



Good Days and Bad Days:

A Child's View of Mental Illness

Instruction Guide for Professionals,

Friends, and Family Members

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Illustrations by Laura Riebschleger

1997

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Author's Acknowledgments: It is hoped that this picture storybook, workbook, and instruction guide can help children understand the impact of a family member mental illness on their lives. Further, it is hoped that the materials can assist people working, living, and interacting with the children to discuss the topic of mental illness directly and openly.

These materials could not have been developed without the support and assistance of many people and agencies. Above all, I am grateful to the professionals, parents, children, and adult children who participated in the study that yielded the information base upon which the materials were developed. They shared their lives with me and taught me more than they can ever know. Their names are not listed, in order to protect their anonymity, but their thoughts and recommendations are the foundation of the materials.

I am also thankful to the members of the Project Advisory Committee who guided the initial study:

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Paul Freddolino
Barbara Kanaga
Jennifer Miller

Michigan State University School of Social Work
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Michigan State University School of Social Work

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Finally, I want to thank my talented twelve year old daughter, Laura Riebschleger. She not only provided valuable input to the writing of text, but also singlehandedly led the effort to bring these works to visual life.

The Good Days and Bad Days picture storybook, workbook, and suggestion booklet are the product of the creativity and effort of so many people. I hope the materials will play a small role in helping many children understand the mental illness of a family member. But truthfully, if it helps one child, it will still have been worth the effort.

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The Research Study Base: Descriptions of mental illness as described by Nicole, the main character, are fictional. However, the kinds of events outlined are derived from formal research by Riebschleger, Freddolino, Kanaga, and Miller (1992-3) in a Michigan State University School of Social Work study of the needs of children of parents with mental illness. The study was partially funded with a grant from the Institute of Children, Youth, and Families of Michigan State University.

Methods: Information from twenty child interviews, twelve adult child interviews, eleven parent interviews, twenty mental health professional interviews, and twenty child welfare professional interviews was combined into integrated data themes. Parents interviewed had mental health diagnoses of schizophrenia, unipolar depression, bipolar depression, and borderline personality disorder. The researchers also studied existing child literature about mental illness and professional literature about the impact of mental illness upon children and families.

Outcomes are categorized into three main data themes of insufficient information, profound developmental effects, and unmet service needs:

- 1. Insufficient information:* Children and families have insufficient information about mental illness. They often do not know that the person has a mental illness. They only know that something is wrong. They do not seem to know what goes on in mental health treatment.
- 2. Profound developmental effects:* Children living with a person with a mental illness report that the mental illness condition affects their own development. For example, the children often function as caretakers, experience social isolation, are subject to inconsistent discipline, and multiple separation experiences. Respondents report that the children have problems with trust. They experience shame and stigma episodes and multiple problems in day to day family living. They may have school problems. They may take responsibility for the illness condition.

3. *Unmet service needs:* The research outcomes found that the children are often "invisible" to the mental health service system serving the mentally ill family member. Some mental health professionals know very little about the experience of children living with a person with mental illness. There are materials, resources, and programs in place to help children understand mental illness.

Recommendations: The study recommendations include a need for nurturing adults to interact with the child, increased information to the child about mental illness, building upon the child's special talents and strengths, and increased integration of service systems to serve these "invisible children." The findings and recommendations are reported in the monograph of the 4th Annual Conference Proceedings of the National Association of State Mental Health Program Directors Research Institute, Inc., October 1993, pages 275-285. The organization's address is 66 Canal Center Plaza, Ste. 302, Alexandria, Virginia, 22314.

The Picture Storybook and Workbook: The picture story book provides an example of the most common scenario identified by the research: a single parent, depressed mother with minor children. The subtopics selected in the materials are all directly derived from the research study findings. The picture storybook and the workbook have both been field tested by the author in an outpatient mental health practice with children and families.

Page by Page Information - The Storybook: The following page by page information explains the connection of subtopics in the story book to findings of the research study. It is intended to provide basic information for persons interacting with children living with a person (especially a parent) with a major mental illness.

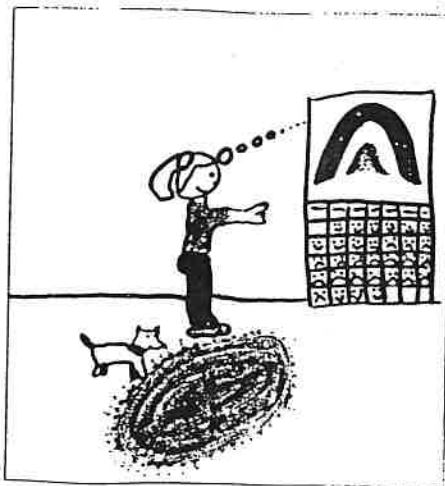
The Messages - Helping Children Understand Mental Illness: The Good Days and Bad Days picture storybook, workbook, and suggestion booklet give a “child’s eye view” of living with a parent with mental illness. Friends, family members, and professionals can use the materials as one way of connecting with children of families with a mental illness. Although most of the information in Good Days and Bad Days is targeted toward situations in which the mentally ill person is a parent, much of the information provided can be used to discuss the mental illness of other family members as well. The information of these materials may help children understand mental illness. It may help concerned adults understand what it is like for children to live with someone who is mentally ill. Important messages for children who live with a parent or other family member with mental illness are:

- *Mental illness can be defined and given a name (such as depression).*
- *Mental illness is not anyone’s fault. It is especially not the fault of the child.
It is not the fault of the ill person either.*
- *People with mental illness may have “good days” (well days) and “bad days” (ill days).*
- *The state of the illness affects how the family functions on a particular day.*
- *It is normal to experience a variety of emotions when living with someone with a mental illness.*
- *One positive way to cope with living with someone with a mental illness is to seek out trusted additional alternative caretakers and support persons (especially on “bad days”).*
- *A second positive way to cope with living with someone with a mental illness is to develop one’s own special talents (dance, art, writing, athletics, etc.).*
- *Childrens’ extracurricular activities and social interaction with others are to be encouraged.*

Instructions for Workbook Activities: The activities of the workbook are designed to capture and “customize” a child’s perspective of living with a mentally ill family member. The workbook goes beyond the scope of the picture storybook. It helps one to gather individual and family information. It also helps one to assess child and family strengths and supports. It allows one to gather information about the current knowledge base of the child about a family member’s mental illness. It provides opportunities to give the child direct information about mental illness. Information about mental illness should be delivered by a person whom the child trusts. Shorter, repeated discussions about mental illness in the family are more effective than one long discussion.

Read the story book and guide book first. Then move around freely within the workbook to address issues that seem pertinent for the child. Move at the child’s pace. Behavioral descriptions from the child’s perspective and in the child’s language work best. Mental illness diagnosis type is usually not as important an indicator of child adjustment than the severity and intensity of the illness and how much the child has been involved in caretaking activities. Focus on descriptions, not diagnoses. The person working with the child should provide the information in a nonjudgemental fashion. It is important to take a nonblaming stance.

It is also possible to use the workbook to assess the child’s view of other kinds of family issues. Remember, it is important to emphasize “good days,” strengths, and positive qualities of the child and the family.



Page One: Families

Like Brittany and Nicole, many children of parents with mental illness live in single parent families. The most common custodial parent is the mother. People with unipolar depressive disorders are more likely to have custody of their children than parents with schizophrenia or bipolar affective disorders. Children in homes with depressed parent/s may have multiple risk factors (i.e., poverty, abuse/neglect, substance abuse, out of home living arrangements, school problems, behavior problems, low self-esteem, divorce adjustment, school dropout, pregnancy, delinquency, etc.). A parent/s depression can have significant impact on the growth and development of children. While Nicole to be settled a bit in "the big blue house," some children of parents with mental illness reported moving frequently during their lives.



Nicole lives with her mother, Betty,
her sister, Brittany, and her dog, Max.
They live in a big blue house.

Page Two - Normal times

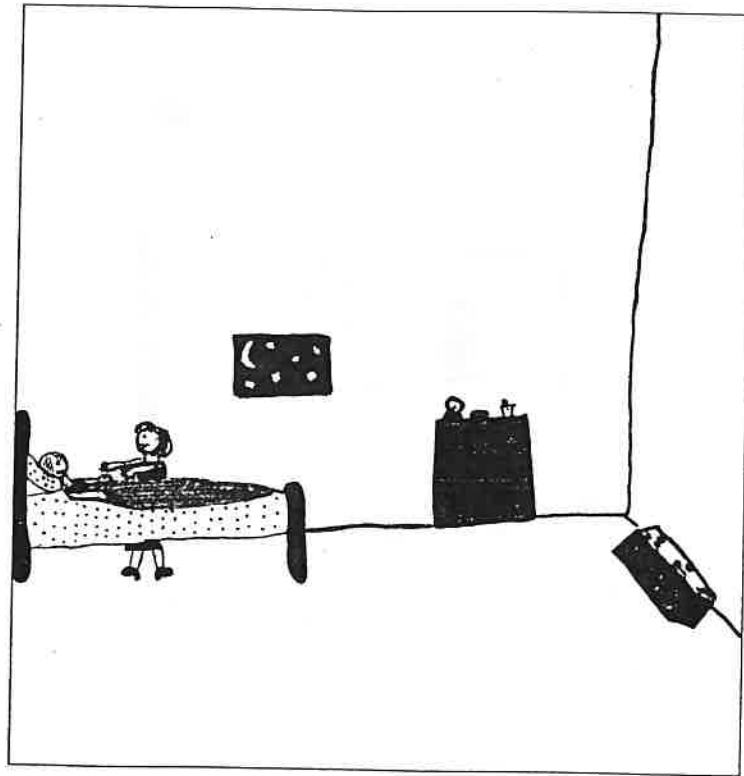
Children of parents with mental illness are similar to other children in terms of their overall needs. They value attention from adults and enjoy spending time with their parents. During times of illness stabilization, these families engage in many normal activities such as Nicole's "day at the beach." Children will often try to think about the "good days" to get through more difficult times or "bad days."



Today was a very good day.
They went to the beach.
They ate ice cream.
They made sand castles.

Page Three - Varying affection, attention, and discipline

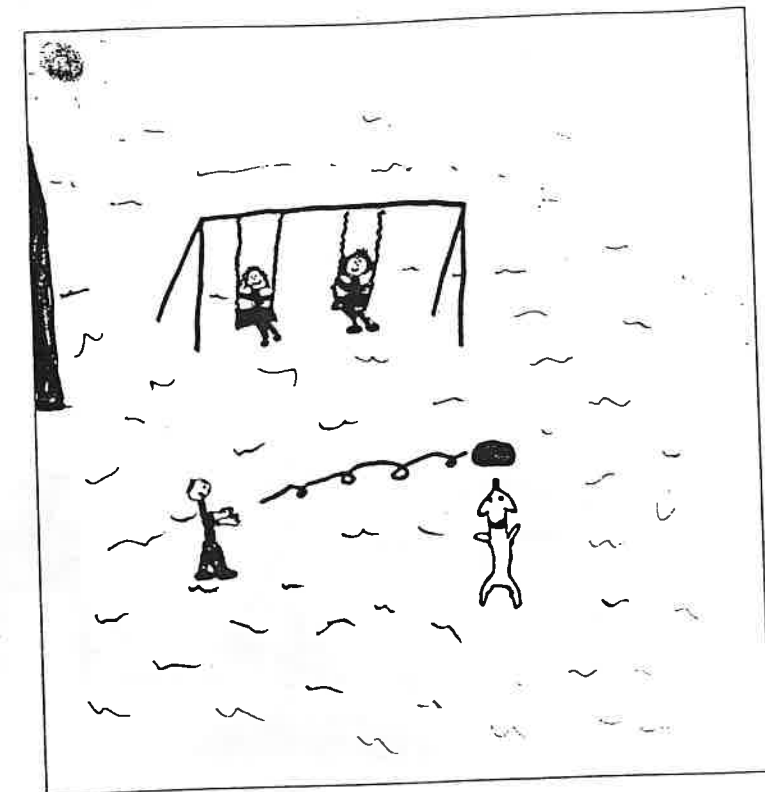
Notice that Nicole reports more physical affection on “good days.” This is consistent with the children in the study who reported decreased physical and emotional attention from parents during times of parental illness. Parents, adult children, and professionals report that the parental discipline can vary greatly between ill and well times of the illness condition.



On good days, Nicole talks a lot with her mother. Mom tucks Nicole in bed at night. She hugs Nicole.

Page Four - Mirroring of Feelings

If Mom is happy, Nicole and Brittany are happy too. Some families report that the emotional health and affective state of every member of the family tends to reflect the overall health and affective state of the parent with the illness condition. Put in simpler terms, children "mirror" the feelings of the ill parent at a given point in time. Children involved in any delusional ideation of the ill parent report increased fearfulness. The literature base reports less positive outcomes for children "involved" in delusional ideation.



On good days, Nicole feels happy.
She plays with Max, Brittany,
and Mom. Everyone gets along great.

Page Five - Parent/child role reversal, and loneliness

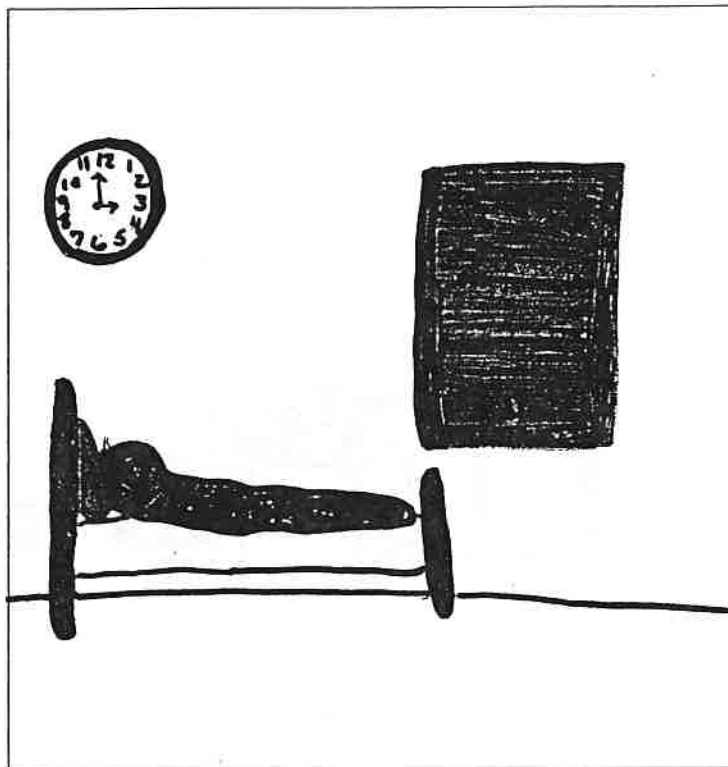
Some children of parents with mental illness appear to increase their caretaking role within the family during times of parental illness. For example, the children may stay home from school to care for younger siblings and/or the parent/s. Since Mom is very depressed in this picture, Nicole is unable to share with Mom the experiences of her day at school. Nicole will probably avoid bring friends home right now.



But some days are bad days.
Mom gets depressed.
She cries and cries. Nicole cannot
talk to Mom after school.

Page Six - Isolation

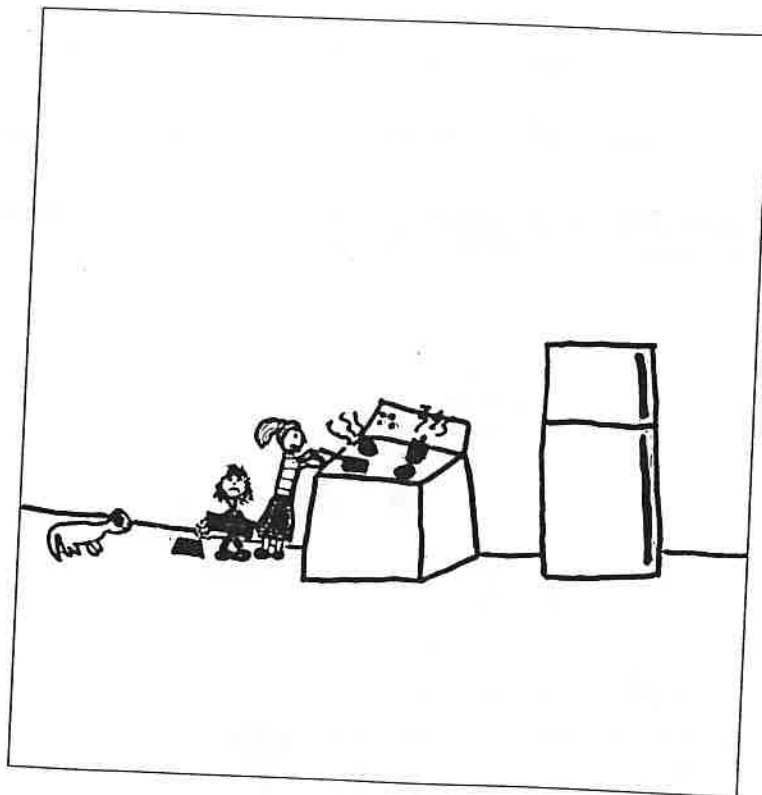
Nicole experiences increased isolation when Mom is ill. This is consistent with children in the study who tended to be less involved in extracurricular activities during times that they are living with a parent with acute depression and/or active psychosis. When the children do engage in extracurricular activities, parents are less likely to attend their childrens' events when the illness is worse. It is common for children to report wishing their parents attended their sporting events, dance recitals, etc. Additionally, many children tend to withdraw from the family during times of increased illness on the part of a family member. They may stay, for example, stay in their rooms for long periods of time.



On bad days, Mom stays in bed all day long. She won't play games or go to the beach.

Page Seven - Care Taking by Children

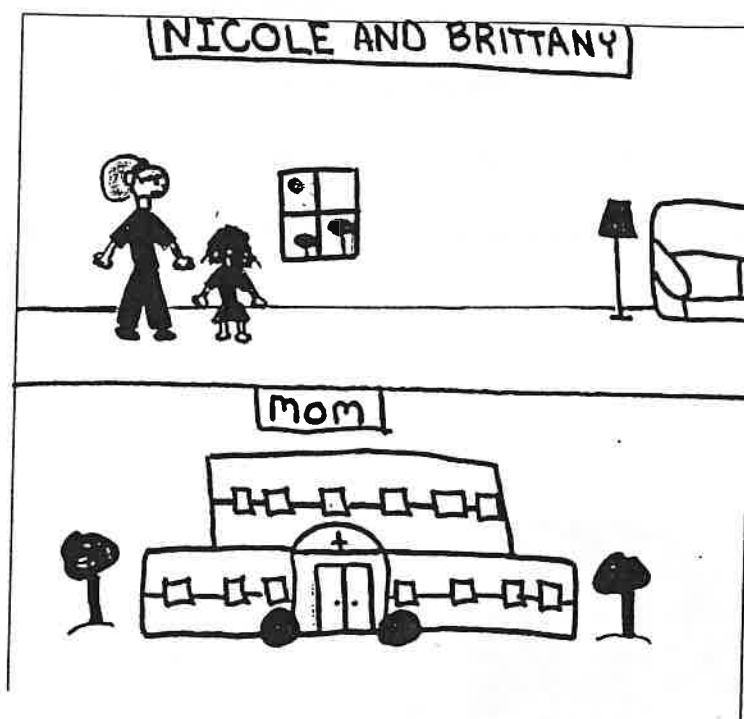
Nicole looks frazzled trying to act as the responsible person in the house when her mother is ill. Children, especially older children, report taking care of household responsibilities and parenting activities during times of parental illness. Adult children report that they sometimes had trouble separating from the family as a young adult because they had worried about the care available to younger siblings if they were to leave home. Some parents in the study express guilt and shame over not having the energy to meet their children's needs during times that their illness worsened. Most parents stated that they really wanted their children to have good lives as children and as adults.



Mom doesn't even get dressed.
Nicole makes dinner.
She takes care of Brittany and Max.
Everyone feels sad and lonely.

Page Eight - The Hospital

Hospitalizations can be perceived as times of trauma by children of parents with mental illness. On this page, Nicole is angry about separation from her Mom. Some children in the study report multiple separations in their lifetime caused by parental inpatient psychiatric hospitalization. Nicole is worried about what is happening in the hospital. Children in the study sometimes talk about the hospital as a negative and confusing place. They worry about what is happening to their parent there, especially if the parent has stated that they do not want to go to the hospital. Some people worry that their parent will be forced to take medications against his or her will. Children may also be confused as to whether the parent is physically ill. Younger children report worrying that the parent has gone to the hospital for life threatening physical condition (i.e., "I thought she was going to die."). Since hospitalizations today are becoming shorter, children may experience shorter periods of physical separation from the parent than in previous decades.



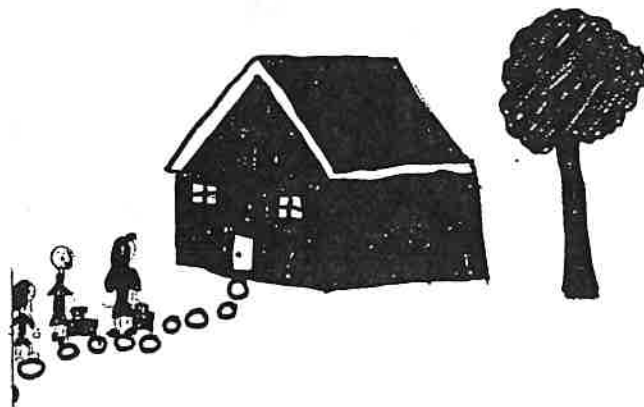
One time, Mom got so depressed that she stayed in the hospital for two weeks. Nicole felt worried and mad.

Page Nine - Alternative Care for Children and Dissolving Blame

Nicole goes to live with Aunt Helen during the time her mother is in the hospital. This is consistent with the research findings which showed that female relatives, especially aunts and grandmothers, were the most common alternative caretakers for children during times of a parent's illness/hospitalization. Some adult children report that their childhood contained many moves back and forth from home care to relative care.

Nicole believes that the illness of her mother is her fault. Many of the children in the research study report taking responsibility for the illness condition of the parent. One four year old describes the illness of his mother as occurring "when I be bad." An adult child reported "They told me to be quiet because Mom wasn't well. Then she went to the hospital. I thought it was because I made too much noise." Each child within the family may have some internally perceived reason why the parental hospitalization is his or her fault. In this story, it is likely that Brittany also has a reason she thinks Mom's hospitalization is her fault. Since the family members don't often share how they are feeling (reported by adult children), it is likely the children will not share these "blame assignment" thoughts with anyone. It is recommended strongly that the children be encouraged to talk about their feelings with a person that they trust who understands the situation.

Nicole and Brittany had to stay with Aunt Helen. Nicole thought she made Mom depressed when she was too noisy.



Page Ten - Resilient children

In this story, Aunt Helen appears to be an emotional “safety net” for the children. The professional literature base indicates that children of parents with mental illness who have the best outcomes in their life often form relationships with other nurturing adults. Adult children of parents with mental illness vividly describe their appreciation for the attentions of a relative, a neighbor, and/or a special teacher who paid attention to them when they were a child. Some adult children report having had multiple alternative caretakers during their childhood.



Aunt Helen said it was not anyone's fault that Mom was in the hospital.
She took Nicole to dance class.

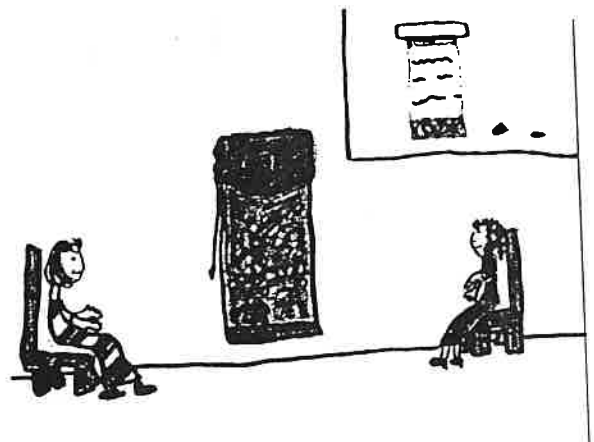
Page Eleven - Treatment

The most important thing to notice about Mom's treatment for depression following her hospitalization is that Nicole and Brittany aren't involved in the treatment at all. The professional literature base, and the overwhelming response of the study participants, conclude that the mental health service system usually does very little to serve the family members of persons with mental illness. While child study participants were drawn in the study from a few exceptional programs for children of parents with mental illness, there is a clear need for more family based interventions.

Many of the respondents in the research report never having had a contact with the mental health system despite having organized much of their lives around the parental mental illness. Further, the parents with mental illness reported that they understood very little about their own diagnosis and/or mental health condition. Parents and relatives are sometimes unable to talk to the children about the illness because they have very little information themselves about the mental illness.

Some children wonder what goes on in the treatment process. Others express concern about parents "taking drugs." Some kids worry that parents wouldn't take medication. Some kids worry that they will inherit the mental illness. Reciprocally, some parents report watching for mental illness in their child. A number of child and adult respondents express alarm about parental suicidal ideation and behavior. Overall, it appears that mental illness and mental health treatment are often a "mystery" to children and relatives.

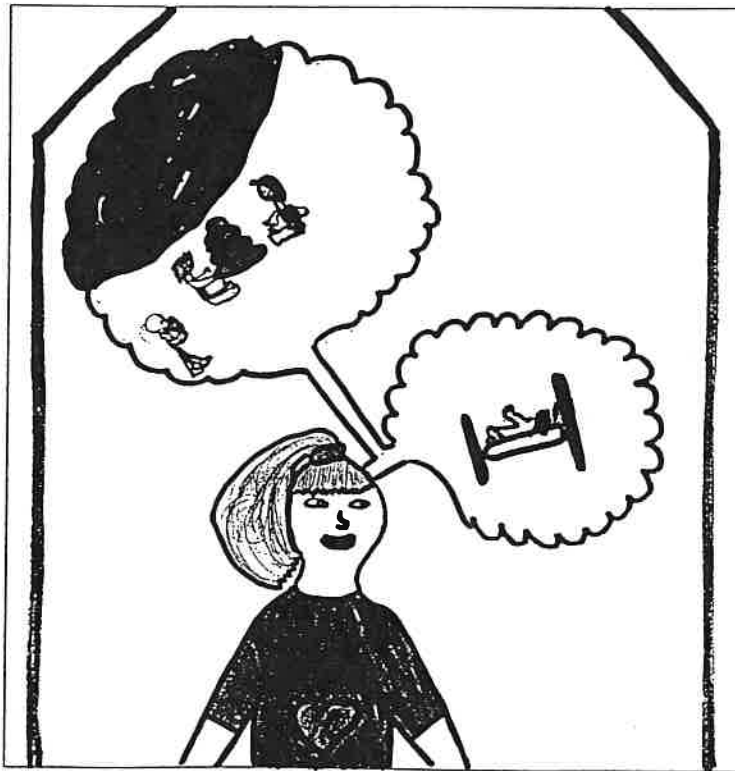
After the hospital, Mom had to take
medicine for depression.
Sometimes Mom went to talk to
a social worker.



Page Twelve - Chronicity

Some child literature seems to say “if your Mom/Dad take their medicine, everything will be okay.” Unfortunately, things are not always so simple. The reality for children in the study is that the illness can be a re-occurring or cyclical phenomenon that has ongoing periods of illness and wellness.

On this page, Nicole thinks about both “good days” (times of parental wellness) and “bad days” (times of parental illness). Notice that the thoughts of the “good days” are in a larger bubble. The children are most comfortable thinking about positive interactions with their parents.



Now there are still good days
and bad days in the big blue house.
Nicole likes the good days best.