMPLE OVERVIEW OF THE DAY

### SUPPORTING FAMILIES WITH PARENTAL MENTAL ILLNESS COMMUNITY EVENT OVERVIEW

Presented by: (add your names and agencies here)

You are cordially invited to a community event on Supporting Families with Parental Mental Illness. The event will be held at Mountain School, 1234 Mountain Drive, North Vancouver, B.C., on Thursday, February 3, 2001 from 8:30 a.m. to 4:00 p.m. This is part of a provincial initiative to develop meaningful education on the topic and best practices for helping families where a parent suffers from a serious mental illness.

- 8:30 – 9:00 Registration and Coffee
- 9:00 – 9:15 Welcome and Introductions
- 9:15 – 10:00 Brief Description of Mental Illness, presented by \_\_\_\_\_
- 10:00– 10:45 Experiences of Parent(s) with a Mental Illness, presented by \_\_\_\_\_
- 10:45– 11:00 Morning Break
- 11:00- 12:15 Experiences of Children Whose Parent(s) have a Mental Illness  
Presented by \_\_\_\_\_
- 12:15 – 1:00 Lunch
- 1:00 – 1:30 Experiences of Adult Children and Families, presented by \_\_\_\_\_
- 1:30 – 2:15 The Advance Planning Process, presented by \_\_\_\_\_
- 2:15 – 2:30 Afternoon Break
- 2:30 – 3:30 Community Best Practice: Self-Assessment Checklist  
Presented by \_\_\_\_\_
- 3:30 – 4:00 Roll up of Action Plans
- 4:00 – 4:15 Evaluation and Feedback

## **L. HELPFUL HINTS IN PREPARING FOR YOUR COMMUNITY EVENT**

- We would not recommend that the community event be held on a Friday. Many people who work part-time do not work on a Friday. There were many more people in attendance when it was held on a Thursday.

### **8:30 – 9:00 Registration and Coffee**

- Make sure that coffee and print materials are easily accessible.
- There should be someone who greets participants and ensures they have nametags. Ask participants to put their agency as well as their name on their nametags. During breaks it is helpful to know where people are from for networking.
- A quiet music CD can add to the atmosphere as people gather.

“The networking was one of the best aspects of this event. It facilitated better working relationships for the sake of families.”

- Duncan MacDonald

### **9:00 – 9:15 Welcome and Introductions (Greetings by Members of the Community)**

The chairperson for the day will gain everyone’s attention. Once everyone is listening:

- Welcome them.
- Provide a brief description of the goal for the day: to learn more about parental mental illness, the impact on children, and to begin a community planning process for supporting families. Participants need to know what is going to be accomplished during the day and what they can expect.
- Acknowledge that for some people, some of the information will be redundant, but for others it will be new. The important thing is to build a common base of understanding in the community.

- Quickly go over the outline for the day, noting the times for breaks, housekeeping items, i.e. location of bathrooms.
- Refer participants to the outline. The day is planned to provide information in each of these six sections:

**OUTLINE FOR THE DAY**

1. Overview of Mental Illnesses
2. Experiences of Parent(s) with a Mental Illness
3. Experiences of Children Whose Parent(s) Have a Mental Illness
4. Experiences of Adult Children and Families
5. The Advance Planning Process
6. Community Best Practice: Self-Assessment Checklist

- Strike a balance between participants not participating and asking so many questions that you fall behind the schedule. Due to limited time, questions can be deferred to the appropriate section later in the day.
- Introduce any dignitaries. It can help your event to have a local dignitary attend for a few minutes to bring greetings and best wishes. This is a
- no-more-than-five-minute exposure. It can add a sense of importance to the day. Try to get your MP, MLA, Mayor, School Board Chair, Superintendent of Schools, Medical Health Officer to attend.
- It is valuable for the participants to have a sense of who is in the audience. In larger communities where participants may not know each other, go through the invitation list and call out the names of different agencies, asking people to stand when their agency is called. In smaller communities, have some brief “mixer” activity for people to be introduced.

**DON'T FORGET!** One of the outcomes of this event we hope will be better knowledge of who is available to help families.

**TIMING, TIMING, TIMING**

As presenters and participants, we all know the frustration of a workshop not keeping to the specified times. If you are waiting to present, it is nerve-wracking as the presenter before you goes five, then ten, then fifteen minutes over his or her allotted time. It is crucial, therefore, to have a timekeeper who keeps an eye on the clock and effectively signals the presenter that time is up.

**9:15 – 10:00 Overview of Mental Illness**

- During the sessions, we found that there were always a number of questions. This is positive as it allows for active participation. At the same time it can lengthen each session, making the day even longer. To save time, we recommend deferring some questions to when they would be covered in a later part of the day.
- To encourage participation, keep in mind that there are always people who feel comfortable asking questions and participating, but there are also those who do not speak up. It is helpful to ask that anyone who has a comment or question to write it on a sticky note and place it on a poster paper on the front of the room during the breaks. This way, the Community Trainers can scan the sticky notes and address questions during the next session.

**10:00 - 10:45      Experiences of Parent(s) with a Mental Illness**

**10:45 – 11:00      Morning Break**

**11:00 - 12:15            Experiences of Children Whose Parents have a Mental Illness**

- While there is a focus on negative challenges for the purposes of this section, we recognize the number of resilient children and the strengths all children and families bring to sharing the burden of mental illness.

**12:15 – 1:00 Lunch**

**1:00 – 1:30            Experiences of Adult Children and Families**

(Video and/or Guest Speaker)

- It is best if you can find a person who has grown up with parent(s) who had a mental illness. This person should be articulate and willing to share their experience with others. If not, have the video equipment cued when people return for lunch.

**1:30 – 2:15            The Advance Planning Process**

**2:15 – 2:30            Afternoon Break**

**2:30 – 3:30            Discussion of Best Practice: Community Self-Assessment**

**3:30 – 4:00            Roll up of Action Plans**

- At this point, participants can join in small community groups and make a plan for how they will use the information they have learned today. This can be the beginning of real action in the community.

**4:00 – 4:15            Closure and Request for Feedback**

- At this point you may want to summarize by talking about what has been covered during the day. If you haven't already done so, you can address any more questions on the sticky notes.
- Ask participants to complete an evaluation before leaving.
- If possible, offer to mail them the overview that emerges from the Community Self-Assessment.
- Mail out an evaluation one month following the community event for further feedback.

## **M. THE OVERHEADS AND HANDOUTS**

The handouts should be collated before the day of the workshop. In each handout, include a pen as well as any flyers from relevant local agencies. Each of the following chapters contains a section that is designed as a handout. For each section, the overheads double as the handouts to be copied for each participant. As the Community Trainer reads the overheads during the presentation, the participants can follow along and make notes on their handouts, which are identical to the overheads.

For each overhead there are *Background Notes for the Community Trainer*, which explain the overheads in more detail. These notes are for the Community Trainers to familiarize themselves and further their knowledge of session content before preparing for the workshop. The content presented in this manual has been documented and researched in literature. The content is not exhaustive due to limited space; however, all references to literature have been chosen based on their authenticity with professional experience and community event participants. These notes are not intended to be photocopied for participants; rather, they are to provide the Community Trainer with valuable information to allow him/her to be better prepared to host the community event.

**You have permission to photocopy these sections and  
prepare a handout for each participant.**

## **N. REQUEST FOR FEEDBACK**

The request for feedback form on the next two pages is for your convenience.



# REQUEST FOR FEEDBACK

What agency or group were you representing today? \_\_\_\_\_

On a scale of 1 to 5, with 5 being “extremely helpful” and 1 being “not that helpful”, rate the components of the training day. *Your written remarks will help us to improve the materials and presentations.*

**Extremely Helpful**

**Not that Helpful**

5 \_\_\_\_\_ 4 \_\_\_\_\_ 3 \_\_\_\_\_ 2 \_\_\_\_\_ 1 \_\_\_\_\_

9:15 – 10:00 **Session A: Overview of Mental Illness** - \_\_\_\_\_

Comments:

10:00- 10:45 **Session B: Experiences of Parent(s) with a Mental Illness** - \_\_\_\_\_

Comments:

11:00 – 12:15 **Session C: Experiences of Children Whose Parent(s) have a Mental Illness** - \_\_\_\_\_

Comments:

1:00 – 1:30 **Session D: Experiences of Adult Children and Families** - \_\_\_\_\_

Comments:

1:30 – 2:15 **Session E: The Advance Planning Process** - \_\_\_\_\_

Comments:

2:30 – 3:30 **Session F: Community Best Practice: Self-Assessment Checklist**\_\_\_\_\_

Comments:

Please rate the **overall format** for the day - \_\_\_\_\_

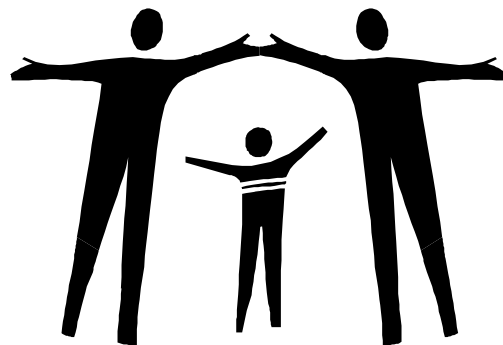
Comments:

## REQUEST FOR FEEDBACK

**Additional Comments:** As we may continue to hold similar community events, do you have any suggestions for what we should include or discard?

# Overview of Mental Illness

Section One: 9:15 a.m. – 10:00 a.m.



**By: Nicole Chovil, PhD**

# Overview of Mental Illness

## Section One: 9:15 a.m.– 10:00 a.m.

This section was prepared by Dr. Nicole Chovil, PhD

### PURPOSE

In this section, the goal is to provide a basic overview of mental illness (schizophrenia, bipolar disorder, major depression and schizoaffective disorder), concurrent disorders and personality disorders.

### LEARNING OBJECTIVE

Participants will gain a basic understanding of the serious and persistent mental illnesses through discussion of overhead notes.

### MATERIALS

- Community Trainer's Overheads and Background Information
- Overhead Projector

**Please Note:** *The Community Trainer would benefit from reading through all materials and preferably some of the resources listed at the end of this section before the Community Event. The focus of this presentation is on serious mental illnesses. Due to time restrictions, it may not be possible to present information on all of the disorders. The presenter may want to select those disorders most relevant to their audience.*

## INTRODUCTION

Good Morning. I would like to thank all of you for coming today and hope that you find the day informative and interesting. I'm going to begin this Community Event by providing an overview of mental illnesses. We realize that the level of knowledge about mental illness probably varies quite widely in this room. The goal is to provide some common ground so that everyone here understands what we mean by mental illness. For those of you who are much more knowledgeable, this will hopefully be a good review. For the rest, I hope I can provide a basic understanding. Please feel free to stop me at any point to ask questions. You may also make comments or ask questions by writing them on a sticky note and placing the notes up on this poster during our break. The Community Trainers will attempt to read the notes and address them promptly.

**Overhead A-1:** I will be covering three general areas: serious mental illnesses such as schizophrenia, concurrent disorders and personality disorders.

## **MAIN PART OF THE PRESENTATION**

### **Introduction on Mental Illness**

Mental illness is a broad term used to describe diagnosable psychiatric illnesses that impair a person's ability to think, feel, behave, and function effectively in day-to-day life. Some people may experience a one-off episode of mental illness, while others may experience ongoing symptoms. Most mental illnesses are episodic and the majority are treatable. People who have a mental illness can and do live quality lives. Mental illnesses can affect persons of any age, race, religion, or income. The type, intensity and duration of symptoms vary from person to person. They come and go and do not always follow a regular pattern, making it difficult to predict when symptoms and functioning will worsen, even if treatment recommendations are followed.

The Diagnostic and Statistical Manual, 4<sup>th</sup> Edition, DSM-IV (TR), the standard manual used for mental disorder classification, distinguishes between Axis I and Axis II disorders.

**Axis I** encompasses the major illnesses such as major depression, bipolar disorder, schizophrenia and the anxiety disorders.

**Axis II** is used to designate "personality disorders," which are basically life-long patterns of maladaptive behaviour that cause significant impairment in social, vocational, or interpersonal functioning, and/or subjective distress.

## **Discussion**

For the remainder of this section, the Community Trainer<sup>1</sup> may use the overheads and go over the main points for each mental illness. Please refer to the notes in the “Background Information” part of this section.

## **Closure**

I would like to thank everyone for your input. Now I would like to introduce the Community Trainer for the next session on *“The Experience of Parents with a Mental Illness.”*

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<sup>1</sup> Community Trainer is the person presenting material at the workshop.

**Today we will be covering three general areas:**

- 1. Serious mental illnesses such as schizophrenia**
- 2. Concurrent disorders**
- 3. Personality disorders**

## **Mental Illness: The Numbers**

### **Prevalence**

---

#### **Schizophrenia:**

About 1% of the population

#### **Bipolar Disorder (Manic Depression):**

Lifetime occurrence

1% - 2% of the population

#### **Major Depression:**

Lifetime occurrence

10% -25% of women

5% - 12% of men



## Schizophrenia

- Dramatic disturbances in thought, perception, and emotion.
- Schizophrenia is NOT a "split" personality.
- Develops between 16 and 25.
- Risk of psychotic episode increased in the post-partum period.
- Symptoms:
  - Heightened/blunted sensations
  - Disorganized thinking and speech
  - Hallucinations
  - Delusions
  - Social withdrawal
- Symptoms not present all the time; many periods of normal functioning with repeated episodes throughout life.
- Treatment:
  - Drugs in combination with
  - Support programs

## **Bipolar Disorder** **(Also known as Manic Depression)**

- Wide mood swings from mania to depression.
- Returns to “normal” mood in between episodes.
- Mania:
  - Rapid flight of ideas.
  - Reckless behaviour (spending sprees, foolish business investments, sexual behaviour unusual for the person).
- Life long illness.
- Onset before the age of 35.
- Cycle of mania and depression occur repeatedly.
- Treatment:
  - Medication
  - Therapy
  - Combination of both
  - A hospital stay may be necessary

## **Major Depressive Disorder/Clinical Depression**

- **Disrupts mood, behaviour, thought processes, physical health.**
- **Extreme or prolonged episode of sadness.**
- **Recurrent, episodic illness.**
- **Symptoms:**
  - **Loss of interest in activities normally pleasurable.**
  - **Appetite and weight changes.**
  - **Sleep disturbances.**
  - **Feelings of worthlessness, helplessness, hopelessness, pessimism.**
  - **Difficulty concentrating, remembering, making decisions.**
  - **Thoughts of death or suicide.**
  - **Persistent body aches, pains, digestive disorders not caused by physical disease.**
- **Onset at any age, commonly first appears during late twenties, sometimes immediately following childbirth (postpartum depression).**
- **Occurs twice as often in women.**
- **Treatment:**
  - **Medication**
  - **Psychotherapy**
  - **Combination of the two**
  - **Hospital stay may be necessary**

## **Schizoaffective Disorder**

- Features of both schizophrenia and a mood disorder.
- Diagnosis sometimes used on provisional basis.
- Incidence and prevalence is unknown.
- Women may be affected more than men.
- Symptoms:
  - Delusions, hallucinations
  - Inappropriate affect, depressed mood
  - Decreased interest in daily activities
  - Decreased ability to concentrate
  - Sleep disturbances, fatigue
  - Elevated or inflated mood
  - Irritability, poor temper control
  - Racing thoughts, more talkative than usual
  - Impaired judgment
  - Impaired social or occupational functioning
  - Decreased ability to care for self
- Treatment:
  - Depends on mood disorder associated with the illness.
  - Medication: antipsychotic medicines, antidepressants, and/or mood stabilizers.

## **Concurrent Disorders**

- **Two separate but interrelated issues:**
  - 1. Psychiatric diagnosis and**
  - 18. Substance use/abuse**
- **Treatment required for both problems.**
- **Interaction effects exacerbate both mental illness and substance use/abuse.**
- **At least 50% of those with severe mental illness also have a substance abuse problem.**
- **Drug use/abuse can prompt development, provoke reemergence, worsen severity or mimic and mask mental disorders.**
- **Diagnosis difficult - symptoms may be due to drugs or illness**
- **Incidence greater among males 18 to 44 years.**
- **Increased risk for violence, criminal offenses, homelessness.**
- **Gaps in services - ineffective treatment for either the mental illness or the alcohol/drug problem.**
- **Family or community may not tolerate behaviour.**

## **Personality Disorders**

- Inner experience and behaviour deviates markedly from the expectation of the individual's culture.
- Pervasive and inflexible.
- Onset - adolescence or early adulthood.
- Stable over time.
- Leads to distress or impairment.
- Diagnosed when behaviours cause distress to the person or others.
- Problems in other areas of life - social skills, moods, emotional states.
- Personality traits inflexible, maladaptive or inappropriate to situation.
- Rigidity of function - old ways of behaving fail, but resistant to change.
- Difficulty establishing normal, healthy relationships.
- Lack ability to have genuine emotions including empathy for others.
- Stem from basic personality traits developed over time.
- Personality disorder traits deeply ingrained in the personality - no quick treatment.

## **Cluster A: Odd and Eccentric Personality Disorders.**

- **Paranoid personality disorder** - pervasive distrust and suspicion of others.
- **Schizoid personality disorder** - detachment from social relationships and restricted range of expressions and emotions.
- **Schizotypal personality disorder** - acute discomfort in close relationships, cognitive or perceptual distortions, eccentricities of behaviour.

## **Cluster B. Dramatic and Emotional Personality Disorders.**

- **Antisocial personality disorder** - disregard for, violation of rights of other people, beginning in childhood or early adolescence and continuing into adulthood.
- **Borderline personality disorder** - instability in interpersonal relationships, self-image and impulsivity.
- **Histrionic personality disorder** - pervasive and excessive emotionality and attention seeking.
- **Narcissistic personality disorder** - grandiosity, loving oneself, need for admiration and lack of empathy.



## **Cluster C. Anxious and Fearful Personality Disorders**

- **Avoidant personality disorder** - social inhibition, feelings of inadequacy, and hypersensitivity to negative evaluation.
- **Dependent personality disorder** - pervasive and excessive need to be taken care of that leads to submissive and clinging behaviour and fear of separation.
- **Obsessive compulsive personality disorder** - preoccupation with orderliness, perfectionism and control at the expense of flexibility, openness and efficiency.
- Treatment:
  - Based on psychotherapy - evaluates faulty thinking patterns, teaches new thinking and behavior patterns.

## **Example: Borderline Personality Disorder**

- Identity disturbance – unstable self-image or sense of self.
- Impulsivity in variety of contexts, potentially self-damaging.
- Unstable and intense relationships.
- Characterized by “splitting” (alternating idealization and devaluation of the other person).
- Frantic efforts to avoid real or imagined abandonment.
- Recurrent suicidal behaviour or threats, or self-mutilation.
- Affective instability due to a marked reactivity of mood.
- Chronic feelings of emptiness.
- Inappropriate intense anger or difficulty controlling temper.
- Transient, stress-related paranoid ideation or dissociation.
- Often bright, witty, funny and life of a party.
- Series of job losses, interrupted education, broken engagements, hospitalizations.
- May have history of child neglect or physical, sexual or emotional abuse.

## **Anxiety Disorders**

- Most common of all mental disorders.
- Extreme sense of fear and worry.
- Physical sensations that cover all systems of the body.
- Intense and paralyzing sense of fear or more sustained pattern of worrying.
- Many misunderstand and believe individuals can overcome the symptoms by willpower.
- Severe fear or anxiety often associated with particular objects and situations.
- Can also take the form of general chronic and exaggerated worry.

## **Some Types of Anxiety Disorders**

### **1. Generalized Anxiety Disorder**

- Chronic and exaggerated worry and tension, without anything apparently provoking it.
- Realize their worries are extreme but can't shake them off.
- Can be very difficult to carry out ordinary daily activities.

### **2. Panic Disorder & Panic Disorder With Agoraphobia**

- Sudden onset of paralyzing terror or impending doom with physical symptoms that closely resemble heart attack or stroke.
- Attacks are unpredictable.
- Last from a couple of minutes to 10 minutes.
- Restricts a person's life considerably – avoiding normal, everyday activities.
- Panic disorder with agoraphobia – the avoidance of situations and environments in which panic attacks occur.

### 3. **Phobias** - excessive irrational fear of:

- Particular objects (simple phobias).
- Situations that expose one to possible judgment of others and result in humiliation (social phobias).
- Situations where escape might be difficult (agoraphobia).

### 4. **Obsessive-Compulsive Disorder**

- Persistent, distressing and unwelcome thoughts (obsessions) that a person attempts to alleviate by performing repetitive, intentional acts or rituals (compulsions).
- Rituals provide temporary relief from the discomfort caused by the thoughts.

## **Symptoms of anxiety may include:**

- Sense of worry or impending doom.
  - Feeling irritable, uneasy and unable to relax.
  - Bodily sensations such as breathlessness, palpitations, dizziness, sweating.
  - Overwhelming feeling of panic.
  - Sleep disturbances.
  - Difficulty concentrating.
  - Changed perceptions – in panic attack, world may seem unreal and strange.
- Because of strong physical component, people often seek help for what they believe to be a physical illness.
  - Can occur in almost all age groups.
  - One in five people will develop an anxiety disorder at some point in their lives.
  - Women seem more prone to Generalized Anxiety Disorder, Panic Disorder, and Phobias. Obsessive-Compulsive Disorder affects men and women equally.
  - Treatment methods may include counselling, cognitive-behavioural and desensitization therapies, and medication.

## BACKGROUND INFORMATION for OVERHEAD A-3

The first mental disorder I will be covering is **schizophrenia**.

- Schizophrenia is a mental disorder characterized by dramatic disturbances in thought, perception, and emotion.
- Schizophrenia is NOT a "split" personality.
- Schizophrenia typically develops between the ages of 16 – 25. It can develop in women at a later age. Risk of a psychotic episode (acute flare-up of symptoms) is increased in the post-partum period.
- Specific symptoms include heightened or blunted sensations, disorganized thinking and speech, hallucinations, delusions, and social withdrawal.
- Individuals with schizophrenia do not show these symptoms all the time; they may experience many periods of relatively normal functioning. However, the illness typically involves repeated episodes throughout the individual's lifetime.
- Treatment includes drugs combined with support programs.
- Women with schizophrenia tend to have poor attendance records at antenatal clinics, and thus have less opportunity to access education regarding their mental health changes due to pregnancy and postpartum. (Refer to *Best Practice Guidelines Relating to Reproductive Mental Health: Principles for Early Identification, Assessment, Treatment and Follow-up of Women with Reproductive Mental Health Illness During Pregnancy and the PostPartum Period*. BC Reproductive Care Program, 2002).

### References

Castle, D.J., McGrath, J., Kulkarni, J. (Eds.). (2000). Women and Schizophrenia. Cambridge, UK: Cambridge University Press.

Miller, L.J., Finnerty, M. (1996). Sexuality, pregnancy, and childbearing among women with schizophrenia-spectrum disorders. Psychiatric Services, 47, 502-506.

## BACKGROUND INFORMATION for OVERHEAD A-4

- **Bipolar Disorder** is the second serious and persistent mental disorder I will be covering this morning.
- Bipolar Disorder is characterized by wide mood swings from mania (euphoric state) to depression (hopeless, unhappy states).
- A person with bipolar disorder usually returns to a normal mood in between episodes of mania and/or depression.
- Mania may be expressed in rapid flight of ideas or reckless behaviour (spending sprees, foolish business investments, sexual behaviour unusual for the person).
- Bipolar disorder is a life long illness generally striking before the age of 35.
- The periods of mania and depression can occur over and over again.
- Bipolar disorder is treated with medication, therapy, or a combination of the two. In severe cases, a hospital stay may be necessary.
- This is the most common type of psychotic illness women suffer from during the perinatal period.
- The risk of an episode of mania, hypomania, or depression for a bipolar woman during the perinatal period is between 13% for women with a previous depression and 21% for those with previous mania or cycling mania and/or depression. The recurrence rate of bipolar relapse with subsequent pregnancies is as high as 50%. (Refer to the *Best Practices Guidelines on Reproductive Mental Health, 2002*).

### References

Dean, C., Williams, R.J. & Brockington, I.F. (1989). Is puerperal psychosis the same as bipolar manic-depressive disorder? A family study. Psychological Medicine, 19. 637-647.

Kendell, R.E., Chalmers, J.C. & Platz, C. (1987). Epidemiology of puerperal psychoses. British Journal of Psychiatry, 150. 662-673.



## BACKGROUND INFORMATION for OVERHEAD A-5

- **Major Depressive Disorder or Clinical Depression** as it is also called is the third major mental disorder.
- Depression is a serious medical illness that disrupts a person's mood, behaviour, thought processes and physical health.
- Depression is an extreme or prolonged episode of sadness. It differs from passing feelings of unhappiness that most everyone feels at one time or another.
- Major depression disorder is often a recurrent, episodic illness. People who develop depressive disorder are like to have one or more episodes of depression in the future.
- Symptoms of depression include:
  - Loss of interest in activities that normally are pleasurable (including sex).
  - Appetite and weight changes (either loss or gain).
  - Sleep disturbances (insomnia, early morning wakening, or oversleeping).
  - Feelings of worthlessness, or helplessness.
  - Feelings of hopelessness or pessimism.
  - Difficulty in concentrating, remembering, or making decisions.
  - Thoughts of death or suicide; suicide attempts.
  - Persistent body aches and pains or digestive disorders not caused by physical disease.
  - Can strike at any age; most commonly first appears during a person's late twenties.
  - This disorder occurs about twice as often in women than in men.
- Basic ways to treat depression include medication, psychotherapy, and a combination of the two. In severe cases, hospital stay may be necessary.

- 12-16% of women experience a major depressive episode and this figure rises to as high as 26% in adolescent mothers.
- 30% of women who have a history of major depression before conception will experience postpartum depression.
- Women with a previous history of postpartum depression are at a 50-60% increased risk of recurrent episodes with subsequent pregnancies. (Refer to the *Best Practices Guidelines on Reproductive Mental Health, 2002*).
- In postpartum women **Psychotic Depression** is usually super-imposed on a primary mood disorder. It usually takes the form of paranoid delusions, thoughts of harming their baby and very rarely hallucinations (Refer to the *Best Practices Guidelines on Reproductive Mental Health, 2002*).

### **References**

Llewellyn, A.M. Stowe, Z.N. & Nemeroff, C.B. (1997). Depression during pregnancy and the puerperium. Journal of Clinical Psychiatry, 58, S15, 26-32.

O'Hara, M.W. (1986). Social support, life events, and depression during pregnancy and the puerperium. Archives of General Psychiatry, 43, 569-573.

O'Hara, M.W. & Swain, A.M. (1996). Rates and risk Of postpartum depression: A meta-analysis. International Review of Psychiatry, 8, 37-54.

Troutman, B. Cutrona, C. (1990). Nonpsychotric Postpartum Depression Among Adolescent Mothers. Journal of Abnormal Psychology, 99, 69-78.

## BACKGROUND INFORMATION for OVERHEAD A-6

- **Schizoaffective disorder** is a disorder that many people are less familiar with.
- Features of both schizophrenia (psychotic symptoms) and a mood disorder (a major depressive episode and/or manic episode).
- Diagnosis sometimes used on a provisional basis when there is uncertainty about the diagnosis or about which symptoms represent the primary underlying disorder.
- Incidence and prevalence is unknown but is thought to be less common than schizophrenia or affective disorders. There is some suggestion that women may be affected more than men.
- Symptoms vary greatly but can include: delusions, hallucinations, inappropriate affect, depressed mood, decreased interest in daily activities, decreased ability to concentrate, sleep disturbances, fatigue, elevated or inflated mood, irritability, poor temper control, racing thoughts, more talkative than usual, impaired judgement, impaired social or occupational functioning, and/or decreased ability to care for self.
- Treatment depends on the mood disorder associated with the illness. Medication typically includes antipsychotic medicines, antidepressants, and/or mood stabilizers.

## BACKGROUND INFORMATION for OVERHEAD A-7

- In the field of mental health and substance use/abuse services, **Concurrent Disorders** means that an individual has two separate but very interrelated issues:
  1. A psychiatric diagnosis (at least one); and,
  2. Substance use/abuse (which may include both drugs and alcohol).
- To recover fully, the person needs treatment for both problems.
- A person with a concurrent disorder can experience an exacerbation of both their mental illness and their drug use/abuse disorder due to interaction effects. Drug use/abuse can prompt the development, provoke the reemergence or worsen the severity of mental disorders. Drug use also can mimic and mask mental disorders.
- Diagnosis is difficult because the symptoms may be the result of the drugs or the illness.
- It is believed that at least 50% of people with severe mental illness also have a substance abuse problem. Alcohol, marijuana and cocaine are the drugs most commonly abused. Individuals may abuse drugs covertly without their families knowing it.
- Incidence is greater among males and those in the age bracket of 18 to 44 years. Violence is more prevalent among the concurrent disordered population.
- Drug use may begin as a recreational activity; an attempt to treat symptoms of their mental illness or to alleviate the side effects of medications; or as a result of their social group.
- Gaps in services for individuals with concurrent disorders can result in ineffective treatment for either the mental illness or the alcohol/drug problem. People may be bounced back and forth between services for mental illness and those for substance abuse, or they may be refused treatment by each of them.
- Individuals' behaviour may not be tolerated by family members or in community housing or rehabilitation programs. As a result, they may lose their support systems.
- They are at increased risk for violence, criminal offenses and homelessness.

## BACKGROUND INFORMATION for OVERHEAD A-8a(i)

- **Personality Disorder** is defined in the Diagnostic and Statistical Manual, 4<sup>th</sup> Edition, DSM IV (TR) as “an enduring pattern of inner experience and behaviour that deviates markedly from the expectation of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment”.
- Personality disorders are typically diagnosed when the behaviours cause distress to the person or if the behaviors repeatedly lead to negative consequences for the client or others. In many, if not most, cases of personality disorder, the person's behavior causes more problems and distress to others than to him or herself. The person may not see their behaviour as the problem but rather believe that it is others who have the problem.
- People suffering from personality disorders typically have problems in many areas of their lives, including social skills, moods, and emotional states. Individuals experiencing these disorders show personality traits which are inflexible, maladaptive or inappropriate for the situation, causing significant problems in their lives. Typically there also is a certain rigidity of function. No matter how many times the old ways of behaving have failed, the person does not change them.
- People with these disorders have difficulty establishing normal, healthy relationships. The illness itself may cause disturbance in emotions or expression of emotions, including empathy for others. In some disorders, sufferers have no desire to have social relationships or they want relationships, but are scared to reach out to people.
- Personality disorder symptoms stem from basic personality traits that developed over time. A person does not suddenly "get" a personality disorder. Because personality disorder traits are deeply ingrained in the personality of sufferers, there is no quick treatment. Treatment can be long and difficult.
- DSM IV has classifications for 10 personality disorders. These disorders are divided into three different clusters:

## BACKGROUND INFORMATION for OVERHEAD A-8a(ii)

### **Cluster A: Odd and Eccentric Personality Disorders.**

- Paranoid personality disorder. Characterized by a pattern of pervasive distrust and suspiciousness of others.
- Schizoid personality disorder. A pattern of detachment from social relationships and restricted range of expressions and emotions.
- Schizotypal personality disorder. A pattern of acute discomfort in close relationships, cognitive or perceptual distortions, and eccentricities of behaviour.

## BACKGROUND INFORMATION for OVERHEAD A-8a(iii)

### **Cluster B. Dramatic and emotional personality disorders.**

- Antisocial personality disorder: A disregard for, and violation of, the rights of other people, beginning in childhood or early adolescence and continuing into adulthood.
- Borderline personality disorder: A pattern of instability in interpersonal relationships, self-image and impulsivity.
- Histrionic personality disorder: Pervasive and excessive emotionality and attention seeking.
- Narcissistic personality disorder: Pervasive pattern of grandiosity, loving oneself, need for admiration and lack of empathy.

## BACKGROUND INFORMATION for OVERHEAD A-8a(iv)

### **Cluster C. Anxious and Fearful Personality Disorders.**

- Avoidant personality disorder: A pattern of social inhibition, feelings of inadequacy, and hypersensitivity to negative evaluation.
- Dependent personality disorder: A pervasive and excessive need to be taken care of that leads to submissive and clinging behaviour and fears of separation.
- Obsessive compulsive personality disorder: A pattern of preoccupation with orderliness, perfectionism and control at the expense of flexibility, openness and efficiency.
- Treatment is typically based on psychotherapy which evaluates faulty thinking patterns and teaches new thinking and behavior patterns.

## BACKGROUND INFORMATION for OVERHEAD A-8a(v)

### Example of a Personality Disorder: Borderline Personality Disorder

*Please note that everyone has troublesome personality traits to a certain extent. In order for a mental illness diagnosis, these traits must be long-standing, persistent, and **intense**.*

- Pervasive pattern of instability of interpersonal relationships, self-image and affects, and marked impulsivity beginning in early adulthood and present in a variety of contexts.
- Frantic efforts to avoid real or imagined abandonment.
- A pattern of unstable and intense interpersonal relationships.
- Characterized by “splitting” (alternating idealization/devaluation of the other person).
- Identity disturbance – markedly and persistently unstable self-image or sense of self.
- Impulsivity in at least two areas that are potentially self-damaging (e.g. spending money, sex, reckless driving, drug abuse).
- Recurrent suicidal behaviour or threats, or self-mutilating behaviour.
- Affective instability due to a marked reactivity of mood (e.g. intensive episodic dysphoria, irritability or anxiety).
- Chronic feelings of emptiness.
- Inappropriate intense anger or difficulty controlling temper.
- Transient, stress-related paranoid ideation or severe dissociative symptoms. A dissociative state is one in which the person becomes removed from “reality” – could be daydreaming, and/or performing actions automatically.
- Individuals with Borderline Personality Disorder are often bright, witty, funny and the life of the party.
- Their lives may be a series of job losses, interrupted educational pursuits, broken engagements and hospitalizations.
- Many have a history of child neglect or abuse, physical, sexual or emotional.



## BACKGROUND INFORMATION for OVERHEAD A-9a(i)

- **Anxiety Disorders**, of which there are several, have in common an extreme sense of fear and worry and physical sensations that cover all systems of the body. With anxiety disorders an individual has an intense and paralyzing sense of fear or a more sustained pattern of worrying when there is no real danger or threat.
- Anxiety disorders are the most common of all mental disorders.
- Many people misunderstand these disorders and believe that individuals can overcome the symptoms by willpower.
- The severe fear or anxiety is often associated with particular objects and situations but can also take the form of general chronic and exaggerated worry. People with anxiety disorders try to avoid exposure to the situation that causes anxiety.
- Women in the postpartum period are at an increased susceptibility to both the onset as well as exacerbation of symptoms of pre-existing panic disorder. (Refer to the *Best Practices Guidelines on Reproductive Mental Health, 2002*).

## BACKGROUND INFORMATION for OVERHEAD A-9a(ii)

### **Some types of Anxiety Disorders**

1. **Generalized Anxiety Disorder** - is a syndrome in which excessive worry and apprehension regarding a variety of events and activities predominate during most days over at least a six-month period. Like other anxiety disorders, it is accompanied by symptoms of physical agitation including muscle tension, insomnia and difficulty concentrating, but is a pervasive rather than a focused.
2. **Panic disorder** - the sudden onset of paralyzing terror or impending doom with physical symptoms that closely resemble a heart attack or stroke. Attacks are unpredictable and most attacks last from a couple of minutes to 10 minutes. The disorder can restrict a person's life considerably – where they may avoid normal, everyday activities. persistent worry about future attacks and the implications of these attacks (i.e. dying or losing bodily control). When associated with agoraphobia, there is marked avoidance of situations and environments in which panic attacks might occur.

## BACKGROUND INFORMATION for OVERHEAD A-9a(iii)

3. **Phobias** - excessive irrational fear of:
  - Particular objects (simple phobias).
  - Situations that expose a person to the possible judgment of others and result in humiliation or embarrassment (social phobias).
  - Situations where escape might be difficult (agoraphobia).
4. **Obsessive-compulsive disorder** – characterized by persistent, distressing and unwelcome thoughts (obsessions) that a person attempts to alleviate by performing repetitive, intentional acts or rituals (compulsions). The rituals provide temporary relief from the discomfort caused by the thoughts. An example of an obsession and compulsion is: obsession with germs or dirt which person attempts to alleviate by continual hand washing.

## BACKGROUND INFORMATION for OVERHEAD A-9a(iv)

### Symptoms of anxiety may include:

- A sense of worry or impending doom.
  - Feeling irritable, uneasy and unable to relax.
  - Bodily sensations such as breathlessness, palpitations, dizziness, and sweating.
  - Overwhelming feeling of panic.
  - Sleep disturbances.
  - Difficulty concentrating.
  - Changed perceptions whereby, in a panic attack, the world may seem unreal and strange.
- Because of the strong physical component in many anxiety disorders, people often seek help for what they believe to be a physical illness (e.g. the extreme sensations of a panic attack may be interpreted as a heart attack).
  - Anxiety can occur in almost all age groups and one in five people will develop an anxiety disorder at some point in their lives. Women seem more prone to Generalized Anxiety Disorder, Panic Disorder, and Phobias. Obsessive-Compulsive Disorder affects men and women equally.
  - Treatment methods will vary depending on the form of anxiety and its severity but may include counseling, cognitive-behavioural and desensitization therapies, and medication.

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## **MENTAL ILLNESS EDUCATION SITES**

British Columbia Schizophrenia Society. <http://www.bcscs.org>

Canadian Mental Health Association, BC Division. [www.cmha-bc.org](http://www.cmha-bc.org)

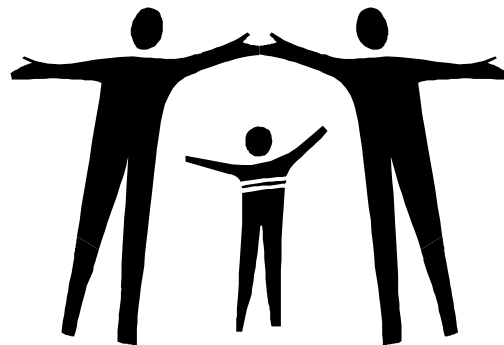
Internet Mental Health. [www.mentalhealth.com](http://www.mentalhealth.com). This is a popular site for basic information on mental illness. Dr. Phil Long maintains this site.

Dual Diagnosis Website - Mental Illness, Drug Addiction and Alcoholism. <http://users.erols.com/ksciacca/>

Mental Health Evaluation and Community Consultation Unit (Mheccu), University of British Columbia. <http://www.mheccu.ubc.ca>

# Experiences Of Parent(s) With A Mental Illness

**Section Two: 10:00 am – 10:45 am**



**By: Eric Macnaughton, MA**

# Experiences of Parent(s) with a Mental Illness

**Before the First Break: 10:00 am – 10:45 am**

This section was prepared by Eric Macnaughton, MA.

PURPOSE	LEARNING OBJECTIVE	MATERIALS
In this section, the goal is to take a closer look at the parents who are experiencing a mental illness and the challenges they face.	Participants will gain further insight into the experience of parenting with a mental illness through watching a video, hearing information and discussion.	<ul style="list-style-type: none"><li>• TV and VCR</li><li>• Video "I Love You Like Crazy"</li><li>• Overheads</li><li>• Overhead projector and screen</li></ul>

## INTRODUCTION

The next section looks at the issues specific to parents with a mental illness. It examines these issues experientially, through the video called "I Love You Like Crazy", which features a group of parents talking about the struggles they face. It also looks at some of the research that identifies key issues related to the support needs of parents with a mental illness. This manual looks at many kinds of families: families with two parents; families with one parent; families where both parents have a mental illness; and, more common, where one parent has a mental illness. In families where one parent does not have a mental illness it is possible that the other parent can be a source of support. We encourage you to present the information in a manner that will be inclusive of all families. We understand that the parenting experiences of men and women are different, however, in this document space restrictions prevent us from specifying those differences. Most of the research has been done on the experiences of women (please refer to the list of references at the end of this chapter). For further information, an excellent resource for Women and Mental Health Care is:

Morrow, M. & Chappel, M. (1999). Hearing women's voices: Mental health care for women. Vancouver: British Columbia Centre of Excellence for Women's Health.



## MAIN PART OF THE PRESENTATION

### The Video

The video "*I Love You Like Crazy*" is 28 minutes long. You may rent this video about parents talking about their illness for a nominal cost from the BC Schizophrenia Society (Tel.: 604-270-7841) or from the Canadian Mental Health Association – BC Division (Tel.: 604-688-3234). To order this video, you can go to <http://www.miepvideos.org/shop/index.html>. Alternatively, you can write to The Mental Illness Education Project, Inc., P.O. Box 470813, Brookline Village, MA 02447, telephone: 617-562-1111, e-mail: [info@miepvideos.org](mailto:info@miepvideos.org). The price for this video is \$39.95 (US).

The presentation uses the last 15 minutes of the film, starting with the discussion on "blame and responsibility". The Community Trainer will have to view the film in advance to find this starting point, or to find a point that is suitable for the allotted time frame. When introducing the film, the Community Trainer should make a note that the issues addressed may be controversial to service providers, since the parents talk about the issues of loss of custody in a way that may be perceived as critical and unappreciative of their role. The Community Trainer should emphasize that loss of custody *is* a significant experience. However, it should not be interpreted as negating the important role played by service providers (especially child protection workers). It highlights the issue, though, that with earlier or more appropriate support, custody interventions could have been avoided. It is also important to mention that the video is American and although different terminology is used, the issues facing the parents are the same in Canada.

## **Discussion**

For the next part of this session, the Community Trainer will lead the participants in a discussion. Please refer to the overheads throughout this session. For each overhead we have included background information for the Community Trainer.

**Overhead B-1** – The Parenting Role

**Overhead B-2** – The Socioeconomic Context

**Overhead B-3** – The Impact of Parenting on Mental Illness

**Overhead B-4** – The Impact of Mental Illness on Parenting

**Overhead B-5** – Parenting as a Barrier to Seeking Help

**Overhead B-6** – Experience of Parents with the Mental Health System

**Overhead B-7** – Experience with Apprehension

## **Closure**

I would like to thank you for your participation in this presentation. Remember to place your questions and comments on a sticky note on this poster and one of the Community Trainers will attempt to address your questions at some point during the day. We will now break for coffee. I will remind you where the food, beverages and washrooms are. After the break we will discuss the experiences of children whose parent(s) have a mental illness.

## **Introduction: The Parenting Role**

- **An important life role for all of us.**
- **People with mental illness, like anyone, are motivated to parent.**
- **Parents with mental illness do parent at the same rate as the general population.**
- **With the right kind of support, parents with mental illness can be good parents.**

## **The Socioeconomic Context**

- **Many are single parents (usually mothers), with low incomes.**
- **Poverty-related issues are struggles: housing, transportation, diet, childcare, etc.**
- **Parents with mental illness are often isolated from family & social support networks.**
- **Protection from domestic violence may also be an issue.**

## **The Impact of Parenting on Mental Illness**

- **Birth, or child rearing may trigger onset of illness for parents (particularly mothers) with a vulnerability.**
  
- **Ongoing stress of parenting can worsen a pre-existing illness, in absence of support.**
  
- **Parents with mental illness may feel added pressure to "measure up" (sometimes to unrealistic standards).**
  
- **Parenting can contribute to recovery by providing:**
  - **a source of motivation to manage one's illness,**
  - **a source of daily and ongoing structure, and**
  - **a sense of identity and status apart from being only "a person with a mental illness".**

## **The Impact of Mental Illness on Parenting**

- **Symptoms can have an impact.**
- **The illness can impact the parent's ability to form attachments and relationships.**
- **Social factors associated with being a parent with mental illness have an impact.**
- **Developmental challenges have an impact.**

## **Parenting and Barriers to Seeking Help**

- **Many personal barriers to help seeking in early stages of an illness (e.g. stigma, misinformation, insight, etc.).**
- **Many system-level barriers (e.g. low visibility of services, restrictive service mandates, reactive vs. preventive orientation, etc.).**
- **Seeking help for a relapse may be difficult if service only offered when people most in need.**
- **Parents may refuse treatment to meet their children's short-term needs.**
- **Fear of losing custody is an additional barrier for parents.**

## **Experience of Parents with the Mental Health System**

- **Help is reactive rather than proactively or assertively offered (earlier support would have prevented the need for child protection).**
- **A need for increased focus on psychosocial forms of support (e.g. counseling).**
- **A need for family-centred (vs. individually centred) care.**
- **University of Massachusetts study showed most professionals unaware of parenting status of clients.**
- **Where parenting status is known, there is a need for strengths-based (vs. a deficit focus) approach to parenting support.**
- **Consideration needs to be given to avoiding side effects that affect one's ability to parent.**



## **Experience with Loss of Guardianship or Custody**

- **A high percentage of parents with severe and persistent mental illness have children removed from their care (MPA study, Univ. of Mass. study).**
- **Many parents with mental illness lose custody after the couple breaks up.**
- **Incapacity needs to be assessed with the assumption that with proper support, parents with mental illness can make good parents.**
- **Professionals need to be aware of the impact of "invisible children" in the lives of their clients.**

## **Supporting the Parent in the Home and in the Community**

- **Foster ability to manage the illness through psychoeducation (individual & family-based), proper diagnosis & treatment, addressing co-occurring substance use.**
- **Build parenting skills through psychosocial rehabilitation, stress management, peer support & mentoring, generic parenting resources.**
- **Support parent to meet practical needs (income, housing, transportation, childcare, etc.).**
- **Help prevent social isolation through: relationship counseling; conflict resolution skill building; involvement of family unit in care; connection to peer support.**
- **Build strategies for relapse prevention (preventively offered care, pre-crisis planning and advanced planning agreements, help person to understand their own relapse signs and triggers, etc.).**

## **BACKGROUND INFORMATION for OVERHEAD B-1**

### **Introduction: The Parenting Role**

- Parenting is an important life role that is valued highly by most people in our society, and people with mental illness are no exception.
- Not surprisingly, they are also highly motivated to become parents, and ...
- As shown by one recent study, done at the University of Massachusetts, people with mental illness *do* parent at the same rate as the general population.
- Having a serious mental illness, as with another serious illness, impacts on one's ability to parent, but does not prevent one from doing so. With the right kind of support, people with mental illness can be good parents.

## **BACKGROUND INFORMATION for OVERHEAD B-2**

### **The Socioeconomic Context of Parenting with Mental Illness**

- When we think of the kinds of issues faced by parents with mental illness, many of them relate not to the illness, but to the fact that many of these parents are dealing with struggles related to poverty, isolation, and in some cases related to gender.
- Many parents are single mothers who live on limited incomes. There are barriers that prevent women from accessing high paying jobs in our society. The barriers may be compounded for women with a mental illness.
- And because they are poor, they face difficulties with meeting basic needs such as decent, affordable housing, adequate transportation, proper nutrition for their family, finding childcare that they can afford, and paying for recreational activities that are conducive to the healthy development of their children (outings, lessons, etc.).

- Since mental illness often causes conflict amongst a person and their social network, parents may become isolated from family and other potential sources of emotional and practical support that most people access through their social networks.
- A final point relates to gender: more women with mental illness than men are parents. For people with schizophrenia, for example, this is partly because the illness often strikes later in women, after they have had children. One issue that may be relevant is protecting themselves and their families from domestic abuse.

Women with mental illness are at a high risk both for having a history of experiencing violence, and for ongoing violence when they are mentally ill. This means that children of these women are likely to witness abuse.

Ros Salvador  
Women's Policy Branch  
Ministry of Community, Aboriginal and Women's Services

## **BACKGROUND INFORMATION for OVERHEAD B-3**

### **The Impact of Parenting on Mental Illness**

Now that we've looked at the impact of social and economic factors on the kinds of issues faced by parents with mental illness, let's look at the relationship between mental illness itself and the parenting role. The relationship goes both ways. That is, having an illness impacts on the ability to parent, and being a parent can have an impact on the way an individual experiences her or his illness. This overhead looks at the latter issue.

- First of all, for some women, the birth of a child can actually trigger the onset of the illness. For others who are vulnerable, the stress of child rearing may be what triggers the illness.

- For a person with a pre-existing illness, the day-to-day demands of parenting, on top of the demands of managing the illness (keeping appointments, taking regular medications, etc.) can be a major stressor that can exacerbate or worsen the course of the illness. The parent might also feel guilt or resentment related to the sometimes conflicting demands of parenting and managing their own illness.
- There may be added stress, since people with mental illness feel pressure to "measure up" or prove themselves as parents, sometimes to unrealistic standards. For example, they may lose sight of the fact that some of their struggles are typical for all parents, and judge themselves negatively.
- It's important to remember that being a parent is not just a source of stress. It can also become a major contributor to a person's recovery, by providing:
  - A source of motivation to manage one's illness (some people will say that they didn't follow through on their treatment in the past, but that they decided that it was important to take responsibility for their health so they could "be there" for another person);
  - A source of structure that helped them be organized enough to "make it through the day;" and,
  - A sense of identity and status apart from being only "a person with a mental illness".

## **BACKGROUND INFORMATION for OVERHEAD B-4**

### **The Impact of Mental Illness on Parenting**

As stated, there is a two-way relationship between parenting and mental illness, so now we're going to look at the other side of the equation, the impact that the illness has on parenting.

- First of all, let's consider the effects that symptoms related to certain illnesses can have: depression either in and of itself, or co-occurring in other illnesses such as schizophrenia, can have negative effects as it can reduce an individual's

motivation and energy level to parent. For people with schizophrenia, "negative symptoms" can have the similar effects, especially if their medications are not adjusted properly. Positive symptoms of schizophrenia that are not properly managed can also have an impact if they distract the parent from attending to "real world" concerns, and if their children are "drawn in" to a delusional worldview, especially if the offspring have not been given any education about the illness.

- The illness may also have an impact on the person's ability to form relationships and attachments. One consequence is to reinforce the tendency that we've already mentioned for the parent - and therefore the family - to be socially isolated. The other relates to the difficulties that the parent often has with forming healthy attachments with their small children. Research shows that they may either be overly detached or overly involved. This may translate, for example, into having difficulty understanding how to play or interact: they may be either overly directive and brusque, or on the other hand may appear not show any interest at all in what the child is doing, or in the needs that the child is indicating. As time goes on, these difficulties in "knowing how" to parent may be compounded if the individual's own parent had a mental illness and was not a positive role model that can be drawn upon for strength.
- The final point on the overhead relates to how the issues of familial mental illness cause concerns for the parent in relation to the healthy development of their children. In reciprocal fashion, these can cause further negative impacts on the parent's own mental health. First of all, mothers with mental illness tend to have more difficult pregnancies and their offspring tend to have more physical health complications over time. Chronologically, the next issue that comes up is the concern over attachment and style of interaction with their children and the impacts this can have on the healthy socialization and mental health of the offspring. As the children get older, the parent may then have to cope with mental health problems or behavioral difficulties in the children themselves. And as the offspring approach the "age of risk" for major mental illness, the parents face the worry over whether their child will develop the same illness they have.

A final issue as the adolescent approaches adulthood is the difficulties parents often have in fostering a healthy degree of separation as the adolescent moves into adulthood. Often the offspring are the parent's primary source of self-esteem, so the eventuality of the "child" moving on represents a threat to the parent.

## **OVERHEADS B-5 to B-8**

The next set of overheads deal with parents' experience with services, when they initially contemplated seeking help from the mental health system, with the kind of mental health services they eventually received, and with the child protection system.

### **BACKGROUND INFORMATION for OVERHEAD B-5**

#### **Parenting and Barriers to Seeking Help**

- Parents with mental illness face the same barriers when they first attempt to seek help from the mental health system (fear, stigma, lack of information, misinterpretation of the problem, lack of insight, etc.).
- There are also many system-level barriers, which make navigating the system for the first time difficult (such as restrictive service mandates, low visibility of services, lack of a proactive approach to intervention, etc.).
- For people seeking help for a relapse the issue of proactiveness, or lack thereof, is also a problem, as help may not be offered until it is too late, and the person is in crisis.
- Additionally, some parents will choose not to seek treatment because they are more worried about continuing to meet the short-term needs of the children than their own mental health-related needs.
- For parents with mental illness, however, a major additional hurdle to overcome is the fear of losing custody over a child.

## **BACKGROUND INFORMATION for OVERHEAD B-6**

### **Experience of Parents with the Mental Health System**

- When help is received it is often too late, and many parents feel that if they had been offered more proactive treatment, it would have prevented the need for child protection.
- They also feel a need for support that is not strictly biological in nature and more oriented to a holistic or psychosocial approach. They express a need for counseling - individual and family - and for the kinds of supports we'll talk about later.
- Also, the support offered needs to be more "family-centred" in the opinion of parents with mental illness.
- As shown by a recent study, however, most professionals are unaware of the parenting status of clients.
- When the parenting status *is* known, the experience is that the approach to treatment needs to be more of a "building on strengths" approach, versus the tendency to "pathologize" the behaviors of parents in the various aspects of their lives.
- A final but important point about the biological aspects of treatment is that there needs to be more consideration and caution taken about whether the medication regimen negatively affects the person's ability to carry on the day-to-day functions of parenting.

## **BACKGROUND INFORMATION for OVERHEAD B-7**

### **Experience with Child Apprehension <sup>2</sup>**

We're now going to focus in on the issue of child apprehension and the context surrounding it from the parent's perspective.

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<sup>2</sup> Currently known as 'child removal' in BC



- First of all, some recent surveys of parents, including one done by the Vancouver Mental Patients' Association (VMPA), shows that it is a relatively high occurrence. The VMPA study found that it had happened to **approximately 60%** of the parent group that was surveyed.
- Many parents also lose contact with their children as a result of custody decisions related to family break-up.
- The feeling of parents, as reflected in the film we've seen, is that their inability to parent is often taken for granted, rather than properly assessed. Competency assessments must also reflect the supports that are, or are potentially available, to the mother, with the assumption that with proper supports, people with mental illness can make good parents.
- In situations where custody and even contact with children has been lost, professionals need to be aware of the effect that these "invisible children" can have in the lives of their clients. For example, the fear of apprehension in the future can cause decompensation. Preoccupation with the loss of the child can distract a parent from working on his or her own recovery process. Loss of a child can also motivate a mother to become pregnant again.

## **BACKGROUND INFORMATION for OVERHEAD B-8**

### **Supporting the Parent in the Home and in the Community**

**Note:** this material will be covered in other parts of the day, so the presenter may want to go through it fairly briefly.

- Being a successful parent depends on a number of kinds of supports. These include: fostering the ability of the parent to successfully manage their illness; building parenting skills; help with meeting practical needs; preventing or addressing social isolation; and providing preventively oriented care in the event of a potential crisis or relapse.

Let's look in a bit more depth at what each of these elements of support entails:

- Being able to manage one's own illness requires providing:
  - Proper diagnosis and appropriate treatment that doesn't disrupt the parent's ability to function.
  - Sensitive and thorough psychoeducation for the consumer and for the family unit, which fosters dialogue about the illness and how to deal with it within the whole family.
  - Interventions dealing with co-occurring substance misuse (for example stress management approaches, as substance use may often be a dysfunctional attempt at coping with the demands of parenting rather than an addiction).
- Approaches to parenting skill-building include:
  - Psychosocial rehabilitation techniques
  - Stress management approaches
  - Peer support & mentoring
  - Parenting resources such as play groups
- Support for meeting practical needs entails help with:
  - Income support (or supported education/employment)
  - Supported/subsidized housing
  - Transportation/recreational expenses
  - Childcare
- Addressing social isolation can occur through ways such as:
  - Relationship counseling
  - Conflict resolution/ assertive communication skill training
  - Connecting parents with others in similar situations

- Preventively-oriented care in the event of a potential crisis requires providing:
  - Support for people, even if they "appear well"
  - Help developing a pre-crisis plan or advance planning agreement

***Note: the following are extra points that can be made if time permits:***

- The ability to parent may also be affected by a number of individually based factors having to do with either the parent or offspring (for example, a mismatch in temperament between the parent and the child, learning or behavioral problems with the children, health problems of the children, etc.) so support plans must consider these more "fine grained" issues.
- Parents also need help understanding the mental health needs of their children which relate to their own illness (e.g. help dealing with the disruption or trauma of being separated from a parent, help dealing with worry over the possibility of developing an illness themselves, etc.). Parents also need help distinguishing "normal" developmental needs or issues with the needs that are more specific to being an offspring of a parent with mental illness.

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Reducing Stigma About Mental Illness In Transcultural Settings: A Guide. Phase One Report. A project funded by the Commonwealth Department of Health and Family Services, Mental Health Branch, and the Australian Transcultural Mental Health Network, University of Melbourne.

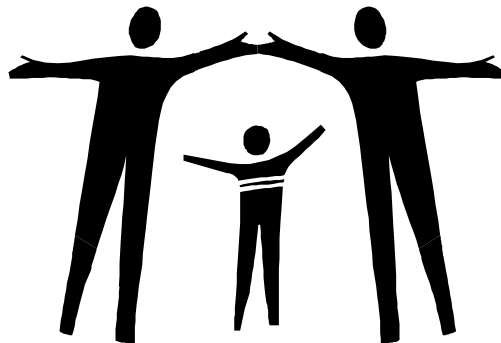
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# Experiences of Children Whose Parent(s) Have a Mental Illness

Section Three: 11:00 am – 12:15 pm



By: Lyne Brindamour, MSW  
and  
Hylde Gryba, RN, BN, MA (Candidate)

# Experiences of Children Whose Parent(s) Have a Mental Illness

## Section Three: 11:00 am – 12:15 pm

This section was prepared by Lyne Brindamour, MSW

and

Hylda Gryba, RN, BN, MA (Candidate)

<b>PURPOSE</b>	<b>LEARNING OBJECTIVE</b>	<b>MATERIALS</b>
In this section, the goal is to focus on the children and their experiences.	Participants will come to a better understanding of what children experience when their parent(s) have a mental illness. This will be done through small group work and discussion.	<ul style="list-style-type: none"><li>• Stickers for the nametags</li><li>• Dollar store trinkets</li><li>• Overheads and handouts</li><li>• Overhead projector and screen</li><li>• Overhead pen</li></ul>

### INTRODUCTION

Growing up in a home where there is parental mental illness affects children in many profound and various ways. The dynamics of any given family, illness presentation, and individual children's temperament and personality will undoubtedly result in unique and individual experiences for any particular child. The resiliency and strength of children who grow up experiencing parental mental illness should never be underestimated. The purpose of this presentation, however, is to raise our awareness of the challenges and risks that are faced by this population. In the process of recognizing the risks and pitfalls, we can hopefully have a positive impact on the lifetime outcome.

We have already noted that no two persons will have exactly the same experience, however, there are also many similarities. In reading the literature and hearing the firsthand stories of adult offspring, several themes emerge. The most often mentioned and felt is that of stigma, shame and embarrassment. The National Institute of Mental Health reports Americans fear leprosy and mental illness as the two worst things that



can happen to them, and that persons who have committed crimes and have served time in prison are more readily accepted in society than a person who has a mental illness (Henderson, 1994). One crucial message that we must deliver is the importance of making every effort to help reduce the stigma of mental illness.

Other themes, which permeate the lives of adult offspring, are that of continual unresolved losses, i.e. the loss of a healthy parent, a stable home, typical childhood experiences, etc. More so, the losses are ongoing as the parent continues to live and be a part of the child/adult child's life. Feelings of hopelessness and helplessness are often themes for these offspring as a result. Important as well, are the feelings of being different, loneliness, rejection, and at times, intense pain and anger.

There are other issues which many times accompany the circumstance of having a parent with a mental illness, and although they are experienced by others where there is no mental illness, for these families it can only compound the family burden. Such things as poverty, family conflict and violence, drug and alcohol abuse, divorce, etc. are all too often part of the experience of children growing up in a home where a parent has a mental illness.

The impact of mental illness on families may be compounded for cultural and ethnic minorities. Immigrant families, refugee families, aboriginal families and families of colour will all experience additional challenges which may increase their vulnerability and will add significantly to the difficulties they face.

The special issues of vulnerability of the children need to be addressed as well. Physical health and safety may be at risk, due to the effects of the illness as well as to other issues such as poverty, lifestyle and drug and alcohol abuse. There is also the possibility of increased vulnerability of biological risk for developing a mental illness themselves.

**It really isn't that much of a problem, is it?**

Dr. Diane Marsh (1998) reports that for children of parents with a mental illness, there is a 10 to 16 times greater chance of developing a mental illness than the general population. Finally, there is the risk of psychological maladjustment for children living within these circumstances. Dr. Marsh also reports that over a lifetime, as high as 50% of children whose parent has a mental illness may experience some form of psychological difficulty. Particularly high is the possibility for development of depression at some point throughout the life span.

For a closer look at the experience of children and how the illness of a parent can impact their lives, we have taken a developmental perspective. We attempt to point out what a child's experience may be and what could be the risks and barriers to healthy development. Again, it is important to mention that resiliency and protective factors in a child's life are not discounted, and there is commitment to recognizing and applauding the families and individuals who have successfully met the challenges they were faced with. Our purpose is not to paint a dismal picture, but rather to increase hope by raising our collective awareness so as to provide greater opportunity for all families to successfully navigate the course of mental illness.

Adult research (Marsh, 1998) indicates that 20-30% of adults will suffer an episode of mental illness. Estimates suggest that by age 20, a child of a parent with an affective disorder has a 40% chance of experiencing an episode of depression and by age 25 this rate increases to 60%. Dr. Marsh suggests that the most consistent finding or result of parental mental illness, not specific to any particular diagnosis, is a presentation in children of major depressive disorder and conduct disorder.

In a study (Beardslee, Keller, Lavori, Klerman, Dorer, Samuelson, 1988) where 81 families were randomly recruited, without knowledge of psychiatric history, 49 of these families were identified as having affective disorder in one or both parents. At initial assessment, 30% of the children of a parent with an affective disorder met the criteria for an episode of affective illness, compared to only 2% in the rest of the sample. At the four-year reassessment, along with continued higher rates of affective disorders,

children of a parent with an affective disorder experienced earlier onset, longer duration, and greater number of co-morbid diagnosis than other children in the study. Only 39% of children with childhood depression received treatment, and interestingly, only half of the adults who met criteria for major depression during the four-year study reported receiving treatment.

To summarize, we need to be aware that mental illness is neither rare nor isolated, but is actually very prevalent and it impacts the lives of a large number of the children with whom we interact every day. Epidemiological studies vary in prevalence rates, however, it is generally understood that the rates of serious mental illness range between 5% to 10% of the adult population. Eighty percent (80%) of adults will have children, and people with mental illness parent at the same rate as other adults. Therefore, one might surmise that the number of children growing up in homes with parents who have a serious or persistent mental illness would be 4% to 8%.

It is important for sensitive, caring adults to reach out to children and not wait for children to make the first move.

The challenge of this presentation is for each person here to personalize this information. How many children do you interact or work with? How many might be dealing with a parent who has affective illness or any other mental illness? How many of the children that you interact with are experiencing difficulties in various domains (home, school, peers, etc.)? Could it be that a large number of the children's difficulties are related to the presence and challenges of parental mental illness?

We now want to have everyone here talk about the impact of parental mental illness on children at all stages from 0-19 years. Our focus is to explore the different experiences of children living in families where there is mental illness. We want your input and response in order for all of us to better understand the impact of parental mental illness on children.

## MAIN PART OF THE PRESENTATION

### Group Work

On each nametag there will be one of six stickers. At the beginning of this presentation, people will find others with the same sticker on their nametag and join in their group of 4-6 people. This is an opportunity for participants to meet other people from different agencies and organizations. There must be six groups to correspond with the six stages of development (Overhead C-1), and the number in each group will depend on attendance. For example, if there are thirty participants, you will need five of each sticker.

STAGES OF DEVELOPMENT:	
1.	Infants (0-8 months)
2.	Toddlers (9 months - 2 years)
3.	Pre-schoolers (3-5 years)
4.	Middle Childhood (6-12 years)
5.	Early Adolescence (13-15 years)
6.	Late Adolescence (16-19 years)

Each group will focus on one stage of development. Please brainstorm what you think the **impact of the parent's mental illness** will be on the child. This is the scenario that you will discuss (Overhead C-2):

*Josie is a single mother who is suffering from a Major Depression. She has been stabilized through medication for the last three months. She has been hospitalized at least once each year.*

Please nominate a recorder in your small group and someone to present your ideas to the whole group. Hand out pens and paper for recording ideas.

#### Helpful Hint

Encouraging participants to do this without looking at their handout will improve the quality of the discussion. People will brainstorm their own experience instead of regurgitating printed material.

## **Group Discussion**

Groups will discuss for 10 minutes, then each group will be directed to refer to their handouts for further information. The overheads for this section (Overheads C-3 – C-8) are identical to the handouts. There is space on the sheets in the handouts/overheads for the trainer and the participants to make notes. Please refer to the section on “Background Information” for more information about the overheads.

Based on research and literature, the major tasks for each stage as well as the impact of parental mental illness on children were put onto an overhead, one for each stage of development. The Community Trainer reads through the information on each overhead and asks the groups, one at a time, to add anything new that they discussed.

Community Trainers will write the new ideas on the overhead. All groups can follow along on handout. As an option, to add some fun, each group could receive a bag full of dollar store trinkets for coming up with an idea not on the overhead, to reward their effort and involvement in this part of the day.

We have also included notes for the trainer in the Background Information Section. These notes correspond to each point on the overheads and give more information on each point. This is to provide background information on each point if there are questions. In this project it was not possible to include an elaborate research component about the developmental tasks of children due to space constraints. The authors, at their discretion, chose what they believe was the most relevant information. Please do not hesitate to revise for your own presentation.

## **Closure**

We would like to thank everyone for your input. We are now breaking for lunch and will meet back again at 1:00 p.m. After lunch we will talk about some of the legacies of parental mental illness followed by a video.

**STAGES OF DEVELOPMENT:**

1. Infants (0-8 months)
2. Toddlers (9 months - 2 years)
3. Pre-schoolers (3-5 years)
4. Middle Childhood (6-12 years)
5. Early Adolescence (13-15 years)
6. Late Adolescence (16-19 years)

Overhead C-2

- Josie is a single mother who is suffering from a Major Depression.
- She has been stabilized through medication for the last 3 months.
- She has been hospitalized at least once each year.

**Developmental Tasks of the Infant  
(0-8 months)**

- The infant learns **basic trust** to prepare him/her for all future relationships.
- Connection and **attachment** play a crucial role in the development of the “self.”



## **Impact of Parental Mental Illness on the Infant (0-8 months)**

### **Children may:**

1. Not receive necessary attention, may be neglected physically and/or emotionally, may experience tension or anxiety or have accidents due to caregiver distractibility.
2. Have deficits in stimulation (caregivers may miss cues).  
Excessive stimulation may occur during manic phase.
3. Show a lack of response (eye contact and connection). The child may develop more slowly cognitively.
4. Experience separation trauma (in relation to hospitalization, etc.).
5. Bond to a sibling, as extended family and community are more involved, a possible benefit.

### **Caregivers may:**

6. Give less time for care giving, may end breastfeeding due to medication.
7. Misread cues (crying due to hunger, boredom, etc.).
8. Lack consistency in routine.
9. Not know or recognize the health needs of the child.
10. Neglect their own physical and emotional needs and, as a result, may be hospitalized and place extra stresses on the family.

**Developmental Tasks of the Toddler  
(9 months - 2 years)**

- **More awareness of the consequences of behaviour.**
- **Beginning of self-confidence.**
- **Time for exploration.**
- **The toddler begins to use symbols (images, words, or actions that stand for something else).**
- **Socialization and language development begin.**

## **Impact of Parental Mental Illness on the Toddler (9 months-2 years)**

- Previous tasks apply

### **Children may:**

1. Experience general neglect as emotional and/or physical needs (hygiene) may not be met.
2. Feel the impact of poverty.
3. Be very adaptable to various situations.
4. Not be aware of social stigma at this stage.

### **Caregivers may:**

5. Experience generalized stress and be inconsistent at setting appropriate limits.
6. Provide inadequate structure and safety required for learning new behaviours (toilet training).
7. Not meet child's special needs (caregiver may not have emotional and/or physical energy/stamina).
8. Not explain hospitalization to the child.
9. Model some inappropriate behaviours (e.g. washing hands repeatedly).
10. Exert either too much or too little control, not allowing for exploring, curiosity or risk taking.

**Developmental Tasks of the Pre-schoolers  
(3-5 years)**

- **Autonomy and mastery.**
- **Socialization begins.**
- **Protection of the child at this stage is important.**
- **The need for safety to explore the environment.**

## **Impact of Parental Mental Illness on Pre-schoolers (3 - 5 years)**

- Previous tasks apply.

### **Children may:**

1. Feel shame and self-doubt if experimentation and exploration attempts are restricted; begin to be aware of social stigma; be confused about reality, theirs versus their caregiver's.
2. Have difficulty with trust and confidence if caregiver's world is one of mistrust, anxiety or paranoia.
3. Not experience complete safety at home (be prone to accidents, have fear of new experiences).
4. Compensate for caregivers who may be under involved – (exaggerated mastery or lost confidence and withdrawal).
5. Lack autonomy due to limited assistance from their caregiver throughout their lives (due to hospitalization).
6. Have unclear boundaries resulting from caregivers being strict one day and over permissive the next. They may not master new skills because of lack of consistent practice (loss of ability, delayed shutdown or exaggerated mastery when caring for the caregiver).
7. Have an unpredictable daily life. Caregiver may not always meet expectations in terms of lunches, field trips, duties, carpool, etc.
8. Have difficulty with socialization, exploration and interaction with outside world.

### **Caregiver may:**

9. Not like change and may not have the flexibility to vary routine in order to meet child's need for growth.
10. Have disorganized life style (frequent moves) especially if the caregiver's management skills and financial resources are limited.

**Developmental Tasks of Middle Childhood  
(6 - 12 years)**

- **Emotional development**
- **Development of concrete operational thought**
- **Educational adjustment**
- **Children become less dependent**
- **Increased association with friends**
- **Development of a sense of competence and importance**
- **Onset of puberty**

## **Impact of Parental Mental Illness on Middle Childhood (6 – 12 years)**

- Previous tasks apply

### **Children may:**

1. Experience loss or disorganization at onset of illness or at hospitalization.
2. Become resilient.
3. Experience anxiety due to chaos and lack of structure and may be afraid to leave caregiver alone.
4. Feel anger toward caregiver for not fulfilling caregiver role, not providing what other caregiver provide.
5. Be vulnerable to stories of fear due to literal and concrete thinking.
6. Have their worldviews impacted by illness (Obsessive-Compulsive Disorder, Delusions).
7. Compete with ill parent for attention to get their needs met.
8. Be accustomed to hostility, violence and verbal abuse in the home.
9. Be emotionally neglected which impacts all aspects of functioning, (skills, learning relations with peers and teachers); develop depression; not experiment with their abilities, be afraid to take risks.
10. Have process of individuation interrupted.

11. Have overdeveloped capabilities in care giving but lack emotional capability.
12. Internalize, become over-achievers, attempt to maintain order.
13. Use coercion (of caregiver or others to get needs met).
14. Continue to have safety issues.
15. Have behavioural problems and substance abuse issues.
16. Feel the need to belong (may feel alone and/or different).
17. Now be aware of a stigma of mental illness (shame, fear, guilt); may be reluctant to bring friends home.
18. Have difficulty trusting outsiders.
19. Feel isolated, or have limited resources, which prevents them from joining social and group activities (clubs, sports, etc).
20. Be under socialized, not aware of social expectations.
21. Straddle two worlds, two sets of rules, inside vs. outside home.
22. Learn and be more aware of normal/abnormal behaviours.
23. Have educational risks, too much or too little involvement.
24. Have difficulty concentrating due to chaos at home and may be seen as disruptive or having behaviour problems.



**Developmental Tasks of the Early Adolescent  
(12 - 15 years)**

- Accepting one's physique and using the body effectively.
- Achieve new and more mature relations with age-mates of both sexes. Peer groups are becoming very important.
- Achieve emotional independence from caregivers, other adults.
- Desiring and achieving socially responsible behaviour.

## **Impact of Parental Mental Illness on Early Adolescence (12 - 15 years)**

- Previous tasks apply

### **Adolescents may:**

1. Live with secrecy and shame, be and/or feel reviled. This affects trust, spontaneity, and ability to feel pleasure.
2. Live with pain and anger. Have underlying anger at injustices. Experience unresolved loss of a “normal” caregiver.
3. Be at-risk for peer pressure and/or feel the need to belong. Have no involvement with peers due to embarrassment at caregiver’s condition.
4. Be confused in regards to relationship with ill caregiver. Experience possible dependence of caregiver on child (caregiver not able to let go) or child feels concern, fear and responsible for caregiver (child unwilling to let go). Grow up too fast – may be more mature than age-mates and have difficulty relating to them.

5. Be particularly sensitive due to hormonal and bodily changes. May experience decreased energy or demonstrate eating disorders.
6. Have poor body image and make poor health decisions, e.g., little exercise or sleep, poor nutrition.
7. Be at-risk for being unable to recognize and meet own needs. Low self-esteem.
8. Have difficulties due to poverty, limited opportunities.
9. Feel different, alone, and/or rejected. Feel distanced from caregiver and express it by running away, acting out, or engaging in substance abuse.
10. Live with intense emotion, emotional self-regulation affected. Walk on eggshells around caregiver. Have difficulties at school, may be busy taking care of things at home. Conversely, do very well at school, able to keep order in their lives. Have difficulties with relationships and establishing boundaries.
11. Not demonstrate socially responsible behaviour.

**Developmental Tasks of the Late Adolescent  
(15 - 19 years)**

- Achieving emotional independence from caregivers and other adults.
- Preparing for an economic career.
- Preparing for significant intimate relationship and family life.
- Achieving masculine and feminine sex roles (i.e. individual sexual identity and orientation).

## **Impact of Parental Mental Illness on Later Adolescence (15 – 19 years)**

### **Children may:**

1. Find emotional independence difficult.
2. Have feelings of ambivalence. Be unable to balance self-care and care of others. Have a care-taking role, feel a need to remain at home to be a support.
3. Have limited choices due to poverty, illness, housing, privacy, lifestyle, etc. Find career choices are affected by self-confidence, resources, mentors, etc.
4. Be overwhelmed by responsibility. Have difficulty with completion and follow-through due to history of stability/breakdown cycle.
5. Have limited attachment and trust which impacts the development of relationships. Not develop healthy interactions due to caregiver's style of social interaction (extreme anger, overly suspicious). Have difficulty forming personal friendships and/or romantic relationships due to inexperience in forming and maintaining healthy relationships.
6. Have a predisposition due to genetics and environmental exposure. Fear of developing the illness as hormones begin to surge.

## BACKGROUND INFORMATION for OVERHEAD C-3a

### Development Tasks of the Infant (0-8 months)

#### Attachment/basic trust

When we talk about attachment, we are looking at the warmth and affection that a caregiver shares with his/her infant. By this, we mean the quality of their relationship. A secure attachment is fostered by a caregiver who demonstrates emotional warmth and support; responds quickly when the infant shows some distress; and provides moderate and appropriate stimulation (Levy & Orlans, 1998). In this stage, the child develops a story about him/herself based on everyday life experiences. The following questions are answered by what the child encounters in his/her relationship with his/her caregiver:

**Is this world safe?**

**Is it a secure place?**

**If I cry, will someone come?**

Children explore their environment and as a result learn to respond to the caregiver (Bee, 1998; Bee, 2000). At this stage, all children's needs are completely dependent on the caregiver. These needs include bodily contact, diapers changed, physical comfort, food for growth, etc. A sensitive and affectionate caregiver responds to the child's needs and in return the infant relaxes and is able to become restful and untroubled (Levy & Orlans, 1998).

The infant comes to trust that a caregiver will be available when needed and present if there is a perception of danger and/or distress (Svanberg, 1998). When the child is hungry and cries and the caregiver responds, the infant learns about personal power, that he/she can make a difference in his/her world. This early learning prepares children for what may happen and how to act in future relationships (Bee, 1998; Bee, 2000). If the infant is well cared for physically and emotionally, it is easier for him/her to be confident that others around him/her will be available to meet his/her needs. When

secure attachment exists, the infant is well prepared not only for future relationships but is better equipped when facing difficult life situations and crises (Fonagy & Target, 1997; Rutter, 1995). This early secure environment prepares the child to be better able to face stressful situations with confidence.

### **Connection and Attachment: A Crucial Role in the Development of the “Self”**

While bonding occurs and the relationship continues to develop, the infant develops a sense of a “self.” This is the time that the infant begins to learn about separation from the caregiver. According to Bee (1998), the infant first experiences what is called the “subjective” self where he or she finds out that he/she is separated from others. The second stage, which extends into the toddler years, is the discovery of an “I” as a separate identity. This is called the “objective” self. The infant learns that he/she is different and has his/her own gender, colour, name, unique qualities, particular size, etc. It is also a stage of development where we see the unfolding of healthy emotional expressions such as sadness, anger, etc. (Bee, 1998; Bee, 2000). The infant stage is when the child goes from complete dependence on the caregiver to slowly becoming a separate entity. This development is continued in the next stage.

## **BACKGROUND INFORMATION for OVERHEAD C-3b**

### **Impact on the Infant (0-8 months)**

#### **Children may:**

1. If the infant experiences emotional neglect, he/she may develop negative expectations and a belief that his/her needs are not going to be met. This may lead to the infant eventually shutting down and he/she may stop trying to solicit a response from the caregiver (Levy & Orlans, 1998). The infant may fail to thrive and have a lack of trust. The caregiver(s) may think they have an easy baby and fail to interact enough with the infant. In reality, the child may be withdrawn and lethargic.

Accidents are high (Hill, 1996). The caregiver may be distracted and/or inattentive due to symptoms of the illness, i.e., lethargy if depressed, too many worries, etc. (Cohler, Musick & Stott, 1996). The infant may be unintentionally left in dangerous locations. For example, the infant may be ready developmentally to roll and could roll off a countertop while a diaper is being changed. The caregiver may not have paid attention to this new stage of development.

The needs of the infant may conflict with the needs of the caregiver (Hill, 1996). People who are ill may be self-absorbed and may have a hard time paying attention to the infant. The need for cigarettes may come before feeding and/or comforting the child.

The infant may experience tension and anxiety because of the caregiver's emotional affect (Radhe-Yarrow, 1991). The infant at this stage can be acutely sensitive to his/her caregivers' emotional experiences.

2. Sometimes a caregiver with a mental illness is less responsive to the infant's cues and may be less apt to stimulate them. As a result, the child may experience developmental delays (Rubovits, 1996; Seeman, 1996). During a manic phase, the caregiver may be excessively stimulating the child.

“A client with a mental illness had irregular sleeping patterns. She was active and busy during the night and slept more during the day. She had an eight-month-old child. When the child woke up at three o'clock in the morning, she would happily feed him, play with him and sing to him. She continued to stimulate him during the day which meant that the child was active both day and night.”

- Lyne Brindamour, Family Therapist

3. A lack of response disconnects the infant from the caregiver, i.e., limited eye contact or limited touch (Hill, 1996). As indicated by Eliot (1999), touching between caregiver and infant is essential for cognitive development. Without enough interaction, the infant



may develop more slowly cognitively. The infant may be deprived of the beneficial exchange that can happen between caregiver and infant through “babbling.”

4. The infant may experience abandonment and separation issues if relapse occurs (Hall, 1996). Supporting the infant to attach to other caregivers during times of health may cause less trauma for the infant when a crisis and/or separation occurs. Extended family members, and/or consistent supportive friends and/or a consistent foster family for respite care may be less distressing for the infant. Infants enjoy familiarity and are less likely to experience acute stress if they are at ease in their surroundings.

5. Infants may bond to a sibling. There may be nothing wrong with this; in fact, it may be a positive alliance. Similarly, extended family and community involvement may benefit the infant, as their world is no longer so isolated.

**Caregivers may:**

6. The attention and support may not always be provided due to special needs of the caregiver (Cohler, et al, 1996), i.e., side effects of the medications such as nausea, constipation, diarrhea, and insomnia. Caregivers may be busy looking after their own physical needs, which may require a great deal of time and energy.

7. Due to the side effects of medication or the illness itself, such as a slow response and the loss of ability to think clearly (Hill, 1996), the caregiver may not be aware of the cues when the infant is crying, i.e., hunger, tiredness, boredom, etc. Not only thought processes may be affected but speech as well (Rubovits, 1996). The caregiver may have difficulties expressing what they want from the infant. This can be confusing not only to the infant but also to children in all age groups.

8. Appropriate responses to the infant help the infant to regulate herself/himself and provide the infant with a structure, i.e., a regular sleeping pattern shows the infant that the world around her/him is safe and secure (Levy, et al, 1998; Kohler, et al, 1996; Seeman, 1996). Infants seem to thrive in a predictable, non-chaotic environment. Routine in the home has been encouraged by most parenting courses in our culture.

9. If the caregiver is quite distracted with his/her own medical and physical needs, the health needs of the child may be unknown or unrecognized. For example, slow cognitive development may go undetected, physical illness may go unrecognized, etc.

10. Alternatively, people who are ill may place priority on their children's needs instead of their own. A caregiver's own physical and emotional needs may be neglected. They may decide not to go to the hospital or take medication. Their child comes first before their own well-being (Nicholson, Sweeney & Geller, 1998). This may have devastating consequences for the caregiver and the whole family, i.e. hospitalization, extra stresses on the family.

### **BACKGROUND INFORMATION for OVERHEAD C-4a**

#### **Stages of Development of the Toddler (9 months - 2 years)**

##### **Awareness of consequences of behaviour**

At this stage children are beginning to picture a certain response even before they act a particular way (Vernon, 1995). The toddler can anticipate that depending on his/her actions, the caregiver response will vary.

If I touch this plant mom will say, "no!"

##### **Beginning of self confidence**

At this stage, the toddler is developing new skills:

I can talk!  
I can feed myself!  
I can walk!  
I can start to dress myself!  
No I won't!

As the toddler succeeds in these activities, his/her confidence increases (Dinkmeyer, 1997). It is also at this stage that the toddler asserts him/herself. According to Vernon (1995), by saying “no” it is the child’s way of separating from the caregiver and building self-competence, a stage very similar to the teenage stage. At this stage, children are egocentric and only think about themselves. Routine and life around them is only understood from their point of view.

### **Time for exploration:**

The toddler alternates between wanting independence and being dependent on the caregiver. They explore new activities such as block building, emptying containers, and playing in sand and water. The toddler puts things into his/her mouth and engages in what is called “sensorimotor play” (Bee, 1998; Bee, 2000). Toddlers are curious about their environment and understand the world through touch. By the age of two they begin to build things and are involved in “constructive play.” This is a time when children want to assert themselves as being separate from their caregiver (Vernon, 1995). Although they are starting to build independence, children at this age want to have close physical proximity to their caregiver as they play. It is a stage that requires patience and some assertive skills on the part of the caregiver.

### **The toddler begins to use symbols**

The toddler is now engaging in pretending play (Bee, 1998; Bee, 2000). All objects can be used to pretend to be something else. A Lego piece becomes a car, a block is transformed into a truck, and a scrap of cloth becomes a royal garment.

### **Socialization and language development begin**

At this stage, play is becoming part of the toddler’s life. It is mostly solitary play and/or parallel play. The interaction between peers is limited. Usually the conversation is one way without any considerable dialogue (Vernon, 1998).

“I’m visiting Grandma today,” said Sally as she played with Mary one afternoon.

“Look, I have a cut on my leg,” said Mary.

Sally replied, “I like bubble gum ice cream.”

“I have a cat named Madeline,” commented Mary.

The toddler also uses emotional cues from the caregiver to know how to react (Bee, 1998), (Bee, 2000). If the child is in an unfamiliar situation, they will often look at his/her caregiver's expression before showing his/her own expression of emotions.

### **BACKGROUND INFORMATION for OVERHEAD C-4b**

#### **Impact on the Toddler (9 months – 3 years)**

##### **Children may:**

1. Caregivers may not notice that their children's physical needs are not being met. These children may appear unwashed and disheveled. Caregivers may be physically present but emotionally absent (Secunda, 1997) which may cause hopelessness and despair in the child. A healthy emotional connection is based on a relationship where the caregiver is committed and present in every sense with the child.
2. Many children in families where there is mental illness experience poverty. Many activities and experiences that other children attend regularly are not an option for these children, thus they miss out on many childhood events and opportunities.
3. Resilient children learn to adapt to new situations and learn how to "fit in," even though their home lives may be chaotic.
4. Although social stigma can be very stressful for children, at this stage the children are not aware of the differences between caregiver(s).

##### **Caregivers may:**

5. The caregiver's abilities to handle the child's noise and/or distress behaviours may be limited (Hall, 1996). If the caregiver has limited tolerance of noise and distraction and little patience to meet the high demands of the toddler, it can be a very difficult period for the caregiver.

The management of age appropriate active behaviours may be overwhelming for the caregiver (Nicholson, et al, 1998; Hall, 1996). Symptoms of the illness may make it stressful to handle the child at this stage of development. For example a caregiver with Obsessive Compulsive Disorder may find that the child eating with her/his hands and creating a mess is very distressing.

The period when a toddler says “no” may be particularly difficult for a caregiver (Hall, 1996). The caregiver may want to appease the child instead of setting limits. For example, the child may be given rewards such as candies as soon as the child shows any distress or makes any demands.

Having a caregiver with a mental illness may be very stressful due to possible family tension, inappropriate communication, ineffective problem resolution and increased possibility of relapse (Miklowitz & Goldstein, 1997).

6. If a caregiver has difficulties with handling their own disorder, this developmental stage may be especially challenging (Nicholson, et al, 1998). Toilet training may be difficult because of the demands for consistency and structure.

7. The caregiver may lack stamina and/or energy to access and follow through with recommended therapeutic services for the child (art therapy, play therapy, special day care) when the child displays serious emotional or behavioural disorders. Adding more commitment to a caregiver who may already be overwhelmed requires energy that is nonexistent, which may lead to what is seen as resistance.

8. Life events such as hospitalization or separation may not be explained to the child resulting in the experience of abandonment, mistrust or confusion.

9. Due to certain mental illnesses such as Obsessive Compulsive Disorder, some children may learn inappropriate behaviours that would seem appropriate to them. The child may wash their hands repeatedly, they may stare for hours at the TV screen, they may pace between rooms, etc. (Secunda, 1997).

**A family may see it as normal behaviour to live in the dark with the curtains drawn, even in the middle of the summer.**

10. Due to the symptoms of the illness, the caregiver may perceive some behaviours as malicious and disruptive instead of normal and age appropriate (Hall, 1996), (Nicholson, et al, 1998; Pound, 1996). The child who does not follow the limits set by a caregiver due to experimentation with the world may be labeled as defiant.

## **BACKGROUND INFORMATION for OVERHEAD C-5a**

### **Stages of Development of the Preschoolers (3-5 years)**

#### **Autonomy/mastery**

At this stage, the child tries to do many things alone and can be separated from his/her caregiver for an extended period without being in a distressed state (Vernon & Al-Mabuk, 1995). The preschooler is curious, active and continues to explore his/her environment without as much adult supervision.

The child is able to recognize different emotions due to his/her expanded vocabulary. The child is also able to link different emotions with specific situations. He/she is now ready to regulate his/her own emotions (Bee, 1998; Bee, 2000). According to Vernon (1995), pre-schoolers start to understand their own feelings as well as the feelings of others. The child will know when sadness occurs and can associate the reasons for displaying particular emotions. They are also more able to be in control of their emotions and watch others as role models for how they handle their emotions. They are able to learn vicariously about controlling emotions such as anger, an emotion crucial in developing autonomy. Fear and anxiety are also present in the child's life.

At this stage fear is the result of the inability to differentiate between fantasy and reality (Vernon, 1995). Irrational fear in pre-schoolers is often non-specific and is not necessarily directed at any particular objects, events or situations.

#### **Socialization**

The pre-schooler begins to try new roles and play at being other people such as a doctor, a teacher or a truck driver. They are still at the pretending stage but are now able to include other children in their play. Bee (1998) called this "sociodramatic play." The pre-schooler may also develop "imaginary friends" at this stage (Bee, 1998; Bee, 2000). As a result of pretending to be somebody else and playing different roles, the child learns and increases his/her ability to look outside himself/herself and becomes less egocentric (Bee, 1998; Bee, 2000). Because preschoolers are less egocentric, they are more able to look outside themselves and look at other people's feelings. This kind of play encourages the child's cognitive development. He/she begins to

understand that others have feelings too (Vernon, 1995), an awareness that helps develop social competence and supports the child in developing healthy relationships.

## **Protection**

Due to the amount of energy children have at this stage and the increased involvement in activities, protecting pre-schoolers from potential hazards in and outside of the home is crucial to protect the pre-schoolers from being hurt. (Vernon, 1995).

<b>Potential Hazards</b>
<ul style="list-style-type: none"><li>• Poison</li><li>• Traffic</li><li>• Interference from Inappropriate Adults</li><li>• Dangerous Objects</li></ul>

## **Self-control**

Pre-schoolers are able to adapt to following directions from others. They are now more able to behave in socially appropriate ways (Vernon, 1995). The caregiver plays a crucial role in supporting a child to understand and know when behaviour is appropriate or not. The child's ability to self-regulate and make good choices is dependent on the caregiver's skill at setting limits and providing guidance in allowing the child to choose acceptable behaviours.

## BACKGROUND INFORMATION for OVERHEAD C-5b

### Impact on Preschoolers (3-5 years)

#### Children may:

1. The child may learn to feel shame and doubt. Shame may result in feelings of self-consciousness, dependence, worthlessness and incompetence. Self doubt may result when the caregiver consistently restricts the child's attempts to experiment, explore, and gain mastery over her/his environment. If a caregiver is paranoid, it may affect the child's ability to trust in her/his judgements (Levy & Orlans, 1998).
2. When a caregiver has fears of going out and being part of the community, the child may not be encouraged to explore and investigate the world around her/him (Seeman & Cohen, 1998). The child may start to see the world as an unsafe place.
3. The caregiver may need to teach the child about safety and explain why the child cannot play with certain objects or why some locations (middle of the street) are unsafe.
4. If the caregiver is depressed and lethargic, the child may need to take care of her/himself.
5. Children may lack the autonomy to explore their environment when they lack caregiver assistance, sometimes due to the caregiver's hospitalization. At this stage, the child needs guidance and support to try new activities such as riding a bike and swimming.
6. Limits are not always set because of the emotional and/or physical needs of the caregiver. The caregiver may have difficulty knowing the difference between symptoms of their illness and what are the normal child's behaviours (Nicholson, et al, 1998). For example, a caregiver may think, "Is it my paranoia, or is my child withdrawn and sulky?"
7. Because the child's world may be unpredictable, the home may be unstructured and the child may feel a lack of control in his/her environment. Caregivers may be rigid one day and permissive the next day (Pound, 1996).
8. As a result of possible lack of interaction with preschool teachers and daycare supervisors, these people may not understand the child's difficulties.



**Caregivers may:**

9. The caregiver may like familiarity and a rigid routine in the home and may not be able to be flexible.

10. Disorganization of the caregiver and the inability to ask for support may result in the family having to move often because of unpaid bills.

A client's apartment was becoming increasingly in a state of disrepair. The toilet was overflowing, the stove did not work, and the water taps constantly dripped. Instead of asking the landlord to do the necessary repairs, the family decided to move.

**BACKGROUND INFORMATION for OVERHEAD C-6a**

**Stages of Development of Middle Childhood (6-12 years)**

This stage is a transition between pre-school and middle childhood. The child begins to understand more complex ideas, and their ways of thinking are changing and becoming more structured. Their understanding of emotions is also changing. They are experiencing more complex emotions. At this stage, the child may now be aware that their caregiver has different behaviours than other caregivers, behaviours that are unusual. Because these behaviours are noticed by others and possibly commented on, children may not want to have people over to visit.

## Emotional development

In middle childhood, the child develops more complex emotions such as shame, guilt, and pride. They realize that they are able to have more than one emotion at the same time (Vernon, 1995). In a way, the child starts to self-reflect more on how he/she is feeling and begins to find new methods of expressing a wider range of emotions. The child is more able to recognize and respond to his/her own feelings (Vernon, 1995). School phobia sometimes occurs. In early elementary school, the child would rather be at home than at school. In later years, the child stays home because of unpleasant experiences and/or difficulties in school or at home (Vernon, 1995). It is a complex task for the caregiver to determine appropriate responses to the child's desire to stay home.

### Early Elementary Student

Caregiver's Response:

"I'm sorry but you have no choice. You need to go to school."

### Student in an Older Grade

Caregiver's Response:

"Tell me about what happened at home or at school that makes you want to stay home."

## Concrete operational thought

According to Vernon (1995), the thinking process begins to become more logical and the child starts to realize the importance of rules and regulations. The child now develops his/her own values and beliefs about his/her surroundings. At this stage, the child is a concrete thinker so he often sees things literally. For example, if the teacher gives a child a disapproving look, the child may believe that the teacher dislikes him/her. The child may not consider other possibilities in certain situations and his/her perception of events may be limited. This concrete way of thinking results in fears being more specific and being overly sensitive to their environment (afraid of being alone in the home, talking in front of the class).

## **Educational adjustment**

In middle childhood, the child learns academic skills such as reading, writing, spelling, subtracting, and telling time (Vernon, 1995). Kindergarten and Grade One represent a major change in expectations and many more demands are placed upon the child (Bee, 1998; Bee, 2000). In our culture, the school experience is directly connected to the advance of cognitive skills and the ability to think (Bee, 1998; Bee, 2000). Learning to read is not the only significant task that the child is going to learn in school; fitting and adapting socially to the school is also important. The caregiver's involvement in the child's school life is related to children attending school longer and not dropping out of school (Bee, 1998; Bee, 2000).

### **Care-giver Tasks in School**

- Report card conferences
- Homework supervision
- Fieldtrip driving
- Baking for fund-raising
- Attending school concerts
- Volunteering for hot dog days
- Returning signed permission slips

The temperament and personality of the child has an impact on his/her interactions with teachers and peers. If the child "fits" in the school system (Bee, 1998; Bee, 2000), he/she is more likely to succeed. It may be that the teachers also have an impact on the success of the child in school. Children at this stage still need a lot of encouragement and being approved of by adults is important.

## **Independence**

Although peers are very important, caregivers and teachers are also very significant in the child's life. The child is learning about their caregiver's attitudes and why the caregivers make certain rules in the home (Vernon, 1995). The teachers are also crucial in teaching acceptable social behaviours and helping in developing healthy attitudes toward authority, school and society (Vernon, 1995).

### **Association with friends**

It is at this stage that the child learns to socialize through managing all the complex issues associated with the socialization process, i.e., collaboration, conflict resolution, and reconciliation. Peer relationships and having individual preferences for friends becomes more common at this stage (Bee, 1998; Bee, 2000). Friendship is viewed as an exchange between two people where generosity and trust are important elements (Bee, 1998; Bee, 2000). The ability to associate with friends is a gradual process during the elementary years that improves over time.

### **Development of a sense of competence and importance**

The child in middle childhood tries new activities such as riding a bike to the grocery store. According to Vernon (1995), the child enters a new world where there are new tasks to be learned. As the child becomes more confident and masters new tasks, he/she has a feeling of achievement and pride. It is at this stage that if a child fails and has difficulty in mastering too many new tasks, the feelings of incompetence and inadequacy may develop. In addition to learning and succeeding at new tasks, praise and positive remarks from adults enhance the child's self-image. If a child does not get any positive responses from adults around him/her, it may make it hard for the child to try again (Vernon, 1995).

### **Onset of Puberty**

This stage is the beginning of many physical changes. The major hormonal changes involved in physical growth and development begin to occur in girls around eight years old and in boys around nine and ten. At this stage it is also the beginning of sexual maturation (Bee, 1998; Bee, 2000).

## BACKGROUND INFORMATION for OVERHEAD C-6

### Impact on Middle Childhood (6-12 years)

#### Children may:

1. The onset of the illness of the caregiver may affect the child at any stage. The child may have lived with a parent with mental illness throughout his/her life or the child may have experienced a consistent, healthy caregiver and has had to adjust to drastic changes in her/his environment due to the onset of the illness.
2. Some children may become very resilient (Beardslee, 1998; Hall, 1996; Pound, 1996). They may have a better understanding of themselves and know that there is an illness in the family and may be able to deal with it effectively.
3. The stress may be high for children when living in a family where the caregiver has a mental illness (Vanharen, et al., 1993). When there is no structure, no stability and no organization in the home it can be very stressful for the child.
4. There are safety issues for the child. The child may be left with inappropriate caregivers. The child could be at a higher risk of also being sexually, emotionally, and physically abused by the parent with a mental illness, at the extreme possibly resulting in death.
5. The child may be vulnerable to stories of fear. They may believe their parents' delusions. Children often take things literally, i.e. "I became sick when you were born."
6. Caregiver may involve the child in their distorted thought processes (Hill, 1996).

The caregiver may believe that eating food from outside the home may be dangerous and potentially deadly. As a result, the child may believe they will be poisoned if they eat any food that has been offered outside the home.

7. There may be competition in the home for the role of the child if the caregivers have a difficult time taking a parental role. The ill caregiver may see their own needs as more important, and thus compete with the children for attention.

8. Emotional neglect may have a long lasting effect on children's functioning within the family, with peers, with teachers, and in regard to coping skills and learning (Pound, 1996).

9. Some children may be "parentified" and easily take on the role of the caregiver (Hall, 1996). They may look after the caregiver's physical and emotional needs by being confident and capable of looking after the household when the caregiver is not well.

10. The child may be an over achiever. They may structure their own lives so that they do not cause any stress to the family. As a result they do not look after their own needs (Secunda, 1997). The opposite may also be true; they may lack confidence in trying new activities. Because children may not reflect on their own needs, individuation may be interrupted. They are unable to reflect on their abilities, their wishes, or their own self-concept.

11. Children may use coercive exchanges to get appropriate responses to get what they want. The caregiver may easily give in if not well (Pound, 1996).

Some children may make unrealistic demands on their caregiver(s). In one family, the daughter would say, "I want pizza every night for dinner." When she did not get what she wanted, she threw the toaster out the window, kicked in the doors of the apartment and broke all the drawers in the kitchen. If she did not get chocolate in the morning she would not go to school.

12. Bringing someone home may be difficult because of the caregiver's bizarre behaviours. Being with a caregiver who looks and acts different may be distressing for children. Children want to fit in with peers. In middle childhood, children are quite aware of the stigma of mental illness in our society (Nicholson, et al, 1998). Children often make comments about who is "crazy" or "mental."

13. The child may not trust others in the community if the caregiver constantly tells the child that nobody is to be trusted, i.e., after being told over and over that the FBI is after them.

14. Families may be isolated (Beardslee, 1998). Children may not have the opportunity to join organizations such as Boy Scouts and Girl Guides or other community organizations that help develop social skills and other interests. This may also be due to limited income.

15. The child may be under socialized. He/she may not have information about what is expected in the school. As a result he/she may often generate negative responses for not meeting the school and educational expectations.

16. The child may have a dual life, one inside the home and one outside the home (Hall, 1996).

17. The child at this stage does not differentiate between acceptable behaviour and affect and behaviours that are not the norm in a community. Irritability, hostility, and verbal abuse may not get a reaction from the child.

18. The educational needs of the child may not be met (Hall, 1996). There may be rigidity and/or over control from the caregiver for the child to perform. As a result the child has no time to reflect, problem solve and develop her/his own study habits.

19. The inability of the child to focus in school may be seen as disruptive he/she may be labeled as a behaviour problem by the school when it may be the result of stresses in the home.

## **BACKGROUND INFORMATION for OVERHEAD C-7a**

### **Stages of Development of Early Adolescence (12-15 years)**

Individual children may continue to experience any or all of the growth experiences of the earlier stages of development. The developmental tasks cannot be separated definitively from one age group to the next but the division of tasks is an approximation only. The developmental perspective must also allow for individuality and some flexibility in terms of when tasks begin or end.

### **Accepting one's physique and using the body effectively**

During early adolescence the changes that accompany puberty can be unsettling and can cause much anxiety for the developing child. The changing body that is theirs can seem strange and unfamiliar. During this time of development the child's task is to learn to accept, understand and appreciate the changes that continue to take place as the body matures. As with other stages of development, the ability to be successful in early adolescence has a great impact on the child's personal evaluation of self and self-worth. As the body changes, previous abilities such as physical coordination may tend to go through a period of discord. The developing child must attempt to regain a sense of balance and coordination and re-master using the body effectively. This task plays a significant role not only for the child who pursues athletic activities but for others as well, because the extent to which they feel comfortable with their bodies can impact their self-esteem.

### **Achieving new and more mature relationships with age-mates of both sexes:**

#### **Peer groups are very important**

In early adolescence, children practice and develop their social skills. This activity can take place for a large part within the peer group. It becomes important to favorably compare oneself with others of the same age. Listening, communication and social skills play an increasingly larger role within the peer group structure. The need to belong to a group is greatest at this age, and children will often participate in previously avoided activities. "The peer group serves six functions: companionship, stimulation, physical support, ego support, social comparison, and intimacy/affection. Intimacy and similarity are common characteristics of friendships" (Santrock, 1993, p. 454).

### **Achieving emotional independence from parents and other siblings**

The early adolescent years are a time of increasing one's sense of individuality and uniqueness. At this age it often becomes more important to establish that one is different from one's parents than to actually have a clear view of what that uniqueness



looks like. Developing decision-making skills often becomes a task that is practiced within and supported by the peer group. Parents tend to spend less time with the adolescent; however, parental influences still play a major role in influencing choices and decision. Recent drug awareness commercials have urged parents to recognise and use that influence even though they no longer believe that it impacts the youth's decision-making processes.

### **Desiring and achieving socially responsible behaviour**

As the child develops, he/she becomes more aware of self, in comparison to others, which gradually includes an understanding of the larger society. It is at this stage that the understanding of the necessity for rules and conventions develops. Early adolescence is a time when loyalty, trust and caring are often the basis of moral judgements (Santrock, 1993). At this stage of development, having opportunity to be successful in society is also important. For example, school performances, clubs and associations, family responsibilities and neighbourhood or community jobs can provide valuable opportunities for young teens to develop a positive understanding of their role in society.

## **BACKGROUND INFORMATION for OVERHEAD C-7b**

### **The Impact on Early Adolescence (12-15 years)**

#### **Children may:**

1. Stigma, shame and embarrassment are potential sources for psychological pain for the children of parents with a mental illness. These children are also in the position of living a dual existence, such as when they move between the reality of their home life, to a very different reality of the public school system. Due to the code of secrecy surrounding mental illness, it becomes a lonely existence, which cannot readily be shared by others, and in this atmosphere of avoiding communication about one's reality, myths and misinformation can be perpetuated.

2. Pain and anger are pervasive themes for children growing up with parents who have a mental illness. In personal communication, one youth painted a picture of continual disappointments and betrayals. "I just wanted someone to go to when I had problems, but it was never safe to do that because I couldn't count on her being there for me."

The pain of the injustice is compounded when not only is this parent neglecting the child's physical, emotional, and/or psychological needs, but he/she is perhaps inflicting pain and maltreatment on the child as well.

3. Because peer groups take on such importance for this age group, some youth may find it safer to join with others who ridicule or stigmatize the mentally ill. This might be apparent in a youth's behaviours such as ridiculing and laughing at the parent, or extreme distancing and alienation from the parent as self-protection. The opposite may also occur where a youth will adopt the illness behaviours as acceptable and a way of surviving. For example, a teen might avoid social interaction and obligations as too stressful if he/she has not been given the opportunity to develop and observe other coping strategies.

4. Although youth at this age are moving toward independence, the process of "moving out on a limb" is much less scary if the "tree" is solid and stable. When the parental support and parent-child relationship is questionable, the ability to move confidently towards independence is compromised. The child may be forced into premature independence or may remain in a place of child-like dependence. With parents who are overly controlling and over involved in a child's life, the move towards independence can cause great conflict, while those parents who are under-involved can force children into situations for which they have not yet developed the emotional and psychological coping skills. For example, some youth may not be given the freedom to participate in age appropriate youth events due to the parent's tight controls. Conversely some youth may be required to set their own limits and boundaries in terms of school attendance and evening curfew for example, because the parent is unaware of the child's need for structure and boundaries.

5. A common perception for youth who have a parent with a mental illness is a personal identification with shame, or family shame as described by Dr. Marsh (1994). (If my

parent is flawed, then I must also be flawed). The result is that children can develop conflicts around being in public or being seen when their internal message is one of keeping things hidden. This can result in difficulties around accepting oneself and predisposes the child to developing feelings of low family esteem and low self-esteem.

6. Having a parent with a mental illness can also impact one's body image and physical health. There is potential for making poor health decisions.

7. Potential for low self-worth and lack of confidence is also present because the nature of a mental illness often means that the parent has little insight or awareness of the needs of those around them. When a child grows up in an environment where his/her needs are not attended to, it is easy to come to the conclusion that those needs are not important and that they themselves have little value to others. To add to this perception, professionals may also overlook the needs of children within the family as the limited resources and energy that is available will usually be directed towards managing the illness.

8. Opportunities to develop physically and artistically can be seriously compromised for children whose parents must survive on a disability income. The opportunity to participate in community clubs and sports teams or to attend sports camps, music lessons, and school excursions that require extra funding (like ski trips) can be severely limited. Not only are these opportunities unavailable due to limited finances, but often the energy structure and consistency required for successful participation is often lacking in these families. This then can seriously limit a growing child's opportunities to experience personal accomplishment and achievement necessary for healthy self-identity.

9. Peer group acceptance is very important at this age as teens move into developing more mature relationships with age-mates. Having a parent with a mental illness can however, leave a child feeling different, alone and rejected. The need to be accepted can play such an important role in this child's life, that they can fall victim to undesirable life choices, and unhealthy peer pressure (drugs, alcohol, street gangs) in an attempt to *belong*.

10. The degree to which chaos and emotionality (extreme mood swings, intense anger, violence and pervasive sadness) are present in the child's everyday circumstances can influence the healthy emotional and psychological development of the child. Offspring often report feelings of being personally responsible for the well being of their parent, and experience feelings of guilt or failure when they are unable to keep their parent well and happy. The result is developing a behaviour of *hyper vigilance* and "walking on eggshells" which can be carried on into adult life. Not only does this remove the possibility for carefree enjoyment and participation in life's opportunities; it can be harmful to future healthy relationship building. Although the chaos can cause some children to act out in an attempt to get their needs met, some children will become "the perfect child" doing very well in school. By never calling attention to themselves they attempt to maintain balance and control when the situation at home seems to be one of chaos and lack of control.

11. Lack of consistent modeling may make it difficult to develop and achieve socially responsible behaviour. If the parent is unable to participate in the larger community life, or if they exhibit social behaviour that is offensive in public, the developing adolescent has little opportunity to experience and practice socially acceptable roles outside the school setting. The youth may have an intense awareness of judgment by others that one's parent is "not right" which often results in further feelings of shame, lack of confidence (especially in the areas of spontaneity and risk taking).

## **BACKGROUND INFORMATION for OVERHEAD C-8**

### **Stages of Development of Later Adolescence (15-19 years)**

#### **Achieving emotional independence from parents and other adults.**

Teens are moving toward independence, and making personal choices in life. The youth moves from being dependent on his/her parents in all areas of life (financially, environmentally, physically and socially) to a more autonomous and independent position, where they participate partially or totally in the decisions that affect them. This process requires not so much a detachment from the parents in order to establish autonomy, as perhaps a mentoring support system that can help a child explore and move into a more complex social world (Santrock, 1993).

#### **Preparing for an economic career**

As youth move from dependence to independence the process includes finding opportunity and ability to become financially independent. Cultural expectations are that adolescents will acquire skills and make choices for an occupation, which will facilitate the move to independence and autonomy.

#### **Preparing for significant intimate relationship and family life**

In today's culture, dating takes on an important role as a setting for learning about close relationships. Dating also serves as a form of recreation, and is important in terms of social status and achievement. Culture, religion and ethnicity all exert influence on the freedom or conflict experienced by youth at this stage.

#### **Achieving masculine and feminine sex role as well as individual sexual identity and orientation**

It is during these later adolescent years that gender related role expectations are more intense as youth prepare to move on toward significant intimate relationships. It is at this age that young girls may feel pressured to perform in *feminine* ways, and young males may feel pressured to perform in *masculine* ways.

## **BACKGROUND INFORMATION for OVERHEAD C-8**

### **The Impact on Later Adolescence (15-19 years)**

#### **Children may:**

1. The move towards emotional independence may be difficult to achieve for various reasons. If the mental illness has been a factor for many years, the parent-child relationship may have deteriorated to such a degree that any attempt at developing an adult relationship with the parent is not possible.
2. Feelings of ambivalence may predominate and the youth may not be able to come to terms with a neglectful, abusive or irrational parent as also being a loving, caring, nurturing parent. In some situations where the parent has been unable to effectively parent, a role reversal may have taken place with the child assuming the parental role. This reversal also complicates the move towards autonomy and independence in that now guilt and over-responsibility prevent the child from moving on to new experiences and relationships because the care-taking role has determined that they will forever remain tied to the ill parent. This care-giving role with a focus on taking care of the needs of others without paying attention to meeting one's own needs may predispose the person to a lifetime of taking care of others, without being aware of whether it is particularly healthy for one's own well being.
3. Because one's career choices are often a result of our growing up exposures and experiences, having a parent with a mental illness can limit the options that a person considers. Without being exposed to the reality of the corporate world, or to different crafts or technologies, the opportunity to select those fields as a career choice is not great. Also, when the consistency and discipline necessary to hold a job and or develop a career are not consistently modeled, an adolescent can be seriously handicapped in terms of being prepared for the demands that will be placed on him in the world of employment.

Availability and access to resources may also be limited when one's parent has a mental illness. As mentioned earlier, financial limitations may not make university

education a realistic choice, and without the active guidance and support of an adult to help the youth maneuver the often-confusing process of registering for post-secondary education, the task can be too intimidating to be considered as an option. The severity of the parent's illness and how that illness has impacted the child's life might perhaps be the biggest limitation to a youth's career and employment development. When daily surviving and coping consumes all of the youth's energy and activity, the ability to reflect on and make plans for the future would be limited indeed.

4. The potential career choices and opportunities can also be limited by the person's own intrinsic sense of personal abilities. If the adolescent has not had the opportunity to develop a sense of confidence in his own abilities and is unable to place himself in situations of risk-taking, the ability to respond to windows of opportunity would be limited. A pervasive theme among offspring as identified by

Dr Marsh (1994) is a sense of loss of personal potential and a sense of having had opportunities pass them by.

5. Because our ability to develop and maintain healthy relationships in our adult life is dependent on the attachment experiences we have had as a child, children who have experienced disruptions to healthy attachments are at risk for later difficulties (James, 1994). Difficulty trusting self and others, difficulty understanding and balancing levels of intimacy, role reversals, and/or dependence or avoidance tendencies can all sabotage the process of developing healthy adult intimate relationships.

Issues of poverty when interfaced with mental illness can present challenges for healthy development in many areas of the youth's life. The successful development of healthy sexual identity is no exception. Low-income housing may be the only choice available, however if the mentally ill parent is unable to recognize unsafe environments, or is unaware of a child's need for space, privacy and boundary protection, the child's opportunity for witnessing and developing healthy sex and gender identities can be compromised.

6. Genetic risks as well as environmental exposure and circumstances can predispose offspring to development of depression. (Beardsley, et al. 1998). When one applies the perspective of the bio-psycho-social model it is not difficult to understand why children

growing up in a home with a mentally ill parent are at extreme risk for developing depression. When one considers the ongoing grief and loss issues, the risks for low self-esteem and self-worth, and the modeled coping behaviours, it is perhaps surprising that there are any offspring who do not suffer from depression.



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## GLOSSARY

This glossary is provided for use when working with children whose parent(s) have a mental illness. It is written in language that is easy for children to understand.

**ANTIDEPRESSANTS:** Medications that help people who are having problems with depression (feelings of sadness, often mixed with anger). These medications help people feel, sleep and eat better. They also help people with their thoughts, behaviours and low energy levels because these change when a person is no longer feeling depressed.

**ANTIPSYCHOTICS:** Medications that help people who have schizophrenia, manic depression and other mental illnesses. These medications help people who are having problems with their thinking. They also help calm their feelings and their actions because these change when a person can think more clearly and feel less upset.

**ANXIETY:** A lot of worry about things that may or may not happen. Anxiety can sometimes cause things like stomach aches, headaches, pains in other parts of the body and shortness of breath.

**BIPOLAR DISORDER (MANIC-DEPRESSIVE ILLNESS):** This is a mental illness where the person has problems with their feelings. Feelings (moods) may go up (making the person feel excited and high) or go down (making the same person feel low and sad.) These feelings can be very strong. The problems with feelings affect how the person is thinking and acting. Sometimes, when the person is very sick, he/she can become psychotic.

**CHEMICAL IMBALANCE:** In order for the brain to work properly, all the different parts of the brain need to have the right chemicals in the right balance. Most of us have the right chemicals. Sometimes a person has too few of these chemicals or the chemicals do not interact properly. Often chemical imbalances are a cause of mental illness.

**COMMUNITY:** In this manual we limit community to a defined geographical area.

**ELECTROCONVULSIVE THERAPY (ECT):** ECT is sometimes used when other treatments do not work for depression or other mental illness. This therapy does not cause pain. For a short time after this treatment, the person may be confused and may also have some temporary memory loss.

**DEPRESSION (UNIPOLAR):** This is a mental illness where the person has problems with their feelings (moods). They can feel very, very sad, angry, discouraged or hopeless. These feelings may affect how they are thinking and acting. When depressed, a person may have very little energy and become unable to do what they usually can do.

**LITHIUM:** Lithium is a medication that is used to treat bipolar disorder (also known as manic-depressive illness). It helps the person who has this kind of disorder to have more balanced feelings (i.e. fewer high and low moods).

**OBSESSIVE-COMPULSIVE DISORDER:** This is a mental illness where the person has problems with stopping unwanted thoughts, feelings and actions. They may do things over and over and may not be able to stop these thoughts or feelings even if they want to do so.

**PANIC DISORDER:** This is a disorder where people have intense anxiety, sudden attacks of fears and all sorts of body changes like chest pain, shortness of breath, and dizziness. They think that something horrible is going to happen to them. They believe that they are really in danger. Sometimes they think they are going to die.

**PARANOIA:** This is when people fear someone or something will harm them. It is usually a fear of something that will not happen but it is hard for them to understand that this is so.

**PHOBIAS:** This is when a person has a fear of things like places, animals, water, high buildings, etc. and avoids those things and places because the fear is so strong.

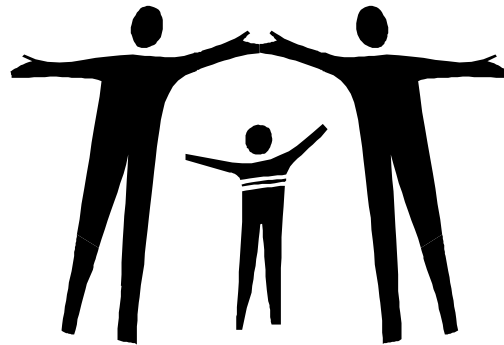
**PSYCHOSIS:** This is when a person is out of touch with reality or is unable to tell the difference between what is real and unreal. For example, he/she believes that things are happening when in real life they are not. It affects how they think, feel and behave. They may act strangely and talk to themselves.

**POST TRAUMATIC STRESS DISORDER:** Sometimes after something terrible happens to a person it affects their memory. Sometimes they cannot remember details of the terrible event or else have a really hard time forgetting about it. It often affects how they think, feel and act. Often they may not want to remember the terrible thing, but they cannot help it.

**SCHIZOPHRENIA:** This is a mental illness where the person has problems with their thinking. These affect how they feel and behave. They may have strange behaviours and see and hear often frightening things that no one else can see or hear. Sometimes they talk to themselves.

# Experiences of Adult Children Whose Parent(s) Had A Mental Illness: The Legacy

Section Four: 1:00 pm – 1:30 pm



By: Hylda Gryba, RN, BN, MA (Candidate)

# Experiences of the Adult Children Whose Parent(s) Had A Mental Illness: The Legacy

## Section Four: 1:00 pm – 1:30 pm

This section was prepared by Hylda Gryba, RN, BN, MA (Candidate)

PURPOSE	LEARNING OBJECTIVE	MATERIALS
In this section, the goal is to focus on the Adult Offspring and their experiences.	Participants will gain an appreciation of the lifelong effects of growing up with parent(s) with a mental illness. This will be done through a guest speaker or video and discussion.	<ul style="list-style-type: none"><li>• TV &amp; VCR, Overhead</li><li>• Video entitled, “A Daughter’s Story” or</li><li>• Guest Speaker on “Growing up with Schizophrenia.”</li></ul>

**Please Note:** This section does not include a separate section for background information as it is all included in the lesson plan. There are overheads that compliment this information. Throughout the text there are quotes by children who were part of a children’s support group on Parental Mental Illness entitled, “Kids in Control.” For more information about this group, please see Chapter Three.

The community trainer has two options for this section. We have found that a guest speaker who can give a first-hand account of growing up with a parent with a mental illness is extremely effective and adds authenticity to the day. Hearing about the experience from an adult child makes it very real, not only something to be discussed. As it is not always possible to find a guest speaker, we have included a video that can be used instead entitled, “A Daughter’s Story of Living with a Mom with Schizophrenia.” This video is also very effective and appreciated by participants. You may rent this video at a nominal cost from the British Columbia Schizophrenia Society (Tel.: 604-270-7841) or from the Canadian Mental Health Association – BC Division (Tel.: 604-688-3234). The video is also for sale as part of a set of two videos, by contacting A. Curtis,



Room B6-221, Department of Psychology, Montreal General Hospital, 1650  
Cedar Ave., Montreal, Quebec, H3G 1A4.

The part that makes me sad is that my mother doesn't really know me, so how can she know if she likes me or not?

## INTRODUCTION

I hope you enjoyed lunch and are ready for a very interesting afternoon. We thought we would begin the afternoon by looking at the legacy of parental mental illness: the adult child of a parent with a mental illness.

- **Overhead D-1 Is Used For This Section.**

“The worst part is feeling that it's all your fault.”

Although mental illness may visit only one individual, all family members experience the trauma. Across a lifetime, families may experience globally traumatizing events such as natural disasters, war, poverty, or more personal tragedies such as bereavement, divorce, and sexual abuse. The experience of mental illness in a family is similar to other traumatizing events in that all members become the victim (Marsh, 1997). However, there are some very important aspects that make the familial experience of mental illness unique. First, mental illness is intrinsically personal as the identity of the person stricken is taken over by the illness. Second, there is no outsider whom we can hold accountable. Mental illness involves the victimization of a loved one. Third, unlike other calamities there is little social validation of the suffering but all too often there is increased isolation and alienation. Following is a brief overview of the lasting impact of growing up in a home where there is parental mental illness.

## MAIN PART OF THE PRESENTATION

### 1. OVERVIEW OF THE LASTING IMPACT

- **Overhead D-2 Is Used For This Section.**

In her book, *When Madness Comes Home*, Victoria Secunda (1997) identifies the themes and key issues that emerged as she interviewed and researched the experience of siblings and offspring of persons with a mental illness. The legacy for adult children who grew up in a home where there was parental mental illness will be presented using the issues as identified by Ms. Secunda.

**Grief that never ends** is one of the most compelling themes reported by the children of the mentally ill. The mental illness can forever alter the personality of the person affected, resulting in what may be termed a “psychological death.” However, as the parent with the mental illness may continue to be present in a child’s life, the loss continues to be unresolved. Secunda describes it as having a person present in body but not in spirit. Dr. Marsh (1997) states that the grief and loss reaches beyond that of losing a normal parent and includes loss in other areas of life (loss of a normal childhood, loss of opportunities in all areas of life, and loss of personal potential).

Sometimes I feel so sad when I think that my life has been sabotaged. I sometimes wonder what my life might have been like if I had been given the chance to have a normal childhood.

Foremost is the **fear of breaking down**. “Will I too become mentally ill?” is a question that remains with the offspring for a lifetime. Self-monitoring and self-questioning become lifelong activities. The fear is not limited to oneself but can be carried forward to fear for one’s own children as well as for one’s siblings and/or their children. *“Every time my mother had an argument with her sister, she would make some comment like, “I sometimes wonder if she might not be a little off also.”*

**Arrested or sabotaged development** and developmental processes across the life span are issues that also continue throughout the life of the adult child. If the parent becomes ill while the child is an infant, it impacts the child's developing sense of self in relation to the world around him/herself. If a parent becomes ill when the child is an adolescent, how does the child move on to healthy independence, especially if the parent's illness presents itself in the form of either over involvement or under involvement in the child's life? How does one move on to an adult-to-adult relationship with a parent whose mental illness prevents healthy relationship involvement?

Offspring frequently report confusion in terms **of a skewed sense of what is normal**. Growing up in situations with emotional volatility, lack or blurring of boundaries, and witnessing frequent bizarre or socially unacceptable behavior, can distort a child's sense of normal. As an adult, the offspring may be unaware of "red flags" indicating potential abuse that similar behaviors within an intimate relationship would suggest.

One young child picked up a piece of paper, ripped off one corner and let the two pieces flutter to the ground. This was her explanation of what it felt like when her mom was taken to hospital and she was placed in a foster home.

**Guilt and shame** are intrinsic to the experience of growing up in a home with parental mental illness. Children almost universally attribute to themselves the blame for having caused family tragedies. The experience of having caused a parent's mental illness is perhaps even more deeply felt by a child for often the onset of illness may coincide with the birth of a particular child, and adults may knowingly and unknowingly blame the child for increasing the stress experienced by the parent. Shame, stigma and family secrets surrounding the mental illness within the family can result in a child experiencing a sense of being genetically (and therefore intrinsically) flawed. Low self-esteem and self-worth are part of the family shame attached to having a parent with mental illness.

As one child shared about his feelings of anger at being shunned and avoided by his parent's family, another member of the group quietly nodded his head in agreement and whispered, "been there, been there."

Attached to the themes of shame is the experience of **dual identities**. In everyday life, offspring often lead an existence that "straddles two worlds" (Dr. Marsh, speaker comments, September 1999). Trying to survive in a home where things may be chaotic, unpredictable or unbearable at times requires a certain coping style. Trying at other times to be like everyone else in the "normal" outside world requires the ability to lead simultaneous dual lives and identities.

**Difficulty with intimacy** and **difficulty setting limits** are two issues that are linked to the child's developmental experience of coping with the parent's mental illness. Trust does not come easily because as a child grows up, their survival may have depended upon *not* trusting the adult completely but rather depending on themselves. Conversely, the ill parent may have been and may continue to be intrusive and abusive in demanding the time, energy and resources of the adult child who, torn between loyalty and fear are unable to turn away from their parent. The adult child may report feeling that the ill parent holds them hostage, both physically and emotionally. Not having had the opportunity to understand, recognize, and/or develop healthy boundaries carries over into the personal lives and relationships of the adult offspring.

**Deferred dreams** are an area of loss due to personal lives being placed on hold in order for families to cope with and take care of the ill relative. At times it becomes a retrospective loss as adult children realize that their opportunities and available choices were limited because of a parent's inability to provide guidance, direction, and opportunity for the developing child and adolescent.

Children of the mentally ill frequently experience **fear of failure**. Many children report trying to compensate for the ill relative by being perfect or without "flaws." Many times in an attempt to prevent more burdens, the children become extremely competent and responsible for others, (unaware of or ignoring their own needs) falling into a lifetime of

care giving and over responsibility, and predisposing themselves to burnout or breakdown.

**Isolation and loss** have both been mentioned previously, but deserve mention as a separate theme as well. As mentioned in the introduction, due to the stigma and shame attached to the mental illness experience, the suffering and pain caused by mental illness within the family is seldom given the validation and understanding by society in general. Added to that can be abandonment by the professional community. All too often the health care professionals, following a policy of outpatient care and in home case management, leave family members on their own to cope without resources and support. In some instances, children have been blamed and treated as a problem or a nuisance as they continue to seek services for an ill relative who is not responding well to the treatment plan. Given the young child's tendency to accept responsibility for the parent having become ill, the adult child may have no choice but to continue to accept the blame and responsibility for the parent's mental illness. Loss of extended family may also be the experience of many adult children.

“In my mother's family, where her father suffered with what we now believe must have been schizophrenia, the maternal family connections were strong. We know all the aunts, uncles, and families of my grandmother's siblings. My grandfather's family, however, seems nonexistent. During my mother's childhood, her father's family withdrew from any connection and ignored the existence of their ill brother's family. In fact, any memories she has of encounters with my father's family were situations involving antagonism or betrayal.”

Linked to the idea of loss of extended family, is the idea of **unfinished family business**. Many times the relationship that a child has with a mentally ill parent is further strained by the emergence of the mental illness. Frequently a relationship that was already experiencing a considerable amount of turmoil, strain and ambivalence due to years of chaos or abusiveness becomes suspended. This leaves the child without an opportunity to revisit, heal and move on from the childhood traumas, since the parent is

neither fully present nor fully absent. Chronic psychological pain may be the result, and may in fact be a more debilitating condition, causing greater suffering than chronic physical pain.

I think I always knew that it wasn't my fault, but my mom kept saying that I am the cause of her problems and still does."

The **search for meaning** is also pervasive and persistent throughout the life of the adult child who asks, "Why my parent? Why not me?" Can dysfunctional parents or spousal relationships be blamed? Are they blameless? And what of the ill parent, what is our moral or ethical responsibility? In instances where there was neglect and abuse, are they to be held accountable? Where can the adult offspring place his/her anger and sorrow? Questions without answers are all too familiar for the child whose parent suffers from a mental illness.

## 2. POSSIBLE RESPONSES

- **Overhead D-3 Is Used For This Section.**

In her book, *When Madness Comes Home*, Victoria Secunda (1997) has identified three broad behavioral categories into which the responses of the adult offspring may fall. These behavioral responses may at times shift or overlap, but to a large degree define the family role that an individual child will identify with as his/her pattern of response to a parent's mental illness. These family roles, or patterns of responses, are influenced by many variables such as the child's temperament, age at onset, socioeconomic status and the severity of the parent's illness to name a few.

I still feel guilty when I go to visit my mother in the hospital because I never knew her. Yet, she is my mother, so shouldn't I feel something? And shouldn't I be doing something to develop a relationship even now? Mostly it's a real empty feeling.

### 3. RESILIENCY - EXTERNAL CHARACTERISTICS

- **Overhead D-4** Is Used For This Section.

Although the purpose of this section is to increase awareness of the trauma that results from parental mental illness, one must also take time to recognize and applaud the tremendous resiliency shown by this same population. Apart from the broader characteristics which can be identified in youth who appear to have resilience across challenging situations, (such as intelligence, communication abilities, understanding of personal power and capabilities, ability to access resources, information seeking skills, etc.), children with affectively ill parents were more resilient if they were seen as:

- **Activists and doers** (External Characteristic)
- **Strong interpersonal relationships** (External Characteristic)
- **Had a good self-understanding** (Internal Characteristic)

These characteristics have also been identified and expanded on by various researchers. Karen Kinsella (1997) identifies five positive and three negative coping skills used by these children (see **Overhead D-5**).

When I heard that it was a chemical imbalance it didn't seem as bad somehow.

### 4. RESILIENCY: INTERNAL CHARACTERISTICS

- **Overhead D-6** Is Used For This Section.

The internal characteristics of resiliency show the incredible internal strength that children may develop when a parent has a mental illness.

## 5. PERSONAL GROWTH

- **Overhead D-7** Is Used For This Section.

When discussing the experience of growing up in a home where a parent suffers from a mental illness, one must also mention that despite the tremendous challenges that may be present, the emergence of individual and family strengths are often the most evident and compelling legacy. The undeniable will of the human spirit, not only to survive but also to emerge victorious in the face of extreme adversity will surely become evident as one listens to the stories of adult offspring. Kinsella (1997) describes the following adult strengths (see **Overhead D-8**).

## 6. CLOSURE

“Even though I am a Mental Health Professional I thought all the material was a useful review. The personal experience of the “adult survivor” really impacted me. It made me aware again of why we need to build better service connections.”

Cindy Thompson, Community Mental Health Nurse

The resiliency shown by adult children whose parent had a mental illness is remarkable and is something that can give hope to others with similar experiences. In the next part of our day we will be looking at the Advance Planning Process.



## Overhead D-1

**The impact of parental mental illness is undeniable and the effects are felt across the lifetime of the offspring.**

## Overhead D-2

### **Personal Legacy for Adult Survivors**

- Grief that Never Ends
- Fear of Breaking Down
- Arrested or Sabotaged Development
- Guilt and Shame
- Dual Identities
- Difficulty with Intimacy
- Difficulty Setting Limits
- Deferred Dreams
- Fear of Failure
- Isolation and Loss
- Unfinished Family Business
- Search for Meaning

## Overhead D-3

### Possible Responses

**The Custodian**: Perpetual caregiver. Find themselves always called upon to respond to crises great and small.

**The Bystander**: Avoids involvement. May try to remain invisible, or at times may be unable to “take sides” and is constantly torn by the ability to see all points of view.

**The Adversary**: Often identified as “the problem.” Loud protestations are the norm. This person will continually challenge and argue against parental decisions, authority figures, schoolteachers and siblings.

## Resiliency - External Characteristics

- Ability to take appropriate actions: resilient youth may be involved in school and extra curricular activities.
- Deeply involved in and committed to strong interpersonal relationships. Often youth who participated in this research stated that the care and concern of one connected adult was a significant factor in helping them cope and survive.

## Positive Coping Skills

- **Constructive Escape** - physical and mental removal from stress through sports, art, music, social activities, etc.
- **Seeking Support** - sought care & understanding from a healthy trusted adult or peer when support was needed.
- **Objectifying the Illness** - being able to separate the illness from the person and from self reduced the tendency to self-blame and allowed for positive relationship with the family member.
- **Acquiring Information** - eliminating misconceptions and misinformation and acquiring illness information helped provide predictability.
- **Spiritual Faith** - finding hope and meaning helped persons despite seemingly hopeless situations.

## Negative Coping Skills

- **Internalization of Emotions** - drug and alcohol use resulted in emotional immaturity and constrictedness and an inability to maintain relationships.
- **Self-Censoring** - rigid self-control & hyper-vigilance in an attempt to bring about stability also resulted in emotional immaturity, constrictedness and an inability to maintain relationships.
- **Self-Isolation** - withdrawing from friends and family & attempting to avoid difficulties resulted in loneliness, guilt and poor social skills.

## **Resiliency: Internal Characteristics**

- **Self-understanding – the ability to reflect on one’s surroundings.**
- **Able to articulate problems.**
- **Awareness of the parent’s mental illness.**
- **Saw themselves as separate from and not responsible for their parent’s mental illness.**

## **Personal Growth**

- **Increased capacity for compassion and caring**
- **Increased self-reliance and independence at an early age**
- **Creativity and unique abilities**
- **Strengthened family bonds and ties**
- **Emergence of family strengths and coping abilities**



## **Adult Strengths**

- **A sense of self-reliance born out of necessity in the early childhood years**
- **An ability to be tolerant and non-judgmental, compassionate and caring**
- **Personal creativity, described in terms such as imaginative, artistic, resourceful, original and focused**
- **A “pulling together” of family members in coping with the illness, as well as an appreciation for the uniqueness and individual strengths of each person including the ill parent.**

**(Secunda, 1997; Marsh, 1997).**

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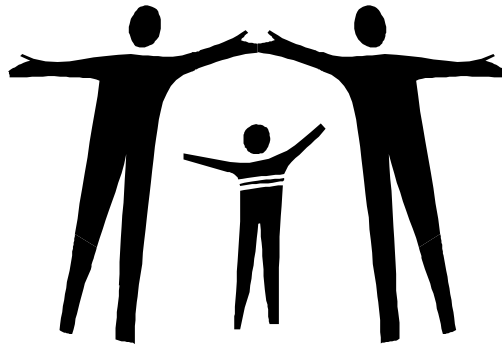
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A Daughter's Story of Living with a Mom with Schizophrenia. This video can be rented at a nominal cost from the British Columbia Schizophrenia Society (Tel.: 604-270-7841), or by contacting Mr. Richard Zurovsky, Department of Psychology, Montreal General Hospital, 1650 Cedar Ave., Montreal, Quebec, H3G 1A4

# The Advance Planning Process

Section Five: 1:30 pm – 2:15 pm



By: Robert Lees, Ed.D., R. Psych.  
and  
Sharon Van Volkingburgh, MSW

# The Advance Planning Process

## Section Five: 1:30 pm – 2:15 pm

This section was prepared by Dr. Rob Lees and Sharon Van Volkingburgh, MSW.

PURPOSE	LEARNING OBJECTIVE	MATERIALS
<p>In this section, the goal is to develop an awareness of the value of the Advance Planning Process and Family Case Management.</p>	<p>Participants will be introduced to an example of the Advance Planning Process and come to see how a parent with a mental illness can benefit from this process.</p>	<ul style="list-style-type: none"><li>• Sample Advance Planning Document</li><li>• Overhead Projector</li></ul>

### INTRODUCTION

The previous section provided us with an important and powerful example of the adult child's experience growing up in a home where a parent has a mental illness. All of us are here today because we have an interest in working with these families. The crucial part that is still to come is how we can best access support services for families where there is parental mental illness.

### THE MAIN PART OF THE PRESENTATION

#### 1. The Advance Planning Process

To begin, we will present and discuss the Advance Planning Process (see Overhead E-1 and Handout E-2). Please follow along in your handout. The example is from an actual family who used the Advance Planning Process with success. All names have been changed. As we go through this agreement, please feel free to add comments and ask questions. (For this section, discuss the overheads as you show them.)

## **2. Integrated Case Management**

The next task is to discuss integrated case management. All families who use a number of services will benefit from using an integrated case management approach. Ideally, the parent can be the case manager. Refer to Overhead E-2 and to the supporting Background Information.

### **CLOSURE**

Please take a coffee break and we will reconvene at 2:30 p.m. for the final part of our day.

## Integrated Service Planning and Delivery

Advance Planning allows parents to informally partner with child welfare and community supports in order to ensure competent care even when they are ill.

### 1. Should there be consideration of the Advance Planning Process?

It is important for parents who have a mental illness with severe recurrent symptoms to make plans for the care of their children in case they suffer a relapse. When parents prepare an advance plan, their family, friends and community workers can come forward to help sooner, in alliance with the parent's wishes for the best possible care for their children.

Advance planning addresses both the needs of the children for ongoing care and the need for the parent to maintain a role in providing for care and continuity for their child. The process of developing the plan also helps the family develop a committed, responsive network of support.

An important feature of advance plans is to allow parents to communicate about their child's particular care needs. This minimizes disruption for the child, and ensures that allergies and medical needs, preferred toys and activities, usual routines and helpful relationships are maintained.

Developing an advance plan is therapeutic in itself, as the parent realistically faces the impact of his or her mental illness on the child, and takes steps to build a support network for the family. Parents who have made such a plan have been surprised at the positive response of friends or family when they asked them to make a commitment to help in the case of a future crisis. Friends, family and community workers often stand back when problems related to the illness are developing, wanting to help, but worried about going against the ill parent's wishes. Knowing in advance what role the parent would like them to take, gives people confidence that they are doing the right thing. Advance planning is also an important aspect of developing an Integrated Case Management Plan.

There are several considerations in developing this kind of plan:

- **An advance plan is not a legal agreement, unless made as an enhanced representation agreement under section 9 of the *Representation Agreement Act*. Such agreements, which are further discussed beginning on page 177, may include provisions for the temporary care, education, and financial support of one's minor children. In such cases, the person making the agreement must consult with a lawyer, and the agreement must be properly signed and witnessed.** An informal plan will depend upon good faith, and will not be enforceable through the courts. For example, even if the parent states in the agreement that he or she does not wish to change it without a defined process, it will remain legally open to be changed by the parent at any time. Laws about child protection, custody, and confidentiality supersede the agreement. **Service providers should consult with their supervisors regarding their ability to enter into advance plans.**
- It typically takes a long time (six months to one or more years) to develop a plan that will actually work in a crisis. The effectiveness of the plan corresponds to the strength of the family's support network. If this network is not strong enough, early efforts to develop a plan may still be helpful but the plan itself may not work out as hoped. For example, a preferred caregiver may not be endorsed by child welfare authorities (if they are involved with the family). However, it is likely that the relationship between the person named by the parent and the child will be respectfully considered by those who work with the family.
- The parent must be well enough to make a good, safe plan. Some parents, especially people living in smaller communities, may be too isolated to be able to enlist others to give sufficient support. The nature of some illnesses (e.g. paranoia) may interfere with the parent's ability to trust others even in developing a plan. Also, parents may not be aware of past histories of friends and acquaintances that would preclude them from being desirable caretakers of children.

- Children can have an active role in the plan as developmentally appropriate. For example, children may be the first to notice symptoms in their parent, and should have the means to seek help for themselves and their parent. An adolescent may have strong views about issues such as alternate care, which should be respected as far as possible.

### **a) Care of Children**

A basic model of an advance plan for the care of children in case of a parent's mental illness relapse should include the following elements:

**Date and Support Team:** List the date of the agreement and the people named in the agreement with their phone numbers. The date is important because this agreement should be frequently reviewed, as the information may change.

**Purpose:** The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by members of the support system if the person making the agreement exhibits symptoms of the illness, which may interfere with the ability to provide necessary care to the children.

**Symptoms:** List the symptoms that the person making the agreement would like others to notice and respond to, and describe the most helpful way to respond. Often it is the children who first notice a worsening of symptoms in their parent, and they need to know how to get help quickly.

**Communication:** Record how the writer would like to deal with the issue of confidentiality, and attach a signed consent by the writer giving permission for various people on the contact list to share information with others. Even with consent, no more information than is necessary for the implementation of the agreement should be shared. The action plan can describe whom the writer would like contacted, the planned order of contact and response, as well as instructions about treatments or medications that have been helpful in the past.

**Plan of Action:** Record the actions the writer requests others to take, including provision of support services, for the implementation of this plan.



**Childcare Information:** Record the writer's wishes for the care of the child, including any information about allergies, special needs, favourite foods or toys, daily routines, etc.

**Involve the Children:** Children can be a valuable resource to include in the agreement. They are often well aware of their parent's symptoms and, depending on their age, could be the first to put the agreement into action when necessary. Involving children could increase their feeling of security as well as their compliance with the agreement.

**Cancellation:** Describe the manner in which the agreement can be cancelled. The agreement is written expressly so that it cannot be easily cancelled when the writer is acutely ill. It is important that the process of cancellation requires a period of time and a set of steps. (Note: this may pose a problem for some professionals who are unable to enter an agreement that does not allow for cancellation within a shorter specified time. It should be noted that this is an informal rather than a legally binding agreement, based on good intentions, and wording to that effect should be included.)

**Periodic Review:** Describe the manner in which the agreement will be reviewed (at least annually, as well as after each time the agreement is used). During the review, a copy of the agreement should be given to everyone named in it, and each person should be clear about his or her role. A meeting can be helpful in that people in the support network become familiar with each other and express their care, concern, and support for the family.

This kind of plan or agreement is not legally binding, and relies on the good intentions of the people named in it to carry out the parent's wishes. Note that legislation regarding child protection supersedes such agreements. Social Workers, in the Ministry of Children and Family Development, should consult with their supervisors regarding their ability to enter into advance plans.

## **b) Advance Planning: Representation Agreements**

New adult guardianship legislation provides a legal format for advance planning. The *Representation Agreement Act* allows adults to authorize representatives to exercise particular powers agreed to in advance. For example, a representative will be able to

arrange for the temporary care, education, and financial support of children, as described in an agreement made by a competent adult. A representation agreement will need to be drawn up by a lawyer if it includes such arrangements. Materials to help people develop representation agreements are available from the Representation Agreement Resource Centre, (Tel.: 604-408-7414) and e-mail: ([info@rarc.ca](mailto:info@rarc.ca)). The Web site ([www.rarc.ca](http://www.rarc.ca)) has a copy of the *Representation Agreement Act* and the regulations.

**A representation agreement is somewhat like a Ulysses agreement which is named after the Greek mythological hero who asked his crew to tie him to the mast of his ship so he could resist the call of the Sirens; it might also be called a Care, Treatment and Personal Management Plan.**

## **2. Is there an Integrated Case Management/Family-Centred Case Management or Care Team?**

There are many models of integrated case management and we are going to talk about two of them:

(i) The Ministry of Children and Family Development (MCFD) has developed a model of integrated case management and collaborative practice which promotes the use of case conferences and a team approach to the development of a treatment or care plan for the family. This model can be empowering for parents, and can often generate workable solutions for complex problems. Integrated case conferences can be used to develop plans to prevent future crisis situations, or to decide on the most helpful ways to support the family. It is very important for the parent or the parent's voice, as represented by a trusted person or recorded in a care plan, to be included at integrated case conferences. Any member of the service providers, including the parent or older adolescent may fill the role of case manager. Any parent who is involved with the MCFD can request a case conference through the assigned worker.

Meetings are recorded and the resulting plan is distributed to all participants, which encourages accountability and follow-up. Face-to-face meetings allow for the clarification of roles, making sure that agreed-upon follow-up occurs. Meetings also allow for the generation of helpful ideas and the creation of a care team that works collaboratively with the family.

Training for communities in Integrated Case Management is available throughout British Columbia . through the Ministry of Children and Family Development. Excellent materials including a user's guide, an instructor's manual and a participant manual are available on the MCFD Web site: [http://www.mcf.gov.bc.ca/reports\\_publications.htm](http://www.mcf.gov.bc.ca/reports_publications.htm)

(ii) Family-Centred Case Management establishes that the parent or person delegated by the parent as case manager will coordinate regular meetings of all care providers. This approach helps everyone work collaboratively, reduces duplication of services and encourages teamwork while reinforcing the parent's role as co-coordinator of services for the family. Family-Centred Case Management is frequently used in situations where the family's complex needs do not include the MCFD services.

### **3. Considerations for Integrated Case Management/Family-Centred Case Management for families with parental mental illness:**

- Is there identification of individual and family strengths and assets?
- Is there consideration and respect for issues around confidentiality for the person with a mental illness?
- Is there a mechanism for resolving problems and misunderstandings that can arise in case management?
- Is there a regular process for educating all members of integrated case management teams in how to deal with conflicts and concerns?
- Are family plans of care developed, as well as individual plans?
- Is there particular attention to understanding, inclusion, and empowerment of both the parent and the child or youth?

## **ADVANCE PLANNING – AN EXAMPLE**

### **Care, Treatment and Personal Management Plan for Mary Grant**

**Updated April 3, 2001**

**This is an agreement between the following people and myself (Mary Grant, 1234 W. 32<sup>nd</sup> St., Vancouver, Telephone (604) 737-8999):**

<b>Mrs. R. Grant (mother)</b>	<b>555-6666</b>
<b>Dr. John Adams (family physician)</b>	<b>555-6123</b>
<b>Carol Noone (friend)</b>	<b>555-7777</b>
<b>Nancy Green (neighbour)</b>	<b>555- 6666</b>
<b>Sue Linde (Midtown Mental Health Team)</b>	<b>555-8441</b>
<b>Diane Diamond (Alcohol and Drug Counselor)</b>	<b>555-6789</b>
<b>Dr. T. White (Midtown Mental Health Team)</b>	<b>555-8441</b>
<b>Cindy Fox (Social Worker, MCFD)</b>	<b>555-4444</b>
<b>Fran Rite (Parent Education Worker)</b>	<b>555-8888</b>
<b>David Grant (family member)</b>	<b>555-2222</b>

**They have agreed to be members of my support team and to follow the guidelines set below, to the best of their ability. In addition, the Mental Health Emergency Services (Car 87) have been informed of my wishes as set out below.**

**Purpose:**

The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by my support team if I exhibit any signs of my illness as outlined below. I appoint Roberta Grant, my mother, or in her absence Carol Noone, as supervisors of this agreement to ensure that, as far as possible, it is completely implemented. The primary purpose of this agreement is to ensure that my son, Douglas, will be properly cared for with the least amount of interference in his daily routine. My request is that support be given to my son and me so that I can continue to care for him at home. However, I understand that may not be possible, and I trust that the people I have named to make decisions, if necessary, for the care of my child if I experience a relapse of my illness.

Sometimes waiting too long before seeking support for a parent with a mental illness may be harmful to the children involved.

**My Symptoms (early symptoms):**

- Difficulties falling asleep and staying asleep
- Increased irritability, anxiety and agitation
- Decrease in appetite
- Emotional withdrawal and social isolation
- Impaired judgement regarding money
- Intrusive, irrational thoughts
- Suicidal thoughts
- Hearing voices
- Increased generalized fear and anxiety

## Plan of Action

Upon onset of any of the symptoms of my illness as detailed above, my support team should take the following actions:

- There should be open communication between the members of my support team. Any member of my support team should speak to me first about his or her concerns, and then contact the Mental Health Team Case Manager.
- The main purpose of this Advance Plan is to ensure the safety and well-being of my son. If there is any concern that he is at-risk or is not being cared for safely, the matter should be reported directly to the MCFD.

In British Columbia and many other jurisdictions, every person who may be aware of unsafe circumstances in the life of a child has a legal duty to contact appropriate authorities.

- The following actions should then be taken:
  1. My mental health case manager, team doctor, myself, and any other member of my support team that I wish to be present should meet for an assessment of my mental status. Adjustments in medication and a care plan will be established.
  2. The team will provide increased support through more frequent contact and by advocating for additional needed services such as homemaking.
  3. The mental health case manager will contact the MCFD worker to enlist her support and to obtain needed services. Specifically, these services would be a homemaker; increased childcare; and placement of my son if necessary.
  4. The area counsellor at the school should be informed of my difficulties so as to be responsive to possible difficulties my son may exhibit at school.

5. The mental health case manager will contact the friends I have listed to enlist their support.
6. If I am abusing any substance, the mental health team may contact my Alcohol and Drug Counsellor and elicit her support.
7. If I am unable to care for my son with the additional support, it is my wish that every effort be made for my son to be able to remain at home under the care of one of my friends or relatives listed above.
8. Attached to this agreement is information important to my child's care.
9. Only after all efforts have been made to meet the above plans and have been exhausted, the case manager will contact the Ministry of Children and Family Development to arrange respite care.
10. If, after review and actions as outlined in # 1 and #2 have not been effective in stabilizing me, then I will give consent to admission to Venture. Arrangements for the care of my son are outlined below.
11. Hospitalization should be considered as a last resort.

### **Medication**

As long as I remain stable, medications will continue to be dispensed to me on a monthly basis. Should I exhibit any symptoms of illness, this agreement will be reviewed.

### **Medical Records**

I authorize my case manager and doctor to discuss my mental status, current functioning and any other medical information required for decision making with any member of my support team, or with any other person responsible for my care.

## Care for My Child

In regard to my son Douglas, I would like the following to take place:

1. If I am not able to care for my son at home, or if I am admitted to Venture or the hospital, I request that Douglas be placed in the care of my mother, Roberta Grant. My mother will need to apply for compensation for the cost of caring for my child through the Ministry of Children and Family Development<sup>3</sup>. I request that Douglas's daily routine be maintained as closely as possible. This includes attending daycare on a regular basis. Please see the attached addendum for information about Douglas' routine and allergies.
2. If my mother is unavailable immediately, I request that the Ministry make assertive attempts to place Douglas in her care as soon as possible. In the interim, Carol Noone or Nancy Green should be contacted regarding their ability to care for Douglas on an emergency, short-term basis.
3. If I have been admitted to hospital or Venture, I agree to have no contact with Douglas for the first week of admission.
4. Douglas knows that if I am unable to care for him, his grandmother will.

## Cancellation

As a result of my illness, I might attempt to cancel this agreement. I wish to cancel this agreement only in the following way:

1. I will inform my case manager or doctor at the Mental Health Team that I want to revoke this agreement.
2. My own team psychiatrist will assess me. The purpose of this assessment is to ensure that I am not showing any symptoms of my illness. I would like another member of my support team to be present. The psychiatrist may consult with another doctor.

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<sup>3</sup> Government support is contingent upon current legislation and policy in any given jurisdiction



3. The case manager and I will inform members of my support team of this revocation in writing.

I expect this cancellation to take approximately two months. Until this process is complete, I want this agreement to remain in place.

### **Addendum to the Advance Plan**

Information Re: Douglas Grant

- Born: \_\_\_\_\_
- Personal Health Number: \_\_\_\_\_
- Family Doctor: \_\_\_\_\_
- School: \_\_\_\_\_ 9:00 - 3:00 phone \_\_\_\_\_
- After school care: \_\_\_\_\_ phone & contact person: \_\_\_\_\_
- Douglas is severely allergic to nut products. He is also allergic to dust, feathers, perfume, and many other irritants. Caregivers must have an epi pen needle at all times. Douglas carries an inhaler for emergencies and uses Intal or Ventalin preventative three times per day. Please consult with his family doctor, who knows him well, about any questions regarding his allergies or treatment.
- Douglas goes to bed at 8:00 with lights out at 8:30. He usually has stories and a light snack (cereal) before bed. He brushes his teeth immediately after eating.
- Douglas has met several times with Barbara Bean, a family and child therapist at the Midtown Mental Health Team, who has helped him learn about my mental illness and express his feelings about how he has been affected by it. It may be helpful for Douglas to meet again with Barbara to provide him more information and support.

## Periodic Review of Agreement

A review of this agreement will take place every six months or as necessary. If this agreement has been put into action, then a review should take place as soon as possible after I am stabilized.

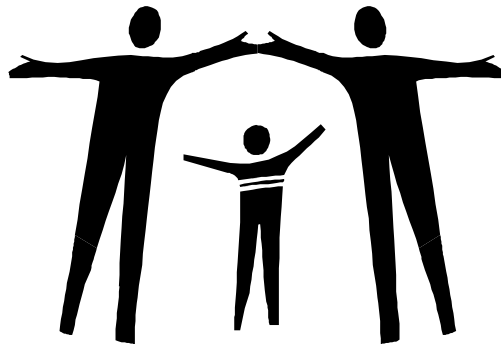
Signatures of all members of the support team should be obtained.

- 1) \_\_\_\_\_  
Signature Date
- 2) \_\_\_\_\_  
Signature Date
- 3) \_\_\_\_\_  
Signature Date

If this document is completed according to the requirements of the *Representation Agreement Act* it can be an enforceable agreement.

# **Community Best Practice: Self-Assessment Checklist**

**Section Six: 2:30 pm – 3:30 pm**



**By: Robert Lees, Ed.D., R. Psych.  
and  
Sharon Van Volkingburgh, MSW**

# Community Best Practice: Self-Assessment Checklist

## Section Five: 2:30 pm – 3:30 pm

This section was prepared by Dr. Rob Lees and Sharon Van Volkingburgh, MSW

PURPOSE	LEARNING OBJECTIVES	MATERIALS
<p>In this section, the goal is to:</p> <ul style="list-style-type: none"><li>• <b>Introduce the Community Best Practice Checklist</b></li><li>• <b>Encourage discussion of the Checklist in relation to the Community</b></li></ul>	<ul style="list-style-type: none"><li>• Participants will be familiar with a range of activities necessary for comprehensive community response.</li><li>• Participants will be able to identify new activities to improve community support in their own community.</li></ul>	<ul style="list-style-type: none"><li>• Best Practices Checklist</li><li>• Overhead Projector</li></ul>

## INTRODUCTION

We have come to the final part of our day, a most important part as it relates to our practice and the changes that can occur in our community.

## THE MAIN PART OF THE PRESENTATION

### 1. The Systems Model Diagram

Now we would like to present the systems model diagram (see Overhead F-1). It is important to point out the need for connection between the parts of the system. Note the connection between basic needs and supportive community attitudes. We will now break into groups of about 10 - 12 (or re-organize participants into a circle) and discuss the following question (see Overhead F-2):

What are the most likely next steps for our community to insure best practices for families with parental mental illness?

Elect a recorder to collect the information discussed, and be ready to present this information to the whole group.

## **2. The Community Best Practice Self-Assessment Checklist**

Ask the participants to refer to their handouts where they will find a copy of this checklist and the identical overhead (see Overhead F-3). The community trainer can refer to the Background Information F-3 for notes that support each point on the checklist. It would be valuable to be familiar with the checklist as well as this supporting documentation for when you are ready to present. Go quickly through the checklist pointing out areas where your community is strong and those where growth may be needed.

Ask the group for other ideas about best practices where your community is strong as well as the areas that are relatively undeveloped. It is unlikely that any community can make advances in all best practices. Each community will differ in their relative strengths and weaknesses. What is important is to meet together to challenge ourselves to make the improvements we can, recognizing that this requires an ongoing process.

## **3. Roll up of Action Plans**

Leave the groups intact but ask them to direct their attention to the front or focal point where the leader and an overhead are situated. (If you ask people to move it will take up important time). On an overhead, white board or flip chart, list points from the group discussion. If there are multiple groups reporting, collect one idea from each group in rotation, until all fresh ideas are recorded. Keep this moving at a good tempo. Ask if there are any people willing to meet to follow up on the discussion from the day. If so, you have the nucleus of a planning/ implementation committee.

#### **4. Next Steps**

It is possible that an idea or a group has emerged that seems like a logical next step for the community. If this is not evident, ask if there are a few people who would be willing to meet with you to review findings from the day. Ask these people to stay behind briefly to set a time with you for this meeting.

You may want to suggest some next steps if these do not emerge from the roll-up.

Here are a few to consider:

- Ask for a planning group to address some Key Best Practices.
- Ask for someone to write up the Action Plans from the roll-up and send them to all invitees.
- Ask about interest in workshops that expand this workshop in a variety of ways. For example, teachers could meet to discuss understanding mental illness; social workers could meet to discuss the Advance Planning Process; community leaders could meet to discuss best practice.

#### **CLOSURE**

Thank participants for their involvement throughout the day. Review the objectives for the day:

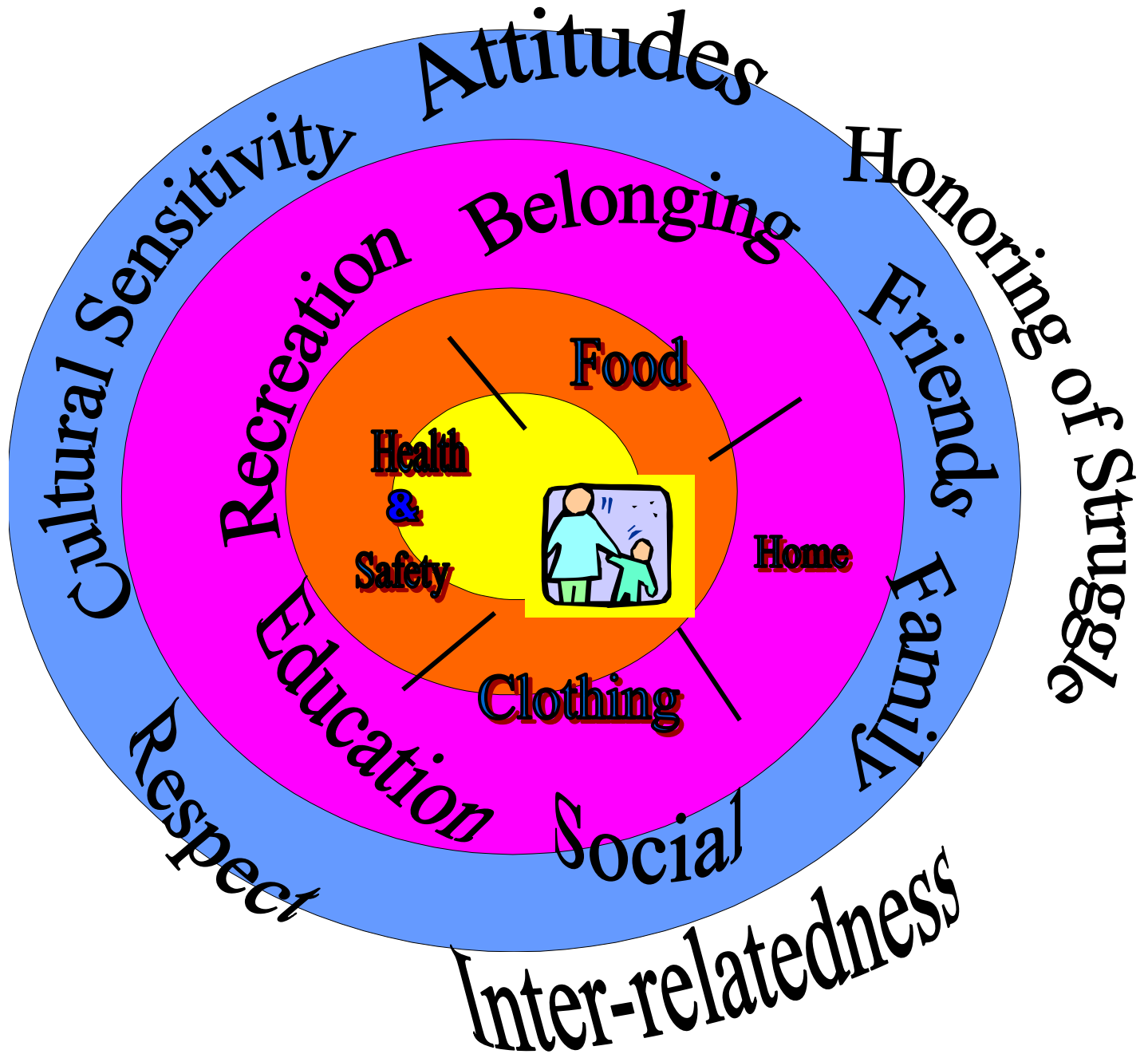
- To raise awareness of mental illness
- To begin the process for thinking critically about existing services
- To consider how we can improve how we support families with mental illness

Ask participants to fill out the evaluation form on the day.

Pat yourself on the back and take the rest of the day off!

#### **FOLLOW-THROUGH**

Review the evaluations, preferably with the planning group. Call those people who volunteered to take the next steps and encourage them.



**What are the most likely next  
steps for our community to  
ensure best practices for  
families with parental mental  
illness?**



## **Community Best Practice Self-Assessment Checklist**

### **I. Integrated Service Planning and Delivery:**

1. Is there advance planning?
2. Is there Integrated Case Management/Family Centred Case Management or care team?
3. Does the planning process always include references to strengths and assets as well as challenges and problems?
4. Is there a mechanism for resolving problems and misunderstandings that may arise in case management?
5. Do treatment plans include a family and relationship perspective and include a Global Assessment of Relational Functioning (GARF) and/or Genograms?
6. Do case managers routinely coach parents to develop a positive supportive social support network?

### **II. Services for the Family and Natural Supports:**

#### **A. For the parent**

1. Is there a range of services available: crisis intervention (quick response), longer-term treatment and rehabilitation as needed, and flexible and continuous family supports?
2. Are there adequate resources for psychiatric treatment for the parent?
3. Are there community programs which provide advocacy services? (In areas such as disability income, housing, child custody issues, employment, etc. especially when a relapse has threatened stability of family i.e. problems maintaining housing during temporary loss of custody.)
4. Is there adequate affordable housing?
5. Is flexible, affordable childcare available?
6. Are there opportunities for planned respite care?
7. Do schools make an effort to help parents support their children in school? (i.e. notification to parents of school absences.) Is there an identified person at the child's school who can actively maintain a positive relationship with the parent?
8. Are parent education and support programs available? Are specific areas of parent training addressed which relate to the parent's illness (i.e. advance planning, effect of parental mental illness on children, etc.)

9. Are family planning information and resources readily available?
10. Is counselling around custody and relinquishment of custody available?
11. Is couple and relationship counselling available if needed?
12. Are family violence resources available if needed?
13. Is parenting capacity assessment readily available in the community from professionals who have training and experience working with people who suffer from mental illness?
14. Is there expertise in the Community for assessing and treating concurrent disorders (i.e. parents with mental illness who also have a substance abuse problem)?

## **B. For the children**

1. Are there psycho-educational materials and/or groups for children appropriate to the child's developmental stage/age?
2. Are mentors/alternative care providers available for each child?
3. Are services available to protect children from taking on too much responsibility for care-giving in the family?
4. Does the parent's mental health worker and psychiatrist know the children?
5. Can an immediate response be made to the child if the parent is suffering a relapse?
6. Is therapy available for the children if needed?
7. When a patient is hospitalized, is there a quick response to the children?
  - Do hospital workers regularly inquire about the children and how they will be cared for?
  - Is direct contact with the children, if appropriate, made by a helping professional when a parent is hospitalized?
  - Are children kept informed about their parent's well being during the hospitalization? Do hospitals have visiting areas appropriate for visits by the children (if desired by both the child and the parent)? Are hospital personnel, or the family doctor willing to talk to the children about the issues around the hospitalization?
  - Are printed materials related to children's needs available at the hospital?

## Overhead F-3 (continued)

### C. For family members, friends, support system and community

1. Are consumer support groups available for (a) parents (b) children (c) family members (d) adult offspring?
2. Are community agencies (community centres, neighbourhood houses, family place, parent-child drop-ins, etc.) knowledgeable about mental illness, and able to reach out to and welcome these families?
3. Is there adequate foster care support and linkage?
- 4.

### III. System Wide Practices

1. Is there cross training of child welfare, adult mental health, child and youth mental health in the areas of:
  - Healthy and unhealthy attachment patterns
  - Developmental needs of children
  - Family systems theory and approaches
  - Legislation
  - New developments in the field, i.e. the needs of children and families when the parent has a mental illness
2. Is there a reduction of stigma through regular community education?
3. Is there an integrated, on going local planning forum or committee where key stakeholders, agencies (child welfare, adult mental health, hospital, child & youth mental health, community health) meet to build working relationships and review and plan services?
4. Is there a community forum for regular review of issues of privacy/confidentiality and sharing of information?
5. Is there a community forum for confidential review of complex issues or cases that fall between the gaps?

## Overhead F-3 (continued)

### IV. Attitudes That Work

1. Promotion of the honouring of the struggle through mental illness
2. Cultural sensitivity
3. Sensitivity to poverty and disability issues
4. Recovery model focusing on strength, empowerment and wellness
5. Blurring boundaries to build a fusion of support for families with mental illness: i.e. expanding mandates to overlap and cover gaps in service.
6. Promotion of natural supports to families.

Check list items are from recommendations provided by over 300 participants at the Provincial Forum on Children Whose Parents Have Mental Illness, September 1999, The Roundhouse Community Centre, Vancouver, British Columbia. The checklist was further refined by a review of the literature and in consultation with experts.

## BACKGROUND INFORMATION for OVERHEAD F-3

### Annotations on Community Best Practice Self-Assessment Checklist

#### I. Integrated Service Planning and Delivery

##### 1. Is there advance planning?

Please see page 166 for further information on this point.

##### 2. Is there Integrated Case Management/Family-Centred Case Management or a care team?

Please see page 172 for further information on this point.

##### 3. Does the planning process always include references to strengths and assets as well as challenges and problems?

Solution Focused therapy has identified the pitfalls of “problem saturated stories”. Stories full of problems may give a distorted perception of the family situation. In order to promote better outcomes, we need a balanced perspective.

Parents with mental illness often feel deeply pathologized. While understanding mental illness is imperative, it is also important to understand the person with the mental illness. The full story of any parent is more than their mental illness. There is also their story of struggle to maintain a healthy family in spite of their challenges.

One way that attention can be given to strengths is to include them as a part of documentation forms and the agendas for meetings. For example, one case manager working within an integrated case management meeting always asks the questions, “What is going right so far?” or “What strengths have people noticed?”

#### **4. Is there a mechanism for resolving problems, hurt feelings and misunderstandings that may arise in case management?**

Case management teams are human groups and it is natural for there to be differences and, sometimes, conflict. Conflict can be healthy if managed appropriately. In fact, conflict is often a sign of growth in the group process. When each point of view is allowed to be respectfully expressed, it provides all concerned with a better understanding of the dynamics, challenges and strengths in the family and team.

Having an advocate, particularly with a large group of professionals, often helps parents with mental illness. The advocate should meet with the parent prior to case management meetings so that they accurately understand the concerns and feelings of the parent. In this way the parent's voice can be more clearly heard. The case manager can act as advocate, but sometimes it may be helpful to have another mental health consumer or friend act as advocate.

One method for encouraging people to deal with conflicts is to regularly ask members for a "feelings check-in". Each member of the group is asked to comment on how they feel about the meeting. This can be done in the middle of a meeting by the Chair, or at the end of a meeting. If there are feelings of hurt or frustration, they can be dealt with then or, put on the agenda for the next meeting.

There are two important principles that may at times seem to be in conflict: confidentiality and family inclusion. Adult mental health services have prized confidentiality, at times to the exclusion and disempowerment of families and patients. There needs to be a balance. Advanced planning is the best place to discuss these issues, but at times, this may not have been possible. In these cases, it would be important for care providers to be routinely prompted to inquire about the needs of dependent children.

Someone needs to ask the question, "What about the kids?" Care providers need to insure that there is an appropriate person able to address the questions

and practical needs of dependent children. This could be a relative, a friend or a social service agency.

What is explained to a dependent child when a parent has been hospitalized with a suicide attempt? Case management processes need to sensitively address the requirements of confidentiality while considering the needs of the children for appropriate information, attention to their feelings and practical needs.

#### **5. Do treatment plans include a family and relationship perspective and include a Global Assessment of Relationship Functioning (GARF) and/or genograms?**

The Global Assessment of Relationship Functioning (GARF) Scale was introduced with the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) and is used in a manner parallel to the Global Assessment of Functioning (GAF), registered on Axis V of the formal psychiatric diagnosis. Clinicians who make specific use of the GARF draw the attention of others to the relational context of mental illness. This may help avoid the error of separating people who suffer with mental illness from the social context in which they live.

Agency planning documents that require overall family assessment insure that the “family perspective” is not lost. Simple requirements, such as the inclusion of genograms with case plans, help treatment staff and planners to understand the context and patterns within the family system.

#### **6. Do case managers routinely coach parents to develop a positive supportive social support network?**

Parenting and mental illness both tend to isolate parents. In relation to the expression “it takes a village to raise a child”, parents with mental illness often do not have a village. Parents with mental illness may need coaching and support to find social networks that fit for them. For example, a family support worker could take a parent to a family place enough times that the parent would begin to form relationships that are enduring and natural. In other cases, a mental health

outreach worker may go with a parent to a church, temple, mosque or synagogue until the parent feels comfortable and included.

## **II. Services for the Family and Natural Supports:**

### **A. For the Parent**

#### **1. Is there a range of services available: crisis intervention (quick response), outreach, assertive case management, longer-term treatment and rehabilitation as needed, and flexible and continuous family supports?**

Most serious mental illnesses are both chronic and episodic, presenting some level of ongoing disability, as well as periodic crises. The level of intensity of services needed by the family will change over time, but the removal of all services after a crisis has been resolved can lead to increased stress for the family, and increase the possibility of future problems. Continuity in family supports allows for quicker crisis response, with corresponding less damage to the child/parent relationship, and encourages appropriate action to promote recovery for both the parent and the family.

Many communities have social and vocational rehabilitation programs. Are staff in these programs trained in issues related to childcare? Does the programming they offer promote a vision of recovery that includes family recovery? The self-worth of parents is inextricably tied to their experience as parents. It is important to strengthen this capacity in order for them to experience themselves as successful parents with significant skills that contribute to client rehabilitation.

#### **2. Are there adequate resources for psychiatric treatment for the parent?**

This is the key factor in the ability of people with mental illness to maintain healthy relationships and functions. Honest, open and collaborative relationship between physicians, mental health workers and client are essential, particularly during pregnancy.



Trauma and abuse counselling are important areas to address in the patient's treatment, as the rates of physical and sexual abuse among both women and men with mental illness concerns are very high. Evidence suggests that parenting often

re-awakens issues regarding trauma, especially childhood trauma (Fisher, 1998). Substance abuse treatment for persons with concurrent disorders should be available if needed.

The psychiatric and physician communities require supports in order to gain greater compliance from their patients in medication use. Training in behavioural medicine and adequate session time to consult with mental health workers can enhance a physician's ability to insure compliance with their prescription regime.

Problems with access to funding may impede compliance with medication treatment. Physicians must be empowered to understand and consider these issues with their patients.

### **3. Are there community programs that provide advocacy services?**

Advocates available in the community help with issues such as poverty and disability income, housing (especially the maintenance of housing if the children are placed outside the home for a period), and child custody issues. Effective advocacy may decrease the harm that occurs with a relapse by maintaining the person's housing, employment, and custody of children. Advocates can also provide information and referral to programs that may assist these families, such as subsidized housing, co-op housing, and supported living environments.

### **4. Is affordable adequate housing available for families?**

Families require affordable housing to maintain stability. Mental illness often brings an aura of "crisis" into the lives of families. All family members benefit from having secure housing in a healthy community. This is a primary prevention activity as it may add opportunities for community support that are so essential in

the lives of children. Without these opportunities, families often move frequently or accept sub-standard conditions. This then adds to a lack of roots so essential to us all.

**5. Is flexible, affordable childcare available?**

Good, consistent care for the child is an important aspect of family stability. This includes before and after school care, as well as daycare for preschool children and home care workers. Childcare reduces stress for the parent, while often providing an enriching experience for the child. Childcare allows the parent to attend treatment and to engage in education or work.

**6. Are there opportunities for planned respite care?**

Respite care refers to overnight childcare arrangements, which may be available as needed, or on a regular weekly or monthly basis. Long term arrangements with respite caregivers in the community, whether extended family members or contracted foster parents, can make a huge difference in the quality of children's early experience, reduce stress on parents, and develop relationships which allow the child to stay in a familiar setting during a crisis.

**7. Do schools make an effort to help parents support their children in school (i.e. notification to parents of school absences)? Is there an identified person at the child's school who can actively maintain a positive relationship with the parent?**

Parents who have a mental illness may require assistance relating to the school system. They may have odd behaviour that is not understood by school personnel, other parents, and students. They may have had a difficult personal history with the education system. A neutral, welcoming contact person at the school can help the parent feel more comfortable, and provide feedback from the school as to how the children are doing before problems build.

**8. Are parent education and support programs available? Are specific areas of parent training which relate to the parent's illness addressed?**

Do the service providers have an understanding of mental illness, and are they able to access mental health consultation when needed? Is parent education available to both parents? Drop-in parenting / family support programs, such as family places, allow the parent to participate at their own comfort level. However, specific coaching may be necessary to assist parents to use these types of resources, as these parents may be isolated and so miss out on much of the informal sharing about child raising with other parents in the community. Specific topics of relevance to parents who have a mental illness may be offered as workshops, as ongoing groups targeted towards mental health consumers (i.e. the Filial Therapy Demonstration Project), or as content in other parenting classes (i.e. the effect of parental depression on children's behaviour). Parents may be dealing with very difficult to manage children, due to the stresses the children may have experienced, as well as psychiatric problems the children may have.

Dr. Judith Cook (2000) suggests that peer support, self-help and parent mentoring are valuable to parents who have access to these supports. She noted, "research suggests that opportunities to be mentored by other parents who have "been there" are important ingredients in client support programs for parents with mental illnesses" (p. 14).

Assistance with parenting may be required by parents who have a mental illness because their children may have moderate to severe behavior problems. The parents may have less effective parenting practices, which lead to child's vulnerability to affective disturbances and interpersonal struggles (Beardsley, 1998). Research indicates that children of depressed mothers are frequently more difficult to raise than children of nondepressed mothers, perhaps because impaired parenting leads to decreased social competence, which in turn leads these children to elicit more negative communications from their mothers (Hammen, 1990).

A research group in Boston specifically targeted the development of resilient traits in children age 8-15 growing up in homes with parental mental illness.

They developed two preventive protocols, which were given to the parents either individually by the physician, or in a group lecture, designed to help parents learn how to promote resilient traits in their children and to modify risk factors associated with the mental illness. Both interventions improved communication about the illness within family members. Both reduced levels of parental guilt and increased understanding of the illness by the child. The findings indicate that providing parents with factual information regarding risk and resiliency in children can result in changes in illness-related behaviours and attitudes and provided for greater family change. (Beardslee, et al, 1997).

### **9. Are family planning information and resources readily available?**

Research has shown that women with mental illness are less likely to receive birth control counselling, and are at a higher risk for unplanned pregnancy (Mowbray, et al, 1995). Research suggests that women may become pregnant in order to replace children lost through custody termination, and this points to the essential nature of counselling around pregnancy decision making: issues of loss and grief need to be dealt with (Cook, 1999).

### **10. Is counselling around custody and relinquishment of custody available?**

Concerns about custody and relinquishment of custody are major issues for parents who have mental illnesses. Professional counselling could support the parents in making the best decision for themselves and their child. Counselling after the ill parent has relinquished custody is particularly important to help the person deal with intense grief. Even parents who have “lost” custody can continue to play an important role in their children’s lives and may require help with parenting in this situation.

### **11. Is couple and relationship counselling available if needed?**

Relationship difficulties have been identified as significant risk for a parent suffering from mental illness (Rutter, 1990). Frequently associated with

depression and other psychiatric problems for spouses (Merikangas, et al, 1988). Relationship conflict often precipitates the onset of depressive illness (Beach & Nelson, 1990). Problems in the relationship have a negative impact on parents' ability to care for their children. The combination of parental mental illness and divorce is associated with poor outcome in the offspring of parent with mental illness (Beardsley, et al, 1993).

## **12. Are family violence resources available if needed?**

Family violence resources, i.e. "On Solid Ground Program" in Upper Fraser Valley, "Peggy's Place" in Vancouver are designed to particularly help women who have a mental illness. Training for transition house workers about mental illness is important so that women with mental illness can utilize the resources in their communities. Cross training about family violence is important for mental health workers as well.

## **13. Is parenting capacity assessment readily available in the community from professionals who have training and experience working with people who suffer from mental illness?**

Dr. Cook (2000) stated that "assessments need to involve the entire family and to be conducted, as much as possible, in the home and larger community. The assessment must focus as much on strength as on weakness" (p. 14). When parents interact with child welfare authorities, they have a deep sense of vulnerability. It is important therefore while considering the limitations imposed on them by the mental illness, their strengths must also be identified, recounted and considered.

Psychologists with forensic training conduct most parenting assessments. This may lead to a "guilty" or "not guilty" mentality that can further wound the capacity of parents to care for their children once their illness is under control. It is important that parenting capacity be considered, in this case, in a formative, not summative manner.

**14. Is there expertise in the Community for assessing and treating concurrent disorders (i.e. parents with mental illness who also have a substance abuse problem)?**

Parents with mental illness may use alcohol or drugs as an attempt at self-medication.

**Epidemiological studies frequently cite prevalence rates of 50% of persons with serious mental illness struggle with substance use or abuse issues.**

This of course complicates the course of the illness and its management. Care providers can be confused or diverted from attending to the underlying mental illness because substance abuse issues appear prominent.

The “dually affected” people are often difficult to house in hospitals. If they do not fit in hospitals they often do not fit in substance abuse treatment programs. They therefore require service providers and programs to be sensitive to both issues and to be prepared to move on both fronts. Collaboration between experts in both fields and specialized services is required.

**B. For the Children**

**1. Are there psycho-educational groups at appropriate developmental stages/ages?**

Family members can benefit greatly from basic information about the mental illness, the usual course of the illness and practices that may help. Equipped with the correct information, even the young child can feel more secure in the face of uncertainties brought by the illness.

The British Columbia Schizophrenia Society (BCSS) has developed a group program for youth called “Kids in Control”. The group was named by participants who said that the information and the group itself gave them a feeling of being

back in control of their lives even though there was mental illness in the family. Groups often overcome a sense of isolation and melt that estrangement of stigmatization.

Psycho-education groups for young children, teens and spouses can be the beginnings of a peer support group. The BCSS has taken a curriculum, designed originally for children from families with parents with substance abuse problems and adapted it to the unique issues of mental illness. Children are taught the three C's:

I didn't cause it  
I can't change it  
I can care for myself

Often people have the capacity for resiliency. Accurate information and the social contact of understanding peers may release it.

Psycho-educational groups usually consist of weekly meetings for eight to ten weeks. Various topics of interest to group members can be pursued. It is usually helpful to deal with some of the misinformation about mental illness, help participants talk about stigma, learn stress management and discuss healthy self-care.

The effectiveness of family sessions where a professional educates the family together about the illness has been demonstrated in recent studies (Beardsley, et al, 1993).

## **2. Are mentors/alternative care providers available for each child?**

Mentors can support children to develop resilience through play, education, and group activities such as sports, artistic/theatrical endeavors, clubs, and skill development. Examples of potential mentors may be volunteers from Big Brothers and Big Sisters, respite caregivers, childcare workers, school personnel, cubs, scouts, and guide leaders, church groups, neighbours, and involved family members.

### **3. Are services available to protect children from taking on too much responsibility for care giving in the family?**

This could consist of parent training which emphasizes teaching parents about normal child development and appropriate roles for family members; providing care giving supports such as homemakers; and counselling which teaches children about appropriate family roles and how to ask for support to care for their ill parent, as well as for themselves and their sisters and brothers. Adult oriented workers may need training about the potential harm to children of taking on a parentified role in the family, as children are still routinely used as interpreters and are often expected to take on a care giving role to their parents and younger siblings. The ill parent should be cared for as if the children are not available as caregivers.

### **4. Do the parent's mental health worker and psychiatrist know the children?**

For many years, children of adult mental health consumers were described as “the invisible children” (Fraiberg, 1978) and were virtually ignored. The adult's care provider is often the first professional to encounter their client's children, and to facilitate resources that may be helpful for them. As well, the adult's care provider is often the first professional aware of deterioration in the parent's mental health, and is in a position to arrange for supports for the children and family when needed.

The presence of mental illness in the parents should alert clinicians to the possibility that the children may be in need of further services (Beardslee, 1998).

### **5. Can an immediate response be made to the child if the parent is suffering a relapse?**

Acute episodes of mental illness can escalate very quickly, posing a risk to the child of neglect or emotional and/or physical abuse. It is frightening and can be traumatic for children to be with a parent with a serious thought or mood disorder.



Long-term damage can occur to the parent-child relationship. In families where there is a history of mental illness, concerns about physical and emotional safety should be responded to immediately. Once again, this also comes down to children having the direct contact with someone they can trust that they know how to contact in a crisis: coaching on who to call and how to do it in a crisis.

## **6. Is therapy available for the children if needed?**

Children of parents who have a mental illness are more likely to develop symptoms of depression, oppositional defiant disorder, and conduct disorder. Trauma, poverty, substance abuse in the family, repeated separations from the ill parent, and unhealthy parent/child relationships may complicate treatment issues for the child. Individual therapy may need to be re-started several times for each child, as the child enters new developmental stages. Obstacles such as transportation difficulties may need to be addressed.

## **7. When a patient is hospitalized, is there a quick response to the children?**

- Do hospital workers regularly inquire about the children and how they will be cared for?
- Is direct contact with the children, if appropriate, made by a helping professional when a parent is hospitalized?
- Are children kept informed about their parent's well being during the hospitalization? Do hospitals have visiting areas appropriate for visits by the children (if desired by both the child and the parent)? Are hospital personnel, or the family doctor willing to talk to the children about the issues around the hospitalization?
- Are printed materials related to children's needs available at the hospital?

When a parent is hospitalized there is also the immediate concern that the child has been living with a seriously disturbed person, and this may have been a traumatic experience. If the parent was committed involuntarily, the child may have had an

upsetting frightening experience during the committal process. Mid to late adolescent children who do not ask for, or reject help may remain in the home with no additional support. This is a case where mental health professionals can make a big difference in providing psycho educational support to the child and the child's caregiver during the crisis, around the needs that the child is likely to have during this time, and the expected behaviours. Workers can anticipate the child's questions and answer them accurately using correct language. Visiting in hospital may or may not be a good idea, and is ideally something that can be discussed with the parent prior to a mental health crisis.

### **C. For Family Members, Friends, Support System and Community**

**1. Are support groups available for (a) parents (b) children (c) family members (d) adult offspring?**

**2. Are community agencies such as family place, parent-child drop-ins, etc. knowledgeable about mental illness and able to reach out and welcome these families?**

Research has shown that parents who have a mental illness prefer to access normal neighbourhood resources (Cook, 2000). However, many of these parents require encouragement and outreach to help them utilize supportive community resources. Volunteers who can provide a "buddy system", or knowledgeable staff who can make a special effort to involve these families can make a significant difference in the family's ability to expand their social network by participating in community programs.

**3. Is there adequate foster care support and linkage?**

There is a critical need to assist parents in connecting with foster placements. If foster parents understand attachment processes and mental illness, they are more empowered to work collaboratively with parents. Foster parents who care for children of persons with mental illness may often experience themselves

working as much with the parent as with the child. There are often serious difficulties because of possible conflicting roles between parents and foster parents. At times foster parents and parents will require additional supports, either through a social worker or other support personnel.

### **III. System Wide Practices**

#### **1. Is there cross training of child welfare, adult mental health, child and youth mental health in the areas of:**

- Healthy and unhealthy attachment patterns
- Developmental needs of children
- Family systems theory and approaches
- Legislation
- New developments in the field, i.e. the needs of children and families when the parent has a mental illness?

Shared understandings are a cornerstone of effective integrated case management and community coordination. Cross training can combine community building, networking with establishing a shared paradigm for supporting families.

#### **2. Is there reduction of stigma through regular community education?**

Public education is important to combat stigma, and could involve the whole community, including the local media. Partnership education programs involving consumer groups along with professionals are particularly effective.

Communities are fluid processes, with new members entering and others leaving. There is a need for continuous regular public education at appropriate intervals to build a base of understanding. While important, “one shot” education campaigns are not sufficient. We learn from the advertising industry that repetition and redundancy are effective principles. This would mean that communities intent on building a culture of understanding have multi-year community education plan.

**3. Is there an integrated, on going local planning forum or committee where key stakeholders, agencies (child welfare, adult mental health, hospital, child & youth mental health, community health) meet to build working relationships and review and plan services?**

If shared understanding is one “leg” of integrated case management; “relationships” are the other. Service providers and service planner require regular, routine opportunities to meet and come to know each other. This can add significantly to the base of trust that is necessary for a sense of community. This in turn supports integrated case management and strategies that may, if necessary “work outside the box” to meet the needs of families with parental mental illness.

In British Columbia, many communities have Child and Youth Committees. These committees meet, usually on a monthly basis, bringing together governmental, non-governmental and voluntary resources to plan for children and families. These committees will often have mandates that include integrated service planning, service coordination, information sharing and at times, advocacy. As educators would say, the “unwritten curriculum” of these processes is the formation of relationships that improve the efficiency and effectiveness of “business”. Sadly, at times this committee work is seen as peripheral to main agency mandates instead of as basic requirement of good service.

**4. Is there a community forum for regular review of issues of privacy/confidentiality and sharing of information?**

Care providers often experience difficulty with protecting confidentiality, as well as sharing information, due to the reality of stigma and serious consequences of how it affects the family. This may improve if parents are more involved with planning and given the opportunity to make clear statements about how they would like information about the family shared among other agencies.

## **5. Is there a community forum for confidential review of complex issues or cases that fall between the gaps?**

Collaborative work is needed between agencies in order to develop links and partnerships, including representation from adult mental health as well as family and child mental health.

Clinical sub-committees of Child and Youth Mental Health Committees (CYC) in British Columbia have provided a forum for review of shared cases. While protecting the privacy of citizens, these committees insure that integrated case management is healthy and taking place, particularly with more demanding cases.

## **IV. Attitudes that Work**

Although difficult to measure and identify, prevailing attitudes form a culture in a human service sector. Certain practices and attitudes promote safety, confidence and a sense of empowerment while others create fear, futility and dependency. Below are some ways of thinking, which if promoted throughout the service sector and with families, can facilitate empowerment.

### **1. Honouring the Struggle Through Mental Illness**

This refers to recognition that mental illness is not a personal flaw, it is not a choice, and it is an illness. This means respecting the sufferer in the way that one would someone with another medical illness that could have severe consequences on one's ability to function, such as multiple sclerosis, diabetes, kidney disease, etc. It means not "talking down" or patronizing. It means taking the time to really listen to the unique experience of the other person.

People suffering from mental illness often go through a very difficult diagnostic process involving years before there is final acceptance. In that process there is often a great deal of pain, misunderstanding and injury caused by societal stigma regarding mental illness. Those suffering from mental illness deserve the same respect and care as someone dealing with a serious, life disrupting physical

illness. Mental illness frequently leads to marginalization. It is important to be sensitive to this pervasive aspect of the sufferer's experience.

## **2. Cultural Sensitivity**

Serious mental illness cuts across cultures, but there may be differential meanings and implications for those affected, depending on cultural factors. Care providers need to seek to understand the differential cultural perspectives on mental illness.

## **3. Sensitivity to Poverty and Disability Issues**

Beyond culture defined by ethnicity, long-term persistent mental illness is so life disrupting that it frequently leaves families in poverty. Care providers are often salaried, middle class acculturated.

Your community might ask, "In what ways are those working with those affected by mental illness helped to understand the culture of poverty and its implications on the mental illness?"

As with any long-term illness, mental illness often has a course and adaptive stages. It is a serious disability and care providers need to understand the economic, practical and psychological implications of such a long-term disability. Do care providers understand learned helplessness? Marginalization? Do they understand that depression often accompanies any disability?

## **4. Recovery Model Focusing on Strength, Empowerment and Wellness**

Mental illness, by definition, is rooted in the discipline of psychiatry and diagnostic formulations. In the classification of disease there is a search for symptoms to understand and describe the illness. This can lead to a focus on illness while limiting an assessment of personal strengths, initiatives taken to minimize the symptoms, and adaptive strengths and mechanisms. Fortunately, it is more common now that psychological and psychiatric assessment will include sections or comments on strength. Nonetheless, it is important to guard the "strengths finding perspective" as a corrective balance.

The metaphor of recovery, taken from addiction studies, can be useful in understanding mental illness. It includes the notion of early and acute phases, of recovery and relapse, or various ways of restoring functioning. It is a more hopeful frame of reference. There is new hope in the treatment of mental illness that makes the recovery model more realistic.

Support providers and community members who balance their understanding of illness with the knowledge that people often grow from their strengths, will look for strengths. This is frequently more empowering to family members as they feel affirmed and noticed for positive qualities and activities.

Finally, balancing the field of mental illness with an interest in mental wellness can again bring a sense of hope, a tonic in long-term disability. What does “wellness” look like in a family where there is serious mental illness? Can moments of wellness be affirmed and celebrated? This perspective will be affirming to those who suffer and those who are affected.

## **5. Blurring Boundaries to Build a Fusion of Support for Families with Mental Illness.**

Currently there is no single agency with a mandate to support all the family members affected by a mental illness. For example, the counselling needs of the children whose parents have mental illness are not a part of the mandate of the provincial child and youth mental health program. Their needs are not a part of the mandate of adult mental health either. Who is responsible to take the lead responsibility for these children? They are not necessarily a child welfare concern. So who?

Social agencies that break out of the strict mandate mould are required to work in partnership with others through integrated case management in order to make the difference. This has to do with the professionals’ sense of commitment to “community” as much as to “mandate” or their organization role. Responsible managers in agencies are needed who provide the flexibility for staff to respond to those clients who “fall between the cracks”.

## 6. Promotion of Natural Supports to Families

Professionals and all involved need to realize the limits of “professionalism” and acknowledge the real power that comes from natural supports: neighbours, clubs/organizations, communities of faith such as churches, and schools. Feelings of belonging, having roots, and community acknowledgment can be important antidotes to the negative consequences of stigma and long-term disability. The building of community itself, through the use of Integrated Case Management and in more naturally occurring methods, can have a similar effect. Best practice in supporting families with parental illness includes communities reviewing the attitudes held and promoting attitudes that empower and affirm.

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# Annotated Bibliography



## Annotated Bibliography

**A Lasting Impression: A Teacher's Guide to Helping Children of Parents with a Mental Illness.** Canadian Mental Health Association, Alberta, South Central Region. 103, 723y-14 Street N.W., Calgary, AB T2N 2A4. Telephone: (403) 297-1700. Fax: (403) 270-3066.

This handbook is a guide for teachers and other community professionals who want to support children who have a parent with a mental illness. The focus is on prevention and on lessening the impact of mental illness in children's lives.

**BC Council for Families Magazine, Family Connections, Volume VII, #1, Spring 2000. Special Issue: Focus on Children Whose Parents Have Mental Illness: Building Best Practices to Support Families in BC**

This special magazine issue displays articles on the topic. Most of the information comes from a Forum supported by the Ministry of Children and Family Development and the Ministry of Health Services held at the Roundhouse Community Centre on September 30, 1999. Articles from the two guest presenters, Dr. Marsh and Dr. Cook are included in this issue as well.

**Brindamour, Lyne. (2000). Someone in my Family Has a Mental Illness.**

**British Columbia: Family Services of the North Shore. 101-255 West 1<sup>st</sup> Street, North Vancouver, B.C. V7M 3G8, Telephone: (604) 988-5281, Fax: (604) 988-3961.**

This is a workbook designed for children between the ages of seven and fourteen. Through art, talking and writing, children can share their experiences. This workbook is to be used by professionals in the community and by parents and caregivers who wish to educate their children about mental illness.

**Clark, J.I., & Dawson, C. (1989). Growing Up Again: Parenting Ourselves, Parenting Our Children.** United States of America: Harper & Row, Publishers, Inc.

This book is written for parents. It is a tool for parents to look at what they may be doing that is not very helpful and how they can try different methods of parenting. Stages of development are explored and the authors are very specific about the kind of behaviors that are not helpful for children to grow. They provide useful suggestions about making some changes for personal and family growth.



**Dinkmeyer, D., Sr., McKay, G.D., Dinkmeyer, J.S., Dinkmeyer, D., Jr. & McKay, J.L. (1997). Parenting Young Children: Systematic Training for Effective Parenting of Children Under Six. American Guidance Service, Inc., Circle Pines.**

This is an educational book for parents. It provides information about parenting styles, children's developmental tasks and parenting skills to support children in all aspects of their development.

**Gopfert, M., Webster, J. & Seeman, M. (1996) Parental Psychiatric Disorder: Distressed Parents and Their Families. Great Britain: Cambridge University Press.**

This collection of articles by different authors looks at the issue of parental mental illness as well as child care issues. The perspectives in every article are varied, from the medical approach to the legal, and psychological and clinical approaches. Some specific programs for families and clinical interventions are of particular interest to professionals working in the community.

**Holley, T.E. & Holley, J. (1997). My Mother's Keeper: A Daughter's Memoir of Growing Up in the Shadow of Schizophrenia. New York: William Morrow and Company.**

This is a captivating first person account of how a mother's mental illness impacted a daughter's life. This is a story of survival, which includes the journey through pain, denial, grasping for hope, surviving days of despair, and coming to terms with her mother's legacy.

**Kids Speak Up: Shining Light on Mental Illness. The Canadian Mental Health Association, #103, 723-14 Street N.W., Calgary, Alberta T2N 2A4. Telephone: (403) 297-1700. Fax: (403) 270-3066.**

Children share their experiences by telling us their stories. This is a vibrant and colorful small handbook.

**Levy, T. & Orlans, M. (1998). Attachment, Trauma and Healing: Understanding and Treating Attachment Disorder in Children and Families. Washington, DC: CWLA Press.**

The authors give us a historical perspective about the theory of attachment. The different stages in early infant, toddler and preschooler and the children's interaction with their caregiver for the development of healthy attachment is well explained and backed by research. In this book the authors explain how to assess and to examine the behaviors displayed by children with Attachment disorder from infants to adolescents. Treatment and "attachment therapy" offered by the Evergreen Consultants and their brief intensive outpatient therapy is described in this practical and informative book.

**Marsh, D.T. (September, 1999). Speakers notes, Vancouver Forum for Children Whose Parents Have a Mental Illness.**

As one of two keynote speakers, Dr. Dianne Marsh shared her knowledge and expertise with an audience of approximately 300 persons who were interested in learning how to better support children and families where there is parental mental illness. An outline of her presentation, was provided to each participant in the forum. The outline included information on the issues and challenges faced by children growing up where there is parental mental illness, as well as the impact or legacy that follows such an experience. Also included in the participant booklet, were speaker notes from Dr. Judith Cook, who spoke to the issue of the challenges of parenting when one suffers from a mental illness.

**Marsh, D.T. & Dickens, R.M. (1997). How to Cope With Mental Illness in Your Family. (Originally published as Troubled Journey: Coming to Terms with the Mental illness of a Sibling or Parent. New York: Jeremy P. Tarcher/G.P. Putnam's Sons.**

This is written for persons who have a sibling or a parent with a mental illness, this book does a superb job of portraying the various experiences of persons who have grown up with family members who have or had a mental illness. Quotations are used extensively, giving readers an intimate portrayal of the very difficult and trying experience that has defined the lives of those whose parents or siblings suffered from a major mental illness. The book identifies the themes that permeate the personal lives and stories of the family members and provides positive direction and suggestions for family members to help improve their own resilience and successful coping. Both of the authors are very familiar with the subject matter, and bring the richness of personal experience as family members to their perspective. Dr. Dianne Marsh works with persons with serious mental illness and their families, and Rex Dickens developed the first support group for siblings and adult offspring, and served on the board of the Adult and Sibling Network of the National Alliance for the Mentally Ill (NAMI).

**Micklovicz, D.J., & Goldstein, M.J. (1997). Bipolar Disorder: A Family Focused Treatment Approach. New York, London: The Guilford Press.**

This book has a practical approach to working with families who have a member with Bipolar Disorder. The authors describe their psychoeducational approach and treatment and include all family members. This book is written with sensitivity and clarity. The handouts provided are easily photocopied by permission of the authors and are quite comprehensible. It is easy to read and includes many case study examples to keep our interest.

**Miller, S.B. (1995). When Parents Have Problems: A Book for Teens and Older Children with an Abusive, Alcoholic, or Mentally Ill Parent. Springfield Ill.: C.C. Thomas.**

This book is written with sensitivity and understanding for the teenage child who is struggling with understanding that many of the problems that clutter one's life may not be all his fault, and may in fact be due to difficulties that belong to the parent. The book does a good job of explaining the concepts of boundaries, self-care, and helps the reader understand the difference between being co-operative and being neglected or abused. By providing explanations, which help a teen to understand themselves and their ill parents better, and by providing information for accessing other resources, the book offers support to teens that find themselves in difficult situations.

**Rice, F.P. (1997). Child and Adolescent Development. Upper Saddle River, NJ: Prentice Hall.**

This is a comprehensive text which covers the physical, emotional, and psychological development of the child from birth to adulthood. The book covers major theories of development, and provides commentaries on different worldviews. It also provides a wealth of information to guide one's study of childhood and adolescence.

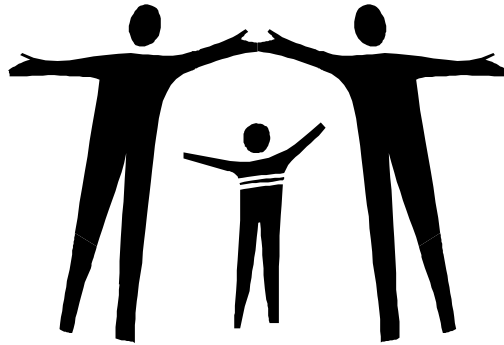
**Secunda, V. (1997). When Madness Comes Home. New York: Hyperion.**

This book recognizes the impact that mental illness has on the other persons in the family, including spouses, siblings and children of persons with a mental illness. Personal accounts and case studies give a poignant portrayal of the experience of mental illness, including the impact that mental illness has had on family ties, relationships, career choices, and sense of self. The book includes practical and helpful suggestions and sources of support. Victoria Secunda writes from the perspective of having an adult sibling with a mental illness, and in an attempt to find her own answers, has researched the experience of other family members.

**Walsh, F. (1998). Strengthening Family Resilience. New York: Guilford Publications.**

This book has a strength-based approach to working with families. Families are seen as facing challenges instead of being filled with problems. Fostering positive communication between family members and looking at their courage, the author does not view distress and difficult situations as pathology but as an opportunity for the families to learn and grow. In her writing she provides therapeutic practice guidelines along with case vignettes for professionals working with distressed and/or multicrisis families.

# CURRENT PROGRAMS



## **KIDS IN CONTROL**

### **Philosophy**

Kids in Control is a psychoeducational support group for children who have a parent with a mental illness. It was first developed by Dr. Rob Lees, Community Psychologist for Chilliwack, together with British Columbia Schizophrenia Society (BCSS) regional representative Marge Delange, and a local adult family member.

This program recognizes that children are family members who share fully in bearing the family burden. They are often required to manage the many difficulties that are present when a person suffers with a mental illness, but are seldom given the benefit of information or provided with support and resource services. A child's experience of growing up in a home where a parent has a mental illness has been compared to that of children whose parents abuse drugs and alcohol. The only difference is, it is ten times worse, owing to the myths and misinformation around mental illness, as well as to the burden of stigma.

### **How is it Run?**

The Kids in Control Support Group runs once per year in each of the four communities in the central and upper Fraser Valley, and consists of 1½ hour sessions once a week for eight weeks. Geared toward young children and early adolescents aged 8-13, the sessions are designed to work with a different theme each week.

**Themes for the Eight Sessions:**

1. Group building and storytelling
2. Group building and learning to identify feelings
3. Learning how to communicate feelings
4. Learning about mental illness
5. Learning about the treatment of mental illness
6. Resilience
7. Societal attitudes
8. Self-care and self-esteem

The group members are given the opportunity to develop and process each theme through the use of different arts, crafts, and interactive game activities. The children develop a sense of belonging and normalcy as they connect to a group of people through shared experiences.

Ongoing support is offered to children who have completed the eight week psychoeducational program, in the form of letters and periodic reunions throughout the year. This allows children the opportunity to remain connected to other group participants, and to discuss and process ongoing difficulties or new challenges in their circumstances.

## **PARTNERING WITH PARENTS**

### **Philosophy**

This is a parenting/social support group that runs concurrently with the Kids in Control Support Group. The purpose of this group is to provide information to parents who have questions in many of the various aspects of parenting. The intent is that the support provided to the parents will in turn result in a decrease of distress and an increase in successful coping for families where there is parental mental illness. During the course of facilitating different children's groups, Hylda found that frequently parents had many questions about how to talk to children about mental illness, how to handle difficult behaviours, and how to better understand their own mental illness. Frequently the families found it useful to visit and to spend time discussing issues with other parents. Based on these identified need, the Partnering with Parents program was started.

### **How is it Run?**

The program is loosely based on the Ready or Not program from Health Canada, and is structured to meet the needs of any given group. The individual make-up of any given group determines the focus, depending on the specific needs of that group. Sometimes there are foster parents who are struggling with how to help children understand the illness of a biological parent. At other times, the parent group may be mostly consumers who are wondering how best to talk about the illness or how to deal with children who have challenging behaviours.

The sessions are held at the same time as the children's group, so that they meet once a week for eight weeks, for 1½ hours each session. However, to allow members of both groups to share freely, the groups are held in separate locations. The facilitator is a family member who is a trained facilitator and has trained for the Ready or Not program or has taken facilitation training for the parenting program.



## THERAPLAY

### **Philosophy**

Theraplay is a demonstration/research project which is being run through the Chilliwack Mental Health Centre, and is funded through the BC Center for Excellence for Women's Health. This program is offered to mothers of young children, aged 4-9, who suffer from a mental illness.

Parenting can be an exhausting and challenging task for anyone, and can be that much more difficult when the parent is also dealing with a mental illness. Traditionally, mothers with mental illness will experience diminished support for their parenting role. This project is designed to help support mothers with a mental illness history, by attempting to improve their relationship with their children in a fun and supportive atmosphere.

### **How is it Run?**

The theraplay sessions are held once per week for 16 weeks, and include mother, child and a specialist trained in theraplay. The sessions are approximately three hours each week. Within each session the trained theraplay specialist begins by modeling interactions with the children that are age appropriate, and then he or she moves to a place of guiding and directing the interactions between mother and child. In this way, the parent and child both benefit from the structure and interaction provided during the session, with the potential for the families to continue similar interactions at home as well.

### **For More Information Contact:**

Hylde Gryba  
2739 Valemont Crescent  
Abbotsford, B.C. V2T 3V6  
(604) 864-9604  
[kidsincontrol@telus.net](mailto:kidsincontrol@telus.net)

<b>Parenting &amp; Mental Illness: Program Models – British Columbia</b>			
<b><i>Program Title &amp; Location</i></b>	<b><i>Program Focus</i></b>	<b><i>Program Description</i></b>	<b><i>Contact Information</i></b>
<b>Kids in Control</b> Chilliwack, Central and Upper Fraser Valley	Children who have a parent with a mental illness, geared towards ages 8-13 years.	A psychoeducational support group, 1.5 hr. theme-based sessions, once a week for 8 weeks, using discussion, and processing of material through arts & crafts, and interactive games. Program encourages ongoing contact and support through letters and periodic reunions.	<b>Hylda Gryba</b> 2739 Valemount Crescent Abbotsford BC V2T 3V6 604-864-9604, <a href="mailto:kidsincontrol@telus.ent">kidsincontrol@telus.ent</a>
<b>Clarica Closer Connections Program</b> A program of Family Services of the North Shore. North Vancouver	A prenatal program that women access early in their pregnancy, continuing through child birth and up to three years later.	Individual counselling and educational support for caregivers to enhance attachment with infants.	<b>Lyne Brindamour</b> Family Services of the North Shore 604-988-5281 Local 306 <a href="mailto:family@familyservices.bc.ca">family@familyservices.bc.ca</a>
<b>Partnering with Parents</b> Chilliwack, Central and Upper Fraser Valley	A parenting/social support group running concurrently with Kids in Control	Provides information to parents with questions on various aspects of parenting, with aim of increasing coping skills and decreasing distress. Addresses issues such as: how to talk to children about mental illness, handling difficult behaviours. Allow sharing of strategies with other parents.	<b>Hylda Gryba</b> 2739 Valemount Crescent Abbotsford BC V2T 3V6 604-864-9604, <a href="mailto:kidsincontrol@telus.ent">kidsincontrol@telus.ent</a>
<b>Theraplay</b> Chilliwack Mental Health Centre	Mothers of children aged 4-9 who have a mental illness	A pilot project which helps to improve the parent/child relationship in a fun and supportive atmosphere, through 16 weekly 3 hour sessions run by a theraplay specialist. Sessions allow the opportunity to model age appropriate interactions in a structured environment.	<b>Marion Fallding</b> 604-702-4860, <a href="mailto:marion.fallding@fvhr.org">marion.fallding@fvhr.org</a>
<b>The Rainbow Club</b> Vancouver			<b>Sharon Van Volkingburgh</b> 604-874-7043
<b>Support Group for Mothers</b> BCSS Squamish	Mothers with a mental illness	Group deals with issues such as: parenting skills, coping with illness, journaling techniques, household management, etc. Uses videos, speakers.	<b>Helen Brownrigg</b> , <a href="mailto:helenbrownrigg@hotmail.com">helenbrownrigg@hotmail.com</a>

## Parenting & Mental Illness: Program Models: BC - Continued....

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information</i>
<b>Mothers in Transition</b> Mental Patients' Association Vancouver	A Support Group for Mothers with Mental Illness	A group developed to increase social support for parents with mental illness who have lost custody of their children.	<b>Dawn Brossard</b> 604-871-0151 <a href="mailto:eleyn@home.com">eleyn@home.com</a>
<b>Women's Supportive Housing Program</b>	Women with mental illness	Provides assistance to women with mental illness in finding appropriate housing and short-term support.	<b>Tina Dunkley</b> 250-744-4306 <a href="mailto:dunkley@pacificcoast.net">dunkley@pacificcoast.net</a> <b>Wilma Van Wiltenberg</b> 250-727-9604 <a href="mailto:wiltenberg@kcorp.com">wiltenberg@kcorp.com</a>
<b>Healthy Connections: You and your Baby</b> Family Services of Greater Vancouver	Pregnant women of any age who have the desire to participate in the therapeutic process.	A therapeutic program that assists pregnant women to work through trauma-related issues that can interfere with their ability to parent their children.	<b>Cherie Rawlins</b> 604-874-2938
<b>Family Support Centre</b> B.C. Schizophrenia Society North Vancouver	Personal Support and Information on Major Mental Illnesses.	Offers personal support to families of the seriously mentally ill, and information on major mental illnesses to the community at large.	604-926-0856
<b>Parent Link and Kid Link</b> North Vancouver	Working Together to Create Strong Families. Group runs for 6 weeks and offers peer support, guest speakers and information on topics important to you.	Parent Link is for parents struggling with mental illness who want to teach their kids about mental illness. Kid Link is a way to help kids know that they are not alone and to learn more about mental illness.	<b>Ann</b> 604-983-6020
<b>Pacific Post Partum Support Society</b> Lower Mainland	Provides a support program for women experiencing postpartum depression (PPD).	Provides phone support, weekly support groups, partners' information sessions and information in print.	604-255-7999
<b>Reproductive Mental Health</b> Outreach Program BC Women's Hospital Vancouver	Pregnant women with mental illness, or women in post-partum stages	Provides psychiatric services to women with mental illness during pregnancy and post partum, launching provincial outreach program.	<b>Deidre Ryan</b> 604-875-2025 <a href="mailto:deryou@unixg.ubc.ca">deryou@unixg.ubc.ca</a> <b>Doris Bodnar</b> 604-875-2424 ex 6469 <a href="mailto:dbodnar@home.com">dbodnar@home.com</a>

### Parenting & Mental Illness: Program Models: BC - Continued....

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information</i>
<b>Post Partum Support Service</b> Thompson Region Mental Health Services, Kamloops	Women with postpartum mental illness	Post partum service, planning to address perinatal needs.	<b>Kerry McLean Small</b> 250-828-4183
<b>Alan Cashmore Centre</b> Vancouver Community Mental Health Service Vancouver/Richmond	Helping families build satisfying relationships with young children who are having social, emotional and/or behavioural difficulties.	Offers a range of centre-based and in-home therapy services.	<b>Screening</b> 604-454-1676
<b>Parent Infant Program</b> Vancouver/Richmond	The parent-infant relationship (Birth to 2½ years).	In home intervention focused on promoting the quality of the parent/child relationship, the social and emotional development of the infant and parental satisfaction.	<b>Mary Lee Best</b> 604-454-1676
<b>Parent Child Therapy Program</b> Vancouver/Richmond	Families with children 2½ - 7 years who are experiencing social, emotional and/or behavioural difficulties. Referral before 5 <sup>th</sup> birthday.	In-centre therapy services including individual, couple, family, play therapy, and parent counselling.	<b>Screening</b> 604-454-1676
<b>Parent Child Day Program</b> Vancouver/Richmond	Families with children 2½ - 6 years who are not managing in a community setting due to social and emotional difficulties. Referral before 5 <sup>th</sup> birthday.	More intensive services offered including morning therapeutic group, play therapy, speech and language therapy, family therapy.	<b>Screening</b> 604-454-1676
<b>Super Saturday Club</b> Cnd. Mental Health Association Vancouver/Burnaby	Fun-filled activities and social support for children aged 8-12 whose parents have a mental illness.	An opportunity for children to benefit from participating in a variety of recreational and social activities.	<b>Vancouver Rec Services</b> 604-872-3148
<b>Supported Housing</b> for Single Mothers with a Mental Illness Vancouver	A long-term housing program for mothers with mental illness	Six two-bedroom suites, with an outreach worker on staff to support pregnant women and women with children under age two. Offers parenting and life skills and education in illness and symptom management.	<b>Jirina Judas</b> 604-738-2811, ex 128 <a href="mailto:vanmpa@direct.ca">vanmpa@direct.ca</a>
<b>Youthnet</b> Vancouver	Youth (ages 15-25) participation in promoting mental health.	Engage young people in discussion about mental health.	<b>Nadim Kara</b> 604-733-6186 <a href="mailto:yphsra@vcn.bc.ca">yphsra@vcn.bc.ca</a>

## Parenting & Mental Illness: Program Models - Canada

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information</i>
<b>The Edmonton High Risk Project</b> Edmonton, AB	Adolescents between ages 13-18 with at least one parent with schizophrenia	A research project looking at the support needs of offspring of parents with schizophrenia.	<b>Philip Tibbo, MD</b> University of Alberta Hospital Dept of Psychiatry Edmonton T6G 2B7 <a href="mailto:ptibbo@pop.srv.ualberta.ca">ptibbo@pop.srv.ualberta.ca</a>
<b>A Lasting Impression</b> CMHA Alberta South Central Region Calgary AB	Children of parents with a mental illness	Psychoeducational workbook for children of parents with a mental illness; teacher's guide for helping children of parents with mental illness and other supports	<b>CMHA Alberta South Central Region</b> #103, 723-14 <sup>th</sup> St. N.W Calgary, AB, T2N 2A4 403-297-1700
<b>Children At Risk Clinic</b> Centre for Addiction & Mental Health Clarke Division Toronto ON	For families where one or both parents have a diagnosed mood disorder	For parents offers support related to learning more about their children's current social/emotional adjustment, managing difficult behaviour, accessing support systems in the community to assist in the parenting role, and understanding the effects of depression on their children.	<b>Nancy Vanderteems</b> Intake Coordinator 416 979 4747 ex 2255
<b>A Service for Women with Schizophrenia</b> Centre for Addiction & Mental Health Clarke Division Toronto, ON	For women with schizophrenia and their families	Offers comprehensive patient and family assessment, with subsequent recommendations to the treating physician about treatment and psychosocial rehabilitation, especially during pregnancy and early parenthood. Also offers home-based outreach services, substance abuse counseling, sex education, instruction of new mothers and parenting training, relationship-focused groups, and self-protection to prevent victimization in an urban environment.	<b>Mary Seeman, MD &amp; Robin Cohen</b> c/o The Clarke Institute of Psychiatry 250 College St. Toronto, ON M5T 1R8 <a href="mailto:ms@sig.clarke-inst.on.ca">ms@sig.clarke-inst.on.ca</a>
<b>Quebec Resources</b>			<b>Joanne Kielo</b>

## Parenting & Mental Illness: Program Models - U.S.A.

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information</i>
<b>Parent Infant Development Project</b> University of Wisconsin Madison	Parents with small children (0-6 yrs)	Offers parenting skills, peer support, individual therapy, family therapy and medication management, therapeutic day care, home visits, crisis intervention, and assessment.	
<b>Peanut Butter &amp; Jelly Nursery School</b> Albuquerque, NM	Parents with mental illness, substance misuse and risk for abuse/neglect of children	Offers parenting skills and home-based life skills training in conjunction with "therapeutic early intervention for infants and pre-schoolers"; rural outreach to young parents.	
<b>Invisible Children's Project</b> Orange County, NY	Parents caring for at least one child or who are seeking reunification	Offers respite and child care, supported work & education, case management, supportive housing, crisis intervention and 24-hr help line.	<b>Lucinda Sloan Mallen</b> ED of NY MH Association 914-294-7411
<b>CAPT Center</b> Huntington, NY	Mothers with at least 1 child under 5 or pregnant	Offers parenting skills, case management, peer support, therapeutic day care, assessment, crisis intervention.	
<b>Thresholds ' Mothers Project's Family Support Program</b>	Mothers 17 yrs old and over, with children 0-5 yrs	Rehabilitation focused, offers case management, medication management, vocational training and opportunities, education preparation, crisis intervention, residential services and independent living skills. Also offers therapeutic infant and preschool program to stimulate development and provide parenting skills and child development training to mothers.	

### **Parenting & Mental Illness: Program Models - U.S.A. (continued)**

<i><b>Program Title &amp; Location</b></i>	<i><b>Program Focus</b></i>	<i><b>Program Description</b></i>	<i><b>Contact Information</b></i>
<b>Ashbury House</b> San Francisco, CA	Housing for Mothers with SMI and children	A crisis stabilization house where mothers receive mental health services while retaining custody of their children. Adult services include crisis stabilization, group & individual counseling, substance misuse interventions, vocational planning & work placement, parenting classes and support system development. Children receive support and attention through child care services, groups and other activities.	
<b>The Employment Options, Inc.</b> Family Project Marlborough, Massachusetts	Parents with or without custody	Run on the clubhouse model using principles of psychosocial rehabilitation. Offers housing, 24-hr support, home visits, and parent support group. Staff supervise visits for parents who do not have custody.	
<b>Parent/Infant Therapeutic Program</b> New York, NY	Parents with at least 1 child 0 - 4 yrs	Offers parenting skills, case management, vocational/educational rehab, individual & family therapy, medication management, home-visits, help with parent-child interaction, assessment, and crisis intervention.	

**Parenting & Mental Illness: Program Models - U.S.A. (continued)**

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information</i>
<b>Parenting Options Project</b>		A 3-yr project to develop education and skill training materials for parents with mental illness. Offers a parent manual, self-assessment tool and a quarterly newsletter. Project has also conducted a nationwide survey of programs for families with parental mental illness and has selected five pilot projects for site visits and indepth assessment.	<a href="http://www.umassmed.edu/POP">www.umassmed.edu/POP</a> 508 856 8722
<b>Center for Mental Health Services</b> Washington, DC	"High risk adults/families with SMI", most often mothers with depression, anxiety, PTSD	Offers parenting skills, case management, support groups, individual & family therapy, medication management, therapeutic day care, home-visits, parent/child interaction support, substance use interventions, assessment and crisis intervention.	



## Parenting & Mental Illness: Program Models - Australia

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information (add international area code 011)</i>
<b>Maroondah Hospital Parent-Infant Early Intervention Program</b> Ringwood East, Victoria	Mothers with children up to 12 months for whom pregnancy, childbirth, or early parenting has been complicated or distressing. Mothers may have depression, or adjustment disorders with depressed or anxious mood. Partners are offered support separately.	Program offers assessment of the parent-infant relationship and where appropriate an intervention in the form of a mother-infant therapy group, and meetings conducted in parallel for fathers and for both mothers and fathers together. Provides a safe forum for mothers to explore distressing experiences in perinatal period, and to help mother and baby to get to know each other better.	<b>Dr. Sophie Constantinides</b> <b>Anne Cumming</b> Ph 61-03-9870-9788 Fax: -7973
<b>Monash Medical Centre</b> Mother Baby Unit Clayton, Victoria	Mothers with children up to 12 months with post partum depression or psychosis	Major goal is to provide psychiatric services to women and infants in postnatal period where inpatient care is necessary. Aims to develop an individual management plan based on multimodal assessment of the woman, her illness, her infant, her psychosocial past and present, using balance of pharmacological, psychotherapeutic, educational and practical measures, in cooperation with woman's support network.	<b>Dr. Pamela Brewster</b> Ph 61-03-9550-1414
<b>Living with Under Fives</b> Southport, Queensland	Parents with a major mental illness and children under five	Offers parenting skills to parents with schizophrenia and early intervention. The parental stream includes education as well as opportunities to discuss any difficulties people are facing as parents. The children's stream includes developmentally appropriate activities, and encourages parents and children to interact during structured and unstructured playtime. Addresses issues such as: nutrition, discipline, play, childcare, care plans for children if illness should re-occur, increasing social networks, accessing community resources.	<b>Chris Lloyd</b> Fax: 61-07-5571-8949, -8909 <a href="mailto:lloydc@scrha.health.qld.gov.au">lloydc@scrha.health.qld.gov.au</a>

### Parenting & Mental Illness: Program Models – Australia (continued)

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information (add international area code 011)</i>
<b>Listening to Children who Have a Parent with Mental Illness</b> Ballarat, Victoria	Children who have been referred to child & youth mental health services who are of primary school age and have a parent with a mental illness	Based on the "Hidden Children - Hard Word" program; provides a venue for children to express feelings and concerns regarding their experiences of having a parent with a mental illness; provides developmentally appropriate education about mental illness; aims to break down blame, develop protective behaviours and to identify supportive people, through use of videos, discussion and drawing activities.	<b>Sonia Boadle</b> <b>Jay Nichols</b> Ph 61-03-5320-4100 Fax: 61-03-5320-4028
<b>Offspring Adolescent Support Program</b> Morphett Vale, South Australia	Adolescents aged 12 to 18 with a parent with a major mental illness	Aims to identify adolescents with a parent with a major mental illness, to establish and maintain a peer support group that promotes expression of relevant issues and concerns, and to develop and maintain links and networking between agencies, and professionals working with families where one or both parents has a mental illness.	<b>Tony Colhoun</b> <b>Ann Kasprzak</b> Ph 61-08-8326-1234 Fax: 61-08-8326-3340
<b>Children of the Mentally Ill</b> Traralgon, Victoria	For adult mental health workers, teachers and others working with offspring of people with mental illness	A train the trainer model that raises awareness of issues related to school learning difficulties, relationship difficulties, developmental needs, etc.	<b>Denise Stranger</b> PO Box 761 Traralgon Victoria, 3844
<b>Children of Parents with Mental Illness</b> Alfred Child & Adolescent Mental Health Service Melbourne, Victoria	Children with a parent with mental illness, who may or may not have emotional problems in their own right, ages 0 - 18	Aims to promote family functioning with particular emphasis on supporting and promoting parenting, and on raising awareness of children's needs and experiences. There is also an emphasis on helping children develop an understanding of the parent's mental illness and making sense of their own experience.	<b>Intake Coordinator</b> Ph 61-03-9526-4400 Fax: 61-03-9529-1931

### **Parenting & Mental Illness: Program Models - Australia (continued)**

<i>Program Title &amp; Location</i>	<i>Program Focus</i>	<i>Program Description</i>	<i>Contact Information (add international area code 011)</i>
<b>The Gaining Ground Project</b> Liverpool, New South Wales	Children aged 0-18 whose parents have a mental illness, with a special focus on parents from non-English speaking backgrounds	Offers supported playgroup to promote confidence in parenting and to assist in meeting developmental needs of children; offers adolescent program which provides information and coping skills. Also seeks to develop awareness and create interagency networks	<b>Michelle Webber</b> Ph 61-02-9601-6288 Fax: 61-02-9827-8010
<b>Children of Mentally Ill Parents Project (CHAMP)</b> Early Psychosis Research Centre Melbourne, Victoria		A major research study aimed at identifying and disseminating knowledge related to the needs of children of parents with mental illness, through conferences and formation of the Australian Association of Children of Parents with a Mental Illness	<b>Vicki Cowling</b> 61-61-3-9389-2403 <a href="mailto:eppic@vicnet.net.au">eppic@vicnet.net.au</a> (attn Vicki Cowling, CHAMP project)