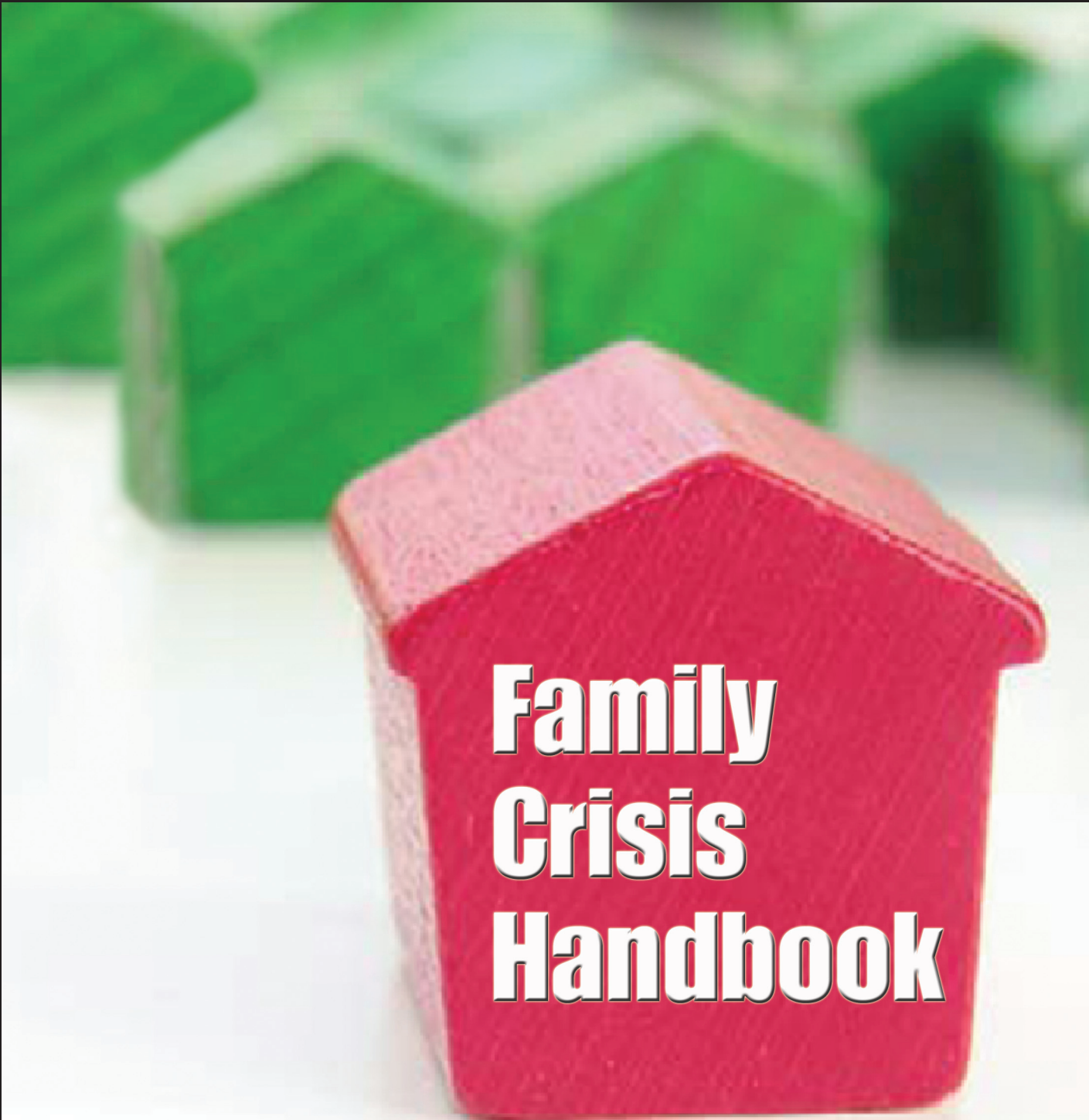




Family Crisis Handbook

**How to cope when an adult
loved one with a developmental
disability experiences mental
health or behavioral issues**

**Donna Icovino
Lucille Esralew, Ph.D.**



Table of Contents

Acknowledgements	2
Authors' Forewords.....	4
Introduction.....	8
Definition of Dual Diagnosis (MI/DD)	9
What is a "Mental Health Disorder" or "Psychiatric Illness?"	10
What is the Relationship between Mental Illness and Behavior?	10
Mental Health Professionals You May Encounter	11
What is a Behavioral Crisis?	12
What Strategies May be Helpful in a Crisis?	13
How to Assess the Severity of a Crisis	14
What to Do in the Event of a Crisis	14
You Have Called 911 – Now What Should You Do?	15
What to Expect in the Emergency Room	17
Why Does Your Relative Need a Medical Evaluation?	18
Why Must You Wait in the Emergency Room?	18
What to Expect at a Psychiatric Screening	19
What are the Criteria for a Psychiatric Hospitalization?	19
What If Your Family Member Needs to be Hospitalized?.....	21
Levels of Hospitalization	21
Voluntary Admission or Involuntary Commitment?	21
2D-the Specialized MI/DD Unit at Trinitas Regional Medical Center	22
What If Your Insurance Company Won't Pay?	23
Diverting Your Relative from a State Psychiatric Hospital.....	23
How is an Individual Committed to Involuntary Care?	23
What to Do if You Object.....	25
Alternatives to Hospitalization	25
The Best Alternative . . . SCCAT	26
Additional Options	26
What if Your Family Member Doesn't Need Hospitalization?.....	27
What if You Aren't Able to Support Your Relative at Home?	27
After the Crisis is Over	28
Family Members Coping Together with Behavioral Crises	29
Creating a Family Emergency Plan.....	30
Additional Points About the Emergency Plan	31
How to Prevent a Crisis	32
What Should You Do First?.....	32
What is a Comprehensive Evaluation?.....	33
What is the Role of Medication?.....	33
Advocacy.....	34
Appendix	38-56



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Throughout the course of developing the *Family Crisis Handbook*, we were keenly aware of the importance of sharing our work while in progress with those who could offer us varying perspectives based on their personal experiences and/or professional expertise.

Due to the enormous complexities surrounding the subject of crisis for adults affected with dual disorders (MI/DD), including existing gaps in services and supports, we were particularly diligent in obtaining feedback to ensure that the information contained in this text would be as comprehensive and straightforward as possible.

Fortunately, because of the dedicated efforts of our very savvy reviewers, we gained an excellent resource in terms of practical information. We were also provided with a wealth of useful recommendations that served to further enhance our work.

We wish to express our deep gratitude to our helpful reviewers: family members Karen D'Ambrosio, Reverend Joe Gratzel, Leslie Mars and William Wills; Anne Marie Biddle, University of Medicine and Dentistry of New Jersey; Julie Caliwan, New Jersey Division of Developmental Disabilities; Dr. Caroline Eggerding, Vice-President, Clinical Services and Chief Medical Officer, Bancroft NeuroHealth; Kim Friend, Chief, Bureau of Guardianship Services, New Jersey Department of Human Services; Amy Golden, Autism NJ; Dr. Daniel Keating, Vice-President, Family Services and Government Relations, Bancroft NeuroHealth; and Beverly Roberts, Director, Mainstreaming Medical Care Program, The Arc of New Jersey.

The importance of understanding your legal rights as a family member or legal guardian is essential during a loved one's crisis episode. We would, therefore, like to extend our sincere appreciation to the State of New Jersey Department of the Public Advocate for providing our readers with detailed legal information pertaining to Danielle's Law, Guardianship and the 72-hour commitment process.

We also wish to recognize the very skillful editing and reformatting talents of Alix Schwartz from the Division of Developmental Disabilities, who devoted a great deal of time and effort to this very challenging task. The results of her hard work and strong commitment to this publication are evident on every page, and we are truly appreciative. Thanks to Julie Caliwan from the Division of Developmental Disabilities for her design of the Portable Emergency Plan, which is at the end of the appendices.

If one were to judge a book by its cover, the graphic illustration appearing on the handbook cover would certainly be worthy of praise. We wish to extend our sincere thanks to Diane Flynn, Communication Assistant, Mainstreaming Medical Care Program, The Arc of New Jersey, for creating an amazing cover design.

A very special note of appreciation to Stephen J. Smith, Communications and Legislative Liaison for the Division of Developmental Disabilities, for his excellent efforts in overseeing the printing of this text. We greatly appreciate the impressive final editing provided by Cece Lentini from the Division of Developmental Disabilities.

Last but far from least, we want to acknowledge with the utmost gratitude and respect all the individuals, their families and caregivers who have shared their experiences of tremendous challenge with us in the hope of generating improved and dignified care for their loved ones and others in times of crisis. We want you to know that your personal accounts were, without question, the driving force behind the creation of this handbook.

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July, 2009



Authors' Forewords

Donna's Foreword

My son, Michael, is a young man whose life is affected by autism and bipolar disorder. Early on, I learned the importance of surrounding Michael with the best quality care and services that I could find. As I worked closely with the team of professionals and service delivery staff who helped me to manage his everyday life in a progressive and fulfilling manner, I took my role as his advocate very seriously. Along the way, there were many obstacles due to numerous unknowns associated with the combined effects of autism and a mental health disorder on his behavior. I found tremendous comfort, however, in being an informed consumer as I attempted to address my son's special needs with strong, collaborative support. I also reveled in the pride I ultimately felt for him. Throughout his life, Michael has demonstrated his happiness in so many endearing ways to all those around him.

Michael's life was abruptly interrupted when, at the age of 18, he experienced a severe behavioral crisis at his community group home. Based on the extreme intensity of his behavior, the direct care staff phoned 911 for assistance. Michael was transported by ambulance to the emergency room of a local hospital where I joined him, and he was subsequently transferred to the hospital's crisis screening center.

Upon admission, I was informed that the crisis screening center was "not equipped" to handle the special needs of an individual with a developmental disability. It was made clear to me that the assigned clinician's goal was only to secure an alternative placement for my son. Because my son was in need of evaluation and appropriate treatment, I had hoped for him to gain admission to Trinitas Hospital's acute care unit for adults with dual disorders located in Elizabeth; however, Trinitas Hospital's ten-bed unit was at full capacity. It was not wise for Michael to return to his group home and my request to bring him home with me was denied by hospital officials; consequently, and against my wishes as his legal guardian, Michael was admitted to a ward at a state psychiatric hospital. It was, without question, the saddest day of my life.

This sadness was very shortly replaced by anger and confusion. I was suddenly immersed in a mental health care system that was completely foreign to me. I felt stripped of my rights as his guardian and I lacked a voice with respect to having any influence over his immediate care. I had lost control over this situation because of my inability to understand this system and its rigid constraints. The only thing I was certain of was that my son's well being was being compromised and it was in serious jeopardy at his greatest time of need. I recall feeling totally overwhelmed in my powerlessness. In retrospect, Michael's crisis placed our family in a bewildering crisis of its own.

I am happy to say that Michael has recovered from this experience and is doing wonderfully well. Following his unwarranted four-day stay at the state psychiatric hospital, a medication change combined with a tremendous amount of support from Bancroft NeuroHealth, the community service provider that has compassionately served Michael for many years, we began to regain our former stability as a family. With the help of an attorney, I began to research my rights as Michael's guardian and I set up an emergency care plan for him. I began educating myself regarding crisis care services throughout the state of New Jersey. I spoke to a wide range of individuals who were very knowledgeable about the existing system of services for people with a dual diagnosis. I started to network with other families whose crisis experiences were surprisingly similar to ours. I soon discovered that regardless of whether I was discussing this issue with a service provider or consumer, everyone was equally frustrated with the undeniable service gaps that plagued the crisis service system.

In a relatively short time, I learned a great deal about crisis care. I received very helpful advice with regard to navigating the system, as well as many practical recommendations to improve its effectiveness. My curiosity began to increase regarding how other families dealt with the system. I tried to imagine what it would be like for family members who were currently as uninformed as I had been. I also began to wonder about individuals who had no one to advocate for them. How deeply did they fall through the cracks of this inadequate system? Could the collective experiences of our loved ones generate needed systems reform?

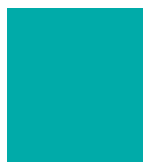
It is with this same spirit that I invite you to explore the pages of this *Family Crisis Handbook*. My hope is that this handbook will communicate the necessity for families to be informed, prepared, and proactive in addressing the special needs of their loved ones. We have all heard it said that knowledge is power. It is, however, how we effectively apply that knowledge that is the key to empowering ourselves. My strongest hope is that this manual will serve as a guide to creating and maintaining the specialized supports required for individuals in need before a crisis situation erupts, in the aftermath of a crisis, and in everyday life as well. Despite every family's individual challenges, the ultimate goal for any family is to provide every opportunity for their relative to obtain effective and compassionate care. Our loved ones are depending on us to do so.

In closing, I would like to highlight the importance of family members communicating their concerns and offering viable solutions in order to promote needed systems reform. The Dual Diagnosis Task Force was established in January 2008 to examine the serious crisis care issues for individuals with developmental disabilities and co-occurring mental health and/or behavioral disorders in New Jersey. This task force was created in response to a proposal I drafted, which was presented to Jennifer Velez, the Commissioner of the Department of Human Services; Kenneth Ritchey, the Assistant Commissioner of the Division of Developmental Disabilities; and, Kevin Martone, the Assistant Commissioner of the Division of Mental Health Services at the time.

The Dual Diagnosis Task Force is comprised of individuals with disabilities, family members, service providers, advocates, professional experts, state officials, and agency representatives. On October 10, 2008, following nine months of deliberations, a report was presented to Commissioner Velez containing recommendations developed by the Task Force that will serve as a blueprint for needed service improvements and system reforms. An Executive Oversight Board convened by Commissioner Velez will manage the implementation of the Task Force priority and longer-term recommendations.

Caring for a family member affected by a dual diagnosis presents extraordinary challenges that few people outside the family circle can truly appreciate. In many cases we are the voices for our loved ones, and there are multiple ways to exercise this ability as a means of making a difference. I hope the advocacy section of this Family Handbook will inspire you to reach outside the boundaries of your own family and get involved. It is my sincere belief that through the knowledgeable and persistent efforts of family generated initiative we can accomplish great things for people with disabilities throughout our state. As far as I am concerned, that is precisely what the true meaning of “family” is all about.

Lucy's Foreword



It has been my pleasure to work with Donna Icovino on this *Family Crisis Handbook*. My hope is that the material covered in this booklet will serve as a resource for families. By reviewing the contents, families will be better equipped to effectively navigate the mental health system and obtain needed supports for their relatives. Donna has been meeting with legislators, service providers, and families throughout the state for the past five years, advocating for much-needed reform in mental health service delivery to the underserved population of individuals with developmental disabilities and co-occurring mental health and behavioral disorders. I have been traveling through the state for the past 12 years delivering non-traditional clinical services to the population of adults with dual diagnoses. This handbook reflects our experiences and what we have learned from others as we traveled throughout the state.

In the course of my work as Program Director for Trinitas Regional Medical Center's Statewide Clinical Consultation and Training (SCCAT), I have met hundreds of family members at screening centers and inpatient units, and in the course of crisis calls to family homes, group homes, and day programs. Mental health providers need to be responsive to the unique needs of consumers and their families. Families need to familiarize themselves with the resources and the limitations of available mental health services for their relatives. Most individuals served by the Division of Developmental Disabilities live in their own homes with their families. When delivering mental health services to individuals who reside with their families, both the consumer and his/her family are our service recipients.

Those of us responsible for service delivery to adults with dual diagnoses (MI/DD) need to facilitate and improve communication between service providers and service recipients. This is a good place to begin...

About the Co-authors:

Donna Icovino is a Family Advocate and Co-Chair of the N.J. Department of Human Services Dual Diagnosis Task Force.

Lucille Esralew, Ph.D., is Program Director for Statewide Clinical Consultation and Training (SCCAT) of Trinitas Regional Medical Center and member of the N.J. Department of Human Services Dual Diagnosis Task Force.

We see this as an evolving handbook that can be expanded to include future changes in the mental health and developmental disabilities delivery systems and provide additional guidelines and hints that are more helpful. We welcome your comments; please let us know your experiences.

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Introduction

Purpose

The purpose of this handbook is to inform and empower families so that they can more effectively advocate for an adult relative with a dual diagnosis during a mental health and/or behavioral crisis.

This handbook also provides important information about many characteristics of dual diagnosis and behavioral crisis, as well as answers to many questions people ask when they are faced with helping a family member through all aspects of receiving care at a critical time in their lives.

At the very end of this handbook, in the Appendices, you will find what we have called the **Portable Emergency Plan**. The **Portable Emergency Plan** gives you the space to record all of the most important information about your family member with a dual diagnosis.

At a later point in this handbook, we discuss the option of creating a Family Emergency Plan, which can consist of a notebook or folder designed to hold all important information about your family member. The **Portable Emergency Plan** would ideally be stored with your **Family Emergency Plan**.

In the event that your relative's crisis results in the need for his/her evaluation at a crisis screening center, the information that you have recorded on the **Portable Emergency Plan** will be invaluable to you. Please fill out the **Portable Emergency Plan** when you have time. You may also wish to make copies of this material so that all family members can have one. You can easily take it with you to the screening center or hospital. It will contain most if not all of the information requested on admission documents. With the **Portable Emergency Plan** in hand, you will not feel pressured, in the middle of a crisis, to try to remember telephone or insurance policy numbers, or the complete list of medications your family member may use. We believe that use of the portable plan will give you some peace of mind as you continue to provide care and support to your family member.

The authors hope that armed with the information in this handbook, families in need of assistance will confidently navigate the screening process with their relatives and will obtain the service outcomes that their relatives both need and deserve.





Definition of “Dual Diagnosis” (MI/DD) and the Importance of a Thorough Evaluation at a Time of Crisis

The term “dual diagnosis” (MI/DD), as used within this handbook, refers to individuals who have both a mental illness and a developmental or intellectual disability. Families can sometimes wonder whether their adult relative’s behaviors are primarily due to their mental health problems or to their developmental disabilities, but having a diagnosis of a developmental disorder does not always explain why their relative is exhibiting unsafe behaviors.

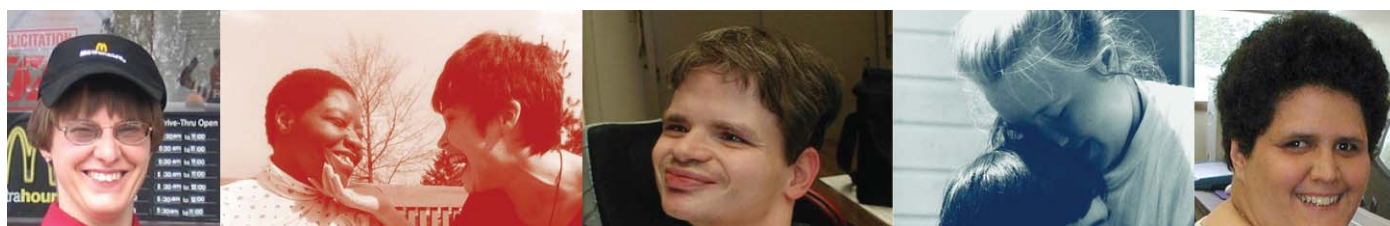
Although individuals with developmental disabilities may exhibit behavioral problems, there is nothing about either an intellectual disability or a developmental disorder that automatically explains aggression, property destruction, elopement, or any other unsafe behavior. Some individuals may have genetic disorders that can be associated with self-injury. Some people may display unwanted behaviors that are associated with mental health problems. There can be as many explanations for problem behaviors as there are people who exhibit them.

Just as in the general population, people with a dual diagnosis (MI/DD) may exhibit signs and symptoms of mental health problems such as depression, mood disorders, and anxiety disorders. However, unlike the general population, individuals with mental health disorders may be more likely to exhibit

signs and symptoms of their disorders in the form of behavioral outbursts including verbal or physical aggression, self-injury, property destruction, impulsive behaviors, and/or elopement.

It is imperative that potential medical issues be identified when someone with a dual diagnosis (MI/DD) is experiencing a behavioral health crisis. Individuals exhibiting unwanted behavior might also be suffering from health problems such as infections and pain. This is why it is important to have your adult relative comprehensively evaluated. This is the best way to attempt to identify all factors that relate to your family member’s behavioral issues.

It is important to remember that not all behavioral outbursts will require medication or hospitalization. It is not uncommon for people who are diagnosed with Pervasive Developmental Disorder (PDD) or who place on the autism spectrum to display aggressive outbursts. These outbursts may be the individual’s response to frustration and limited communication skills. When aggression is the individual’s response to environmental stressors, the best approach is to arrange an evaluation by a behaviorist or another professional who is familiar with conducting functional assessments and capable of developing behavioral shaping programs.



What is a “Mental Health Disorder” or “Psychiatric Illness?”

While there is no single definition for the term “mental health disorder,” it can be described as a clinically significant behavioral or psychological pattern that any individual may experience. Mental health disorders are usually associated with distress, disability, and an increased risk of suffering and/or loss of freedom.

Mental health disorders, sometimes referred to as psychiatric illnesses, are medical problems that can affect emotion, behavior, and the ability to think realistically. They often impact

an individual’s quality of life and his or her capacity to follow daily routines or to sustain meaningful relationships.

These disorders can include:

- **problems of mood**, such as depression, anxiety, obsessive compulsive disorder, or bipolar disorder;
- **problems of thinking**, such as schizophrenia, schizoaffective disorder, or psychosis; or
- **problems of behavior**, such as self-injury, elopement, or property destruction.



What is the Relationship between Mental Illness and Behavior?

Behavioral outbursts, which can take the forms of verbal or physical aggression, self-injury, property destruction, elopement, and/or inappropriate touching, may be signs or symptoms of mental health problems.

These behaviors may increase in frequency or severity within the context of an episode of psychiatric illness. For instance, individuals may become more intensively self-injurious when depressed, more aggressive during a manic episode, or more impulsive when anxious. This is particularly important to remember when treating people who cannot report their own distress because of language limitations.

State-of-the-art treatment for mental health disorders consists of medication and psycho-social supports. This is as true for a person with a dual diagnosis as it is for anyone in the general population.

While hospitals are not the preferred location in which to effectively address behavioral problems, some individuals can demonstrate behaviors that are too dangerous to warrant their continued stay at home. They may need to be hospitalized, in order to be observed and treated in a supervised setting.



Mental Health Professionals You May Encounter

You may encounter different types of clinicians and practitioners at the emergency room or screening center, on hospital units or in community settings, to include:

- **Behaviorist** – A bachelors, masters or doctoral level practitioner trained in the use of learning techniques to assess behavior problems and develop approaches to teaching individuals to replace target problem behaviors with adaptive skills. Behaviorists can have different types of training or certifications: some may be trained in positive behavioral support techniques, while others may be certified (BCaBA at the bachelors level and BCBA at the masters and doctoral levels) in Applied Behavior Analysis.
- **Physician** – An individual who has obtained an M.D. or D.O degree. A physician can prescribe medications.
- **Professional Counselor** – A masters level clinician who provides counseling and psychotherapy to individuals with mental health or behavioral problems. Some counselors are licensed professional counselors (L.P.C.)
- **Psychiatrist** - An individual who has obtained an M.D. degree and also has completed specialty training in mental and emotional disorders; a psychiatrist may prescribe medications for the treatment of psychological disorders.
- **Psychiatric Advanced Nurse Practitioner (A.N.P.)** – A nurse practitioner who specializes in the treatment of mental illness and is able to prescribe medications.
- **Psychologist** - An individual with a doctoral degree in psychology (Ph.D., Ed.D. or Psy.D.) from an accredited university or professional school; a psychologist may specialize in the non-medical treatment of individuals with mental health or behavioral problems but cannot prescribe medication.
- **Screeners** - A clinician with a bachelors degree who may also hold a masters degree and who has received basic training in psychiatric screening. Currently, screeners can receive both the mandatory basic training and advanced training required for retaining Continuing Education Credits, through the Technical Assistance Center (T.A.C.) affiliated with the University of Medicine and Dentistry of New Jersey (UMDNJ). T.A.C.'s basic screeners' training includes a module on the evaluation of individuals with developmental disabilities that is taught by handbook co-author Lucy Esralew. It also includes an advanced module for screening of individuals with developmental disabilities that is taught by Dr. Andrew Levitas, who is Medical Director/Associate Professor, Center of Excellence for Mental Health Treatment for Persons with Intellectual Disabilities at UMDNJ in Stratford, NJ.
- **Social Worker** - A Masters level clinician (M.S.W.) who may provide non-medical clinical services to individuals with mental health or behavioral problems.



What is a Behavioral Crisis?

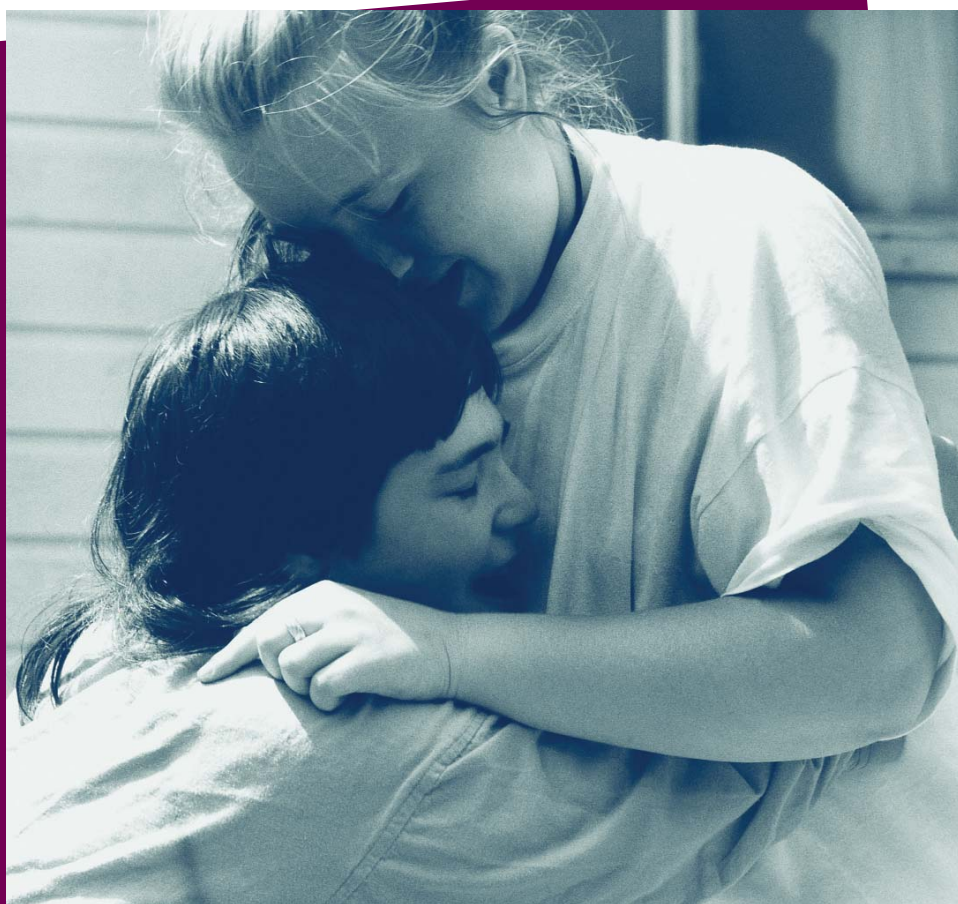
A person is considered to be in a **behavioral crisis** when she or he acts in a way that negatively or even dangerously represents a dramatic departure from their usual and characteristic “normal” behavior; in other words, behavior that is normal for them.

During a behavioral crisis, the individual’s family and/or caregivers may not have the resources available to safely manage the behavioral outburst or to stabilize the individual. Communication techniques and strategies that might have worked in the past may no longer be effective.

As a result of this severe communication breakdown, your family member is potentially dangerous to himself, herself or others. These escalating circumstances can result in a disruption of work and daily activities and can increase the likelihood that your relative will lose his or her job, school, or residential placement. People around your relative are likely to become concerned about his or her lack of self-control and may worry about someone getting hurt.

Some examples of behaviors that could indicate the onset of a behavioral crisis:

- A strong demonstration of non-compliance with routine task requests, such as refusing to take the usual, prescribed medications, taking medication inconsistently or “cheeking” medication to avoid swallowing it;
- Sleeplessness or dramatic changes in appetite compared with usual, characteristic patterns of sleeping and eating;
- Mildly aggressive acts that begin to increase in intensity;
- Quick bursts of energy, such as pacing back and forth;
- Verbal and non-verbal expression of a violent physical action
- Changes in the person’s emotional and/or physical demeanor that might indicate anger, frustration, confusion, fear, or a general threat;
- Displays of violence such as biting oneself or others; hitting, kicking, or punching another person or the wall; or, pulling hair or any other similar attempts to cause harm to oneself or others;
- Any type of inappropriate behavior that appears to become more frequent and intense than usual.





What Strategies May Be Helpful in a Crisis?

According to Donna:

I worked with a behaviorist to explore many different strategies for dealing with my son's challenging behaviors. The following strategies proved effective in helping Michael maintain control:

1. Use of a time-out procedure gave my son the opportunity to calm down, and regain his composure. It also gave our family a chance to regroup, and to think about the next steps to take.
2. Teaching my son breathing exercises to reduce his anxieties was an effective coping skill for him, and at times helped defuse a tense situation.
3. Changing the environment by going for a walk, taking a soothing bath, or providing any type of reinforcing distraction (i.e. watching a favorite movie) proved helpful for him.
4. Practicing extinction* by ignoring certain inappropriate behaviors and not calling attention to them actually helped to decrease their frequency, and in some instances removed them entirely. For example, by applying "extinction" in situations when my son was verbally perseverating (i.e. demanding an excessive amount of ketchup on a hamburger), we were able to reduce the number and intensity of the perseverations that had previously resulted in very aggressive behavior.

**Extinction involves withdrawing attention in order to reduce the frequency of a target problem behavior. This is particularly effective when the behavior selected for extinction is a behavior that may have been unintentionally reinforced through the provision of attention. For instance, if you are in the habit of reprimanding your relative for yelling you are actually providing attention (although negative), which may result in an increase of your relative's yelling. In order to extinguish this behavior, you would ignore yelling in the future. Eventually, your relative will be less likely to yell because there is no "payoff". In effect, you have extinguished yelling behavior by withdrawing attention that was reinforcing the behavior.*

However, you cannot use this technique when your relative is exhibiting aggressive or self-injurious behaviors, and it is unsafe to ignore behaviors that are dangerous to your relative or others.

Although you can use praise or a technique of "planned ignoring" to help shape your relative's behaviors, a more complex response to your relative that involves a behavior plan or a series of strategies is best developed by a behavioral consultant.



How To Assess the Severity of a Crisis

At the onset of a behavioral crisis, you must assess the level of danger to your relative and to others in the environment. At this time, ask yourself the following questions:

1. Has my family member lost control?
2. Is she or he unable to follow instructions to calm down?
3. Is there a strong possibility that someone could be hurt physically?
4. Is someone in immediate danger because of my relative's out-of-control behavior?

If the answer to any of these questions is "Yes," your family member may be experiencing a serious behavioral crisis.



What To Do in the Event of a Crisis

In the event of any serious behavioral crisis, you should ask yourself, “Should I call 911?” or, “Is there anyone else I can call?”

Do not attempt to manage your relative by yourself if he or she is self-destructive, engaging in property damage, or behaving in a way that is a danger to self or others. In those situations, your only safe alternative is to call for emergency assistance by dialing 911.

In situations that do not involve immediate danger to the individual or to others, you can call Trinitas Regional Medical Center’s Statewide Clinical Consultation and Training (SCCAT). SCCAT is dually funded by New Jersey’s Division of Developmental Disabilities (DDD) and Division of Mental Health Services (DMHS) and provides mobile crisis response. You can call SCCAT to report your relative’s crisis regardless of where or when the crisis is occurring.

If your adult family member is behaving unsafely and you have called for emergency assistance by dialing 911, you can also call SCCAT and inform them that your relative is en route to the emergency room or crisis center. A SCCAT clinician can become involved in your relative’s care soon after he or she arrives at the hospital, can interact with emergency room and crisis center personnel, and can begin planning for future behavioral health management.

SCCAT clinicians will conduct face-to-face interviews with your relative, other family members or staff in order to recommend the optimal level of mental health or behavioral support. SCCAT clinicians will also work with adult consumers in daytime settings such as places of employment, day programs, or mental health and residential settings.

Taking this step might help to avoid an unnecessary emergency room visit. The SCCAT clinician can assist the family through telephone support as well as through face-to-face intervention. SCCAT responds to crisis calls when the situation does not involve imminent danger. Call **SCCAT for Crisis Response at 1-888-393-3007**.

If your family member resides in and has a crisis in Burlington, Cumberland, Gloucester or Salem counties, UMDNJ’s Crisis Response team will respond. If your family member presents for emergency services in one of these counties and if you call SCCAT, a clinician will coordinate a response for your relative with UMDNJ. If your family member resides in one of these counties but experiences a crisis elsewhere in the state, you can call SCCAT.

If your relative resides in a group home or receives residential supports, staff may call 911 in the event that your relative behaves in a dangerous manner. This is the legal responsibility of the provider agency according to Danielle’s Law. Please refer to the detailed material regarding Danielle’s Law, which is located in the Appendix.





You Have Called 911 – Now What Should You Do?



1. **DO NOT attempt to transport your family member to the nearest hospital emergency room by yourself!**
2. While waiting for the police to arrive, try to make your surroundings as safe as possible by removing dangerous objects.
3. Tell the 911 dispatcher that the person in crisis is developmentally disabled. This will alert police, who are usually the first responders, to avoid unnecessary force. This includes not having weapons drawn upon arrival, if they know the person is aggressive. If a relative is available to meet the emergency personnel before entering the home, restate that the person in crisis is developmentally disabled.
4. Other individuals who do not need to be present to support the person in crisis should leave or be removed to a safe area.
5. If the individual in crisis needs emergency medical services, the police officer responding to your call will arrange for ambulance transportation. You can follow the ambulance to the hospital in your own vehicle.
6. If you have already filled out the **Portable Emergency Plan** at the back of this handbook, or if you already have a Family Emergency Plan notebook or folder, take it with you when you travel to meet your family member at the hospital.
7. Your family member may calm down before the police arrive, or when they arrive. However, it is also possible that he or she may become even more distressed or agitated at the sight of first responders. The police will assess the situation and if they believe your relative does not present a danger to self or others, they will not transport your relative to a hospital. If this happens, you can call SCCAT for assistance by dialing 1-888-393-3007. A clinician will follow-up with you at your residence.

The following practical tips are offered by Leslie Mars, a trainer of EMS personnel, in regard to issues relevant to persons with developmental disabilities, particularly autism: *I suggest that parents make contact with training officers or chiefs of these agencies. introduce yourselves and your family member. It is less threatening for your relative if he or she meets first responders (i.e. police, mobile crisis and emergency personnel) when there is no crisis. Your relative will be able to become more familiar with first responders, their vehicles, uniforms, equipment, etc. Families should find out if these agencies have received, uniforms, equipment, etc. Families should find out if these agencies have received training about developmental disabilities. There are several programs available to provide education to emergency/crisis personnel. All emergency departments have annual mandatory training requirements and you can request that training in developmental disabilities be offered to the personnel at your local emergency department.*

Autism Speaks has developed an online tool kit for individuals with autism, their families and first responders that provides information and tips to foster safety in emergency situations. To learn more about the “Autism Speaks Safety Project,” see <http://www.autismsafetyproject.org/>.



What To Expect in the Emergency Room

1. You will be asked to sign a consent form for emergency room treatment for your family member and to complete a general information form. This part of the emergency room visit will be easier if you have a Family Emergency Plan with you. (The Plan is described more fully beginning on page 30 of this handbook.)
2. You will be required to provide information regarding your relative's health insurance, including Medicaid and/or Medicare.
3. If you are the legal guardian for your adult family member, you should be prepared to produce a copy of the official court document.
4. It will be helpful if you can provide updated contact information for your relative's professional support team including doctors, therapists and staff at community provider organizations.
5. The emergency room physician will inquire about your family member's official diagnosis and medical history.
6. The emergency room physician probably will ask you about the circumstances that led to your family member's visit to the emergency room. It also will be helpful if you can share pertinent information about recent changes in your family member's life with the medical staff, including the crisis unit screener and the psychiatrist. This might include information about recent medical problems or change in medications,, any significant events at work or at home including the deteriorating health or death of a family member or the loss of a well-liked neighbor, co-worker or direct care staff person.



7. The emergency room physician will conduct a routine physical exam to rule out major medical problems that might be a contributing to your relative's behavioral crisis. Inform the doctor of any changes in your relative's medical condition.
8. You may want to remain with your relative through all the examinations in the emergency room, especially if he or she is non-verbal, minimally verbal, or has significant communication problems.

As soon as you arrive in the emergency room, you may ask personnel there to contact SCCAT by dialing **1-888-393-3007**, **or you can call SCCAT yourself**. SCCAT services are available 24 hours a day, 7 days a week. A SCCAT clinician can become involved in your relative's care by interacting with emergency room and crisis center personnel. A SCCAT clinician also can participate in planning the next steps.



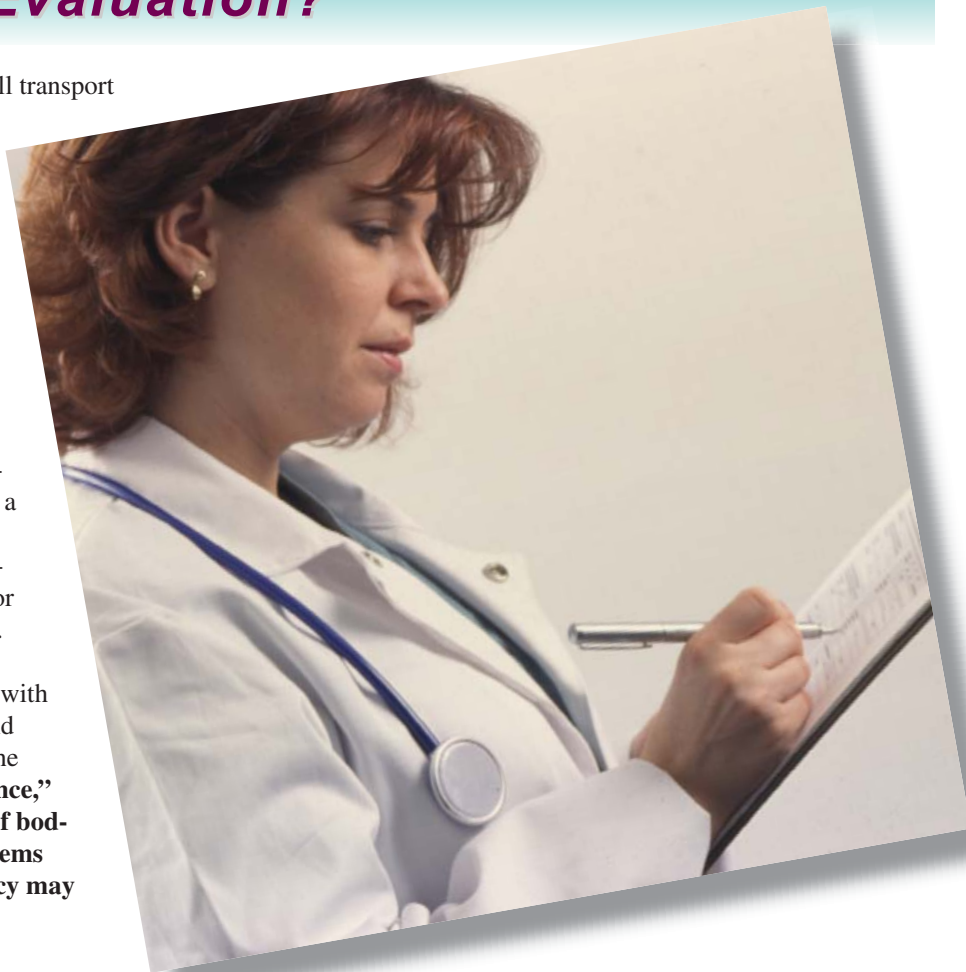


Why Does Your Relative Need a Medical Evaluation?

If the police judge it to be necessary, they will transport your relative to the hospital emergency room for a medical evaluation. The medical evaluation, which includes blood work, is done to rule out any infections or major medical problems that might be affecting your relative's behavior. This process is called "medical clearance" and it must occur if your relative is to be hospitalized.

It is always wise to remember that your family member may be reacting to pain or physical discomfort related to a physical illness in a way that makes it seem as though he or she has psychiatric problems. For example, individuals with upper respiratory, urinary tract or other infections may become highly agitated.

The purpose of beginning a crisis evaluation with medical clearance is to attempt to identify and medically treat those individuals for whom the major problem is physical. **"Medical clearance," however, is only intended as an overview of bodily systems. Other medical or dental problems that contribute to your relative's emergency may be missed in this general overview.**



Why Must You Wait in the Emergency Room?

One of the most difficult challenges for anyone visiting an emergency room is the required waiting time. Caregivers sometimes feel these extended waiting times are due to a lack of knowledge or understanding about behavioral issues on the part of some hospital personnel. It is important to remember that **everyone** waits in the emergency room.

Although the goal of the emergency room staff is to evaluate, treat, and discharge patients in a timely manner, the reality is that you may encounter a lengthy waiting period.

It is also important to remember that the amount of time needed for medical clearance can vary, depending on what else is going on in the emergency room at that time. Be prepared to wait for several hours until your relative is medically cleared.

It is also important to remember that receiving medical clearance does not mean that your family member has been accepted for inpatient psychiatric care or has been admitted to the hospital. Once medically cleared, your relative may be seen by a screener and a psychiatrist; this may involve moving to a separate area for psychiatric screening. Psychiatric screening itself may also take several hours.

If possible, while waiting in the emergency room, contact your loved one's doctors to inform them about the crisis. SCCAT can also help facilitate communication between the individual's personal physicians and the emergency room physician.



What To Expect at a Psychiatric Screening

Hospitals vary in the services that are offered in the Emergency Department (where medical clearance is typically obtained) or in the psychiatric screening center (where a determination is made regarding hospitalization on an inpatient psychiatric unit). Some hospitals have their medical and psychiatric emergency screening services at the same site, while others have them in separate locations.

If emergency room personnel determine the need for a psychiatric evaluation, they will arrange for your relative to be transferred to the hospital's crisis screening center.

A crisis screening clinician assigned to your family member's case will conduct an intake interview. The screening unit's at-

tending psychiatrist also may meet with you and your family member.

It is likely that blood work will have been done during the medical clearance. However, you may request additional testing not previously ordered by the emergency room physician if you feel they are needed. If you suspect a broken bone, for example, you may request an x-ray, or if you suspect gum or tooth problems, you may request a dental evaluation. Unless there is a clear medical indication that more extensive testing is needed, tests such as CAT scans or MRIs usually are not performed in the crisis or psychiatric screening center.



What are the Criteria for a Psychiatric Hospitalization?

The criteria used to determine the need for psychiatric hospitalization is based on whether or not individuals present a danger to themselves, to others, or to property.

If emergency room staff believes your family member presents such a danger, they may need to utilize any or all of the following:

- **Medication to help manage the crisis**

Your relative may be given a short-acting psychiatric medication often referred to as a "PRN." PRN refers to a medication that is given on an as-needed basis to help an individual become calmer and less agitated while in the emergency room.

It is possible that as the PRN's sedating effects wear off, your relative may feel confused and disoriented and become agitated again.

- **Mechanical restraints to ensure safety**

If your family member is exhibiting extreme agitation or dangerous behavior, emergency room staff may opt to place him or her in mechanical restraints.

It is true that in some cases, prolonged use of mechanical restraints can increase agitation. You may wish to advocate to have the restraints removed if they seem to be directly contributing to your relative's agitation, especially if your relative is unfamiliar with hospital settings, uncomfortable around strangers, or unfamiliar with restraints.

In lieu of mechanical restraints, you may request that trained security staff be added to your relative's care as a support to the hospital staff.

At any point that you feel confident that your loved one has gained a more subdued demeanor and is in control of his or her actions, you may ask the ER staff to remove the mechanical restraints.

In all cases, however, the decision to use mechanical restraints ultimately rests with the hospital personnel.

Note: The above-mentioned best practice measures taken by the hospital medical support staffs are implemented to help an individual undergoing a behavior crisis. Keep in mind that it is not in the best interest of our loved one to remain in an agitated state.



What if Your Family Member Needs to Be Hospitalized?

Levels of Hospitalization

If it is determined that your family member will benefit from psychiatric hospitalization, he or she will be assigned to a level of hospitalization based on treatment needs. Adults receive psychiatric care via voluntary or involuntary (commitment) admission onto inpatient units especially dedicated to the treatment of psychiatric illness.

If commitment to inpatient care is indicated, your relative is likely to be transferred to either Trinitas' specialized unit (2D) or a local Short Term Care Facility (STCF). These are designed for acute care and short term stays.

If your relative cannot be psychiatrically stabilized during a short-term stay, he or she may then be transferred to a county or state hospital. While treatment in a county or state hospital is not always a family's first choice, it will permit your relative to receive longer-term care than is available on an STCF unit.

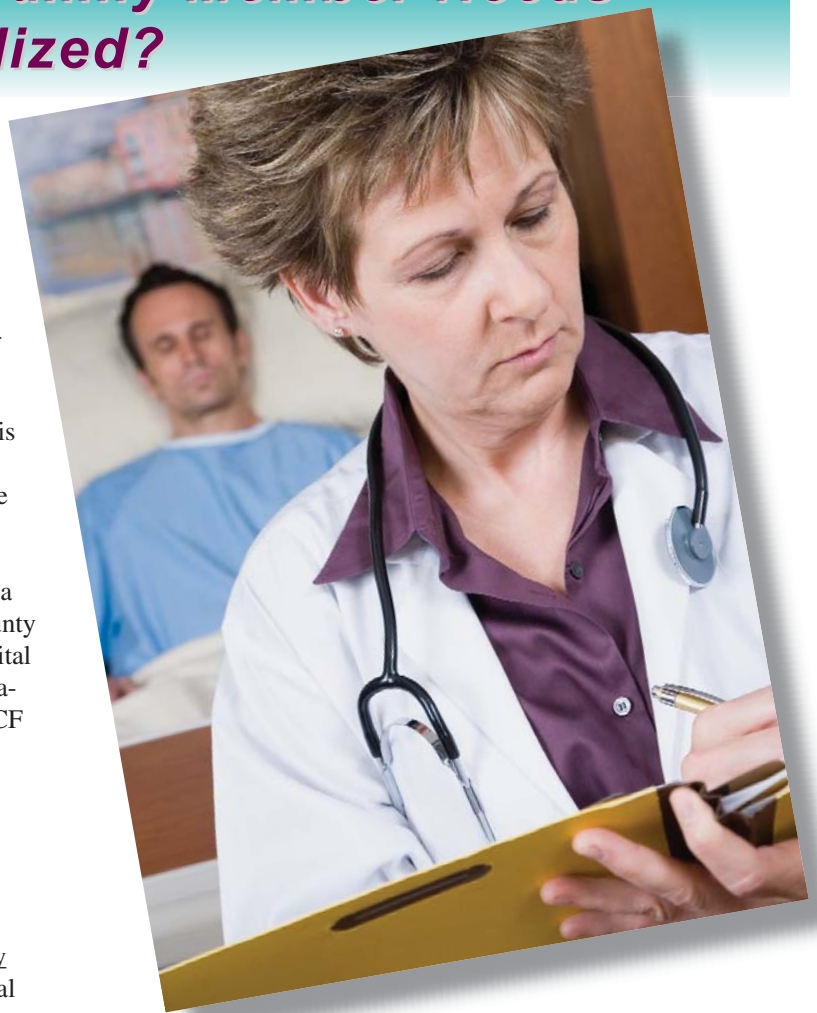
Voluntary Admission or Involuntary Commitment?

Your relative may be eligible to receive care on a voluntary unit, which is considered a less restrictive setting for mental health treatment than commitment to a STCF. Adult consumers who are their own guardians can sign themselves into treatment and court-appointed guardians can sign-in their ward for voluntary admission. However, Bureau of Guardianship Services workers, who are employees of the Department of Human Services able to serve as court appointed guardians for individuals eligible for DDD services, are not able to sign-in consumers. These options do not apply to children under the age of 18.

If an individual requires a higher level of care than is typically available on a voluntary unit, this individual will be committed to psychiatric care and will typically go to a facility with a STCF. Individuals will be committed when they are found to be incapable of giving informed consent due to the severity of their psychiatric illness. They may also have been deemed ineligible to make their own medical decisions for other reasons.

2D- The Specialized MI/DD Unit at Trinitas Regional Medical Center

Trinitas Regional Medical Center has a specialized inpatient psychiatric unit (2D) for adults (18+) who are developmentally disabled and have a mental health disorder. This 10-bed



unit, which is located in Elizabeth, is the only community hospital-based short-term, acute care psychiatric unit in New Jersey dedicated to the treatment of adults with dual diagnoses. The individuals who are admitted often cannot be treated successfully on an outpatient basis because of the severity of their behavior. Individuals must meet criteria for hospitalization based on dangerousness to self or others. Individuals can enter the unit from any crisis or screening center in New Jersey. As of this writing, the average length of stay on the specialized MI/DD unit at Trinitas Regional Medical Center is approximately 15 days.

Individuals cannot enter the MI/DD unit directly from the community or be transferred to the unit from a STCF. On occasion, individuals have been sent to the medical unit of their local hospital for treatment (seizures, infections, etc.) and then transferred to the Trinitas MI/DD unit if they met criteria for psychiatric hospitalization following their medical stabilization. All individuals are screened for admission at their local hospital crisis or screening center.

Children (under the age of 18) also are screened for hospitalization at their local screening and crisis centers. The commitment law does not apply to children, so they are not committed to treatment. If they are eligible for hospitalization,

there is a statewide search for an available placement on a Children's Crisis Inpatient Service (CCIS). Trinitas currently has eight beds on its Child and Adolescent Inpatient Unit that are dedicated to short-term treatment for children with mental illness and developmental disabilities. SCCAT is not involved in the hospitalization or follow-up of children or adolescents who are under the age of 18. Screeners can obtain information about the availability of MI/DD beds for children and adolescents by contacting Trinitas' psychiatric screening services.

While your relative is on an inpatient unit, regardless of location, encourage the attending psychiatrist on that unit to dialogue with the community-based psychiatrist who has been treating your relative. This will help to ensure continuity of care.

What if Your Insurance Company Won't Pay?

What if your relative is hospitalized and you receive word that he or she will be discharged because the insurance company has refused to authorize a continued inpatient stay on the psychiatric unit? You can request that the attending inpatient psychiatrist have a doctor-to-doctor consultation with a doctor for the insurance company to state the clinically and medically necessary reasons for continued hospitalization. You also can contact the care manager for your family member's insurance company to advocate for continued inpatient treatment.



Diverting Your Relative from a State Psychiatric Hospital

The state psychiatric hospitals in New Jersey serve an important function for individuals who need *long-term psychiatric care* and have not responded to shorter term, less restrictive alternatives, such as treatment on a local STCF or a county hospital. State psychiatric facilities generally are not designed to support the needs of adults with dual diagnoses who may have significant behavioral problems. A state psychiatric hospital is unlikely to be the appropriate placement if this is your relative's first hospitalization.

Recently, the state psychiatric hospitals have given priority to taking individuals from the STCF units who need longer-term care in order that people in the emergency rooms can be di-

rectly admitted to STCFs for observation. This lessens the likelihood that someone will be transferred to a state hospital directly from the screening center. It also reduces the likelihood of a state hospital admission for someone experiencing their first hospitalization. This creates an opportunity for determining if an individual can be stabilized on a short-term care unit without being transferred directly to a state hospital from the emergency room.

How is an Individual Committed to Involuntary Care?

Involuntary psychiatric commitment is a legal status. The first step toward that legal status is taken when a certified screener and psychiatrist separately conduct face-to-face evaluations of an individual. Based on these evaluations, a determination is made whether the individual has a mental illness and/or may be dangerous to self, others or property. If so, the screener and psychiatrist complete certifications and the individual is sent to inpatient psychiatric care, usually a short-term care facility (STCF).

Upon completion of the psychiatrist's certificate, the individual may be detained by the STCF for not longer than 72 hours. At the conclusion of this 72-hour period, STCF staff must initiate proceedings for the involuntary commitment of the individual. A clinical certificate completed by a second psychiatrist is submitted to the court along with the first psychiatrist's certificate.

If the court agrees with these certificates and finds there is probable cause to believe that the individual is in need of involuntary commitment, the court will issue a temporary order of commitment (not to exceed 20 days), setting a date for a full hearing on the issue of the need for continuing commitment.

Based upon this order, the individual may be transferred to a state psychiatric hospital or may be kept at the STCF. Pending the hearing, the facility's treatment team will conduct a mental and physical examination, administer appropriate treatment and prepare a discharge assessment. **It is important to note that the hospital treatment team, on its own authority, can discharge a patient before a hearing.**

The full hearing regarding the need for continuing commitment must take place within 20 days from the initial inpatient admission to the facility, unless the patient has been discharged. The county counsel, county adjuster, or attorney general will present the case for commitment. The patient has the right to be represented by counsel at the hearing.

The law states that at least 10 days before the full hearing, the patient or the patient's family, guardian or legal representative should receive notice of the date, time and location of the court hearing and with copies of the clinical certificates and supporting documents, the temporary court order, and the

statement of the patient's rights at the court hearing. These hearings are held at the facility to which the individual has been committed.

Families should be alert to these time frames, even if notification has not been received. You should contact the inpatient unit social worker if you have any concerns or questions.

A psychiatrist and other members of the patient's treatment team who has conducted a personal examination of the patient as close to the court hearing date as possible, but no more than five calendar days prior to the court hearing, testifies at the hearing as to the clinical basis for the need for involuntary commitment. Other witnesses with relevant information may also testify.

If the court finds that the patient needs continued involuntary commitment, the judge will order continued commitment and schedule the next court review of your relative's commitment status. If the judge determines that your relative no longer meets criteria for commitment he/she may order a date by which your relative must be discharged from the hospital.

What to Do if You Object

You have the right to object if you disagree with decisions that are made during the commitment process. For example, if you object to the treatment team's recommendations to continue involuntary inpatient care or discharge from an inpatient facility, you can express your concerns to the team.

You also can ask for the name and contact information of the judge who will be reviewing the papers. However, it is important that you express your concerns and issues to the treatment team prior to contacting the judge.

If you speak with the judge, he will want to know your objections and you should be prepared to state them clearly. Despite your objections, and no matter how well you articulate them, there will be times when the judge may not be in agreement with your concerns.

Once a date has been set for a full hearing, you can call the county adjuster and obtain the name and telephone number of the attorney who will be assigned to represent your relative. Contact that attorney and discuss the case in advance, including your concerns and what you would like to see happen.

You have the right to be present at the commitment hearing.

Finally, it is important to remember that the hospital treatment team, on its own authority, can discharge a patient before a hearing.

Alternatives to Hospitalization

No one disputes that psychiatric hospitals are important resources for individuals who need inpatient management of a

severe psychiatric illness. Hospitalization, however, is not always the appropriate response to a behavioral crisis. If your relative is displaying behavior problems that do not constitute a danger to self or others, the best place to manage the crisis may be at home or in a specialized community-based program.

Your family member will need an evaluation to determine what levels of mental health and behavioral support are most appropriate. Sometimes, problems of behavior are best treated within a familiar environment and with familiar supports.

In cases of non-psychiatric behavioral crises, hospitalization will not result in the types of changes that will have lasting effects and that can avert future crises. Programs exist that can teach your relative skills as alternatives to disruptive and difficult-to-manage behaviors.

Please remember that neither a hospital nor a crisis screening center has the ability to obtain a residential placement for your family member.

Another alternative to hospitalization would be a partial care or partial hospitalization day program. These are mental health programs that may be located in the outpatient services of hospitals. They may also be free-standing programs, meaning that they would be located in a non-hospital setting.

Partial programs are day programs designed to be either a "step down" from psychiatric hospitalization or programming to prevent hospitalization. Individuals learn coping skills and about medications, and other mental health-related topics. Participants return home at the conclusion of the program day. To be considered appropriate for a partial care program, individuals need to have sufficient verbal ability to communicate with others and be able and willing to follow instructions and abide by rules for program participation. Participants need to be motivated to cooperate and participate.

The best alternative to hospitalization is to address crises before they become unmanageable... Statewide Clinical Consultation and Training (SCCAT)

SCCAT is DDD's crisis response service for adults. You can (and should!) call 1-888-393-3007 to report your relative's crisis, regardless of where it is occurring.

SCCAT clinicians will conduct face-to-face interviews with your adult relative and with other family members in order to recommend the optimal level of mental health or behavioral support. SCCAT clinicians will also work with adult consumers in daytime settings such as places of employment, day programs, or mental health and residential settings.

SCCAT workers will also dialogue with crisis workers at the Emergency Room and at the psychiatric screening center.

Additional Options

At the point of the writing of this handbook, there are a limited but growing number of relevant supports available through DDD and DMHS.

Although SCCAT is the only statewide crisis response program, several programs in the state offer local crisis support services. In particular:

- **UMDNJ's Crisis Response Team** offers supports to individuals in Burlington, Cumberland, Gloucester and Salem counties.
- **Center for Innovative Family Achievement (CIFA)** offers crisis response to individuals referred to that program by DDD.
- **Integrated Service Delivery Team (ISDT)** offers clinical case management to adults referred by DDD Community Services who reside in DDD's Upper and Lower Central administrative regions. These encompass Somerset, Union, Essex, Hunterdon, Mercer, Middlesex, Monmouth and Ocean counties.

If you are eligible to receive services funded by DDD, you can call your DDD case manager to see what additional supports may be available. SCCAT will coordinate with other agencies to ensure that you do not need to make multiple phone calls during a crisis. You also can use your Interdisciplinary Team (IDT) as an important source of information regarding what supports can be built into your home environment in order to avert or better manage future behavioral crises.

What if Your Family Member Doesn't Need Hospitalization?

If it is determined through an evaluation that your relative will not benefit from hospitalization, he or she will be discharged from the crisis or screening center and be able to return home.

The screening center will provide you with discharge instructions. You will be responsible for scheduling any necessary follow-up appointments with your family member's support team, including doctors, therapists, teachers, and/or direct care staff.

What If You Aren't Able to Support Your Relative at Home?

There are steps you can take if you decide you need more assistance, or that you can no longer support your loved one at home due to the severe nature of his or her behavior:

1. If your family member is eligible for services from DDD, notify your family member's DDD case manager of your concerns. In-home support services, such as respite, are available. It is important to identify needed supports and to start planning as soon as possible when your relative's continued residence at home begins to become unfeasible.
2. **Planning is essential.** It is wise to avoid seeking a permanent, out-of-home placement for your relative during times of crisis. Because of the emotional distress you and your relative will be experiencing, the middle of a crisis is not the best time to make such long-term decisions. Placements should be developed based on your relative's long-term needs, not just on what is immediately available.
3. If you are not already involved with SCCAT, you can call 1-888-393-3007 for help in identifying appropriate mental health and behavioral services for your relative. SCCAT clinicians can provide information to help families recognize the symptoms of mental health and behavioral disorders. They also can help caregivers create an individualized response plan.





After the Crisis is Over

Steps to take following a crisis

1. If your family member is eligible for services from DDD, request an emergency IDT meeting from your DDD case manager. After a crisis event, it is essential for you to work closely with your family member's support team of doctors, therapists, teachers, community provider staff members, et.al.
2. Take the lead, in suggesting a re-evaluation of your family member's behavior plans, medication regimen, current supports; encourage the IDT to explore new therapeutic options and untried resources.
3. Share information among the various support service specialists. This is ultimately the family's responsibility. It will help provide your loved one with more consistent, quality-based care and services.
4. If you have not already contacted SCCAT during your family member's crisis, contact SCCAT now at **1-888-393-3007** for post-discharge follow-up training of family members and staff, development of coping skills, and referral to additional resources.
5. ALWAYS FOLLOW INSTRUCTIONS regarding prescribed medications following a crisis event!
6. Notes regarding medications:
 - a. Work closely with your family member's prescribing doctor. Sometimes changes are needed because the medication no longer seems to be effective, or the individual appears to need a change for some other reason such as difficult side effects.
 - b. New medication can initially be sedating. This does not necessarily mean that your relative is over-sedated. Medications can take time to reach optimal effectiveness.
 - c. There occasionally may be problems caused by the interaction of multiple drugs. The family should keep a log of what appear to be the side effects from medications, and share this information with the provider who prescribed the medication.





Family Members Coping Together with Behavioral Crises

A crisis affects the entire family. We tend to focus on the individual in crisis without realizing that each episode can have an immediate and destabilizing effect on everyone else in the family. The family may initially experience a loss of control over the situation; family members also may experience a range of emotions including fear, anger, and guilt.

In the midst of a crisis, family members' feelings of shock, confusion, and self-doubt can seem paralyzing and affect their ability to act. It is understandable that family members would not immediately reach out for help during a behavioral crisis; but when the usual strategies are not working, they need to adapt and develop new strategies.

These new strategies will naturally vary, based on the individual's special needs, specific dangerous behaviors during crisis episodes, and existing support systems. Families will need to rely on past experiences to determine which strategies should be used to maintain control, and to avoid further escalation of inappropriate behavior.

Keep in mind that it is best to discuss and agree on these plans when the household atmosphere is calm, well before the onset of a behavior crisis. These strategies can always be revised after being put to the test.

Consider the following as your family moves forward toward developing strategies for helping your family member in crisis:

1. A family can work together to build a solid foundation of trust and mutual understanding. Exploring new strategic opportunities together can empower all family members and strengthen a family's resolve to face its problems together by developing needed supports.
2. All members of the family should be reassured that they are not alone in dealing with their loved one's challenges. Finding solutions will be a family effort, and families will become even stronger as their coping skills improve.
3. Seeking appropriate professional advice and support is an important step in the process of addressing the special needs of your loved one. Begin by obtaining referrals from trusted physicians, service providers, families, and/or friends in order to identify qualified professional resources. Your relative's wellness and recovery will best be achieved through a collaborative therapeutic treatment approach involving professionals and family members.
4. There is no shame or failure in seeking help from people outside your family. Sometimes neighbors, fellow congregants at your regular place of worship, or friends can be helpful in providing another perspective or actual support to you and your relative.
5. Parents and/or guardians sometimes believe they should protect younger children by isolating them from severe behavioral episodes. Often, however, this is not realistic, and siblings can benefit if they develop an understanding of what the family is facing during crisis situations. Family-centered problem solving is an invaluable skill younger family members can use throughout their own lives. However, if younger children are in danger of physical harm during a behavioral crisis, they should be kept isolated from the event.
6. Families can "track behaviors" in a journal, which can serve as a great tool in evaluating medications (are they working or not?) and identifying trends, triggers or antecedents to problem behaviors.
7. By openly discussing the difficult challenges your loved one and each family member is experiencing, you have an opportunity to lessen a sibling's confusion and fear with sensitive and age-appropriate explanations.

Donna would set aside quiet time to speak with her daughter, Lauren, (who is younger than Michael) about what her brother was experiencing, and the fact that he could not control himself under certain circumstances. The Icovinos would discuss their next steps (i.e. doctor's visits, medication changes, IDT meetings), and give Lauren a chance to discuss her concerns, ask questions, and help plan coping strategies as a family. The Icovinos purposely did this with the hope that their daughter would begin to develop a better understanding of the challenges faced by family and the important role she played in addressing these issues alongside her parents. Donna believed that the open dialogue that she and her husband modeled with Lauren would help her gain a sense of security that would serve to reduce her fears and worries. The Icovinos wanted Lauren to grow up to recognize how resourceful, determined and successful their family could be when they worked together in order to resolve their problems. This exemplifies how open and honest communication among all members of the family is the basis for helping the individual who is in need. At the time of the publication of this handbook, Lauren is 22 and a recent graduate of the University of Connecticut with a B.A., Psychology major. She is currently pursuing a Masters in Social Work.

Lucy's note: Lauren is a lovely and well-integrated young lady whose experiences as a sibling of someone with dual diagnosis have helped her develop into a caring young adult with genuine empathy and sensitivities to others.



Creating a “Family Emergency Plan”

Any family working to help support a relative with behavioral health issues will want to develop a Family Emergency Plan for possible future use. This individualized plan should contain strategies that will help diffuse the crisis, or help to maintain control in the event that it is necessary to call 911 for emergency assistance.

The ultimate goal is to prevent a crisis. By developing an individualized, practical plan for maintaining safety in an emergency, and by implementing the strategies outlined in the plan when a crisis arises, families can lessen the negative impact of these events for their loved ones as well as for everyone present.

You will want to record your plan in a notebook or folder that is both easily reachable and portable. Following are some suggestions that can be incorporated into your Family Emergency Plan notebook or folder:

1. A contact list of people who would be willing to come to your aid at the onset of a crisis, such as friends, relatives, and/or neighbors.
2. A contact list of all the individuals who contribute to the care of your loved one; for example, doctors, therapists, teachers, social workers, his or her DDD case manager, the provider agency management team, and/or direct care staff.



3. All telephone and address information for the people listed above.
4. A list of any outreach support services that might be needed during an emergency situation; i.e., SCCAT Crisis Response **1-888-393-3007**.
5. Up-to-date medical information about your family member, including current daily medications, the reasons they were prescribed, the doctor(s) who prescribed them, dosages, special medical needs, allergy information, etc.
6. A one-page summary about your family member and his or her special needs. Include current program information, prior hospitalizations, and any important details that would help acquaint someone with your relative's likes, dislikes or fears.. Include all information that you think you might need in an emergency.



Additional Points about the Emergency Plan

1. Make copies of the Family Emergency Plan notebook or folder so that it can be with you and your immediate family members at all times.
2. You may wish to also give copies of your Family Emergency Plan to other family members and/or close friends who are willing to support you in a time of crisis.
3. Ask that the details of the emergency plan be included in the individual's IEP or IHP.
4. If your loved one no longer lives in the family home, it is still advisable to establish an individualized emergency plan for his or her full-time residence. It is advisable to be prepared, because a crisis can take place anywhere, at any time.
5. Remember to update your emergency plan as necessary, particularly as new and successful behavior management strategies are discovered, or as new or different medications are prescribed.
6. Include the following information in your emergency

plan: a) triggers to behavioral outburst, b) de-escalation techniques that have been successful with your relative, c) preferred activities, favorite topics of conversation, interests.

7. Attach to the notebook any information or copies of official documents that you might require in an emergency pertaining to medical insurance, Medicaid/Medicare coverage, Certificate of Guardianship, etc.
8. The Portable Emergency Plan, the format for which can be found in the Appendix on pages 54-55, can be included in the “Family Emergency Plan” notebook or folder.
9. Guardianship (See Appendix)

Once you have developed your plan you may want to review it with members of your relative's interdisciplinary team (IDT) in order to incorporate their suggestions. You probably also want the input of any clinicians or practitioners involved in your relative's treatment or care.



How to Prevent a Crisis

What should you do first?

If you notice a change in the frequency, intensity, or duration of problem behaviors for which you have no logical explanation, that do not respond to your usual efforts to contain such behavior and persist for more than two weeks, your relative may be displaying signs and symptoms of a mental health disorder.

As an example, if you know that your family member is experiencing dental pain or has had a recent injury, you might logically expect his or her aggressive behavior to increase. You also might see changes in your relative's behavior if you are moving, or if another family member is ill or dies. These transitional points or common stressors of life are often associated with an increase in problem behavior.

While increases in problem behaviors do not necessarily mean that your relative is in need of hospitalization, these stressors and/or transition points can sometimes be associated with extreme behavioral reactions that may require swift clinical intervention.

If you notice that your relative appears to be in unusually upset, or have uncharacteristic problems sleeping, eating, or regulating behavior, your first step should be to arrange for a comprehensive evaluation.

What is a comprehensive evaluation?

A comprehensive evaluation might include a general medical exam, a neurological exam (particularly if your relative has a seizure disorder or a known neurological disorder), laboratory

work, medical testing, a psychiatric evaluation, a psychological assessment, and a behavioral assessment.

A comprehensive evaluation should also include an assessment of your home environment and other appropriate settings such as school, day program, work, or any other location your relative spends time during the day. The purpose of such a comprehensive assessment would be to identify factors that may be contributing to changes from characteristic or "normal" functioning and behavior.

All this presumes that you have the time and the resources to arrange for such an assessment. However, if you find yourself facing a crisis situation, your first priority must be to keep your family member and those nearby safe. **If an individual's behavior is dangerous to self, to others, or to property, you must quickly seek help from emergency services.**

What is the role of medication?

If diagnosed with a mental health disorder, your relative may be a candidate for medication.

A psychiatrist might recommend an anti-depressant medication to address signs and symptoms of depression, or an anti-anxiety medication for anxiety disorder, or an anti-psychotic to address signs and symptoms of a thought disorder. The psychiatrist may also prescribe several different medications that are thought to work well with one another. For a listing of commonly prescribed psychoactive medications, please refer to the Appendix.





Advocacy

You may wish to become involved as an advocate. Advocates take advantage of every opportunity available to them to work for a cause in which they firmly believe. In the process of advocating on behalf of people with dual disorders, you can help improve the quality of life and the level of services for those who are depending on your continued strong support. The unique and personal perspective that individuals and families can offer as advocates is truly meaningful in terms of on-going and sustainable service, system and policy reforms. Every contribution you make, no matter how limited or extensive in scope, can have a positive impact on your relative and others with similar challenges throughout the state of New Jersey.

The following are some things you can do to help advocate on behalf of people with dual disorders.

1. Familiarize yourself with the current system of crisis intervention services.

- a. Research all options, available resources, outreach services, State agency programs, and State Legislative reform packages.

2. Begin writing letters.

- a. Draft a letter describing your personal experience dealing with the present crisis service system.
- b. Include a summary of your family's crisis experience and highlight any service gaps.
- c. If you have suggestions about how to improve the current crisis service system, include them.
- d. It is important for the letter to be written in an informative, courteous, and constructive manner. Abusive language or other expressions of anger may not be taken as seriously as constructive criticism aimed at improving the current system of care.
- e. This letter can be sent to any number of individuals including State government agency officials at the Department of Human Services (DHS). DHS oversees:
 1. the Division of Developmental Disabilities
 2. the Division of Mental Health Services

Note: State department and agency information is available online at www.state.nj.us/humanservices, and PublicAdvocate@advocate.state.nj.us. Additional contact information includes:

New Jersey Division of Developmental Disabilities
P.O. 726
Trenton, NJ 08625
Phone: 609-631-2200 or 1-800-832-9173
E-Mail: www.state.nj.us/humanservices/ddd



New Jersey Division of Mental Health Services
P. O. Box 700
Trenton, NJ 08625-0212
Phone: 609-292-3717 or 1-800-382-6717
E-Mail: <http://www.nj.gov/humanservices/dmhs/community-services.html>

New Jersey Department of the Public Advocate
the Division of Developmental Disabilities Advocacy
the Division of Mental Health Advocacy
P.O. Box 851
Trenton, NJ 08625
Phone: 609-826-5090
E-Mail: PublicAdvocate@advocate.state.nj.us

- f. A copy of your letter can also be forwarded to the hospital Crisis Screening Center management team; your DDD case manager, if you have one, and to State Government representatives. Information regarding the State Legislature can be found at www.njleg.state.nj.us
- g. Submit an Op-Ed letter to the local newspapers. (Sample in Appendix)

3. Address the issues facing individuals with dual diagnoses in a public forum:

- a. Give testimony at State Government public hearings.

Throughout the year, New Jersey citizens are given the opportunity to voice their concerns and to make recommendations

in a variety of public forums. These may be sponsored by the Senate and Assembly Budget Committees, State Senate and Assembly Human Services Committees, New Jersey Department of Human Services, and/or established task force panels. It is essential that our State legislators and State department officials hear from consumers in order to understand the challenges families face when trying to help a loved one with a dual diagnosis.

(Samples of Donna's testimonies presented at the N.J. Assembly and Senate Budget Public Hearings (2008 and 2009 respectively) are in the Appendix)

4. Meet and speak to the Governor of New Jersey at a "Community Dialogue" session.

- a. Public announcements for these events appear online at www.state.nj.us/government and in local newspapers.
- b. Consult the State government website www.njleg.state.nj.us for scheduled event notices.

5. Contact outreach service organizations and support groups, for example:

ABCD: Alliance for the Betterment of Citizens with Disabilities.
127 Route 206 (Suite 18)
Hamilton, N.J. 08610
Phone: 609-581-8375
E-Mail: www.abcdnj.org

The Arc of New Jersey
985 Livingston Avenue
North Brunswick, N.J. 08902
Phone: 732-246-2525
E-Mail: info@arcnj.org

ASPEN: Asperger Syndrome Education Network
9 Aspen Circle
Edison, N.J. 08820
Phone: 732-321-0880.
E-Mail: info@aspennj.org

**Autism New Jersey formerly COSAC:
The N.J. Center for Outreach and Services
for the Autism Community**
1450 Parkside Avenue (Suite 22)
Ewing, N.J. 08638
Phone: 609-883-8100 or 1-800-4-Autism
E-Mail: information@autismnj.org

Autism Speaks New Jersey Regional Office
1060 State Road (2nd Floor)
Princeton, New Jersey 08540
Phone: 609-228-7310
E-Mail: newjersey@autismspeaks.org

Family Support Coalition of New Jersey
P.O. Box 1052
Mt. Laurel, NJ 08054
Phone: 1-800-372-6510

NAMI New Jersey: National Alliance on Mental Health
1562 U.S. Highway 130
North Brunswick, N.J. 08902
Phone: 732-940-0991
E-Mail: <http://www.naminj.org>

New Jersey Council on Developmental Disabilities
P.O. Box 700
Trenton, N.J. 08625
Phone: 609-292-3745
E-Mail: <http://www.njddc.org>

SPAN: Statewide Parent Advocacy Network
35 Halsey Street (4th Floor)
Newark, N.J. 07102
Phone: 973-624-8100
E-Mail: span@spannj.org

Ask about their interest in discussing issues related to people with dual diagnoses as part of their regular meeting agendas. Volunteer to speak.

6. Encourage and support a relative who shows interest in self-advocacy.

This can be a very productive and rewarding experience for your loved one and an effective means of having their voices heard. Sharing their experiences and recommendations in various venues, including testifying at public hearings, participating on task force/advisory committees, joining self-advocacy groups or initiatives, can serve as a true catalyst to improving the quality of care and services for people with disabilities.

7. Consider having your family member accompany you when advocating on their behalf, as well as others.

This type of personal association with the cause you are attempting to advance can be very meaningful. For example, Donna's son, Michael, recently sat beside her as she testified before the N.J. State Senate Budget and Appropriations Committee. Donna believes Michael's presence at this public hearing had an invaluable impact on the Senate Committee members, and of equal importance, Michael's experience (captured by two photos in a local newspaper) was very reinforcing to him.



Appendix

Op-Ed letter	39
2008 Testimony, NJ Assembly Budget Hearing	40-41
2009 Testimony, NJ Senate Budget Hearing	42
Danielle's Law	44-49
Planning for the Future	50
A Life Plan	50
Guardianship	51
Advanced Psychiatric Directives	52
Psychoactive Medications	53-54
Portable Emergency Plan	55-56

Example of an Op-Ed Letter

Letter to the Editor
December 11, 2006

Over the past twelve years, my son, Michael, who is affected by autism and bipolar disorder, has received effective, compassionate care and professional services from Bancroft NeuroHealth, a non-profit organization that serves individuals with special needs.

On December 7, I had the privilege of testifying before the State Assembly Human Services Committee in support of the Bancroft program. I found the December 8 article "Panel Probes Conditions at Child Facility" very disappointing, because it did not offer your readers a completely accurate account of the proceedings. The reporter failed to highlight much of the positive information brought to the committees' attention through testimony from the Office of the Child Advocate, Bancroft President, Toni Pergolin, V.P and Chief Medical Officer, Dr. Caroline Eggerding, and family members.

The meeting focused on a favorable report issued by Steve Eidelman, an expert appointed by the state Office of the Child Advocate. Over a six- month review period, consisting of more than two-dozen visits to Bancroft's Haddonfield campus, this expert found 39 of the 41 individual requirements to be in compliance. The other two items were not related to the quality of care provided. In the report, Mr. Eidelman stated, "The organization (Bancroft) has, to its credit, instilled a sense of pride and professionalism in its staff that is to be commended."

As a parent who places the highest priority on providing my son with the best education, vocational training, and therapeutic services available, I am sincerely confident in the supportive quality services offered by Bancroft. Presently, my son is working in Bancroft's Adult Services Program. He resides in a lovely community residence, and participates in a variety of clubs and events offered by Bancroft, including the Special Olympics, and numerous community activities. Michael is living a truly active, productive and happy life that is meaningful to him. We are immensely proud of Michael's accomplishments, and deeply grateful to Bancroft for their instrumental role in his many successes. This kind of peace of mind is our greatest gift this holiday season, and throughout all the years we have been members of the Bancroft Family.

Donna Icovino

Examples of Testimony

New Jersey Assembly Budget Public Hearing

Fiscal Year 2009

April 1, 2008

Testimony by Donna Icovino, Family Advocate and
Co-Chair of the Department of Human Services Dual Diagnosis Task Force

Chairman Greenwald, and Members of the Assembly Budget Committee,

I am the mother of a young man affected with autism and bipolar disorder. Four years ago, my son, Michael and our family underwent an unfortunate experience involving New Jersey's system of crisis care services. Having been refused community-based treatment, my son ended up at Ancora Psychiatric Hospital, a completely inappropriate placement based on his needs. As a result of the advocacy efforts of our family, and tremendous support from Bancroft NeuroHealth, a non-profit community provider, Michael returned to the comfort of his former vocational placement and residential life.

Michael went on to graduate at the age of 21. He is currently employed in a business established by Bancroft's Adult Services Program, and he participates in adult clubs and classes also sponsored by Bancroft. He resides in a group home nearby his workplace. Michael is actively engaged as a member of the community, and he is living a good life. However, due to the complex nature of his disabilities, my son will forever require specialized care and supportive services.

Each fiscal year, consumers and family members throughout New Jersey speak out in support of a fair Cost of Providing Care increase incorporated into the State budget, and for every year thereafter. Every June, as the state budget is finalized, families are once again enormously disappointed by the inadequate state contract increases for community provider agencies. We understand all too clearly that insufficient State funding jeopardizes the stability of the programs that people with disabilities and their families strongly depend on. Sadly, we recognize that without a reasonable COPC increase, non-profit agencies like Bancroft will no longer be able to survive financially. Families are fearful regarding the uncertainty of their loved ones' future. Knowing that we cannot confidently rely on adequate state funding creates a constant source of worry and frustration for consumers.

It is an extremely difficult task within this limited time frame, to adequately describe all that it takes to maintain a good quality of life for my son. However, I can tell you that when I witness the large number of direct care staff members forced to leave the field because they cannot support their own families on such a low income, the immediate and long term effects are undeniably devastating. Beyond the destabilizing staff turnover, qualified applicants stay away discouraged by poor salaries, and unsatisfactory benefit programs. Community providers are left with huge vacancies, as well as a demoralizing atmosphere in respect to the staff members who remain. As a result, the individuals served by provider organizations are adversely affected. Consumers and their families are keenly aware that the quality of the program is directly related to the quality of the staff. Recruiting and retaining direct care staff has been in a critical state for many years, with no relief in sight.

Year after year, as the cost of living continues to rise without proportionate state compensation, our most vulnerable citizens pay the price. Recently, Governor Corzine gave a sobering budget address to a silent audience in which he stated that, "New Jersey has a government its people cannot afford." But even in light of the dismal fiscal atmosphere in New Jersey, can we honestly afford to deny people with disabilities the type of quality care and supportive services that they require and rightly deserve? I think we often lose sight of the fact that when we financially invest in people affected with disabilities, that as a society we all reap the benefits. Being given the opportunity to reach your potential is every person's right. However, I don't believe we in New Jersey demonstrate that we value the meaningful contributions that individuals with disabilities can make, especially when the state government financially short changes service provider agencies. Given the appropriate financial support, people with disabilities have a tremendous amount to offer our state in return.

(continued next page)

Examples of Testimony (continued)

I respectfully urge you to approve a reasonable 3.6% Cost of Providing Care increase in the FY2009 budget, and pass legislation to mandate an annualized COPC increase. By not approving this modest 3.6% increase, the state only compounds the problems faced by our most vulnerable citizens when the quality of care and services is compromised. Consequently, future plans to rectify the neglect will be cost prohibitive.

I hope that you will thoughtfully and compassionately exercise the power of your office to effectively support citizens affected by disability. Thank you for this opportunity to voice my opinion, and for your serious consideration.

Final Note: This past January, Department of Human Services Commissioner Jennifer Velez established a Dual Diagnosis Task Force to examine the service delivery areas of crisis care affecting children and adults with developmental disabilities, and co-occurring mental health disorders. I was honored to be appointed Co-Chair of the Dual Diagnosis Task Force by Commissioner Velez. The Dual Diagnosis Task Force is charged to develop recommendations, including defined time lines, priority and long term recommendations, with the goal of creating a quality consumer and family directed system of care. The work of the Task Force will be completed within a nine-month period ending in September. However, the work required to implement agreed upon systems reforms and potential policy changes will move forward until we have in place a service delivery system that effectively, compassionately, and cost effectively supports the needs of people with developmental disabilities and co-occurring mental health and/or behavioral disorders.



Examples of Testimony (continued)

New Jersey Senate Budget and Appropriations Committee Public Hearing
State Fiscal Year 2010
March 17, 2009
Testimony by Donna Icovino
Family Advocate and Co-Chair of the New Jersey Department of Human Services
Dual Diagnosis Task Force

Senator Buono, and Members of the Senate Budget and Appropriations Committee,

All across the state of New Jersey, families work hard to identify and secure quality services and supports for their children affected with developmental disabilities throughout the course of their children's lives. The daily challenges for people with disabilities and their caregivers are extremely taxing, and more often than not, incredibly overwhelming. For those whose lives have not been dramatically affected by disability, it must be difficult to imagine the emotional and financial burdens placed on those who are ultimately responsible for the individual's special, and at times, extraordinary needs.

If you listen closely to the personal stories shared by family members, certain common themes become apparent. For instance, the truly challenging aspects of fulfilling the special needs of an individual are not merely related to the active process of obtaining and mobilizing critical services. Most families are deeply devoted to meeting the needs of their loved ones. Instead, family members are more overwhelmed by a lack of appropriate resources; because of the devastating affect this deficiency has on their relative's overall well-being and future endeavors. Families also eventually conclude that their inability to effectively navigate the system of existing services is not a reflection of their know-how or advocacy skills, but a clear sign that the system is broken. Their greatest concerns for their loved ones speak volumes in terms of insufficient and inadequate care and services largely due to the severe lack of state funding support.

In light of the current national economic crisis, and its detrimental affect on our state, how do we reconcile attempting to meet the urgent and critical needs of the developmental disability community, including those individuals affected with co-occurring mental health and/or behavior disorders? Recently, during Governor Corzine's budget address he stated that his priorities in developing the 2010 budget included, "services for children, seniors, and our most vulnerable citizens." He added, and I quote, "We should not balance the budget on the backs of people with disabilities." It is clear that Governor Corzine recognizes that fulfilling the special needs of this population cannot be ignored. By not effectively addressing these essential needs in a timely manner, conditions for people affected with disabilities will eventually worsen, and rectifying these problems in the future will prove cost prohibitive.

It is my contention that the initiation of any cuts in services relative to people with developmental disabilities, whether in the current or 2010 fiscal year state budgets would be absolutely devastating to the already substantially underfunded service system. For many years, individuals and their families have dealt with numerous and serious gaps in the service delivery system, including exclusion from adequate crisis care services, long waiting lists for services, the destabilizing turnover of grossly underpaid direct care staff, inadequate state contract increases for non-profit provider agencies, etc.

Although families have long demonstrated great resiliency, in the end they understand all too clearly that insufficient state funding jeopardizes the stability of the programs and specialized services that their loved ones strongly depend on. Potential cuts in services will only compound the problems faced by our most vulnerable citizens when the availability of necessary services and supports is compromised. Regardless of the economic climate, the complex needs of people with disabilities remain, and therefore, our concerted efforts to address these issues must be treated as an utmost priority.

Let us work together to develop and implement financial strategies that will genuinely improve existing services, and stimulate the incremental building of an effective and quality driven service delivery system for New Jersey's developmental disabilities community.

Ultimately, my greatest hope is that we, as citizens of the great State of New Jersey, will collectively demonstrate the value we place on the lives of those individuals affected by disability, as we continue to make crucial decisions based on the value of the state and federal dollars we have at hand.

Danielle's Law

AN ACT concerning staff working with persons with developmental disabilities or traumatic brain injury and supplementing Titles 30 and 45 of the Revised Statutes.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey: C.30:6 D-5.1 Short titles

1. This act shall be known and may be cited as "Danielle's Law."

C.30:6D-5.2 Definitions relative to staff working with persons with developmental disabilities, traumatic brain injury

2. As use in this act:

"Commissioner" means the Commissioner of Human Services

"Department" means the Department of Human Services

"Facility for persons with developmental disabilities" means a facility for persons with developmental disabilities as defined in section 3 of P.L. 1977, c.82 (C.30:6D-3).

"Facility for persons with traumatic brain injury" means a facility for persons with traumatic brain injury that is operated by, or under contract with, the department.

"Life-threatening emergency" means a situation in which a prudent person could reasonably believe that immediate intervention is necessary to protect the life of a person receiving services at a facility for persons with developmental disabilities or a facility for persons with traumatic brain injury or from a public or private agency, or to protect the lives of other persons at the facility or agency, from an immediate threat or actual occurrence of potentially fatal injury, impairment to bodily functions or dysfunction of a bodily organ or part.

"Public or private agency" means an entity under contract with, licensed by or working in collaboration with the department to provide services for persons with developmental disabilities or traumatic brain injury.

C.30:6D-5.3 Responsibilities of staff at facility for persons with developmental disabilities, traumatic brain injury.

3.a. A member of the staff at a facility for persons with developmental disabilities or a facility for persons with traumatic brain injury or a member of a staff at a public or private agency, who in either case works directly with persons with developmental disabilities or traumatic brain injury, shall be required to call the 911 emergency telephone service for assistance in the event of a life-threatening emergency at the facility or the public or private agency, and to report that call to the department, in accordance with policies and procedures established by regulation of the commissioner.

The facility of the public or private agency, as applicable, and the department shall maintain a record of such calls under the policy to be established pursuant to this section.

b. The department shall ensure that appropriate training is provided to each member of the staff at a facility for persons with developmental disabilities or a facility for persons with traumatic brain injury or member of the staff at a public or private agency, who in either case works directly with persons with developmental disabilities or traumatic brain injury, to effectuate the purposes of subsection a. of this section.

C.30:6D-5.4 Violations, penalties

4. A member of the staff at a facility for persons with developmental disabilities or a facility for persons with traumatic brain injury or a member of the staff at a public or private agency who violates the provisions of section 3 of this act shall be liable to a civil penalty of \$5,000 for the first offense, \$10,000 for the second offense, and \$25,000 for the third and each subsequent offense, to be sued for and collected in a summary proceeding by the commissioner pursuant to the "Penalty Enforcement Law of 1999," P.L. 1999, c. 274 (C:2A:58-10 et seq.).

C.30:6D-5.5 Record of violations

5. The department shall maintain a record of violations of the provisions of section 3 of this act, which shall be included in the criteria that the department considers in making a decision on whether to renew the license of a facility or whether to renew a contract with a public or private agency, as applicable.

(continued next page)

P.L. 2003, CHAPTER 191

2

C.45:1-21.3 Violation of the responsibility to make 911 call, forfeiture of license, authorization to practice.

6. A health care professional licensed or otherwise authorized to practice as a health care professional pursuant to Title 45 of the Revised Statutes who violates the provisions of section 3 of P.L. 2003, c.191 (C.30:6D-5.3) shall, in addition to being liable to a civil penalty pursuant to section 4 of P.L. 2003, c.191 (C.30:6D-5.4), be subject to revocation of that individual's professional license or other authorization to practice as a health care professional by the appropriate licensing board in the Division of Consumer Affairs in the Department of Law and Public Safety, after appropriate notice and opportunity for a hearing.

C.30:6D-5.6 Rules, regulations.

7. The Commissioner of Human Services, pursuant to the "Administrative Procedure Act," P.L. 1968, c.410 (C.52:14B-1 et seq.), shall adopt rules and regulations necessary to effectuate the purposes of this act.

8. This act shall take effect on the 180th day after the enactment, but the Commissioner of Human Services may take such anticipatory administrative action in advance as shall be necessary for the implementation of the act.

Approved October 26, 2003.

New Jersey Department of Human Services
Division of Developmental Disabilities
Danielle's Law Facts

1. Danielle's Law became effective on Friday, April 23, 2004.
2. You must call 911 in the event of a life-threatening emergency.
3. Life threatening emergencies include, but are not limited to the following examples.

When a person is:

- a) Unresponsive to pain or stimuli;
- b) Unconscious, unusually confused or seems to be losing consciousness;
- c) Having difficulty breathing, is not breathing, or is breathing in a strange way;
- d) Having a weak pulse or there is no pulse;
- e) Having persistent chest pain, discomfort or pressure which persists for more than 3-5 minutes or that goes away and comes back;
- f) Bleeding from an orifice (eyes, mouth, or rectum);
- g) Severe bleeding from a body part;
- h) Having weak, low, or no blood pressure;
- i) Showing signs of a break or fracture to a limb or a bone;
- j) Showing signs of severe headache or slurred speech;
- k) Having seizures that are not typical; or prolonged or multiple seizures;
- l) Having a seizure resulting in injury, or seizures to one who is pregnant or diabetic;
- m) Injured in the head, neck or back.

Events that are life threatening:

- a) Fire, explosion, downed electrical wires; the suspected presence of poisonous gas
- b) If you are unsure whether a situation is a life-threatening emergency, always call 9-1-1.

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Danielle's Law (continued)

New Jersey Department of Human Services Division of Developmental Disabilities Danielle's Law Facts

Frequently asked Questions about Danielle's Law

1. Can I drive the individual to the emergency room or doctor's office?

No. If the individual has a life-threatening emergency, call 911. Follow the instructions of the 911 Operator.

2. How can I prepare for the emergency?

Attend Training regarding Danielle's Law. Keep a fact sheet on each individual that includes:

- i. List of all current medications
- ii. List of medical conditions and medical history
- iii. Phone number of guardian, next of kin and physician

3. Will a community care residence provider, developmental center employee, or agency staff member have the right to appeal a licensing action or a fine imposed as a result of violating Danielle's Law?

Yes. The letter that a violator of Danielle's Law receives will contain information about the fine and the appeal process.

4. When the individual, family member, or guardian doesn't want me to call 911, do I still need to call 911?

Yes. Danielle's Law requires that 911 be called in a life-threatening emergency. Handle the individual's refusal with sensitivity and explain that calling 911 is necessary.

5. When the individual has a DO NOT RESUSCITATE ORDER, do I still need to call 911?

Yes. Even if the individual has a DO NOT RESUSCITATE ORDER (DNR), Danielle's Law requires that 911 is called in a life threatening emergency. Once the call is made, the Emergency Medical professionals who respond will determine what type of medical care should be provided. Have the DO NOT RESUSCITATE ORDER available to show the Emergency Medical Service technician and the phone number of the Hospice program, if applicable.

6. Do I need to call 911 if I think another staff person has called 911?

You must call 911, unless you are absolutely certain that the 911 call has been made. This means that you must see or hear another staff person place the call to 911. If you have any doubt, you must call 911.

7. Who will investigate situations in which a 911 call was not made in a life-threatening emergency?

The Department of Human Services' Office of Program Integrity and Accountability (OPIA) will conduct the reviews of alleged violations.

8. When a doctor or nurse is available on staff, should I check with them before calling 911?

No. You must immediately call 911 in the event of a life-threatening emergency. A doctor or nurse can be notified after the 911 call is made. Doctors or nurses at the developmental center are available to assist with emergency treatment and should be notified immediately after calling 911.

9. What if I don't have access to a phone?

In such an instance, yell for help to persons passing by in cars or walking by, and tell them that the individual has a life-threatening emergency and 911 must be called.

10. What if I can't afford the fine?

Don't take the risk. No one can afford NOT to call 911 in a life-threatening emergency if they are caring for someone who is receiving services in a DDD or brain injury program.

Planning for the Future

A Life Plan

Consider developing a Life Plan for your loved one. Begin by thinking about how your loved one could best use his or her time each day in order to live a more meaningful, productive, and fulfilling life. It is important for individuals to have a structured day that offers opportunities to be with peers and have access to community resources.

Consider the following possibilities:

1. Employment, including supportive day programs.
2. Social activities, including joining clubs, attending creative classes, special community events, dances.
3. Physical activities, such as a routine exercise program, or participating in the Special Olympics Program.
4. A hobby or other interest.
5. Community service projects and volunteer opportunities.
6. Self-advocacy.



Guardianship

At 18, all individuals, including those with developmental disabilities and/or a mental illness, reach the legal age of majority. This means that parents can no longer make decisions legally on behalf of their children, regardless of the nature of their disability and regardless of whether or not they still live with their family.

Depending on your family member's situation, you may want to consider becoming a guardian at that time. Guardianship is the court appointment of a person or an agency to make personal decisions for an individual who is not capable of making decisions independently. The guardian's role is to act on behalf of an individual to assure his or her health, safety and welfare, and to protect his or her rights in accordance with the judgment of guardianship.

Guardianship should be viewed as a solution of last resort because it removes an individual's fundamental right of self-determination. You also should not look to guardianship as a way to gain greater control over your family member's care because you disagree with the decisions he or she makes. Courts render guardianship decisions based on an individual's ability to provide informed consent, not his or her ability to make good decisions.

For these reasons it is important to carefully consider why you think a guardian is needed and to also consider alternatives to guardianship that may be more appropriate. For example, individuals without guardians can use a HIPPA Release Form to authorize others to receive medical information. In New Jersey, individuals without a guardian are also able to appoint someone to be their Power of Attorney (POA) to make decisions on their behalf.

In order to appoint a POA, an individual must be able to understand on a basic level that he or she is appointing someone else to make decisions on his or her behalf. Also:

- An individual providing a POA must be able to consent to it
- A POA can cover person and/or property
- A POA can be revoked and/or changed any time, based on changing needs
- A POA is significantly less costly than guardianship
- It is best to work through an attorney to establish a POA

If you do decide to pursue guardianship, you should be aware that there are different types of guardianship to consider. Also, it is a legal process and you have options as to how you move through that process. You can pursue guardianship:

- With the assistance of the Bureau of Guardianship Services (BGS) at the Department of Human Services; BGS can only assist individuals eligible to receive services through the Division of Developmental Disabilities.
- Through a private attorney
- Pro Se, which means without an attorney; you would represent yourself.

Families can pursue guardianship *pro se*. This is a great choice for families who can complete the process on their own, especially if the individual is not already under DDD Services. Pro se means "without a petitioning attorney." The proposed guardian represents himself or herself in court.

- o The forms and instructions can be found at www.judiciary.state.nj.us or by clicking here: <http://www.judiciary.state.nj.us/prose/10558.pdf>.
 - Click on "Represent myself in court."
 - Click on "How to file for guardianship of a developmentally disabled person."
 - This process eliminates the cost of hiring an attorney to file the petition.
- o Remaining costs include court fees, guardianship assessments by a psychologist or physician, and the required court-appointed attorney to represent the individual.

For more information on guardianship, we suggest you visit the following websites:

Guardianship Association of New Jersey (GANJI) at: <http://www.ganji.org>

New Jersey Department of Human Services at: <http://www.state.nj.us/humanservices/ddd/services/guardianship/>

PLAN/NJ at: www.plannj.org

In addition, the New Jersey Judiciary publishes a "Manual for Guardians" that can be obtained from your county Surrogates Office. In at least some counties, this manual is automatically mailed to new guardians. It is only available in hard copy.

Psychiatric Advanced Directives

A psychiatric advanced directive allows individuals to make decisions in advance about their future mental health treatment, including medications and voluntary admission to inpatient treatment and electroconvulsive therapy. It is also possible for individuals to appoint someone to serve as their mental health care representative. This person has a duty to act consistently with the wishes, or best interest if the wishes are not known, of the person who made the appointment.

For more information about this option, and forms that can be used to create an advanced directive or appoint a mental health care representative, see the website of the Department of Mental Health Services at:

http://www.state.nj.us/humanservices/dmhs/consumer/advance_directive_english.pdf

Psychoactive Medications (for mental health disorders)

Given the on-going advances in medical treatment of psychiatric illness, it is unlikely that we can provide a definitive list of medications prescribed by physicians, psychiatrists and advanced nurse practitioners without such a list become outdated by the time this handbook is published and in circulation. However, we can review the major classes of psychoactive medications.

To begin with, you should inquire about your relative's Axis I diagnosis. "Axis I disorders" refer to mental health disorders/psychiatric illnesses that are described in the Diagnostic and Statistical Manual of Mental Disorders (DSM), which at the time of this writing is in its fourth edition. There are no medications for intellectual disability, poor coping or personality disorders. All these may pose significant challenges for your relative and be associated with crises. However, they are not medical conditions and cannot, therefore, be treated with psychoactive medications. Medications that are prescribed should be linked with specific diagnoses. For instance, anti-depressants should be prescribed for depression, anti-psychotics for psychoses, anti-anxiety medications for anxiety, etc. Sometimes individuals carry multiple diagnoses and may be on a therapeutic regimen that includes multiple medications. All questions regarding medication should be directed to your relative's prescribing practitioner. The foregoing is meant as an overview, only.

Mental health disorders are considered medical illnesses. If your relative is diagnosed with an Axis I disorder, the doctor may recommend medications to address the signs and symptoms of the disorder in order for your relative to obtain relief. Severe mental health disorders require medication much in the same way that severe diabetes requires medication. Please do not initiate, change the dosing and administration of medication or stop medication without consulting with your relative's doctor. Unsupervised abrupt changes in your relative's medication regimen can result in serious medical problems.

Your relative's doctor will determine dosing of medication and review and adjust medications based upon your report, your relative's report and staff report. It is extremely important to keep records regarding behaviors to see if there are changes that coincide with beginning new medications or are associated with medication adjustments.

Classes of Medication Prescribed for Mental Health Disorders

Anti-depressants

These medications are meant for the medical treatment of clinical depression. This class of medications includes Selective Serotonin Reuptake Inhibitors (SSRIs) such as Paxil and Zoloft.

Anti-anxiety

These medications may be used in the treatment of Generalized Anxiety Disorder or other forms of anxiety such as Obsessive Compulsive Disorder, social anxiety or phobias.

Mood Stabilizers

These are medications prescribed for treatment of cyclic mood disorders associated with Bipolar Disorder or Schizoaffective Disorder.

Anti-psychotics

These medications are prescribed for the treatment of thought disorder, delusions, and hallucinations associated with Schizophrenia or other psychosis.

Psychostimulants

These medications are prescribed for the treatment of Attention Deficit Disorder and Attention Deficit Hyperactive Disorder (ADD and ADHD). This class of medications includes Adderall, Ritalin, and Concerta.



Portable Emergency Plan

Include this two-part Portable Emergency Plan in your Family Emergency Plan.

Section 1: Emergency Information

Call 911 if my family member:

- ☐ Has lost control ☐ Is unable to follow instructions to calm down
☐ Is likely to physically hurt someone (including self)

Also call SCCAT: 1-888-393-3007

Tell SCCAT where your family member is being taken for emergency services _____

Closest ER/Screening Center: _____
Phone #: _____

Behaviors include:

- ☐ Non-compliant with routine task requests e.g. refuses meds
☐ Dramatic changes in sleeping and/or eating patterns
☐ Increasingly intense aggressive acts
☐ Quick bursts of energy, such as pacing back and forth;
☐ Demeanor indicating anger, frustration, confusion, fear, or a general threat;
☐ Violence to self, others or property
☐ Increasingly frequent or intense inappropriate behavior
☐ Other: _____

What is happening now? Identify any medical or environmental changes that may have led to this crisis: _____

Section 2. Consumer Profile

Name: _____ DOB: _____
Address: _____
Phone: _____ Insurance: _____
SSN: _____ Primary Diagnoses: _____

Guardian

Name: _____ Address: _____
Home Phone: _____ Cell Phone: _____ Fax: _____ Other Phone: _____

Treating Psychiatrist Contact Information

Name: _____
Phone Number: _____ Pager Number: _____ Answering Service: _____

DDD Case Manager: _____ Phone: _____

Recent (five years) relevant medical history, including allergies. _____

Current List of Medications (continue on back if necessary):

Medication	Daily dose	Prescribing Physician

Communication Needs:

☐ Wears hearing aids ☐ Wears glasses ☐ Uses an assistive device (describe): _____

Primary form of communication _____