

Chapter Five

Empowering Parents and Family Members

When parents first learn that their child has been diagnosed with a brain disorder, they are faced with starting on a new and perhaps overwhelming journey. It seems like every time they visit the doctor they will come home with a whole new set of initials. ADHD, OCD, ODD, CD, Aspergers.... Today it is Bipolar Disorder.

They have begun the process that could be called the “diagnostic journey.” It is possible that the child may have more than one diagnosis because the child’s symptoms can change with the changes that are occurring in their bodies. This chapter was designed to help clinicians help parents not only get involved in their child’s care but to empower them to become their child’s primary case manager.

Why Empower Parents?

As the diagnoses, symptoms, psychiatrists, therapists, and even schools change, the parents are the constant in the child’s life. It is the parent or primary caregiver who deals with the daily ups and downs of mood and behavior and it is the parent who feels the ultimate responsibility for helping the child successfully navigate the challenges of childhood and adolescence to achieve a happy and productive life. Conscious effort on the part of the clinician to build parental empowerment can have these benefits:

1. Increase medication compliance
2. Increase care coordination
3. Decrease parental frustration
4. Increase parents understanding and acceptance of the child
5. Decrease parent’s self blame
6. Improve child outcomes
7. Increase partnership
8. Increase parent disclosure
9. Increase treatment compliance—i.e. charting moods at home, monitoring symptoms, attempting recommended interventions
10. Increase family awareness—If family accepts diagnosis and treatment, more likely the child will ultimately do the same—begin the lifelong acceptance and management of illness
11. Increase the possibility of parent, child and siblings becoming experts about their diagnosis and treatment
12. Increase family strengths and relationships

Assessing Parents Vestment/ Empowerment in Treatment

Vesting parents in treatment begins with understanding the parent’s experience of living with this disorder. Taking the time to ask and understand the following questions will in itself signal to the parent the clinician’s level of respect, compassion and interest in their role and build a necessary first step towards partnership and empowerment.

1. Where are parents in the diagnostic journey?
2. Where are they in the stages/cycle of emotional healing/grief? Denial, anger, bargaining, depression, acceptance?
3. Level and nature of guilt regarding child’s illness.

4. Level and sources of family/caregiver stress, sibling stress, ill child's stress. (Such as External factors/circumstances or internal factors (parent illness).)
5. Validation of what has the family already tried/done to manage the child's disorder/behavior?
6. Fear of the future? Level of hope?
7. Level of current support.
8. Types of support needed.
9. Issues of stigma present?
10. Education needs: disorder/treatment options/medications.
11. Education needs: which systems do the family need to access? Social security, advocate, case management—where to go to get help.
12. Advocacy: Does the parent know/not know how to ask to get help where to get help?

An assessment tool to help you and your client's parents is included in the Bipolar Toolbox.

As parents begin this process there is a predictable cycle of emotions they experience.

The first stage is: Dealing with the news. This is the stage where there is shock, denial, crisis, chaos and confusion. Common statements are, "That's it, the diagnoses are wrong," "If I just change this one behavior, it will all go back to normal." It feels like the world as you know it has disappeared.

Stage two is: Learning to cope. This stage can contain the feelings of anger, guilt, and resentment. It can be anger at the child, world, yourself. Sometimes it feels like, "What did I do to cause this?" Parents have made statements like, "Doesn't my child want to change?" "Why can't my child be perfect like my sister's?" "If I hadn't married into this family this

wouldn't have happened." "Why is my spouse's family so messed up?"

Grief is a key emotion of this stage. It is one that is felt often. "What about the dreams we had for our child?" "Our child is so smart, how can this be happening?" "Will they ever live on their own?" "What happened to our child who used to be so happy?"

Trying to find answers is a tough journey. This stage can be felt numerous times. For every step forward sometimes it feels like two are taken back. A parent can move on past this stage and return here when the child develops a new symptom. This is a journey. Revisiting the stages is part of the process, not regression.

Sometime along the way, there is recognition. It sinks in. "This is my life. It is not bad, it is not good. It is just how it is. It is a step towards healing."

Stage three is: Moving Into Action. This is the stage where a parent tries to find out as much about the illness as possible. As one learns about the illness, the anxiety and the mystery of it decrease. This can be accomplished by reading books, articles, attending classes, and by finding a support group. This cannot be emphasized enough. Finding out that you are not alone is like a breath of fresh air. It will help move parents forward towards acceptance. It is important to reaffirm, "*We are not bad parents!*"

As parents move into action, they can begin to ask questions and become advocates for their child. They begin to ask, "What can I do?" Communication is an important part of the process. As parents begin to advocate for their child, talking with the school is crucial for the child's success. Give information to the school about the illness; ask the teachers how you can help make the transitions into the school easier for both the teacher and the child. It is impera-

tive to build a partnership with the schools. It is not an adversarial relationship. Be cautious of making it so. Become a team player with the school.

Intervention

- Normalize feelings to build trust
- Validate strengths “you know your kid the best,” “You’ll probably know more about this disorder than I do someday”
- Validate previous efforts, struggles, strategies and successes in dealing with child’s illness and behaviors
- Identify what works and what doesn’t work for this family
- Address issues related to stage of emotional healing
- Review assessment issues
- Establish credibility
- Instill hope (Families learn how to cope in their own ways, which lead to successful, happy familial relationships)

- Building family communication and problem solving skills
- Sorting through and strategizing illness management issues—building the MH team
- Help with identifying other resources for support, education and advocacy—i.e. websites, support groups, school liaison, navigating I.E.Ps, insurance

Sales Pitch: What can “Therapy” do for you and your child?

Validate parents’ role: “As therapist, I’m one piece of the puzzle—but this is your life!”

Describe therapist’s possible role/piece of the puzzle as this:

Helping the family learn and try out strategies for dealing with behavior—

- Help you become an expert about disease
- Dealing with oppositional/defiant/explosive behaviors
- Strategies for relapse prevention-triggers
- Stabilizing daily rhythms
- Dealing with interpersonal stressors
- Stress management