

THE FAMILY SUPPORT TOOL KIT

**A Resource to Assist Professionals in
Empowering Parents Living with
Psychiatric Disabilities**

The Mental Health Association in New York State

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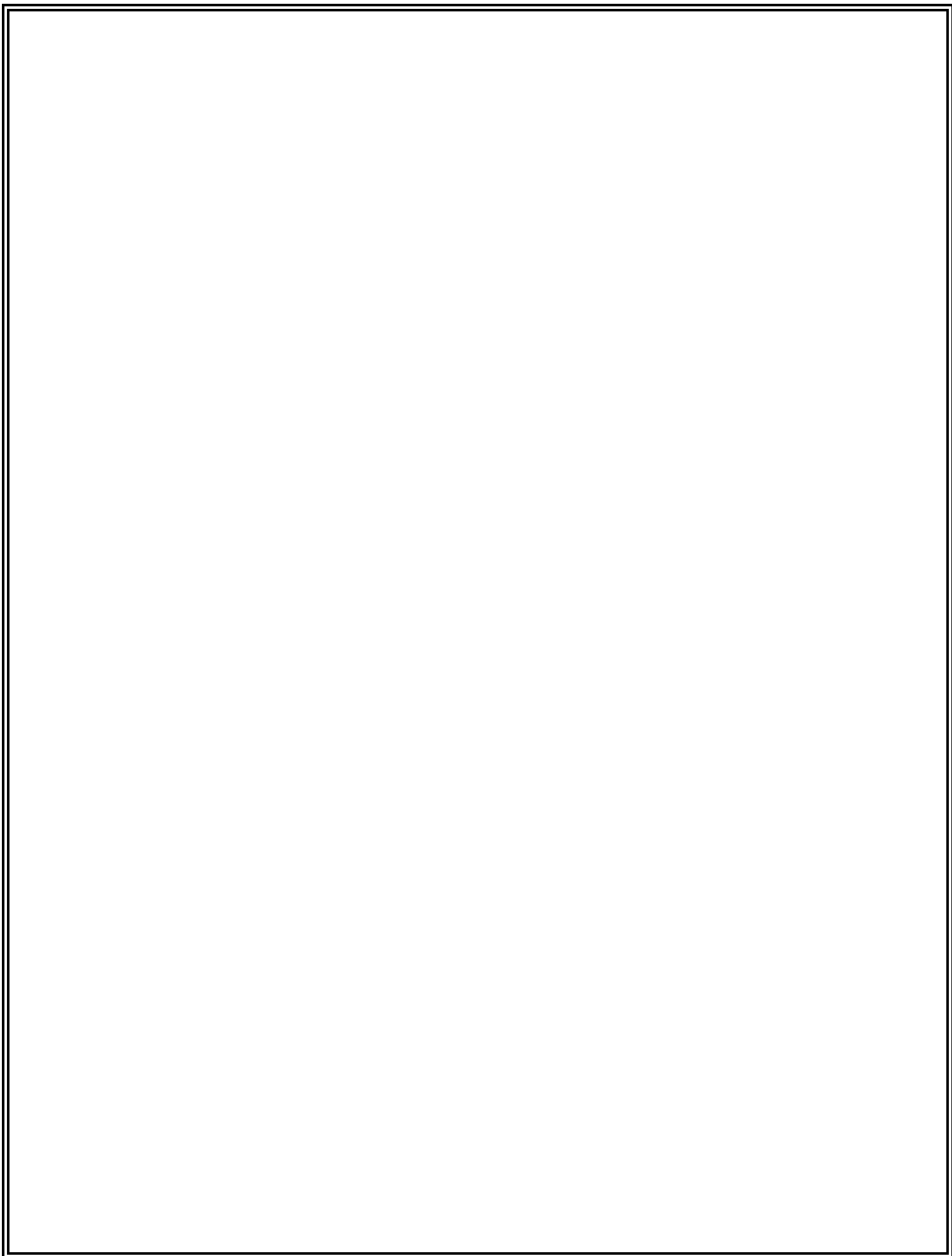
PART I

UNDERSTANDING THE NEEDS OF PARENTS WITH PSYCHIATRIC DISABILITIES

OUR DESCRIPTION OF PSYCHIATRIC DISABILITIES IS A COMBINATION OF SEVERE EMOTIONAL DISTRESS AND AN INTERRUPTION OF A PERSON'S PLACE IN THE COMMUNITY AND SOCIAL ROLE – BEING A WORKER, PARENT, STUDENT, A PARTICIPANT IN OVERALL COMMUNITY LIFE – WHICH IS NOT DISSIMILAR FROM WHAT IS CONSIDERED A MENTAL DISORDER IN DSM-IV.

THE MOST IMPORTANT FINDING IN OUR RESEARCH IS THAT PEOPLE WHO HAVE SHOWN SIGNIFICANT OR COMPLETE RECOVERY FROM SEVERE PSYCHIATRIC DISABILITIES...HAVE CITED HOPE AS AN EXTRAORDINARILY IMPORTANT COMPONENT IN THEIR RECOVERY. PART OF THE RECOVERY WAS BEING AROUND PEOPLE WHO SAW THEIR CONDITION AS NOT PERMANENT, A CONDITION FROM WHICH THEY COULD TAKE INCREASING CONTROL OF THEIR LIFE AND REESTABLISH A PLACE IN SOCIETY.

From "An empowerment model of recovery from severe psychiatric disabilities: an expert interview with Daniel B. Fisher, MD, PhD" in Medscape Psychiatry & Mental Health 10(1), 2005



Introduction

During the 1970's and 1980's, mental hospitals in New York State closed and former patients returned to the community for what promised to be both recovery and re-integration. Unfortunately, communities were not fully prepared to discharge their mandates in this regard.

The funding that existed was organized under two headings: adults and children. The policymakers did not think about individuals living with psychiatric disabilities as being part of family units that also would need assistance if parents were to recover and their children were to thrive. During those decades, and even still today, providers who serve people living with psychiatric disabilities and their families forget that consumers are members of families and probably parents with childrearing duties.

As some consumers joined peer support and peer advocacy groups, they began to find their voices and to tell providers who were willing to listen that they wanted to succeed as parents and that with a little help and support they could do just that.

In the 21st Century, two more variables have increased the challenge of parenting successfully while living with a psychiatric disabilities:

1. Constantly shrinking financial support for community mental health services
2. *The Adoption and Safe Families Act of 1997*

The purpose of this tool kit is to assist everyone in the community who works with parents with psychiatric disabilities. In working with parents over the years, the most important thing we have learned is this: **Parents living with psychiatric disabilities can parent successfully, usually with only a little additional support. Most parents living with psychiatric disabilities want to be the very best parents they can be; they firmly believe that being allowed to parent their children and learning to do so successfully is a vital part of their recovery.** We must be able to see what parents can do as well as what they cannot do. If we expect parents to succeed and we give them the tools to do so, they will succeed.

Putting It All Together: How the Tool Kit Was Born

This Tool Kit was born out of two distinct concerns: 1) Parents living with psychiatric disabilities know what they need to succeed as parents and they often complain that when they work with case managers, therapists, or the legal system, these professionals make assumptions about parents rather than asking parents what they think.

2) Providers, DSS, and Family Court judges often encounter situations that overwhelm them because they do not have the training, experience, or adequate clinical consultation to deal with them. In recent years, caseloads have increased and family problems seem to have become more acute and complex. At the same time, shrinking resources have meant less supervision and training provided for staff. Finally, *The Adoption and Safe Families Act of 1997* has placed additional pressure on providers and parents to achieve a safe environment for the children within 18 months or possibly lose custody for good.

As the writer traveled throughout New York State providing training for providers and hearing parents' stories about the challenges of accessing service and maintaining custody of their children, the sheer volume of data collected called out to be organized and shared.

In fall and winter of 2003, Barbara Callahan, Director of the Hudson River Family Support Coalition, had similar experiences and concerns, and approached the writer. We began a dialogue and the idea of the Tool Kit was born.

In order to make the Tool Kit a true voice for parents, we conducted three consumer focus groups. We asked consumers about their challenges with parenting and what they needed to succeed. In order to make sure that providers had what they needed to help parents, the writer used the first five minutes of each training or presentation to ask participants what they needed to know.

We are greatly indebted to the consumers who took the time and found the courage to share their wisdom. We are indebted to the providers who are dedicated to helping families stay together and strive to get the information they need to do a great job.

FACTS AND MYTHS ABOUT LIVING WITH PSYCHIATRIC DISABILITIES

Myth: There is no such thing as recovering from psychiatric disabilities. Once you get it, you are doomed to a life of disability.

Fact: Today, with increased knowledge about what promotes recovery and many new medications, most people can recover and lead productive, fulfilling lives.

Myth: Many people living with psychiatric disabilities can be violent.

Fact: Media coverage of people living with psychiatric disabilities, whether newspapers, television or film, have tended to leave us with the impression that violence is a pervasive symptom of psychiatric disabilities.

Nothing could be further from the truth! If you were to compare the statistics for violence among people with psychiatric disabilities and other populations, you would discover that people living with psychiatric disabilities exhibit far less violent behavior than other groups. In the one percent of people living with psychiatric disabilities who do commit violent acts, it is seldom because of the illness but often because of alcohol or street drugs interacting with their medication or making their symptoms much worse.

Myth: People living with psychiatric disabilities are seldom parents.

Fact: A great many people living with psychiatric disabilities are parents. The trouble is that many providers forget to ask if consumers are parents and if they have treatment goals about parenting. Unfortunately, a great many parents living with psychiatric disabilities lose custody of their children. More often than not, the precipitating event is fear and ignorance on the part of the legal personnel rather than parental inability. Here are some interesting facts:

- 75% of women with severe, persistent psychiatric disorders are mothers (Nicholson et al., in press).
- 75.5% of men with severe, persistent psychiatric disorders are fathers (Nicholson et al).
- Custody loss rates for parents with psychiatric disabilities are 70% to 80% (Burton, 2002).

Myth: Parents living with psychiatric disabilities cannot succeed at parenting.

Fact: Parents living with psychiatric disabilities often can raise their families safely and successfully with just a little extra help and support. However, parents living with untreated addiction will not be able to parent appropriately until they have successfully completed treatment and are on the road to recovery. Addiction causes changes in the thought process that render the addict unable to accept responsibility for his/her behaviors, unable to empathize with others, and unable to put others' needs ahead of his own.

Myth: People living with psychiatric disabilities have subnormal intelligence and are generally incapable of living a productive life.

Fact: Psychiatric disabilities and intellectual ability are two different things.

It can sometimes appear as though individuals living with psychiatric disabilities are slow to learn because they have not had the appropriate models to teach them how to function as adults in the community. Also, medication may slow their cognitive processes. In most cases, people living with psychiatric disabilities are very capable of learning and problem solving.

CHALLENGES OF PARENTING WHILE LIVING WITH PSYCHIATRIC DISABILITIES

Challenges within Oneself

- Low self-esteem due to stigmatization, discrimination, scapegoating and internalized stereotypes
- Lack of models for appropriate, effective parenting
- Belief that everything that goes wrong is due to one's psychiatric disability
- Side effects from medication
- Learned helplessness

Challenges within the Family

- Children's physical, developmental, and/or emotional needs may be unmet
- Children exhibit behavioral problems due to home environment
- Children have difficulty with academic achievement
- Children may lack models for socialization skills
- Children are very vulnerable to bullying by peers
- Children have a emotional or behavioral problems
- Overwhelmed spouse
- Spouse also has a mental health diagnosis
- Domestic violence
- Addiction
- Scapegoating by extended family
- Poverty
- Isolation from family and/or community means lack of support or respite
- Lack of proactive crisis planning
- When a parent who is on Disability must go in-patient for treatment, they carry their benefits with them. This may throw the family into financial crisis – even increase the potential to become homeless.

Challenges within the Community

- Lack of coordinated services for individual and family
- Access to services is complex
- There may be a long waiting list (sometimes months) for services

- Providers may be judgmental
- Parents may lose custody of children simply because they have a diagnosis, parenting skills notwithstanding
- Inadequate funding for community services
- Lack of adequate insurance coverage for mental health treatment, both therapy and medications
- Inadequate housing
- Inadequate transportation to services
- Lack of public awareness for consumers as parents
- Providers may be ignorant about recovery-based or strength-based interventions
- Ignorance about advanced directives
- *The Adoption and Safe Families Act, 1997* – Once a parent loses custody of a child, s/he has only 18 months to recover and prove his/her ability to parent. This is often not a realistic span of time, especially if there is a lack of appropriate services for the parent or difficulty in finding medications that will work. While extensions of the deadline can be considered, the writer does not know of any situations where this has occurred.
- Lack of specialized training for providers, DSS, and law enforcement
- Lack of adequate supervision for direct service staff
- Often, there are no provisions made to facilitate children visiting parents who are in-patient.

IN THEIR OWN VOICES: WHAT CONSUMERS NEED TO SUCCEED AS PARENTS

What Helps

- Having information on child's mental health and normal child development
- Aftercare and respite after childbirth to get medication regulated
- Respite care/coach to teach me how to care for my child
- Someone who is emotionally supportive who could visit and give me a social break
- A case manager who will engage my spouse and children, too
- My spouse and I taking an active part in designing the service plan
- Having my children in my life, even if they don't live with me
- Advocacy in the education system
- Learning how to communicate with pediatricians so they will take my concerns about my children seriously
- Help children learn social skills
- Having someone help me organize my thoughts, prioritize my needs, and help me express things clearly
- When there is a problem, having a case manager who will follow through to resolution
- Being reminded that there are things I can do well despite my diagnosis
- Being reminded that everyone has bad days
- Help me figure out what information to share and what to keep to myself
- Help with social skills and daily life skills
- Advance directives and proactive planning for crises
- A proactive recovery plan to avert crises
- Age-appropriate service for children to help them understand
- Hospital consults with spouse as part of discharge planning and listening to spousal needs
- Good case/service coordination
- A list of available services so I can know what to ask for
- Having family unity or reunification as a primary goal
- Have someone designated to spend a good amount of time explaining important information during hospitalization
- Family therapy while one family member is in-patient
- A family case manager
- Having a clear definition of the mental health diagnosis

- Description of signs and symptoms that indicate treatment is needed
- Having information about medication side effects and what to do about them
- Having a supervisor's telephone number
- Access to attorneys who understand psychiatric disabilities
- Good quality, affordable daycare
- Being able to fire people who don't work well with me
- Someone I can call and vent to
- A therapist who sees the big picture
- Doctors who are not afraid to learn new ideas
- Long term groups/treatment
- Helping us learn our entitlements and regulations
- Being recognized and praised for our accomplishments
- A good worker who goes by the law, not his/her opinion
- Time for myself
- Case workers who know new SSI regulations and how they impact the family – how to work with them

What Gets In the Way

- Pediatricians don't know enough about psychiatric disabilities and don't recognize when a child has a psychiatric disabilities diagnosis
- Pediatricians don't take our concerns seriously and are slow to refer children for ancillary services they might need
- Lack of information about adequate housing for families
- No encouragement from providers to work on keeping family united. More is needed than taking meds and staying out of the hospital.
- Stigma is tremendous
- Fear that if someone knows I have a diagnosis, my kids will be taken away
- Services are not coordinated. We need help with employment, childcare, relationships, child's behavior, school advocacy financial problems, and help to find decent housing.
- When one parent goes in-patient, the SSDI payment follows him/her to the hospital and leaves the family in financial crisis
- Case managers who start working on a problem but don't follow it through to solution
- Providers judging us and expecting us to fail

- Discharge planning without consulting the family
- Failing to involve the consumer in service planning
- Services that stop too abruptly when you make progress.
There needs to be a gradual step down.
- Communication between case managers and doctors
- Providers constantly canceling and re-scheduling
- Lack of confidentiality – case managers gossiping about consumers
- Workers not respecting the dignity and rights of consumers
- Workers who take no action until the consumer or family is in a crisis mode
- CPS failing to or refusing to collaborate with providers
- Isolation
- Traumatic inpatient experiences
- Homemakers and aides who take advantage and complaints to DSS that fall on deaf ears
- Kids being put into the juvenile justice system instead of the community mental health system
- Benefits are denied and system is punitive when you try to develop alternative plans for your kids
- Misdiagnosis
- Trauma/sexual abuse are not recognized or considered important enough to be made part of the treatment plan
- Workers who use your psychiatric disabilities against you
- Parental authority is undermined by workers
- Too many uncaring workers

PART II

**HELPING THOSE WHO WORK
WITH PARENTS**

WHAT WORKERS WANT TO KNOW

During the past three years, the writer has delivered approximately 40 presentations and trainings. At every event, participants asked the same questions. While many of these issues will be addressed later, it seems useful to put them all in one place to begin the problem-solving process as quickly as possible.

How do I convey parenting education information to parents who seem to have difficulty learning?

Unless you, yourself, are a recovering parent, you are a stranger in a strange land. You must act accordingly. You will need to put on your anthropologist cap and learn about the parents' world. Suspend all judgments and assumptions and begin asking questions that begin with "how" and "what". Here are some examples:

- How can I help you?
- What would make this easier?
- Where are you getting stuck?
- What did you learn before this class?
- What's the hardest part of this for you?
- With what do you need help first?

Also ask yourself: "What in this parent's history might keep them stuck?" Some possibilities might include:

- Lack of a parenting model
- Parental difficulty in bonding
- Parent has unresolved childhood issues from abuse that occurred when s/he was the child's age
- Short term memory problems due to anxiety or PTSD
- Untreated or inadequately treated depression that prevents one from taking initiative
- An active addiction or latent, untreated addiction (i.e., no longer using, but never had treatment)
- Medication side effects slowing the cognitive process

Your curiosity and detective skills will serve you well in solving this concern. You may also need to speak more slowly, speak in short sentences, and put things in writing.

What should I do differently when working with parents with psychiatric disabilities?

Again, you will need a lot of insight, curiosity, and your anthropologist's cap. Remember, people living with psychiatric disabilities, especially those who are parents, have been scapegoats, misjudged, discounted, ridiculed, and sometimes much worse, for most of their lives. Many have internalized the negative beliefs they heard or saw acted out against them. It is not only difficult for these parents to trust "professionals"; it is difficult for them to trust themselves.

- Start by asking what parents' concerns are and what they would like to achieve. Listen intently to the answers and affirm them.
- Catch parents doing or saying things right and give them positive feedback
- Expect success. Provide hope. If possible, find a peer who has succeeded and can share their experience.
- On a regular basis, remind parents that child-rearing is very challenging for everybody and many of the places where they get stuck have less to do with psychiatric disabilities and more to do with the challenges of the job.
- Remind parents and yourself: "Everyone has some bad days".
- Avoid judgment and assumptions. Be curious, form hypotheses, but be ready to let them go as they are disproved.
- Be patient, be supportive, and be encouraging; provide models.
- Keep checking in: make sure the pace is right; make sure the quantity of information is right. Less is more. Ask how the parent best processes information – by hearing, doing, or reading/seeing.

When things get stuck, don't blame – yourself or the parent. Get curious and get into problem-solving mode. Ask yourself: "I wonder what might help to get this unstuck?"

- Above all, keep breathing! If you are not breathing, you are stuck. If you are stuck, you cannot help the parent.
- Always follow this rule: Pace and then lead. You can only lead someone forward when you have spent enough time where they are to understand their needs.

How can I motivate parents whose initiative has faded or never existed?

Once more, the same over-arching rules apply: 1) pace before you lead and 2) be curious rather than assuming or judgmental. How will this help? It will allow you to do the detective work that will be necessary to find the cause. First, review the history and assessment. Make a list of any questions that arise and seek the answers. Then, find out the following:

1. Why does the parent think s/he is getting stuck?
2. Ask the parent about pacing in sessions: is it too fast or too slow?
3. Is the same true in other areas of his/her life?
4. Are there any changes in other patterns such as sleeping, eating, and socializing?
5. What is the parent's clinical history?
6. What are the parent's habits regarding alcohol and/or street drugs?
7. What medications are currently prescribed? Are they being taken as instructed?
8. What did the consumer learn about parenting as a child?

As you might have deduced from the questions, you generate as many theories as possible as to why there is no motivation. Next, you generate a list of questions (above) to rule out these theories. Based on the questions, what theories might we be considering?*

*Theories might include undiagnosed or worsening depression due to ineffective medication or lack of compliance with instructions, reaction to mixing alcohol or street drugs with psychotropic medication, physical problems such as anemia, hypothyroid condition, or chronic fatigue syndrome; inability to bond with child, lack of parenting models, secondary gain of having this supportive service and fearing it may end, symptoms of PTSD, and medication side effects.

How can I stay joined with the family if I have to hotline them?

Making a report to CPS is one of the most challenging aspects of working with the family. It may even seem like a conflict of interest. No matter how you prepare, filing a hotline report is never easy. You can expect that there will be at least a temporary disruption of trust, but you can also expect that in most cases trust can be repaired. The challenge is further heightened by your personal feelings about having to file the report. It is very important that you process your feelings with your supervisor or a trusted co-worker so that they do not interfere with the work you must now do with the family. As a general rule, there are several steps you can take with all families that will lessen the blow if, at some point, a report must be filed with CPS:

1. At your first session with clients, always inform them that you are a mandated reporter. Carefully explain what that means in general, and what that might mean in the course of your working together.
2. Advise that if at any time you believe you need to file a report, you will tell the client first – and even give him/her the choice of filing the report himself, in your presence.
3. Predict for the client that should such a report ever be necessary, that the family will feel very angry, which is normal, and that you will all be able to heal the relationship and move on.
4. If, at some time, you must file a report with CPS, remind the family once again of the foregoing points.
5. Allow family members to vent their feelings and concerns. Affirm these. Avoid defensiveness at all costs.

I work with a parent who can't bond with his/her child. What can I do?

Once again, you will have to play detective and ask both yourself and your client a lot of questions. There are several reasons why a parent may have problems bonding with a child. Rather than asking the parent directly, you can ask if s/he has had certain experiences or not – like playing Twenty Questions. Below are the steps you will need

to take and the questions you will need to ask to determine the cause. Figuring out the cause will determine the intervention. The question below will help you discover why the parent cannot bond:

1. Has it always been this way? With all kids? Just at certain ages?
2. Where did you spend your early years? What was it like?
3. Did any really scary or upsetting things happen to you as a child? Between what age and what age, more or less?
4. Are you having any problems with sleeping, eating, grooming, energy levels, or feeling withdrawn?
5. What are your habits around street drugs? Alcohol? Has anyone ever told you that you have a problem with drugs and/or alcohol?
6. Does your child look like or remind you of his/her estranged parent?

Questions 1 and 3 will help you find out if there might have been any trauma resulting from childhood abuse. If you get the same age span for each question, there is a very good chance that the parent has PTSD that has not been treated or resolved. If this is the case, you will either have to refer the parent to a therapist who can help with this or, if you have the training, help the parent yourself. Once the parent has begun to do some work on the trauma issues, s/he will be more able to bond with the child.

Question 2 will help you find out what kind of bonding models the parent had as a young child. If the child's early years were spent in an institution or if his/her primary caretaker was emotionally absent in the early years, it is very likely that this parent does not know what bonding is and is clueless about how to do it. Responses to Question 2 may also tell you that if the parent lived at home as a child, perhaps the primary caregiver was suffering from addiction, depression, or Post Partum Depression. You will find that these parents do not know how to form bonds with other adults or children. You will have to work very slowly

and carefully to try to form a bond with the parent. As you are able to achieve a step, show the parent how to do the same thing with his/her own child. You will need to do a lot of modeling and processing both with the parent.

Question 4 elicits data about the symptoms of major depression. If the parent is suffering from this disorder, they will need assessment and treatment before they will be able to reach out and begin to bond with the child. Two symptoms of major depression, withdrawal and lack of initiative, can make it impossible to bond with the child. Once treatment is initiated and recovery begins, there will be a much higher likelihood of the parent being able to bond, both with you and the child.

Question 5 addresses the classic behaviors of addiction which were previously discussed. Individuals who have active addictions or no longer use the substance but have not had treatment, have certain hallmark behaviors and ways of thinking. These behaviors include: inability to empathize with others, inability to put others' needs first, blaming, inability to accept responsibility for their behavior, and lying. Individuals who have these behaviors and thought processes will be unable to bond with other adults or children under any circumstances. Their only bond is with their substance(s). The only way an addict can acquire the ability to bond is by successfully completing treatment and maintaining recovery.

Question 6 speaks to a phenomenon often found in fractured relationships. If a child strongly resembles an estranged parent who was very abusive to the custodial parent, the custodial parent may be unable to separate his/her anger at the estranged parent from feelings towards the child. Cognitive therapy and expressing feelings about the estranged parent can help a lot. Also, it is helpful to ask the custodial parent two questions: a) How does the child remind you of the estranged parent? b) How is the child different from the estranged parent? Often, when the parent answers these two questions, s/he can then move on and begin to bond with the child.

How can we help the children?

There are many ways to help children whose parents are living with a psychiatric disability.

- Make sure the parent has an advanced directive
- If you cannot arrange respite for the parent, try arranging respite for the child
- Help the parent explain their illness to the child in an age-appropriate way.
- Make sure the child understands that the parent's symptoms are not the fault of the child.
- Work with school and community groups to make sure the child has places to learn socialization skills, to have fun, and be a child.
- If the child is old enough, give him/her a written protocol to follow in case of emergency.
- If a parent must go inpatient, provide opportunities for the child to visit, or at least converse by telephone. Make sure someone is available to hear the child's concerns and fears and answer his/her questions. Make sure the child understands he/she did not cause the crisis.
- Help the parent understand the child's developmental needs. If the parent cannot fully support these needs, help the parent enlist assistance from others. Help the parent learn what expectations are reasonable, given the child's age.
- Help identify a trustworthy adult who can be an anchor for the child.
- Make sure the child has opportunities to feel special: a birthday cake, a special outing with little gifts that show that the adult sees who the child truly is.

- Help the parent learn to set limits and communicate them appropriately.
- Make sure the child receives adequate amounts of support and praise
- Find age-appropriate story books about similar situations to read to the child.
- Help the child learn social cues and how to respond to them.
- Support the family's celebrating important holidays, even in simple ways.
- Help the family build their own traditions.

ASSESSING AVAILABLE PARENTING RESOURCES

Internal Resources

It is very important that we focus on parents' abilities as well as their challenges. Creating this balance of perspective will help us work more effectively to assist the parents. In addition, being able to see what parents can already do helps the parent combat stigma and low self-esteem. Parents who have been scapegoats and victims of discrimination will have a hard time seeing their strengths unless you share your observations.

Generally, service providers automatically see the deficits when they work with a parent. It is the responsibility of providers to be objective about their assessments of clients so it is imperative to make a conscious effort to take inventory of clients' strengths as well as challenges.

External Resources

In addition to determining the parent's internal resources, it is important to notice what external resources the parent has. These resources may include a variety of community services and informal networks such as family, neighbors and religious congregations.

Community resources vary from place to place so it will be important for you to create a list of community supports to assist the parents, the children, and the family as a whole. Below is a list of places and services that may be available:

- Parent support groups
- Respite services for parents
- Respite services for children
- School activities such as Head Start, school clubs, scouting
- Opportunities for family outings and celebrations
- Adequate food and clothing for the family
- Adequate shelter
- Transportation
- Assistance to make the home neat and inviting
- Companionship for parents
- Adult support for children

- Books, toys, music and games for the home
- Warm line for parent support and questions
- Family Counseling
- Assessment and counseling for children, if needed

HOW PSYCHIATRIC DISABILITIES IMPACT PARENTING AND THE FAMILY

Major Depression

There are several hallmarks of major depression. If symptoms last more than two weeks or if the person discloses that they are having strange ideas (e.g., they need to murder their children to save them, or everyone is against them), seek immediate help. Assessment should include a physical exam as well as a psychological evaluation because some physical disorders create symptoms that look like mental health problems. This is especially true for women who have recently given birth and for people over the age of 60. Symptoms of depression may include any combination of the following:

- Feeling sad most of the time and crying for no apparent reason
- Feeling hopeless
- Changes in eating patterns (over or under eating)
- Changes in sleep patterns (too much sleep or sleep disturbance)
- Anxiety or panic attacks
- Withdrawing from friends and family
- Irritability
- Having suicidal thoughts
- Feeling very negative about oneself
- Inability to practice normal grooming
- Inability to complete normal, daily tasks
- Speech may be very slow with a flat tone

Major depression may interfere with parenting in the following ways:

- Parent goes through the motions of caring for the child but is emotionally absent
- Parent is unresponsive to child's physical needs (grooming, appropriate clothing, proper meals)
- A parent who is sleeping a lot may not be able to provide adequate supervision for child safety

- Parent may feel very overwhelmed by child's normal needs and may blame and criticize the child. Parent may yell a lot and become frustrated.
- Parent is unable to keep the house moderately clean and organized
- Child may begin to act out and get in trouble in hopes of arousing the parent
- Child may become a perfectionist in an effort to take care of the parent's emotional needs or because the child believes his/her misbehavior is the cause of the parent's illness.
- Child may be chronically tardy or absent from school due to the parent's inability to regulate child's schedule
- Child may become school phobic out of concern for parent
- Parent fails to take child to appointments and fails to communicate with teachers regarding child's needs

Major depression responds readily to treatment, which may include talk therapy and/or medication. Individuals can help their own recovery with exercise, proper nutrition, adequate rest, and assistance with responsibilities until they are feeling better. It is also helpful to provide an emotional outlet for the child so that s/he has somewhere to ask questions and get feelings validated.

NOTE: It is important to seek help as soon as possible. Left untreated, depression can deepen to the point of psychosis and hospitalization may then be necessary. If left untreated, psychosis may deepen to the point where the parent is dangerous to him/herself and others. If treated early, recovery can occur in a few weeks with little disruption to family routines.

Bipolar Disorder

Bipolar Disorder is sometimes called Manic Depressive Disorder. Individuals with Type I Bipolar Disorder will have intense manic moods during which they will:

- Feel grandiose
- Have no impulse control
- Speak very quickly while jumping from one idea to the next
- Begin lots of new projects without finishing any of them
- Act very restless
- Require little or no sleep

- Become very irritable and even violent
- Be verbally, physically, and/or sexually abusive to adults and children in the family
- Engage in very high risk behaviors
- People with acute manic moods can be dangerous to themselves, too. There is a 10% to 15% rate of suicide among people in manic moods.
- Individuals experiencing mania do not believe they are sick and will refuse to take medication.

Note: People in acute manic moods need to be hospitalized to keep them and their families safe until they are assessed and stabilized on medication.

Without knowing a person's history, it is difficult to know if manic behavior is the result substance abuse, medication side effects, or an actual episode of mania. In any of these cases, it is important to make sure that the individual sees a professional as soon as possible.

Bipolar Disorder can be very disruptive to the family unit. If mood swings are frequent, children may become very anxious because they never know what to expect. When the parent is experiencing depression, the children's emotional and/or physical needs may be neglected. During manic episodes, depending upon the intensity, the parent may be very irritable, frequently criticizing household members. When manic moods are intense, the parent may exhibit behavior such as verbal abuse, physical abuse and/or sexual abuse toward children and spouse. The parent may involve the children in risky behaviors such as driving them in the car while enraged. A parent's manic behavior may involve impulsive, excessive spending or stealing, either of which can leave the family in financial ruin.

Because the symptoms of Bipolar Disorder can so acutely impact the family, it is critical to work with the parent to learn ongoing behaviors to support recovery as well as early warning signs that steps need to be taken to bring symptoms under control. Once an individual's mood is stabilized, managing stress, getting enough rest, and avoiding illicit drugs and alcohol can help the parent maintain mood stability. Because manic episodes may be triggered by unavoidable life stressors, it is important that the parent and family members learn the early warning signs of mood instability and help the parent seek help right away.

Schizophrenia

Schizophrenia is a very serious disease which usually requires strong psychiatric medications to manage symptoms. There are two types of symptoms which may be present with schizophrenia: positive (behaviors that are not present when one is well) and negative (normal behaviors which are absent when an individual has schizophrenia).

Positive symptoms include:

- Bizarre behaviors (derailed or incoherent speech)
- Hallucinations (perceiving things than aren't real)
- Delusions (believing things that are not real)
- Thought disorders
- Nicotine addiction

Negative symptoms include:

- Emotionless expression
- Apathy
- Withdrawal
- Remaining almost motionless

While there is some potential for violence among parents living with Schizophrenia, it is not known whether the incidence of violence is different from parents without the disease. Nevertheless, depending on thoughts and hallucinations, there may be a potential for violence. In addition, approximately 10% of individuals with Schizophrenia attempt suicide.

Depending on the acuteness of symptoms, the effects of Schizophrenia on the family can be similar to those of Bipolar Disorder. In addition, because a parent with Schizophrenia may behave oddly in public, children will experience guilt or shame towards the parent, and fear peers teasing because of the parent's public behavior. In addition, without sufficient adult help, one or more children may become parentified and assume the duties of caring for the parent and siblings. At the very least, a parent with Schizophrenia will have great difficulty bonding with his/her child if there is an inability to make eye contact. This situation may create serious developmental problems if children are ages 0 to 3 at the onset of the parent's symptoms.

It is important to note that many parents who have Schizophrenia can control their symptoms with medication and psychotherapy and can be good parents. Since both recovery and relapse are possible, the parent and other family members will need to learn early warning signs of relapse so that stability can be maintained in the family.

Post Traumatic Stress Disorder

Some people will argue, and this writer will agree, that Post Traumatic Stress Disorder (PTSD) is not really a disorder, but a syndrome. PTSD is actually a normal set of reactions to experiencing a very abnormal event. People get PTSD as a result of feeling trapped in an event that makes them feel endangered and powerless. Such events might include the following:

- War
- Street violence
- Accidents
- Natural Disasters
- Medical procedures
- Severe Illnesses

People with PTSD may show a tremendous variety of symptoms. For this reason, the initial diagnosis is often incorrect. Symptoms of PTSD can include some or all of the following:

- Sleep disturbance
- Appetite loss
- Irritability
- Social isolation
- Forgetfulness
- Fatigue
- Headaches
- Abdominal pain
- Muscle pain
- Flashbacks
- Jumpiness
- Escalating from calm to rage without warning
- Inability to concentrate or focus
- Impaired short-term memory

People with PTSD may try to manage their symptoms with caffeine, alcohol, and/or marijuana or other street drugs. These will only make symptoms worse. In addition, the parent may ask the doctor for sleeping pills. When Viet Nam Era veterans returned home and could not sleep, doctors discovered that giving them sleeping pills prevented them from dreaming. The vets who could no longer dream began acting violently during their waking hours because they could no longer process their war experiences through their dreams.

PTSD is very frightening for the person who has it as well as for the family. The individual's functioning has suddenly changed dramatically for the worse and s/he may feel like s/he is going crazy and can't get over it. Fortunately, nothing could be further from the truth. With simple self-care techniques like exercise, rest, humor, someone to talk to, and good nutrition, many victims can recover in a few weeks to a few months. Others may need additional help from a counselor who specializes in working with trauma survivors. Needing a counselor's help is not a sign of weakness; it is a sign that the traumatic experience was way more than the brain could process at one time.

Because the victim's symptoms can make life in the family very unpredictable, other family members may become very stressed and/or anxious. Arguments may erupt and a victim of trauma who is already on adrenaline overload may lash out violently, especially if using caffeine, alcohol and/or street drugs to medicate feelings. When one family member is suffering from PTSD, it is often useful for the whole family to get at least short-term help.

Addiction

Addiction has many faces. People can be addicted to substances (alcohol, street drugs, prescription drugs, inhalants) or behaviors (gambling, internet, sex). There is a particular group of behaviors that is common across addictions as well as a few that are unique to certain addictions. The common behaviors include the following:

- lying (about everything)
- blaming
- inability to identify feelings in self or others
- constantly breaking promises
- inability to maintain behavioral changes for more than very short periods (less than 30 days) the individual will steal from anyone, including family, to support the habit

- Be so involved with the habit that family and job are ignored
- Will be in complete denial that he/she has an addiction
- Often will criticize and belittle others
- Because substance addictions loosen normal inhibitions, the parent may emotionally, physically or sexually abuse other family members

Family members will protect the addict, cover for the addict, and collude with the addict's denial. At the same time, family members will fear for the addict's safety, feel angry for the problems the addict causes, feel rejected by the addict's broken promises, lies and abuse; feel torn between a sense of loyalty to the addict and a sense of rage against him or her. Immediate family members will begin to live by the following rules:

- Don't feel
- Don't speak
- Don't trust

Children will assume rigid family roles which serve to draw attention away from the addict. Common roles children may assume include:

- The mascot (jokester)
- The rebel
- The hero
- The lost child

Assuming these roles will prevent the children from acting on their true feelings and needs and may curtail their ability to know themselves. This in turn may lead to acting out behaviors, perfectionism, manipulative behavior, and addiction.

HOW TO EMPOWER PARENTS AND SUPPORT CHANGE

Advanced Directive Documents

Completing an advanced directives document is an important way to plan for possible crisis before it occurs. If there has been no advanced planning, it is very difficult to make good decisions in the midst of crisis.

The purpose of the advanced directive is to assure that the parent's treatment and care of the children will occur in an orderly way that will represent the best interests of the family. A parent advocate or other service provider should work with the parent to complete the document. Some models for this document can be found on the websites for the following organizations: NAMI, Bazelon Center, and the National Mental Health Association (NMHA). Once the document is complete, copies should be distributed to the following agencies and individuals:

- The immediate family household
- Person(s) designated to care for the children in emergency
- Family mental health providers and advocates
- Psychiatrist
- Parent and children's primary care physicians
- CPS and Family Court, if there is an open case
- Inpatient facility if parent is hospitalized

It is important to note that the advanced directive is not a legal document and therefore is not enforceable by law. Nevertheless, it is a useful guide for which all collaterals and family members will be grateful.

Preventing Vicarious Traumatization or Compassion Fatigue

What is *vicarious traumatization*? Vicarious traumatization is the process by which providers become traumatized through exposure to clients' traumatic events. Vicarious traumatization is often called *burnout or compassion fatigue*. Each provider's threshold is different and is influenced by the provider's history and ability to take care of his/her own emotional health. When providers experience burnout, they are separated from their own personal power and no longer can empower their clients.

How does this burnout get in the way of our helping clients?

- It prevents us from feeling hopeful for our clients
- It prevents us from feeling resourceful
- It prevents us from giving our full attention to clients when we are with them
- It makes us irritable and/or distracted
- It prevents us from seeing possibilities for our clients
- It prevents us from maintaining an objective perspective

How do we know when we or our colleagues are suffering from vicarious traumatization or burnout?

- The burned out provider may over-identify with a client and as a result may over protect or collude with him
- The burned out provider may be in denial or block out clients' most important needs or issues and may act as though the issues don't exist; may forget or discount the client's concerns
- The provider may dread seeing the client and cancel numerous appointments at the last minute or miss appointments entirely.
- The provider may take the easy way out in choosing interventions rather than following the most effective protocols.
- The provider may begin to exhibit excessive absenteeism.
- The provider may become very delinquent in completing paper work.

Laws of Nature regarding burnout:

1. If you avoid working on your own issues, you will be unable to help clients who present with similar issues. You cannot lead someone where you, yourself, have not gone.
2. If you fail to take care of burn-out symptoms early, you will harm yourself and your clients.
3. When you are burned out, your assessments of clients will be inaccurate because your perspective will be distorted.

How to prevent and/or recover from burnout:

- Keep balance in your life: work, play, relationships, spiritual pursuits
- Pace yourself in work
- Eat properly
- Get enough rest and exercise
- Know your limitations. Know when to ask for help.
- Share what is on your mind instead of keeping it inside
- Take a few minutes each day to connect with yourself. Notice what you are feeling. Notice what you need.
- Practice progressive relaxation or deep breathing daily
- If you find your issues are being triggered by your clients, get help! Use your EAP or find a counselor for yourself.

Active Listening

Active Listening is a form of listening where you not only listen to what the client is saying, but you listen for the feelings behind the words and reflect them back to the client. Active Listening helps the client feel heard, believed, and cared for; it allows him to go deep within himself to find his own wisdom and share it. Active Listening makes the client feel validated. It is a technique that helps you and the client access the highest part of yourselves. Active Listening is one of the most empowering behaviors we can use with another person.

Usually, when we listen to others speak, we do not really hear what they say because we are too busy thinking about what we want to say next! Active Listening blocks this behavior so we can truly hear the speaker.

I-Messages

I-messages are used to communicate concerns in a way that helps the listener stay open to hear you. The reaction of the listener is very different than it is to you-messages, which the client perceives as blaming, threatening, and possibly humiliating.

You-messages start with the word "you" and feel blaming and threatening or belittling to the listener. When the listener hears this type of message, she will either become angry, anxious, or shut down. The message will not hit home.

When using I-messages to voice concern, we share our feelings instead of our judgment about a behavior. For example: "I feel concerned when you forget to take your medication. I worry that it will put your request for custody in danger." When you express concern in this way, the listener does not feel debased and can stay open to problem solve about how to change the behavior.

We often use you-messages like: "You forgot your medication again; this is the third time this week. How do you expect to keep your kids when you act like that?" Upon hearing this type of message, the listener will feel blamed and/or shamed and will feel a need to defend herself instead of focusing on problem solving.

Used together, Active Listening and I-messages are a powerful set of tools to enhance problem solving and help the client achieve goals.

Praise

The parents we work with are accustomed to being blamed and scapegoated. In addition, parents assume that because they are having difficulty with some aspects of child-rearing, that their psychiatric disabilities is the cause. It is important for us to let parents know that everyone has challenges with parenting – that we all encounter times when we feel helpless or powerless and can't find a solution to the challenge.

It is important for parents living with psychiatric disabilities to know what they are doing well. It is crucial that parents receive praise so they will know their own minds and begin to build confidence in their own abilities and instincts.

The more a parent trusts his/her ability to parent, the better he/she will be able to fill the role of executive of the family. Therefore, however often you can find something to praise honestly, the more confidence the parent will gain both in his/her own parenting ability as well as trust your intentions to support his/her efforts.

Remember: Catch parents doing something right and let them know about it.

Linguistic Techniques

1. Negative statements - Negative statements can often have an outcome that is opposite of what is intended. Why? There are two reasons: first, when we tell someone not to do something, we also need to state the behavior we want instead. We cannot assume that the listener is a mind reader or knows how to do the behavior we have in mind. Second, when we hear a negative directive, our subconscious does not register the word "don't"; it only hears the verb. For instance, if you tell a parent: "Don't treat your child that way", the parent's subconscious will only hear "...treat your child that way." In the meantime, the

parent is left with the question: "How do you want me to treat my child?" To make a long story short, we can be more helpful to parents by expressing to them what we want them to do rather than what we don't want them to do.

2. The imbedded message is a form of linguistic hypnosis where we embed a suggestion for making change into a conversation. Generally, when we are discussing possible changes with a client, we will ask: "Can you....?" "Do you think you can...?" The response to this question will either be "yes" or "no". In other words, there is a 50% chance the client will not choose to try to change. If we express the change to elicit a "when" response instead of a "yes or no" response, change is much more likely to occur. Here is how we embed the message: "I can hear that you are concerned about trying this, but *when you are ready to do it*, it will make a big difference for you." The embedded message lets the listener know that change is a foregone conclusion and the only question is *when* it will occur. This approach markedly increases the chance that change will occur.
3. A very famous hypnotherapist named Milton Erickson used to teach his students about more than just embedded messages. Dr. Erickson recognized that when people were in a state of curiosity or a state of confusion, their minds were open. The good Dr. Erickson used to use this technique with oppositional teenagers and terrified adults with great success. For instance: when a client is reluctant to trust a statement you have made about something that would be beneficial, you can respond with: "It's okay if you don't trust what I'm saying; it will take time for you to discover if I've given you correct information. But would you be willing at least to be curious about whether I'm telling the truth?" Unless you are working with someone suffering from acute paranoia, there is a high degree of likelihood that the client will be curious about what you have said. Since creating confusion requires some complex verbal gymnastics, we will not discuss this technique.
4. When working with a very oppositional client, especially in the first session, you may be able to win him/her over if you can elicit the answer "yes" three times in a row. You can do this by

asking three questions or making three statements to which the obvious answer is "yes". The following example will illustrate the technique: "So, I guess you aren't too happy about being here. You'd rather be someplace else. Perhaps you're wondering if I think you're a loser." Once this has been achieved, go ahead and try to engage. "So given the fact that the court says you have to be here, what you would like to do with the time?"

Crystal Ball Technique

When you are helping a client set goals for changes he or she would like to achieve, help the client to be clear and concrete about what changes s/he wants to make with the following directive:

Imagine that you have a crystal ball and as you gaze into it, you can see what your life would be like if this problem did not exist. Take a moment to gaze into the crystal ball and tell me what emerges. Describe the scene as completely as possible.

As the client shares the description, ask questions which will help details become clearer:

- What is the scene? How does it look?
- What do you see?
- What are people feeling?
- How are you feeling as you experience this scene?
- What is the first thing you would like to do to work towards making this scene a reality?

Any ideal state that a client can imagine can be achieved. Looking into the imaginary crystal ball give the client a chance to see a solution where perhaps s/he previously believed none existed. Doing this exercise in guided imagery helps the client move from a state of hopelessness and/or helplessness to a state of possibility.

What is the smallest thing you need to achieve this goal?

Asking this question as a follow up to the Crystal Ball Technique will help you and the client identify the first step to achieving the goal. When you ask for the *smallest* thing that is needed to the client will feel that doing this piece is very possible. This accomplishment will lead to motivation for identifying and achieving the next objective.

See the whole person

It is very easy to see only the client's flaws or problems but this serves no useful purpose. Since nobody is all bad, all clients have positives. Psychiatric disabilities are only a small part of who your client is. Your client is a multi-faceted individual with many roles, gifts, and talents. It is important to learn what these facets are. By seeing the whole person, you will expect your client to achieve. When you hold this expectation, it helps the client in two ways. First, in the beginning, many clients cannot see their own positive qualities and therefore believe they are incapable of success. It is important for us to hold a positive image for them until they can carry it themselves. In addition, if you expect a person to succeed, they **will** succeed. If you expect a person to fail, they **will** fail. Your positive expectations for your client are crucial to his or her successes as a parent. If you see only the client's symptoms or disabilities, you contribute to their stigma.

NECESSITIES AND CHALLENGES IN WORKING WITH PARENTS

A good history is the best tool to solving any problem but not everyone takes the time to organize and get needed information. History is just as important as what is happening in the present. It is crucial find out the following:

- Medications – psychotropic and otherwise, including herbal supplements and over-the-counter
- Hospitalizations – physical and psychiatric disabilities
- Chronic conditions
- Parent's experience growing up – are memories consistent or are there gaps? Does the parent say everything was ideal? (Both are red flags) Did anyone have problems with drugs, alcohol, emotional problems?
- How was the parent disciplined as a child?
- Has parent been abused or been a crime victim as an adult?
- What are the parent's habits around alcohol? Street drugs? Prescription drugs? Gambling? Internet? Shopping?
- What were the gifts and talents in the parent's family of origin?
- What did the relationship between the parent's mother and father look like?

You may not be able to get the answers to all of the above questions at the same time, but as trust grows between you and the parent, you will be able to collect needed data.

Because many symptoms and behaviors are shared by several diagnoses or situations, having an historical context will help you sort quickly for the right piece of the puzzle. It is just as important to understand the motivation behind a behavior as to notice the behavior itself. Discovering the rationale or belief behind the behavior will make it much easier for you to choose the right intervention to help the client take his/her next step.

Differential diagnosis is a complex process which can be made easier by taking a thorough history. What is differential diagnosis? It is considering all possibilities and choose the one which most closely matches with all symptoms and history. While providing a diagnosis may not be part of your job, it is still useful to be able to make one because it will help you organize your thoughts around creating an effective treatment plan. Many disorders have similar symptoms or behavior patterns. When clinicians make a diagnosis on only the most obvious symptoms, often both the diagnosis and treatment plan are usually incorrect and the parent's chances for recovery diminish. Here is a prime example: Many people who have Dissociative Identity Disorder (DID) go for years without adequate help. Why? Because they report hearing voices and automatically get a diagnosis of Schizophrenia. Hearing voices is a common symptom of both disorders, but the provider needs to watch for what other symptoms and history emerge as well. Depending on the most obvious symptom to make a diagnosis or assessment will almost always lead you astray. Look at the obvious symptoms, ask about others, and look back at the history. Using this protocol will allow you to lead the parent toward recovery in the shortest possible time.

Learned helpless is, more than anything, a state of mind. Some people, who have been repeatedly abused and traumatized since childhood, constantly feel very vulnerable and powerless. This belief makes them very passive and unable to consider the possibility of asking for what they want, making plans to achieve a goal, or saying "no" to things that are not in their best interest. If you are working with clients who appear to have this pattern, you will notice that they

believe they cannot succeed at anything and/or do not deserve anything and therefore will not try things you suggest. Parents who have learned helplessness are unable to set limits and consequences for their children. The good news is that what is learned can be unlearned. While it is possible to teach a client how to feel capable and assertive, it is a slow process that must be done in small steps. The following steps will help achieve this goal:

- Frequently ask: what's the smallest thing you can do?
- When the client complains about something, respond by asking: "What do you want to do about it?"
- Catch the client doing things well or displaying strength and point it out to him or her.
- Engage the client's curiosity about whether they can do something to solve the problem.
- Engage the client's curiosity about what it would be like to be able to take a specific action.
- Use the Crystal Ball guided imagery to help the client get in touch with what it would be like to be able to achieve a goal.

Remember to keep your expectations small and your pace slow. Doing too much or doing it too fast will derail the progress. In this case, less is more.

Parent is not making progress in parenting goals – This is a very frustrating situation in which it is easy to assume that the parent does not care. You might also assume that you are doing a poor job. It is likely that neither one of these assumptions is correct. When you encounter this problem, it is time for you to get curious and wonder what is causing the problem. If you keep yourself in a state of curiosity instead of frustration, you will be able to discover the cause and the solution. In addition, keep reviewing the history to discover clues. There are several reasons why a parent may not progress:

- Experience deficit – If the client's parents did not bond with him or if the client was raised in an institution, he does not know what bonding looks like, let alone how to do it. You will need to break skills down into very small units and spend lots of time demonstrating and coaching. Find television shows that demonstrate the techniques and ask the parent to watch them. Describe a behavior and then demonstrate it. Finally, coach the parent to do it.

- Addiction – The parent who has an active addiction will be unable to change behavior or maintain it for an extended length of time. For the parent with an addiction, rehabilitation must be the first step.
- Depression – A parent suffering from untreated depression may really want to do what you are asking but will be unable to act. Depression robs the individual of initiative. S/he may want to do something, may sit on the bed and imagine doing it for hours on end, but will be unable to initiate the action to make it really happen. In order to activate the depressed parent, you may have to begin by asking them: “What is the smallest thing you can do?” If the depression is severe, the parent may not be able to benefit from your interventions until her mood is stabilized with medication.
- Unresolved childhood abuse and trauma – A parent who was severely traumatized as a child may be unable to connect with her own children when they are the age at which the parent was abused. If this occurs, you will need to put parenting goals on hold for a while and work on the traumas. Once this occurs and once the children get past the trigger age, things will begin to improve.
- Can't seem to learn skills – There are three basic learning modalities: auditory, visual, and kinesthetic. Each of us is strongest in one modality and also uses a second modality. Some individuals are more rigidly entrenched in their primary modalities than other people. You are probably coaching in your primary modality. If you and the parent do not share the same primary modality, you may need to change the modality in which you coach her.

To identify the modality in which the parent best receives information, you only need to listen and watch for clues.

Parents who are visual will say things like: “I see what you mean.” They may look up before answering a question because they are visualizing the answer in their imagination. The visual person will learn best by watching or reading.

People who are auditory will say things like: “That doesn’t ring true for me” and may slightly tilt their head to one side when you speak, as though they are listening intently. The auditory person will learn best by listening to what you say or using a tape.

The person who learns best kinesthetically will say things like: “I feel okay about that.” When asked a question, the kinesthetic learner will first look down and check his feelings and then will go back to his brain to check his thoughts. The kinesthetic learner will do best when he can learn by doing.

Please note: Your client may be illiterate or unable to concentrate long enough to read. The client will carry a lot of shame about this. If you suspect this might be the case, simply ask the client: “Can you see this okay or would you like me to read it for you?”

Compliance with psychotropic medications – There are several reasons why parents may not take their medications as directed. Part of the reason for noncompliance may be lack of education about this class of medications and how they differ from others. Other reasons may have to do with side effects or stigma about having to take the medication. It is crucial that you take the time to find out what is causing noncompliance so the behavior can be remedied. Below you will find some of the most common roadblocks to compliance with medication and suggestions to remove them.

Lack of information: Only rarely does a doctor explain how psychotropic medications work and what kind of cooperation is needed between patient and doctor in order to achieve the best results. You can communicate this information to parents without breaching your scope of practice. The biggest difference between psychotropic medications and those used for physical ailments is that the medications react differently in each person – it is not a matter of one dose fits all. Therefore, prescribing can be more of an educated guess than exact science. This fact has a very important implication: unless the parent tells the doctor how s/he is responding, the doctor will have no way of knowing. In addition, doctors seldom know the

right questions to ask to elicit the information they need! It is very helpful to advise parents that when they take the medication, they need to be the eyes and ears for the doctor and let the doctor know any positive changes they notice as well as side effects. If side effects are interfering with a client's parenting duties, it is very possible that the doctor will suggest taking the medication at a different time of day or making other changes. **IMPPOINTANT: Under no circumstances should an individual stop taking the medication without directions from the doctor or pharmacist. Some medications need to be tapered. Stopping suddenly could put the client in danger by creating a rebound effect of symptoms that were present before treatment.** It is also critical to remind parents that it is dangerous to mix psychotropic drugs with alcohol or street drugs. These will make some medications to stop working or may cause brain chemistry to become very unbalanced, resulting in a psychiatric emergency.

It is important for parents to know that when they begin taking a medication, it may need to build up to a certain level in the blood before it is fully effective. This means that it may take two to six weeks for symptoms to disappear completely. Forgetting doses will slow the process. On the other hand, sometimes clients will have bothersome side effects when they begin the medication. In many cases, side effects disappear in a week or two. If side effects feel unmanageable, it is important to notify the doctor immediately. Sometimes starting with a smaller dose and gradually building to a full dose will keep side effects in check.

Forgetfulness: Parents who tend to be forgetful or disorganized due to medication side effects or illness symptoms, may have a difficult time remembering to take their medication. It is important to help these parents develop a strategy that will enable them to take their medication on time, every time. Missing doses will delay recovery.

Stigma and misperceptions - Some parents may view having to take medication as a failure or weakness. In this case, it will be useful to draw comparisons to medications which are taken for chronic physical conditions like Diabetes or thyroid problems. As a last resort, it may be helpful to review how the parent's symptoms impede her ability to care for her children and emphasize that since symptoms have not improved without medication that it will be necessary to use medication if she is to succeed. In the end, the parent may have to choose between medication and custody of the children.

Respecting our clients is the very best way to empower them and promote their recovery. No matter what else we do with or for clients, respect is the most important ingredient. Behaviors that indicate respect include:

- We see and appreciate clients' positive attributes as well as their struggles.
- We are open to learning about clients' cultural practices and beliefs rather than judging them.
- When clients get stuck or make poor choices, we help them process and learn. We expect success.
- When necessary, we confront clients and hold them accountable, but we do it in a caring way.
- We always keep information about our clients confidential.
- We are supportive and keep appropriate boundaries with our clients.
- We respect our clients' time in the way we want them to respect our time. That means: keeping appointments, arriving on time, and ending on time.
- We trust our clients to know best what goals they need to achieve.
- We help our clients take responsibility for their recovery.
- We are always honest with our clients.
- We take good care of ourselves so that we can do our best for our clients.

III

RESOURCES

WHAT WILL THE FAMILY NEED?

Asking what the family will need, both today and later, is crucial to the recovery of the parent and the family. Needs fall into several categories. A detailed, well documented needs assessment is as important as a psycho/social history and should be part of the workup on each client family. It is very helpful to have a list where you can check off items or briefly fill in blanks.

Basic Needs

- Adequate housing
- Adequate food
- Adequate utilities
- Clothing that fits and is appropriate to each season
- Easy access to affordable transportation
- Access to medical and dental care for family
- Applicable medications
- Prescription eye glasses, if needed
- Telephone at home or nearby
- Child care, if needed
- List of emergency phone numbers
- Household furnishings and utensils
- Appropriate toys, books for children
- Calendar for appointments

Psychiatric and Socio/Emotional Needs

- Advanced directive
- Parent or family advocate
- In-home coaching if needed
- Individual and/or family therapy as needed
- Support group(s)
- Respite service – crisis or scheduled
- Respite opportunities for children
- Hotlines
- Warm lines
- Easy access to any needed psychotropic medications
- Emergency psychiatric assessment and/or care
- List of healthy self-soothing activities for tough times
- Substance abuse assessment and or rehabilitation

- Emotional enrichment groups: stress management, journaling, art, drama for adults and children
- Healthy Families of New York State provides services for qualified parents with babies

Social Needs

- Family support
- Support from friends and/or neighbors
- Religious or spiritual community support
- Hobbies
- Classes for adults and children
- Exercise
- Holidays and birthdays celebrated
- Free community activities
- A place to do community service
- Scouts or other social groups for children
- Athletic opportunities for children
- Work or volunteer opportunities

WHAT IS AVAILABLE IN YOUR COMMUNITY?

Since resources vary from county to county and from community to community, it is helpful to network with other providers periodically in an effort to discover what new services are available and which may have closed. While few of us have time during the work day to really play detective to find out what undiscovered services are available, it might be helpful to set aside one hour per week to devote to this or, if possible, get a student from a nearby community or four-year college to develop a resource list for you for academic credit.

Even when services are present in the community, there may not be space available without a very long wait. Therefore, before crises occur, it will be helpful for you to develop a Plan B or fall-back position.

When trying to identify services in your area, think outside the box. There may be help available where you least expect it. Besides county-run clinics and hospitals, check about programs through schools and churches; check peer-run programs or, using the resource

assessment checklist you have completed for a client, develop a community of support to assist the family until professional help is available. Remember to ask your client: what is the smallest thing that will make a difference?"

Finally, remember the saying: "Give a man a fish and he eats for a day. Give a man a net and he eats for a lifetime." Clients need coaching and encouragement to identify as many self-care activities as possible that they can do to support their own recovery. Help clients choose between one and three things that will help them stay healthy and/or manage symptoms while they are waiting for professional help. These things may be small, but they can make a big difference!

In summary, there are a few basic rules to keep in mind when identifying resources for families:

- Keep updating your resource list through research and networking
- Always have a fall-back position or Plan B
- Think outside the box when looking for services or support
- Ask the parent: "What is the smallest thing that will help?"
- Encourage clients to develop a self-care plan

HOW TO HELP CLIENTS ACCESS SERVICES

It is easy to get caught up in arranging all the services for your client. In many cases, it is in the client's best interest for the two of you to work in partnership to make things happen. Below is a list of activities that will enable you to help clients help themselves.

- Clients, like everyone, like to know what to expect.
- Explain how the service access process will unfold.
- If possible and appropriate, help the client make the call.
- Help the client make a list of problems or symptoms and a list of goals to share with providers at intake.
- Help the client create a timeline of symptoms.
- Help client identify triggers to symptoms and identify ways to manage them.
- Help the client learn how the system works and how to work the system.

- If the client frequently asks you what s/he should do, respond by asking the client the same question. If the client cannot answer, try helping him/her find the answer through additional questions. This will help the client begin to trust his/her own judgment.
- If the client is anxious or shy, you may want to accompany him to the first session
- If the client is willing, get a Release of Information so you can communicate with the provider
- If problems arise between client and provider, coach the client to problem solve with the provider

HELPFUL RESOURCES FOR YOU AND PARENTS

Legal Services

Mental Hygiene Legal Services

- Upper Hudson Valley Eastern NY, Third Judicial Dept.
(518) 474-4453
- Bronx & Manhattan, First Judicial Dept. (212) 779-1734
- Lower Hudson Valley Long Island Second Judicial Dept.
(516) 746-4545

Central/Western NY, Fourth Judicial Dept. (585) 530-3050

Court-Appointed Special Advocates (CASA)
(518) 426-5354

Greater Upstate Law Project, Inc. (518) 462-6831 (SSI & SSDI issues.
Does not take individual cases, but gives referrals to statewide agencies that will.

Children and Parenting Websites

Families Together in NYS, Inc. <http://www.ftnys.org>

Families Together in NYS is a non-profit, parent-run organization that strives to establish a unified voice for children with emotional, behavioral, and social disorders. Their mission is to ensure that every family has access to needed information, supports, and services.

Children's Mental Health Resource Kit

<http://www.childrensdefense.org/mentalhealthresourcekit.php>

One in 10 children and adolescents has a serious psychiatric disabilities that is severe enough to cause some level of impairment. Only about one in five of them receive mental health services in any given year. The Children's Mental Health Resource Kit is designed to help promote access to and increase availability of mental health screens and assessments for children through Medicaid and the Children's Health Insurance Program (CHIP) programs as an essential first step in ensuring appropriate mental health treatment for children. It will help you gather information in your state and lead you to other resources as you work to improve and expand mental health screens and assessments for children.

Parenting Well <http://www.parentingwell.org/index.html>

Parenting Well is a group of researchers and practitioners - psychologists, occupational therapists, counselors and policy analysts, parents and

grandparents affiliated with the University of Massachusetts Medical School (UMMS) who, together, have over fifty years of experience working with adults, children and families living with psychiatric disabilities. This web site provides parents, providers, policymakers, and researchers the latest research data and treatment information to aid in parent skills training, program supports, and policy development, and gives parents with psychiatric disabilities and their families the hope, knowledge, and tools they need to succeed.

Prevent Child Abuse New York <http://www.preventchildabuse.org>

Prevent Child Abuse NY is a not-for-profit organization whose primary mission is the prevention of child abuse and neglect. Among other programs, they operate a 24-hour helpline in English and Spanish (1-800-342-7472), offer parenting education and support groups, and services for children.

American Academy of Child and Adolescent Psychiatry <http://www.aacap.org>

The AACAP maintains a well designed and informative web site which includes Facts for Families, a series of articles on various issues ranging from bedwetting to adoption to depression to puberty.

Children's Defense Fund <http://www.childrensdefense.org/>

This site contains news and resources for children's advocacy, especially minority and special needs children, and articles by CDF President Marian Wright Edelman. Also includes information on Healthy Start, Head Start, Fair Start, Safe Start and Moral Start.

New York Yellow Pages for Kids with Disabilities

<http://www.fetaweb.com/help/ny.htm>

The New York Yellow Pages for Kids with Disabilities is part of the 'From Emotions to Advocacy: The Special Education Survival Guide' website put together by Pam & Pete Wright. The Yellow Pages list a wide range of services for children with disabilities and their parents. The 'From Emotions to Advocacy' website is an exceptional resource for parents who are advocating for services, especially special education, for their children.

ERIC Clearinghouse on Elementary and Early Childhood Education

<http://ericeece.org/>

The Educational Resources Information Center (ERIC) is a national information system supported by the U.S. Department of Education. Their website is an amazing resource for educators, parents, and students. It includes links to the National Parent Information Network (<http://npin.org/>), a collection of resources for parents; AskERIC and Parents AskERIC (Internet-based question-answering services sponsored by the ERIC system); LISTSERV discussion groups

sponsored by ERIC/EECE (discussion groups on topics related to early childhood, elementary, and middle level education)

.Partners for Children www.nyspartnersforchildren.org/

A collaborative project between The New York State Office of Mental Health (OMH) and the New York State Education Department (SED) to develop effective, innovative, collaborative school-based mental health services for children and their families in communities that have identified the need for such services.

Federal Interagency Coordinating Council (FICC) <http://www.fed-icc.org>

Provides information on federal, state and local programs that serve infants, toddlers, and preschoolers, ages birth through 5, who receive services under the Individuals with Disabilities Education Act (IDEA), as well as other federally funded programs.

Kids Count Data Book <http://www.aecf.org/kidscount/databook/>

Easy-to-use information that will allow you to generate your own state profiles, graphs, maps, ranked lists, and more.. A project of the Annie E. Casey Foundation, KIDS COUNT is a national and state-by-state effort to track the status of children in the United States. By providing policymakers and citizens with benchmarks of child well-being, KIDS COUNT seeks to enrich local, state, and national discussions concerning ways to secure better futures for all children.

Forgotten Kids Official Webpage <http://forgottenkids.virtualave.net/>

"Forgotten Kids: the children that have nearly invisible disabilities. They have their arms and legs, can see and hear, run, play, etc., but most have never been to a birthday party or a sleepover. They are last to be chosen to play, and first to be blamed. Their illnesses aren't fatal, but a small part of their hearts and souls die with every rejection. Their behaviors may seem odd or unpredictable to themselves as much as society. They are overlooked, thus the name "Forgotten Kids".

The Instant Access Treasure Chest <http://www.fln.vcu.edu/ld/ld.html>

This site includes government resources, assistive technology, college policies for students with disabilities.

Juvenile Justice Home Page <http://www.abanet.org/crimjust/juvjus/home.html>

The website of American Bar Association's Juvenile Justice Center: a project to improve access to counsel and the quality of representation for children in the juvenile justice system.

Kathy's Resources on Parenting, Domestic Violence, Abuse, Trauma & Dissociation <http://www.mcs.net/~kathyw/home.html>

The title is self-explanatory, but this site also contains deeply moving messages from Kathy and her daughter Rachel. The site uses a rating system which should be helpful in viewing the site with children.

National Center for Learning Disabilities <http://www.nclld.org>

Looking for answers to the following? "My child has learning disabilities and I want to know how the school can help my child." Check out this site for information on legal rights for children with learning disabilities.

LDOnline <http://www.ldonline.org/>

The interactive guide to learning disabilities for parents, teachers and children. This site includes a resources section, 'Ask the Expert', bulletin board and a recent article entitled "The Uses and Misuses of Processing".

New York State Council on Children and Families Homepage

<http://capital.net/com/council>

The site offers information on child care, human services toll-free numbers, Headstart, welfare reform and more.

Parents Helping Parents <http://www.php.com>

A San Francisco Bay Area-based group, but their website has extensive resources for parents of special needs children.

Pediatric Points of Interest <http://www.med.jhu.edu/peds/neonatology/poi.html>

Brought to us by the folks at the Johns Hopkins University School of Medicine Department of Pediatrics, this site provides a plethora of great links for parents and kids, ranging from seriously educational to downright fun.

Resources for Children With Special Needs <http://www.resourcesnyc.org>

Resources for Children with Special Needs website provides frequently updated news that impacts the lives and welfare of children with special needs and disabilities, plus a FAQ page, and extensive information about parent and professional training programs and workshops, activities and services, and parent groups. There is also registration information for free training sessions, and a links page.

Youth Booth <http://www.youthbooth.org>

The Youth Booth, sponsored by the MHA in Ulster County, is an interesting and non-judgmental environment where teens can comfortably approach a caring adult with questions and concerns. It provides a safe place to obtain information on such topics as drugs and alcohol, motor vehicle information, sexuality, mental health issues, AIDS, recreation, job referral, and substance abuse intervention.

Weaver's Website for Parents of Children with Brain Disorders <http://a-o.com/d-g-weaver>

Weaver's Website draws heavily on personal experience in managing a child's major depression, anxiety and Asperger's Syndrome. The site provides links and resources regarding children's psychiatric disabilities issues.

YouthInfo <http://youth.hhs.gov>

Developed by the U.S. Department of Health and Human Services (HHS) to provide the latest information about adolescents, YouthInfo currently includes the following: a statistical profile of America's teenagers; the latest reports and publications about adolescents; information for parents of teens; speeches by federal officials on youth topics; links to youth-related websites at HHS, other federal agencies, private foundations and research organizations.

Other Resources and Organizations

Mental Health Association in New York State (MHANYS) Mental Health Information Center can be reached at info@mhanys.org or by phone at (800) 766-6177. *Will provide information and referrals to other organizations throughout New York State.* <http://www.mhanys.org>

Helping Families to Help their Loved Ones with Serious Mental Illness. A white paper of the National Alliance on Mental Illness of New York State (NAMINYS). Developed by Jeff Keller, Deputy Director of NAMINYS, this paper is a must read for all treatment providers and advocates as well as family members. Download at <http://naminys.org/famservwp.pdf>, or phone 1-800-950-3228 to request a hard copy.

Peer-Run Groups

- Mental Patients Liberation Alliance 1-800-654-7227
Round-the-clock peer support
- Resource Center (518) 463-9242. Self-Help information for peer-run group or 1-800-811-1175 *for self-help only.*
- Mental Health Empowerment Project (518) 434-1393 or -800-MHEP-INC (643-7462). Consumer run, OMH-funded project provides technical assistance and training for peer-run groups

Evidence-Based Practice Parenting Trainings

Name: Functional Family Therapy (FFT)

Purpose: Functional Family Therapy (FFT) is a family intervention program for dysfunctional youth.

Description: The FFT works with at-risk youth and their families in both clinic as settings as an outpatient therapy, and as a home-based model. The FFT model organizes intervention in specific phases. The phase-based goals of FFT are to:

Engage and motivate youth and their families by decreasing the intense negativity (blaming, hopelessness) so often characteristic of these families. Rather than ignoring or being paralyzed by the intense negative experiences these families often bring (e.g., cultural isolation and racism, loss and deprivation, abandonment, abuse, depression), FFT acknowledges and incorporates these powerful emotional forces into successful engagement and motivation through respect, sensitivity, and positive reattribution techniques.

Reduce and eliminate the problem behaviors and accompanying family relational patterns through individualized behavior change interventions by working to strengthen family communication, parenting, problem solving, and conflict management skills

Teach families to address problem situations by increasing the family's capacity to utilize multi-systemic community resources adequately, and to engage in relapse prevention.

Intervention ranges from, on average, 8 to 12 one-hour sessions for mild cases and up to 30 sessions of direct service for more difficult situations. In most programs sessions are spread over a three-month period. FFT has been applied to a wide range of problem youth and their families in various multi-ethnic, multicultural contexts.

The data from numerous outcome studies suggests that when applied as intended, FFT can reduce recidivism between 25% and 60%. Additional studies suggest that FFT is a cost-effective

intervention that can, when appropriately implemented, reduce treatment costs well below that of traditional services and other family-based interventions.

Target Population: FFT targets at-risk youth aged 11-18 with very serious problems such as conduct disorder, violent acting-out, and substance abuse. Younger siblings of referred adolescents also often become part of the intervention process.

Organization Name & Contact: Functional Family Therapy (FFT)

Website: <http://www.fftinc.com/>

Name: Homebuilders Program

Purpose: The Homebuilders program provides intensive, in-home crisis intervention, counseling, and life-skills education for families who have children at imminent risk of out-of-home placement, or who have already been placed out of the home.

Description: The goal of the Homebuilders program is to remove the risk of harm to the child instead of removing the child. The program provides therapy to families in immediate crisis, and works with families on specific psycho-educational interventions as well as educating them on how to meet basic needs. Therapists not only teach families skills such as child development, parenting skills, anger management, other mood management skills, communications, and assertiveness, but also will educate them on basic skills, as appropriate, such as using public transportation systems, budgeting, and dealing with the social services system.

Target Population: Families with children at imminent risk of out-of-home placement, or who have already been placed out of the home.

Organization Name & Contact: Institute for Family Development

Address: 34004 16th Ave South, Suite 200, Federal Way, WA 98003-8903

Phone: (253) 374-3630

Website: <http://www.institutefamily.org/>

Name: Invisible Children's Project

Purpose: The Invisible Children's Project's provides a broad range of services to families with children in which a parent(s) has a psychiatric disability, with the goal of keeping the family together and strengthening the parent's ability to create a safe and nurturing environment for their children.

Description: Critical program components of the Invisible Children's Project include: family case management with 24-hour access; supported housing; respite child care; planning in the event of parental hospitalization; advocacy with schools; social services; and family court; parenting training; vocational training; educational support; in-home clinical services; information; referral; linkages to the community; budget counseling; recreational family activities and family support. Other program features include support and education during pregnancy and postpartum periods, the use of art therapy with the children to address parental mental health issues and funding of special needs to enrich the family. Services are delivered to families as needed.

Target Population: Families with children in which a parent(s) has a psychiatric disability.

Organization Name & Contact: Invisible Children's Project, Mental Health Association in Orange County, Inc.

Address: 20 Walker Street, Goshen, NY 11924

Phone: (845) 294-7411

Website: <http://www.mhaorangeny.com/invisiblechildren.htm>

Research Reference: Hinden, B., Biebel, K., Nicholson, J., & Mehnert, L. The Invisible Children's Project: a family-centered intervention for parents with psychiatric disabilities. Report prepared for Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, submitted April 15, 2002

The Mental Health Association in New York State, Inc. (MHANYS) has available for sale through the Parents With Psychiatric Disabilities

Initiative a manual for the Invisible Children's Project entitled *Working with Parents with Psychiatric Disabilities and Their Children: A Family-Centered Approach*. Contact PWPd at MHANYS for more information or e-mail pwpd@mhanys.org

Name: Common Sense Parenting®

Purpose: Common Sense Parenting® teaches parents practical strategies for interacting more positively with their children, and to use effective and constructive discipline.

Description: Common Sense Parenting® classes form a practical, skill-based parenting program in which parents learn techniques to address issues of communication, discipline, decision-making, relationships, self-control and school success. The program aims to develop parents in their role as "teacher of their children". Parents learn how to communicate clearly and positively with their children, and how to establish clear and realistic expectations for their children. Parents learn the value of positive interactions such as giving effective praise, and focusing on the good things their children do. At the same time they learn how to correct misbehavior by using appropriate consequences and showing their children what to do instead.

Target Population: Parents raising children

Organization Name & Contact: Girls and Boys Town

Address: 14100 Crawford Street, Boys Town, NE 68018

Telephone: (402) 498-1300

Web Site: <http://www.girlsandboystown.org/>

Research Reference: Girls and Boys Town has researched the effectiveness of Common Sense Parenting's basic principles. In addition, Common Sense Parenting® earned an "outstanding" rating from The Parent Council and was a 1997 Seal of Approval Winner from the National Parenting Council. The U.S. Air Force selected Common Sense Parenting to support its outreach efforts to military families. Contact Girls and Boys Town for more information.

EVALUATION

Please help us improve this toolkit! We need your ideas!

Name (optional) _____ County _____

Parent Consumer Peer Advocate Counselor

Clinical Supervisor CASA staff Law Guardian

Family Court Judge or Staff CPS Caseworker DSS

Supervisor Other _____

Please answer these questions about the Tool Kit:

Was it easy to find information? yes no

Was it well organized? yes no

Was it easy to read? yes no

What needs to be added? (use back of paper if necessary)

What needs to be changed? (use back of paper if necessary)

How is the layout? (use back of paper if necessary)

7. What else would you like to say?

Thank you! Your feedback will be used to revise the Tool Kit

Please return to:

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