

THE REVISED FAMILY CRISIS **HANDBOOK**

A Mental Health, Stabilization, and Wellness Toolkit



**This material is based on work supported with a grant awarded by the
New Jersey Council on Developmental Disabilities.**

This work is also supported with funds contributed by Community Access Unlimited.

April 2019

Co-Authors

Donna Icovino, Family Member and Advocate, Peer Support Counselor Rutgers/University Behavioral Health Care Mom2Mom Helpline, former Co-Chair, N.J. Department of Human Services Dual Diagnosis Task Force

Lucille Esralew, Ph.D., Director of Clinical Services Redwood Coast Regional Center, Ukiah, California

Project Support Team

Jeremy Lefever: MSW, LSW, Behaviorist Community Access Unlimited

Sarah Eibach: MSW, LCSW, Behaviorist Community Access Unlimited

Tracy LeBaron: MSW, LSW, BCBA, Managing Director of Behavioral Services Community Access Unlimited

Carolee Marano, BA, Director of Grants Development Community Access Unlimited

Acknowledgements

This material is based on work supported with a grant awarded by the New Jersey Council on Developmental Disabilities.

This work also is supported with funds contributed by Community Access Unlimited.

TABLE OF CONTENTS

INTRODUCTION	1
OVERVIEW OF MENTAL HEALTH AND DUAL DIAGNOSIS	2
Mental Health – Mental Illness vs. Mental Wellness	2
What is Dual Diagnosis?	3
Steps to better understand the mental health needs of individuals with developmental disabilities:	3
What is Mental Illness/Psychiatric Illness?	4
What is the Relationship between Behavior and Mental Illness?	4
What Does Intellectual/Developmental Disability have to do with Behavioral Crisis?	5
Behaviors are Sometimes Linked to a Specific Developmental Disability.	5
Prevention is the Best Intervention for Behavioral Crisis	5
RANGE OF SERVICES THAT ADDRESS DUAL DIAGNOSIS	6
Types of Professionals You Might Encounter	6
How to Work with a Therapist/Counselor	7
Programmatic Approaches: Partial Care and Partial Hospital Programs	7
Children with Dual Diagnosis	8
The Role of Children's System of Care (CSOC) in Support of Children with Dual Diagnosis.	8
Determining Eligibility for Services for Children and Adolescents Affected with Dual Diagnosis.	8
Initiating the Eligibility Determining Process through PerformCare NJ	8
Assessment Tools Used by CSOC to Develop an Individual Service Plan (ISP)	9
Case Management Services	9
Behavioral Stabilization Programs	9
Accessing New Jersey's Long-Term, Out-of-Home Behavioral Stabilization Programs	9
Short-Term Developmental Disability Crisis Stabilization and Assessment Centers.	10
The Role of the Team in Supports of Persons with Dual Diagnosis	10
CRISIS ASSESSMENT	12
How to Assess if a Crisis Situation Exists	12
What is a Behavioral Crisis?	12
What Strategies are Helpful when a Crisis is Assessed?	13
CRISIS RESPONSE	14
When to call 9-1-1	14
You Have Called 9-1-1, Now What Should You Do?	14
What to Expect in an Emergency Room	15

Why does the Individual Need a Medical Evaluation?	15
Why Must You Wait in the Emergency Room?	15
What to Expect at a Psychiatric Screening	16
What are the Criteria for a Psychiatric Hospitalization?	16
What if a Person with a Disability Requires Hospitalization?	16
Voluntary Admission or Involuntary Commitment?	16
2D–The Specialized MI/DD Unit at Trinitas Regional Medical Center.	17
What If Your Insurance Company Will Not Pay?	17
Diverting Your Relative from State Psychiatric Hospital Admission.	17
How is an Individual Committed to Involuntary Care?	18
What to Do If You Disagree	18
What If Your Family Member is Determined as Not Needing Hospitalization?	19
Additional Options	19
What If You Are Not Able to Support Your Relative At Home?	19
AFTER THE CRISIS	20
Stabilization	20
FUTURE PLANNING	21
Family Members Coping and Planning Together	21
Creating an “Emergency Plan”	22
A Life Plan	24
SPECIAL TOPICS IN MENTAL HEALTH	26
Substance Use and IDD	26
Suicidality and IDD	26
Non-suicidal Self-injury	26
Dementia and IDD	26
Trauma	27
What We Know About the Abuse and Neglect of People with Disabilities	27
Responding to Sexual Trauma	27
Laws Protecting People with Disabilities	28
State and National Resources	30
Summary of Appendix	33

INTRODUCTION

The purpose of this handbook is to empower individuals with disabilities and their families and professional caregivers by providing information with which they can more effectively advocate for treatments, supports, services and the conditions that promote mental wellness. Individuals with the dual diagnoses of developmental disabilities and mental health disorders face multiple challenges in their daily lives. When the original *Family Crisis Handbook (2010)* was developed, co-authors, Donna Incovino and Lucille Esralew envisioned this as a tool for family caregivers. The authors once again joined forces to develop the *Revised Family Crisis Handbook (2019)* which includes updated resource information and expanded content, including information pertaining to children with dual diagnoses.

How to Use this Handbook

This publication is designed to assist a person with a developmental disability experiencing mental health challenges or crises. It therefore deals with targeted topics, resources and suggestions.

The Table of Contents lists the main topical sections of the revised handbook and the page number at which each section begins, to guide the reader to the topic they wish to read about:

1. An overview of mental illness and dual diagnosis. There are basic definitions and information about the nature of mental illness and dual diagnosis as they pertain to persons with developmental disabilities. This section notes the distinction between mental and behavioral health yet also the relationship between a mental health crisis and a behavioral crisis. In addition, it provides the initial steps you should take when you notice a change in baseline behaviors that persists for more than two weeks.
2. The range of services that address dual diagnosis. Lists of the various professionals and teams that provide services that address children adult dual diagnosis. It also includes a discussion of the role each can play in support of you or your loved one. This section discusses programmatic approaches such as partial care and partial hospital programs and services available to children with dual diagnoses including behavioral stabilization programs.
3. Crisis assessment. Explains what to look for if you suspect your loved one is in behavioral crisis including the behaviors that may signal an onset of crisis. This section also offers helpful strategies to use to try to defuse a crisis. It also lets you know when and why to call 9-1-1 and other crisis supports.
4. Crisis response and resources. Explains each basic step in crisis response from calling 9-1-1 to the emergency room visit to potential hospitalization and provides distinctions between short-term care and long-term care as well as voluntary admissions and involuntary commitment.
5. Post crisis resources. Outlines the steps to take following crisis. Includes information on contacting CARES or your loved one's Care Management Organization (CMO) Care Manager and requesting meetings with the interdisciplinary team at the Division of Developmental Disability (DDD) for adults, or the individual family team at Children's System of Care (CSOC), and addresses monitoring the administration of newly prescribed medications.
6. Future planning. Discusses the preparation and implementation of an Emergency Plan and the maintenance of mental wellness.
7. Special topics. These topics include a discussion of trauma, substance abuse and

suicidality. It also references laws that protect persons with disabilities.

8. Resources. Contains a list of public and private offices and agencies that you may contact for further information and/or assistance.
9. Appendix. Additional resources are listed in the Appendix at the end of the handbook. Since this is an emergency guide, this publication is intentionally concise and

targeted to be useful to individuals and families navigating a crisis, therefore as a supplement to this handbook, information pertaining to a variety of extended topics is available in the Resources section of the Community Access Unlimited (www.caunj.org) and the New Jersey Council on Developmental Disabilities (www.njcdd.org) websites.

OVERVIEW OF MENTAL HEALTH AND DUAL DIAGNOSIS

Mental Health – Mental Illness vs. Mental Wellness

According to the World Health Organization, mental health is defined as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.” (https://www.who.int/features/factfiles/mental_health/en/)

Mental wellness is more than the absence of mental illness or emotional distress. Wellness involves choices the individual makes to advance their physical and mental well-being. It calls for a holistic, person-centered, consumer-driven, strengths-based, and culturally competent approach to their care and the approach used by others to support them. It includes important life considerations, such as, does the individual have meaningful connections to others? Enjoy school or work? Live in a situation in which they are getting along well with others? Have access to leisure activities, family, social opportunities, and/or faith-based experiences?

When we refer to mental health, we do not usually mean mental wellness. Instead, we are referring to the treatment services for individuals with mental health disorders. The goal of mental health treatment is to reduce the signs and symptoms of the illness (depression, anxiety, bipolar disorder)

that interfere with the individual’s daily living and quality of life. The treatment of mental health disorders usually involves taking psychoactive medication for the medical management of the mental health condition and involves some psychosocial interventions such as counseling, psychosocial rehabilitation, and/or behavioral intervention.

Mental wellness takes the whole person into account and not just the disorder with which the person may be challenged. In considering mental wellness, we do not allow the person’s diagnosis to define them, shape their daily life or interfere with their personal life goals. We look to remove barriers to the person having the life that they want. We build on identified character and other strengths to help us address limitations. The person, not his or her illness, determines their life goals, services and supports. The health care provider is a consultant to the team, but does not determine the direction in which the person will go.



While we are making distinctions, be aware that mental health and behavioral health are not interchangeable terms. In NJ, we usually refer to behavioral health as third party reimbursed outpatient services that may involve mental health disorders, but may also promote well-being. As to mental health, we may be referring to inpatient or outpatient services used to treat significant mental health disorders, substance abuse or other addictions. While the Division of Mental Health and Addiction Services (DMHAS) oversees inpatient treatment and outpatient

treatments of mental illness (www.nj.gov/health/integratedhealth/dmhas/), behavioral health services may be obtained in a private practitioner's office, a community mental health center or other settings that are not managed through DMHAS.

Individuals with dual diagnosis may access behavioral health services or mental health services depending upon their level of service need. When individuals are in a crisis, they will often be accessing mental health services that are managed through DMHAS.

What is Dual Diagnosis?

According to The National Association for the Dually Diagnosed (NADD), dual diagnosis is a term applied to the co-existence of the symptoms of both intellectual or developmental disabilities and mental health problems.

Individuals with a dual diagnosis are found at all ages and levels of intellectual and adaptive functioning. Estimates of the frequency of dual diagnosis vary widely; however, many professionals have adopted the estimate that 30-35% of all persons with intellectual or developmental disabilities have a mental health disorder. The full range of psychopathology that

exists in the general population also can co-exist in persons who have intellectual or developmental disabilities.

Having a dual diagnosis can have serious effects on a person's daily functioning by interfering with educational and vocational activities, jeopardizing residential placements, and disrupting family, peer relationships and other vital relationships. In short, the presence of behavioral and emotional problems can greatly reduce the quality of life of persons with intellectual or developmental disabilities. It is important to obtain accurate diagnosis and appropriate treatment in a timely manner.

Steps to better understand the mental health needs of individuals with developmental disabilities:

If you notice changes in a person with a developmental disability from his or her characteristic, baseline appetite, sleep, mood, activity level and behavior that persist for more than two weeks, bring the individual to the attention of his or her primary care physician to rule out medical problems that may affect mood, thinking or behavior. Additionally, you should do the following:

1. Collect information about any changes observed at home, school, or work so that you can advise the individual's health care provider about any changes that may not be observable during an office visit.
2. Obtain a mental health assessment from a clinician who is familiar with dual diagnosis.
3. Obtain a functional behavior assessment from a behaviorist to determine the role of environment, interpersonal relationships and everyday stressors in driving behavior change.
4. Involve the individual's multidisciplinary team in problem solving changes that may support him or her and reduce depression, anxiety or stress-related behaviors.
5. For youth under the age of 21, involve PerformCare **1-877-652-7624**. PerformCare can provide in-home supports as well as Mobile Response and Stabilization Services (MRSS) to youth with intellectual and

developmental disabilities and co-occurring mental health and/or behavioral needs.

6. For adults age 21 and older, involve CARES

1-888-393-3007. CARES is an outreach and engagement mental health team that specializes in working with adults with dual diagnoses.

What is Mental Illness/Psychiatric Illness?

Mental illness (sometimes referred to as “mental health disorder” or “psychiatric illness”) refers to long term problems with mood, behavior and thinking. Major depressive disorder, generalized anxiety and bipolar disorder are mood disorders. Psychosis, delusional disorder and schizophrenia are thinking problems. We often extend the concept of mental health needs to include individuals with severe behavior problems. These behavior problems may or may not be linked to a mood or thinking problem. However, people who display significant behavior issues need special attention when they behave in ways that are unsafe for themselves or others.

A psychiatrist, psychologist or other licensed mental health clinician diagnoses mental illness. Often, the individual living with mental illness experiences significant distress and/or problems functioning in social, employment or family relationships. The clinician will evaluate the individual through observation, conducting various assessments as well as interviewing any caregivers or other relevant parties involved in the individual’s life. Upon conducting this comprehensive assessment, the clinician will reference Diagnostic and Statistical Manual of Mental Disorders, 5th version (DSM-5) to ascertain the corresponding diagnosis presenting by the individual.

The current treatment for mental health disorders involves a combination of medication and psychosocial interventions. However, the best practice treatment for most mental health disorders also involves non-medical practices including strengthening social supports, developing coping skills, providing environmental and lifestyle changes.

In addition to environmental factors, culture, individual values and belief systems can influence treatment and supports for someone with a mental health disorder. When someone lives with a mental illness, it is likely to impact upon all areas of their life. It is also likely to affect family members, friends and others regularly engaging with the person living with mental illness in settings ranging from work to home to community.

It is important to note that the information provided in this handbook is meant to touch on general considerations for people involved in mental health care decision-making. It does not substitute for the advice and recommendations provided to a person with a disability by their current practitioner, clinician or health care provider including a psychiatrist, advanced practice nurse, psychologist, social worker, professional counselor, behaviorist or other credentialed practitioner.

What is the Relationship between Behavior and Mental Illness?

Mental illness can affect an individual’s overall social, emotional and behavioral functioning. When experiencing a stressful event, an individual may respond to their environment in such a way that results in strained interpersonal relationships, leads to problems in the workplace or other aversive life experiences. Though not all concerning behaviors are the result of mental illness, it is helpful to recognize the

interconnections between thoughts, feelings and behavior. Keeping this association in mind, when an individual is diagnosed with a mental illness, often, it is the individual’s behavioral presentation that draws attention to the presence of mental illness and supports the referral for comprehensive assessment and subsequent diagnosis.

What Does Intellectual/Developmental Disability have to do with Behavioral Crisis?

Intellectual disability, which is the most common type of developmental disability, is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. Individuals with a developmental disability may have more difficulty learning age-level social and emotional coping skills. They may be non-traditional communicators who are not easily understood by others because of limited verbal

skills, which can cause frustration in their daily living. Individuals who live with disabilities may have had fewer opportunities to learn skills and strategies to deal with the everyday hassles and stressors of living with mood and thinking problems. These are among the factors that may leave someone living with disabilities more prone to behavioral crisis than some individuals without disabilities.

Behaviors are Sometimes Linked to a Specific Developmental Disability

In determining whether an individual's presentation is a manifestation of mental health or behavioral problems, professionals (service providers, practitioners) consider whether any of the problem behaviors might be linked to the individual's specific developmental disability. Emergency Room (ER) screeners or mental health practitioners who are unaware of disability-related behaviors might mistakenly diagnose someone with a mental health

disorder. It is therefore wise to ask professionals who are knowledgeable about a specific disability whether there are any behaviors associated with the disability that might be mistaken for mental illness. That way, you are prepared, in case the behavior emerges, to discuss the link between the behavior and the developmental disability when it is time to discuss treatment options.

Prevention is the Best Intervention for Behavioral Crisis

The best way to manage behavioral crisis is to prevent its occurrence. This section reviews the importance of timely, comprehensive evaluations to identify what individuals need to remain safe, healthy and pursue their valued outcomes. We also provide considerations about how the individual and his or her valued supports can utilize the findings from comprehensive assessment to plan, shape and implement the services and supports that promote safety, wellbeing and support valued outcomes. We consider what difference services and supports might be relevant to different stages of development during childhood, adolescence (transition age), adulthood and old age. To avert crisis providers in the individual's life need to be equipped with the knowledge, attitudes and skills needed to advance quality of life despite behavioral challenges. This may include learning skills, understanding the unique challenges of

developmental disabilities, understanding the unique needs of dually diagnosed, the role of environment, and services that flexibly expand and contract given the needs of the individual, and how to create a scaffolding of support as needed.

There are clinical teams that will respond to your call before the situation becomes a crisis. Their job is to try to prevent a crisis from happening. For children/youth (under 21 y/o) contact Mobile Response Stabilization Services (MRSS) by dialing PerformCare at 1-877-562-7624. For adults (ages 21+) contact Crisis Response and Enhancement Services (CARES) at **1-888-393-3007**.

RANGE OF SERVICES THAT ADDRESS DUAL DIAGNOSIS

Types of Professionals You Might Encounter

You may encounter some of the following professionals in both medical and non-medical settings depending upon the type of service provided and setting in which the service is offered:

Resources and Services Coordinators

- Intensive Case Manager – available through the NJ Department of Human Services – Division of Developmental Disabilities (DDD).
- Support Coordinator – provides Support Coordination Services under the DDD Supports Program and Community Care Program for each eligible individual by performing the following four general functions: individual discovery, plan development, coordinator of services, and monitoring.
- DCPW Workers – assigned through NJ Department of Children & Family Services, Child Protection and Permanency Division (DCF – DCPW). This professional’s role is designated based on one of the following services: child protection, case management, foster care, adoption, family supports and services through community providers, or information and referral.
- Care Manager – available through the NJ Department of Children & Family Services, Children System of Care (DCF – CSOC).
- Family Partner – available through the Family Support Organization through the NJ Department of Children & Family Services, Children System of Care (DCF – CSOC)
- Direct Support Professional (DSP) – provides support to an individual with disability to lead a self-directed life in the community, assists with activities of daily living (ADLs) if necessary, and encourages attitudes and behaviors that enhance the individual’s community inclusion.

Medical Practitioners/Providers

- Physician – a healthcare professional who has obtained an MD (Medical Doctorate) or DO (Doctor of Osteopathic Medicine) degree. Physicians can prescribe medications. Neurologists are another group of specialty medical practitioners that often are consulted by individuals with developmental disabilities.
- Psychiatrist – a physician who has completed specialty training in mental and emotional disorders and who may prescribe medications for the treatment of psychiatric illness and mental health disorders.
- Psychiatric Advanced Nurse Practitioner (ANP) – a nurse practitioner who is qualified to treat certain medical conditions without the direct supervision of a doctor; a psychiatric ANP specializes in the treatment of mental illness and can prescribe medications.

Non-Medical Practitioners/Providers

- Psychologist – a trained professional with a doctoral degree in psychology (PhD, EdD. or PsyD) who specializes in non-medical treatment of individuals with mental health issues or behavioral problems. A psychologist cannot prescribe medication.

- Social Worker – a clinically trained professional who may provide non-medical clinical services to individual with mental health or behavioral problems.
- Licensed Professional Counselor (LPC) – a clinician who provides counseling and psychotherapy to individuals with mental health or behavioral problems. Some counselors are licensed professional counselors.
- Behaviorist – a practitioner trained in the use of learning techniques to assess behavior problems and develop approaches to teach individuals to replace target problems with adaptive skills.
- Screener – a clinician who has received basic training in psychiatric screening.
- Allied Professionals – A category of licensed practitioners who may offer non-medical rehabilitation services in a hospital or outpatient setting such as occupational therapy, physical therapy, speech therapy or nutrition/diet.

How to Work with a Therapist/Counselor

Therapists and counselors, including psychologists, professional counselors, social workers, marriage and family therapists, and pastoral counselors, are non-medical practitioners and cannot prescribe medication, but they can better help individuals to understand their thoughts, feelings and behaviors and assist in developing improved coping skills to handle the stressors of everyday living and larger life challenges.

Counseling services tend to have the most successful outcomes with individuals who are open to and want to receive these services. When working with a counselor or therapist, be sure to

share the issues that are interfering with goals at work, in relationships, within the family, and in the community. It is also helpful to ask about the frequency and format for sessions including how billing for services is handled.

Some therapists/counselors offer homework assignments, readings, or work with family and staff to promote skills development. Counseling may be in private practice or within an outpatient setting or clinics, which may be within hospitals or may be freestanding community mental health centers.

Programmatic Approaches: Partial Care and Partial Hospital Programs

Programs Designed to Meet Mental Health Needs

There are psychosocial rehabilitation programs designed to assist individuals with mental health needs. Many of these are offered as partial care or partial hospitalization programs as a step-down from hospitalization, or, as a step-up from counseling to provide more intensive support in order to avert hospitalization.

These programs usually provide group skills building sessions regarding lifestyle factors relevant to mental health, medication management, stress and coping skills. The individual may learn about specific mental health disorders. Many of these programs are intended to be time-limited

while the individual is stabilized sufficiently to move on to work or generic day programming.

Some programs have developed specialized tracks for individuals with developmental disabilities with modified curriculum including more leisure and art therapy and other traditional programs. Again, the language skills of the individual, the attention span and ability to tolerate being in a group setting all day are factors to be considered when deciding about attending these mental health programs. These programs are not typically designed for people with severe behavioral problems.

Children with Dual Diagnosis

Children in behavioral crisis often have not had their mental health needs addressed prior to the crisis. Children with dual diagnosis can work therapeutically to address their mental health needs. Therapy approaches might need to be modified in order to make them accessible and useful for children. Important factors to consider include age, language and attention span.

Children with dual diagnosis are more likely to exhibit difficult to manage, sometimes-dangerous behaviors because of their limited coping skills and communication challenges and resource limitations. Children with limited use of language might be able to participate with expressive arts including

art and dance therapy. Children can benefit from play therapy, for example, sand therapy. Children also benefit from early intervention. In some cases, timely intervention can eliminate the need for psychoactive medication.

For children exposed to a traumatic event, techniques such as Trauma Focused Cognitive Behavior Therapy (TF-CBT), expressive arts and sand play are used. Consult the National Child Traumatic Stress Network (NCTSN) website for extensive resources in the area of trauma-informed care for children. Contact information for the NCTSN is provided in the State and National Resources section of this handbook.

The Role of Children's System of Care (CSOC) in Support of Children with Dual Diagnosis

The Department of Children and Families (DCF) through the Children's System of Care (CSOC), formerly the Division of Child Behavioral Health Services (DCBHS), serves children and youth with intellectual and developmental disabilities, emotional and behavioral challenges, and substance abuse, and serves their families. CSOC focuses on the individual's needs and safety within their

family and community environment and builds on strengths to achieve optimal outcomes. It offers a variety of services to address the challenges of children and youth affected with dual disorders, including community-based and in-home services, out-of-home residential services, and family support services.

Determining Eligibility for Services for Children and Adolescents Affected with Dual Diagnosis

CSOC is responsible for determining eligibility for intellectual/developmental services provided by the state of New Jersey for children and adolescents under age 18.

Please Note: For individuals over the age of 18,

The N.J. Department of Human Services, Division of Developmental Disabilities (DDD) is responsible for determining eligibility. DDD contact information is included in the State and National Resources section of this handbook.

Initiating the Eligibility Determining Process through PerformCare NJ

PerformCare New Jersey is the Contracted System Administrator for the Children's System of Care (CSOC).

PerformCare manages the State of New Jersey's service delivery system. It was established to provide a single point of entry for children and youth to obtain existing supports and services for developmental disability, behavioral health

and substance abuse. PerformCare applies their knowledge and integrated technologies to register, authorize, and match services and supports for children and adolescents diagnosed with the aforementioned challenges.

Contact information for PerformCare is provided in the State and National Resources section of this handbook.

Assessment Tools Used by CSOC to Develop an Individual Service Plan (ISP)

The CSOC employs the Child and Adolescent Needs and Strengths Assessment (CANS) tool. The CANS is a multi-purpose communication tool that comprehensively assesses the needs of children/adolescents and of their parents or caregivers. The CANS also was designed to identify the strengths of the individual and their family. The results of the CANS are utilized to create individual service plans (ISPs), to determine intensity of care, and to offer a built-in quality improvement and assurance component for intervention outcomes.

In addition, the CSOC has adopted the use of the CANS-Crisis Assessment Tool (CANS-CAT). Similar to the CANS tool for children and youth

with developmental disabilities, the CANS-CAT supports the planning and evaluation of individual care and of service systems, however, the CANS-CAT additionally focuses on addressing the mental health needs of children/youth and their families.

More detailed information regarding the CANS and CANS-CAT assessment tools is available on the CSOC homepage via links to the CANS-New Jersey Children's System of Care Information Management Decision Support (IMDS) Tools section. Contact information and website address for the CSOC is provided in the State and National Resources section of this handbook.

Case Management Services

Most youth and their families served by the CSOC do not require an assigned case manager. However, families should inform PerformCare of any unmet needs or challenges that their child is experiencing so that these issues can be assessed. On a case-by-case basis, CSOC/PerformCare does authorize the connection of an individual to a local Care Management Organization (CMO) when their challenges are considered highly intensive and complex. The CMO Care Manager provides person and family-centered service/support coordination.



Behavioral Stabilization Programs

Typically, behavioral stabilization programs are comprised of professionals specializing in behavioral psychology, psychiatry, neurology, pediatrics/primary care, nursing, social work, speech/language pathology, and/or education. Challenging behaviors are identified and evaluated, including the existence of possible psychiatric disorders. A treatment plan is developed to decrease these behaviors and to replace them with behaviors that are more desirable. The need for medication

and for possible adjustments to medication is examined. The training of teachers, support staff, and family members on the behavior management plan is fundamental to the ultimate success of these programs, as is the securing of a post-treatment placement (family home, community-based residence-group home, or appropriate school/day program).

Accessing New Jersey's Long-Term, Out-of-Home Behavioral Stabilization Programs

Long-term, out-of-home behavioral stabilization programs in New Jersey are currently only

available for children and youth under the age of 21. CSOC oversees three such programs, which

are each operated by a different community service provider. They serve approximately fifteen individuals per program in three separate locations in the state. It is recommended that parents

and legal guardians contact their child's Care Management Organization (CMO) Care Manager or PerformCare at **1-877-652-7624** to discuss this potential option.

Short-Term Developmental Disability Crisis Stabilization and Assessment Centers

The CSOC has established Developmental Disability Crisis Stabilization and Assessment Centers for intellectually/developmentally disabled (I/DD) youth under the age of 21. These regionally based short-term emergency group homes serve I/DD youth in urgent need of out-of-home services and supports due to severe challenges (behavioral, emotional, co-occurring medical issues, or abuse/neglect) and a family member/caregiver's inability to care for the youth safely and effectively.

This program offers community based, person-centered care and treatment, including stabilization,

assessment (medical, psychiatric, biopsychosocial, behavioral, etc.) and developmentally appropriate services, skill building opportunities, and coordination in maintaining current educational services, or other school options. The program's multi-disciplinary approach naturally includes family/caregiver engagement throughout the process. If possible, the goal is for the individual to return home. Following discharge from the program, in-home services/supports might be provided for the youth and their family to avoid future hospitalizations and longer term out-of-home placement.

The Role of the Team in Supports of Persons with Dual Diagnosis

Children: How can the Individualized Education Plan (IEP) be utilized to help dually diagnosed children?

The purpose of the IEP is to identify school-based supports that children need in order to be successful in the classroom. For children that have special needs, particular protections exist to make sure that they receive evaluations, proper classification, and necessary services. For the child with dual diagnosis, this may include supports for emotional and behavioral problems that can interfere with

learning. Consult the Parental Rights in Special Education (PRiSE) material to make sure your child is taking full advantage of supports and services available through school. This material is available for viewing, downloading and printing on the NJ Department of Education website in English, Spanish, Arabic, Chinese and Portuguese.

Adults: The Individualized Service Plan (ISP) and Interdisciplinary Team (IDT) in Support of Persons with Dual Diagnosis

Adults who are eligible for the Medicaid-based, fee-for-service system and wish to access DDD-funded services select or are assigned to a Support Coordination Agency (SCA). The SCA assigns a Support Coordinator to work with the individual and their family to ensure completion of the Person-Centered Planning Tool (PCPT) and to develop the ISP.

Every eligible and enrolled individual also has an IDT that consists of the individual receiving

services, the plan coordinator and the legal guardian. Others relevant to the identification of the individual's needs and preferences, and the design and evaluation of programs to meet these needs and preferences can be included if desired by the individual. These others might include parents or other family members, advocates, friends, staff or other service providers. The IDT can convene to develop an ISP or to discuss changes in supports when the need arises. The ISP is based on individual values, preferences and meaningful

activities and can be used to identify and support mental health needs. Such needs can add layers to the needs of a person with a dual diagnosis. The person's mental health needs can interfere with school, work or relationships — the ISP should address all of the individual's needs.

The IDT can be used to respond to the person's changing needs. Before and after a behavioral crisis, the IDT can meet to coordinate relevant resources and advance the best plan for addressing the needs and interests of the person with a disability.

Everyday Supports for Persons with Dual Diagnosis

All people need to feel they have choice and voice in their own lives. It is helpful to consider how people with dual diagnosis can gain an increased sense of control and independence in important areas of daily life. There are things that we can do on an everyday basis to support individuals with dual diagnosis. These include:

- **Functional communication**
If the person with a disability is a non-traditional communicator, consider an assessment to determine if there is augmentative assistive technology (AADs), visual communication systems such as PECs, sign language or some other way in which the person can learn how to indicate needs and preferences and how to let others know that they need help or are in pain.
- **Positive routine**
Provide a daily schedule of meaningful activity and contact with others as it will reduce anxiety and promotes a sense of security.
- **Increasing choices**
Identify areas where the individual can make their own decisions so they feel empowered, respected and more comfortable.
- **Opportunities for work and play**
Learn about the individual's interests and preferences and work with them to explore employment or vocational and recreational activities that are satisfying for them.
- **Opportunities to remain connected to family, friends and community**
Facilitate connections between the individual and their circle of support and discover community opportunities that are of interest. This might include arranging visits with friends or family, attending services at a favorite house of worship, and enjoying acquaintanceships with friendly community members while visiting the local community center, a local park, shopping, or engaging in any other community activities the individual likes.
- **Building skills to increase personal confidence and effectiveness**
Create opportunities for the individual to learn skills that will make them successful in activities of daily life (grooming and hygiene, communication, navigating emotions, etc.) and help to cultivate a sense of accomplishment in increasing those skills.



CRISIS ASSESSMENT

How to Assess if a Crisis Situation Exists

What is a Behavioral Crisis?

Crises occur when an individual and/or their personal support system are overwhelmed, in other words, when the individual can no longer effectively cope with stressors and their supports can no longer effectively support their behavior. Elements that contribute to crisis include poor person-environment fit, unrecognized and untreated medical problems, poor social emotional coping skills, limited relevant services to support the needs and preferences of people with disabilities, and behavioral disorders that are associated with select developmental disorders and dual diagnosis.

A person is in a behavioral crisis when they act in a way that is unsafe and when they cannot be restored to safety utilizing usual strategies to address the behavior. This behavior may be dangerous and may represent a dramatic departure from their usual and

characteristic behavior (i.e., behavior that is normal for them).

During a behavioral crisis, the individual's family and/or caregivers may not have the resources available to manage safely the behavioral outburst or to stabilize the individual. Communication techniques and strategies that might have worked in the past may no longer be effective. Because of this communication breakdown, individuals with disabilities are potentially dangerous to themselves or others. The escalating circumstances can result in a disruption of work and daily activities and can increase the likelihood that the person will lose placements in a job, school, day program, or residential situation. Others around the person in crisis are likely to become concerned about the person's perceived lack of self-control and might worry about someone getting hurt.

Examples of behaviors that could indicate the onset of a behavioral crisis:

- Non-compliance with routine task requests, such as refusing to take the usual, prescribed medications, taking medication inconsistently, or “cheeking” medication (hiding it in the cheeks until it can be removed from the mouth unseen) to avoid swallowing it.
- Dramatic changes in appetite and sleep patterns
- Mildly aggressive acts that begin to increase in intensity
- Quick burst 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, hitting, kicking, or punching oneself, others, or property, or other similar attempts to cause harm to oneself, others or property
- Any inappropriate behavior that appears to be a departure from characteristic baseline and, becomes more frequent and intense than usual

Questions to consider when determining whether a crisis exists:

To make a quick, informal assessment as to whether a behavioral crisis is in process, consider the following questions:

- Has the person lost self-control?
- Is the person unable to follow instructions toward calming down?
- Is there a strong possibility that the person or others in the surrounding environment might be hurt physically?

If the answers are “yes,” then there is a strong possibility that the individual is in the midst of a severe behavioral crisis. In such a situation, it is important to seek assistance in handling the situation.

What Strategies are Helpful when a Crisis is Assessed?

Do your very best to remain visibly calm and in control of the situation. Any extreme reaction can serve to intensify the individual’s loss of control. (Avoid yelling, crying, demonstrating fear or anxious expressions, quick or unexpected movements or gestures, etc.) In addition, assigning blame or becoming defensive or argumentative and/or physical toward the person in crisis will only exacerbate the situation by causing further confusion, guilt and potential harm. These reactive and/or defensive behaviors can also become highly reinforcing to the individual and therefore, make it more difficult to decrease the unwanted behaviors.

Use breaks and pauses to give the person the opportunity to calm down and regain their composure. This also might provide the family or caregiver with a chance to regroup and to consider, effectively, the next steps to take.

Teach the person breathing exercises to reduce their anxiety and to help defuse a tense situation. Remember to teach, practice and reinforce these skills when the person is calm and not upset. Then, they can be used readily in a crisis.

Change the environment by going out for a walk, taking a soothing bath, or providing any type of reinforcing distraction (i.e. watching a favorite TV show or DVD, listening to music, etc.).

Ignore certain inappropriate behaviors and do not call attention to them. This can decrease their frequency and in some instances remove them entirely. This approach has been termed “extinction” and “planned ignoring.” It can be used for behaviors that are annoying or difficult, but not dangerous. For example, by ignoring the behavior of verbal perseveration (repetitious responses or behaviors that continue even when a stimulus is

absent, such as demanding an excessive amount of food during or in between meals), you might be able to reduce the number and intensity of the perseverations. Reducing this may reduce overall frustration that previously has resulted in very aggressive behavior.

Maintain safety by ensuring that the individual is in a safe place and removing any objects around that may be used to harm self or others. This would include sharps (e.g., knives, anything with glass in it, etc.), objects that can be thrown, or objects that might be used otherwise to harm (e.g., belts or linens that could be used to choke, etc.).

Redirect the individual by suggesting things to change the dynamics of the situation, such as saying, “Come sit in the chair” or “Let’s take deep breaths together.”

If the crisis behaviors tend to cause significant physical harm, family members may want to consider becoming trained in a physical management package, which would provide further information on how to prevent problem behaviors, strategies for personal safety, as well as strategies for physically intervening if necessary. Crisis management programs such as Devereux’s Safe and Positive Approaches, CPI’s Nonviolent Crisis Intervention, JKM’s Safe Crisis Management, or PCMA’s Professional Crisis Management are possible options for families and are sensitive to the use of these strategies with individuals who have autism, intellectual disabilities, and mental health issues such as anxiety disorders, bipolar disorder, or depression. Physically managing a crisis situation while waiting for emergency services can prevent injuries to the individual, family members and caregivers.

CRISIS RESPONSE

When to call 9-1-1

When usual containment methods are not working and the person with a disability behaves in a way that is dangerous to themselves or others, do not attempt to manage the situation without qualified help. Call 9-1-1 to ensure the individual and others can be safe. This is emergency response for when someone is behaving in a dangerous way and needs further assessment within a supervised setting. Do not call 9-1-1 about something that happened hours ago or about something you are worried might happen.

In situations that do not involve immediate danger to the individual or to others, you can call Trinitas Regional Medical Center's Crisis Assessment Response and Enhanced Services (CARES—formerly known as SCCAT), which provides services to adults ages 21 years old and older who have an intellectual or developmental disability and co-occurring mental health needs. The CARES clinician can provide telephone support or face-to-face intervention. Taking this step might help to avoid an unnecessary emergency room visit.



If you have called 911, you can also call CARES and inform them that your relative is on the way to the emergency room or crisis center. A CARES clinician can become involved in your relative's care soon after they arrive at the hospital, can interact with emergency room and crisis center personnel, and can begin planning for future behavioral health management.

If the person already has been assigned to a Care Management Organization (CMO), contact the individual's Care Manager and/or Supervisor during Monday-Friday business hours. After business hours or weekends, contact the designated on-call CMO representative. (Contact information is provided in the State and National Resources section of this handbook.)

You Have Called 9-1-1, Now What Should You Do?

1. DO NOT attempt to transport the individual in crisis to the nearest hospital emergency room by yourself!
2. While waiting for the police to arrive, make your surroundings as safe as possible by removing dangerous objects.
3. Tell the 911 dispatcher that the person in crisis has an intellectual/developmental disability to alert the police, who are usually the first responders, to help avoid the use of unnecessary force. If you or someone else is available to meet them before they enter the home, restate that the person in crisis has an intellectual/developmental disability.
4. Individuals who do not need to be present to support the person in crisis should leave or be moved to a safe area.
5. If the police officer responding to your call arranges for ambulance transportation to the ER, you can follow the ambulance in your own vehicle.
6. If you have a Portable Emergency Plan (at the back of this handbook) or an Emergency Plan notebook or folder, take it with you to the ER.
7. If the police assess the situation and 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 the following programs to report the person's crisis episode: Psychiatric Emergency/Mobile Outreach at 908-994-7131, or Crisis Assessment Response and Enhancement Services (C.A.R.E.S.) at 888-393-3007.

What to Expect in an Emergency Room

1. You will be asked to sign a consent form for emergency room treatment for your family member, to complete a general information form, and to provide their health insurance information, including Medicaid or Medicare. This part of the emergency room visit will be easier if you have a Family Emergency Plan with you.
2. If you are the legal guardian for your family member, you should be prepared to produce a copy of the official court document.
3. 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.
4. The emergency room physician will inquire about the individual's official diagnosis and medical history.
5. The emergency room physician may ask you about the circumstances that led to the emergency room visit. It is helpful if you can share pertinent information about recent changes in the person's life with the medical staff, including the crisis unit screener and the psychiatrist. This might include information about recent medical problems, change in medications and/or significant events at work or at home (i.e. death or deteriorating health of a loved one).
6. The emergency room physician will conduct a routine physical exam to rule out major medical problems that might be contributing to your relative's behavioral crisis. Inform the doctor of any changes in your relative's medical condition. Consider remaining with your relative through all the examinations in the emergency room, especially if they are non-verbal, minimally verbal, or have communication challenges.

Why does the Individual Need a Medical Evaluation?

The medical evaluation, including blood work, is performed to rule out any infections or major medical problems that might be affecting your relative's behavior. Your family member may be reacting to pain or physical discomfort related to a physical illness in a way that presents as mental health problems. This process is called "medical

clearance," and it must occur if your relative is to be hospitalized. 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?

Although the ER staff's goal is to medically clear patients in a timely manner, you may encounter a lengthy 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. However, everyone waits in the ER and the time needed for medical clearance can vary depending on what else is going on in the ER at that time. Be prepared to wait for several hours until your relative is medically cleared.

psychiatrist to determine if they need in-patient psychiatric care or to be admitted to the hospital. Psychiatric screening may involve being moved to a separate area and can take several additional hours.

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

Once medically cleared, but not discharged, your relative may be seen by a screener and a

What to Expect at a Psychiatric Screening

If the ER personnel determine a need for a psychiatric evaluation, they will arrange for your relative to be seen at the crisis-screening center, which may or may not be in the same area as the ER. A crisis screening clinician assigned to your family member's case will conduct an intake interview. The screening unit's attending psychiatrist also may meet with you and your

family member. While it is likely that blood work will have occurred during the medical clearance, you may request additional testing if you feel it is needed (i.e. if you suspect a broken bone, you may request an X-ray). Unless there is a clear medical indication that more extensive testing is needed, tests such as CAT scans or MRIs usually will not be performed.

What are the Criteria for a Psychiatric Hospitalization?

The criteria used to determine the need for psychiatric hospitalization is based on whether the individual presents a danger to themselves, to others, and/or to property. If ER staff believes your family member presents such a danger, they may need to utilize any or all of the following:

Medication to Manage the Crisis – The individual might be given a short-acting psychiatric medication on an as-needed basis (referred to as “PRN”) to help an individual become calmer and less agitated while in the ER.

Mechanical Restraints to Ensure Safety – If the

individual is exhibiting extreme agitation or dangerous behavior, emergency room staff has the authority to place them in mechanical restraints. While the decision rests with them, you may request that, in lieu of restraints, trained security staff be added to your relative's care. In some cases, prolonged use of mechanical restraints can increase agitation. You may wish to advocate having the restraints removed if they seem to be directly contributing to your relative's agitation. Moreover, if at any point that you feel confident that your loved one has become calmer and is in control of their actions, you may ask the ER staff to remove the mechanical restraints.

What if a Person with a Disability Requires Hospitalization?

Levels of Hospitalization

If it is determined the individual will benefit from psychiatric hospitalization, they will be assigned to a level of hospitalization based on treatment needs. Adults receive psychiatric care via voluntary or involuntary (commitment) admission to 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, they 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?

The person may be eligible to receive care on a voluntary unit, which is considered a less restrictive setting for mental health treatment than commitment to an STCF. Adults with disabilities who are their own guardians can sign themselves into treatment and court-appointed guardians

can sign-in their ward for voluntary admission. However, while Bureau of Guardianship Services workers are able to serve as court appointed guardians for individuals' eligible for DDD services, they are unable to sign-in people with

disabilities. These options do not apply to children under the age of 18.

If an individual requires a higher level of care than is available on a voluntary unit, they will be committed to a psychiatric care facility and

will typically go to an STCF. Individuals will be committed when they are found to be incapable of giving informed consent due to the severity of their psychiatric illness or 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, which is located in Elizabeth, NJ, has a specialized inpatient psychiatric unit (2D) for adults (18+) who are developmentally disabled and have mental health disorder who often cannot be treated successfully as an out-patient due to the severity of their behavior. This 10-bed unit is the only community hospital-based short-term, acute care psychiatric unit in New Jersey dedicated to the treatment of adults with dual diagnoses.

Individuals can enter 2D from any crisis or screening center in New Jersey, but cannot enter directly from the community or be transferred from an STCF. On occasion, individuals have been sent to the medical unit of their local hospital for treatment (seizures, infections, etc.) and then psychiatric hospitalization following their medical

stabilization. The average length of stay on 2D is approximately 15 days.

Children (under the age of 18) are also 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, Children's Crisis In-Patient Services (CCIS) conducts a statewide search for available placement. Trinitas currently has eight beds on its Child and Adolescent In-Patient Unit dedicated to short-term treatment for children with mental illness and developmental disabilities. Screeners can obtain information about the availability of MI/DD bed for children and adolescents by contacting Trinitas' psychiatric screening services.

What If Your Insurance Company Will Not Pay?

If your relative is hospitalized and you receive word that they will be discharged because the insurance company has refused to authorize a continued in-patient stay, you can request that the attending in-patient psychiatrist consult with

a doctor for the insurance company to state the clinically and medically necessary reasons for continued hospitalization. You also can ask your family member's case manager to advocate for continued inpatient treatment.

Diverting Your Relative from State Psychiatric Hospital Admission

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 at a Short-Term Care Facility (STCF) or a county hospital. State hospitals are not designed to support the needs of adults with dual diagnosis who may have significant behavioral problems. A state hospital is unlikely to be the appropriate placement if this is your relative's first hospitalization.

Recently, the state 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 directly admitted to STCFs for observation. This reduces the likelihood that someone will be transferred to a state hospital directly from the screening center and the likelihood that someone experiencing his or her first hospitalization will be admitted to a state hospital.

How is an Individual Committed to Involuntary Care?

Involuntary psychiatric commitment starts when a certified screener and psychiatrist separately conduct face-to-face evaluations of an individual, and based on these evaluations, determine 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 in-patient psychiatric care, usually an STCF. Once there, the individual may be detained for up to 72 hours.

At the conclusion of this 72-hour period, STCF staff must initiate proceedings for the involuntary commitment of the individual to continue. A second psychiatrist's clinical certificate is submitted to the court along with the initial psychiatrist's certificate. If the court finds there is probable cause to believe the individual is in need of involuntary commitment, the court will issue a temporary order of commitment (up to 20 days) and set a date for a full hearing on the issue of continued commitment. Based upon this order, the individual may be transferred to a 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. The hospital treatment team, on its own authority, can discharge a patient before a hearing.

The full hearing takes 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 representation by counsel at the hearings.

The law states that at least 10 days before the full hearing, the patient or patient's family, guardian, or legal representative should receive notice of the date, time, and location of the court hearing. These parties should also receive copies of the clinical certificates and supporting documents, the temporary court order, and the statement of the patient's rights at the hearing. These hearings are held at the facility where the individual has been committed. Families should be alert to these timeframes, even if notification has not been received. You should contact the in-patient unit social worker if you have any concerns or questions.

A psychiatrist and any other members of the patient's treatment team who have conducted a personal examination of the patient no more than five calendar days prior to the court hearing will testify 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 the patient needs continued involuntary commitment, it will order continued commitment and schedule the next court review of your relative's commitment status. If the court determines that your relative no longer meets criteria for commitment, it may order a date by which your relative must be discharged from the hospital.

What to Do If You Disagree

You have the right to object if you disagree with the decisions that are made during the commitment process. For example, if you object to the treatment team's recommendations to continue involuntary in-patient care or to discharge from an in-patient 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 do speak with the judge, they 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 agree with you.

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 the

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.

What If Your Family Member is Determined as Not Needing Hospitalization?

If it is determined through an evaluation that your relative will not benefit from hospitalization, they 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, therapist, teachers, and/or direct care staff.

Additional Options

Although CARES is the only a statewide crisis response program, several programs in the state offer local crisis support services. If your relative is eligible to receive services funded by DDD, you can call their DDD Support Coordinator to see what additional supports may be available. You

also can use your Interdisciplinary Team (IDT) as an important source of information regarding what supports can be built in your home environment in order to avert or better manage future behavioral crises.

What If You Are Not Able to Support Your Relative At Home?

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

1. If your family member is eligible for services from DDD, notify their DDD Support Coordinator 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. It is wise to avoid seeking a permanent, out-of-home placement for your relative during times of crisis as the emotional distress you and your relative will be experiencing interferes with making sound long-term decisions. Placements should be developed based on your relative's long-term needs, not just on what is immediately available.
3. For those individuals 21 and under, PerformCare may authorize mobile response stabilization services (MRSS) to come your home within one hour of notification to provide face-to-face crisis services (24/7) for up to eight weeks. The goal is to stabilize behavior and keep your child at home. Contact PerformCare at **1-877-652-7624** to reach the MRSS.
4. For adults in crisis, contact CARES, **1-888-393-3007** for help in identifying appropriate mental health and behavioral health services for your relative. CARES clinicians can help caregivers create an individualized response plan. The CARES team can become involved with the individual with mental health needs before it reaches a point of crisis. They can also follow the individual regardless of whether a mental health crisis is averted for 120 days. Call the toll-free hotline **1-888-393-3007** to receive further guidance.

AFTER THE CRISIS

After a crisis, everyone involved can learn from the experience to fashion better supports and avert future crises by evaluating need. Family members, caregivers, and all other service providers will also want to review the supports they need to manage their own responses and better cope in the aftermath of a crisis.

Steps to take following a crisis:

1. If the individual is eligible for services from DDD, request an emergency interdisciplinary team (IDT) meeting. If the person is served by the N.J. Department of Children and Families - Children's System of Care (CSOC), request an emergency Individual Family Team (IFT) meeting, including school program personnel if possible.
2. Take the lead in suggesting a re-evaluation of the person's behavior plans, medication regimen, and current supports and encourage the IDT or IFT to explore new therapeutic options and untried resources.
3. Share information among the various support services specialists. It will help provide the individual with more consistent, quality-based care and services.
4. If you have not already contacted a designated outreach support service during your family member's crisis, contact CARES 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. If the individual is served by CSOC/ PerformCare call **1-877-652-7624** or contact the CMO Care Manager or Supervisor.
5. ALWAYS FOLLOW INSTRUCTIONS regarding prescribed medications following a crisis event.
6. Notes regarding medications:
 - a. Work closely with the individual's prescribing doctor. Sometimes changes are needed because the medication no longer seems to be effective or presents difficult side effects.
 - b. New medication can initially be sedating. This does not necessarily mean that the person is over-medicated. Medications can take time to reach optimal effectiveness.
 - c. Problems caused by the interaction of multiple drugs may arise. The caregiver should keep a log of apparent side effects from medications and share this information with the prescribing provider.



Stabilization

Stabilization refers to the period when an individual is no longer actively in a crisis situation and can return to their usual activities and behaviors. However, stabilization may also be a period in which supports need to be in place to prevent a person from relapsing into a mental health or behavioral crisis.

How Do You Know When a Behavioral Stabilization Program is the Appropriate Treatment Option for an Individual with Dual Diagnosis?

There are circumstances when a loved one affected with dual diagnosis, regardless of their age, requires an out-of-home intensive therapeutic treatment program to address the highly complex and severe behavioral challenges they are facing on a routine basis, but how and when does a parent/legal guardian know that this is the appropriate next step for their relative? While every individual's

special needs and environmental situation are unique, a common thread of behavioral experiences connects individuals, including acute and persistent problem behaviors such as aggression, self-injurious behavior, disruptive and destructive behavior, restrictive and repetitive behavior, pica, and elopement.

Convening the Interdisciplinary Team (IDT) after a Crisis

After the crisis is resolved, it is important for the IDT to review “lessons learned.” Does the person need a new residence or day program? Does the

person need other supports? This is an opportunity to revisit the ISP to make sure it reflects the individual's needs.

FUTURE PLANNING

Family Members Coping and Planning Together

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 prior 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 behavioral crisis. These strategies can always be revised after being put to the test.

Consider the following as your family moves forward to develop strategies for helping your family member in crisis:

- 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 identifying and obtaining needed supports.
- 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.

- 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.
- There is no shame or failure in seeking help from people outside your family. Sometimes neighbors, fellow congregants at your place of worship, or friends can be helpful in providing another prospective or actual support to you and your relative.
- Parents and/or guardians sometimes believe they should protect their non-disabled children by isolating them from severe behavioral episodes. However, often this is not realistic, and siblings can benefit if they develop an understanding of what the family is facing during crises. Family-centered problem solving is an invaluable skill younger family members can use throughout their own lives. However, if your other children are in danger of physical harm during a behavioral crisis, they should be kept isolated from the event.
- 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.
- 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.



Creating an "Emergency Plan"

In order to better support an individual with behavioral health issues, it is important to develop an Emergency Plan for possible future use. This individualized plan should contain strategies that will help diffuse crises or help to maintain control in the event that it is necessary to call 911 for emergency assistance.

The Ultimate Goal of the Emergency Plan 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 and caregivers can reduce the negative impact of these events for people with disabilities and everyone present.

You will want to record your plan in a notebook or folder that is both easily reachable and portable. The following are some recommended items that can be incorporated into the Emergency Plan notebook or folder:

1. A contact list of people who would be willing to come to the person's 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 the individual including doctors, therapists, teachers, social workers, their DDD Case Manager or Support Coordinator, CMO Care Manager/Supervisor, the provider agency management team, and/or direct care staff.
3. A list of any outreach support services that might be needed during an emergency (i.e. CARES **1-888-393-3007**, MRSS/ PerformCare **1-877-652-7624** or CMO Care Manager/Supervisor).
4. Up-to-date medical information about the individual, including current daily medications, the reasons they were prescribed, the prescribing doctor(s), dosages, special medical needs, allergy information, etc.
5. A one-page summary about the individual and their special needs. Include all information that you might need in an emergency, current program information, prior hospitalizations, and any important details that would help acquaint someone with the person's likes, dislikes or fears.

Additional Suggestions

- Make copies of the Emergency Plan notebook or folder so that it can be with you and the individual at all times and so that you can give it to other family members and/or close friends who are willing to support you in a time of crisis.
- Ask that the details of the emergency plan be included in the individual's IEP, ISP or IHP.
- If the person no longer lives in the family home, it is still advisable to establish an individualized emergency plan for their full-time residence. 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.
- 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, etc.
- Attach to the notebook any information or copies of official documents that you might require in an emergency pertaining to private health insurance, Medicaid/Medicare coverage, Certificate of Guardianships, etc.
- The Portable Emergency Plan, sample provided in this handbook, can be included in the "Emergency Plan" notebook or folder.

Once you have developed your emergency plan you should review it with members of the individual's interdisciplinary and/or child study team in order to incorporate their suggestions. You may also want the input of any clinicians or practitioners involved in the person's treatment. Finally, it is essential that all persons responsible for the direct care and support of the individual be completely familiar with the emergency plan, including periodic updates, in order to follow its instructions effectively during a crisis episode.

Autism Speaks has developed an online toolkit for individuals with autism, their families, and first responders that provides information and tips to foster safety in emergency situations as well as crisis intervention resources. To learn more about the "Autism Speaks Safety Project," see <http://www.autismsafetyproject.org>. Autism Speaks Crisis Intervention Resources can be accessed online at <https://www.autismspeaks.org/family-services/crisis-intervention-resources>.

A Life Plan

Sometimes families put off making plans for the future for a loved one affected with dual diagnosis, because it is difficult to know where to get started, particularly given the complexity of their adult child's challenges. It is certainly natural for families to be so busy caring for their daughters or sons on a daily basis, that they just do not have the time or energy to begin planning their future. Planning for the future can produce dreaded thoughts among parents about what will become of their adult children with special needs when they are no longer around.

Some family members might not be sufficiently informed about existing services and supports, or perhaps unaware of what is potentially achievable, as far as their loved one's personal growth. Other families cannot imagine their adult child living a life apart from them, and/or lack faith in the service delivery system, and related personnel. Each of these reasons is understandable when it comes to postponing the development of a life plan. However, it is never too late to begin this important long-term planning process, which can be remarkably life changing for the individual, and everyone involved in implementing the plan.

Developing a life plan for your relative requires an understanding of the methodologies of person-centered planning, which examines the whole person, not just their identified needs. Person centered planning upholds the core belief that an individual affected with intellectual and developmental disabilities is, first and foremost, a person. Furthermore, he/she is entitled to live a happy and fulfilling life according to their strengths, interests, preferences, personality traits, their abilities, and their capacity to develop skills that are meaningful to their personal lifestyle.

Person centered planning focuses on the positive, in terms of what a person can accomplish, instead of what is believed to be out of reach for them to achieve. This planning process requires the active involvement of the individual if they want to, and are able to participate, along with a group of people who have a good understanding of the individual and are strongly committed to helping guide and support their future progress. The group might include family friends, educators, instructors, clinicians, community service provider and direct support professionals; etc., basically, the "support team"). For those individuals who may not be able to speak for themselves, the caring and devoted people in their lives can serve as their voice, because they are presumably the most familiar with all aspects of the individual's life.

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 rewarding life. It is important for individuals to have a structured day that offers opportunities to be with peers and have access to community resources.

Some recommended preliminary questions that can be explored as the individual and his or her support team begins creating plans for the future:

- What is important to the individual?
- How can the person's experience and opportunities be capitalized on to achieve the greatest benefit?
- In what areas of the individual's life does he/she and/or the support team see an opportunity to affect positive change?
- What activities, services and supports will promote greater independence, community integration, and social skills building?
- What specifically are the agreed upon life plan goals?



- Besides the Support Team, who else can be identified to assist with facilitating and carrying out of these goals?
- What are the desired outcomes for each of the life plan goals?
- What types of services and supports will be needed to achieve agreed upon life plan goals?
- What is the recommended level of support?
- What are the individual's problem/challenging behaviors?
- What funding resources are available to put the life plan into practice? What are the funding limitations? The answers to these questions will help the individual and/or their circle of support team begin a process of examination and discovery that can eventually lead to the development and adoption of a plan for the future that respectfully and constructively addresses all the things that make individuals truly unique and valued.

In terms of possibilities for true personal growth, consider researching and adapting some or all of the following when creating a life plan:

- Employment opportunities, including supported employment (i.e. job coach or crew), vocational training and job sampling.
- A residential setting that is considered the most appropriate for the individual.
- Social activities, including joining clubs, attending creative skill-based classes, special community events, dances, etc.
- Day and overnight trips, exploring a local or nearby town or city, attending local festivals, sightseeing bus or walking tours, etc.
- Educational and instructional courses and classes (i.e. college-level, computer science, dance, music, art, etc.).
- Physical fitness activities, exercise programs, participating in the Special Olympics Program, etc.
- Participation in a faith community, and regular attendance at religious services.
- Increasing and refining self-help and daily living skills (i.e. cooking, chores).
- Developing a hobby or other special interests.
- Community service projects and other volunteer opportunities.
- Self-advocacy.

Keep in mind that a life plan should reflect the desires and interest of the individual, although the family/support team's values and stands will no doubt play an important part in the overall planning process.

There are numerous person centered planning, and life plan resources, including tools that can be easily accessed online. The toughest part might just be summing up the needed motivation to get started. Like any worthwhile planning process, it will take time, research, and much thoughtful consideration for the life plan to evolve into a viable strategy that will provide your loved one with the chance to live the kind of life he or she desires and, above all, a life that is genuinely meaningful to them. Perhaps it will turn out to be a life far better than you had ever imagined possible for your loved one, all because you seized upon the opportunity to creatively and respectfully help them plan their future.

SPECIAL TOPICS IN MENTAL HEALTH

This section aims to alert the reader to some of the important issues that affect many people with dual

diagnosis. It is not meant to be a comprehensive discussion of complex mental health issues.

Substance Use and IDD

Individuals with disabilities can become addicted to substances such as alcohol, painkillers and street drugs. These substances can induce psychosis, or further impair the individual's functioning. When individuals take substances they can

grow accustomed or habituate to the substance causing them to need more and more of the same substance in order to feel good. Seek treatment in programs that offer substance use counseling and motivational interviewing.

Suicidality and IDD

People with disabilities do attempt suicide. The standard risk assessments can be difficult because of language and cognitive limitations. A suicide risk assessment looks at intent, opportunity and means to hurt oneself. Among common reasons for increased risk of taking one's life is severe depression, the recent loss of a loved one, or chronic and intractable pain associated with illness.

The best way to address is by understanding the emotional or physical pain that might cause one to want to end their lives. If you have reason to believe an individual (child or adult) is at risk for self-harm, refer the individual to their treating clinician and have the individual screened at a psychiatric emergency service. Once the person is out of danger, refer to a counselor.

Non-suicidal Self-injury

People who engage in non-suicidal self-injury potentially hurt themselves without the intent of dying but may still sustain injury or even die because of their pattern of self-harm. For some, this pattern of self-harm (head-banging, skin picking, scratching and biting oneself) is linked to their developmental disability. For others, this may be a response to environmental stressors. For still others, depression, anxiety, cyclic mood and thinking disorders can result in self-harmful

behavior. Behavioral interventions (Applied Behavioral Analysis - ABA and Positive Behavior Supports - PBS) are approaches of choice for self-injurious behavior not thought to be caused by mental health disorders. Connect with information and professionals that can help differentiate the cause of the behavior. If related to mental health issues, there may be medical ways of treating self-injury; consult with a professional.

Dementia and IDD

Individuals with Down syndrome past the age of 50 and individuals with non-Down syndrome disabilities past the age of 65 can show signs of cognitive and functional decline associated with dementia. The National Task Group Early Detection Screen for Dementia (NTG-EDSD) is a rating tool that can help caregivers (family and DSPs) capture observations of change in important areas of functioning and share these observations with the team and with health care providers in order to move along health care, services and supports. You

can download the NTG-EDSD from www.aadmd.org/ntg as well as obtain other valuable information about dementia and intellectual disabilities. Trinitas Regional Medical Center has also partnered with the New Jersey Geriatric Education Center/Rowan University to offer training to agencies supporting individuals with dementia through its Geriatric Workforce Education Project (GWEP).

Trauma

Abuse and its Relation to Trauma

Abuse is a pattern of behavior exhibited by one person to gain and maintain power over another. Individuals who are exposed to abuse or witness the abuse of others are more likely to develop post-traumatic stress disorder and disorders of extreme

stress. Trauma can be experienced as a single episode or over time. Perpetrators of abuse can be a family member, neighbor, friend, stranger, teacher, therapist, employer or direct care staff member.

Types of Trauma Exposure

- Physical abuse is any non-accidental physical injury to an individual. It can include punching, hitting, and beating, slapping, shaking, kicking, biting, strangling, burning, or physically restraining an individual against their will.
- Sexual abuse is a specific form of physical abuse that is sexual in nature. A secretive and isolating act can cause fear, shame, and confusion for the person being victimized. Please refer to the section below for more detailed information.
- Verbal and emotional abuse, unlike the common signs of physical abuse, is harder to identify and prove. It involves constant belittling, berating, and assigning of blame, which wears away at a person's sense of wellbeing and health.
- Neglect is defined as the failure of a parent/caregiver with responsibility for the individual to provide needed food, clothing, shelter, medical care or supervision to the extent that the person's health, safety, and wellbeing are in jeopardy. This can occur intentionally or unintentionally.

What We Know About the Abuse and Neglect of People with Disabilities

Parents and caregivers are more apt to become frustrated and stressed because of the demands placed on them supporting and caring for a child or adult with a disability, which can lead to all forms of abuse. Those with behavioral disorders are more likely to experience physical abuse. Individuals who are more dependent on adults for their care are at higher risk to be sexually abused or neglected by their caregiver. Abusers take advantage of children and adults with intellectual/developmental disabilities who are non-verbal or have difficulty communicating and those who lack understanding in social situations. The severe repercussions for people with disabilities who are abused or neglected are many. Beyond the results of physical

abuse (i.e., fractures, burns, internal injuries, etc.). Individuals are left to deal with the ensuing emotional trauma. The development of behavior problems can occur as well as a generalized fear of situations and people, including those who do not pose any real threat to the individual's safety. Unfortunately, these behavioral changes often are attributed to their intellectual and/or developmental disability, so the abuse can go undetected. Frequently, how an individual affected with disability processes and copes with the violent, abusive and neglectful acts against them can remain unknown to those who are providing necessary healing treatment.

Responding to Sexual Trauma

(Provided by Tracy Higgins and Melissa Keyes DiGioia - Finding Your Individuality)

It is especially important to be trauma sensitive

when providing support to people with intellectual and developmental disabilities. Survivors of sexual trauma, including those with intellectual and developmental disabilities, may experience a

variety of symptoms including intrusive thoughts and flashbacks about the abuse, social withdrawal, emotional detachment, difficulty sleeping, nightmares, poor body image, feelings of low self-worth, shame, guilt, fear, anxiety, depression, and a decrease in sense of safety and lack of trust in self and others.

Survivors who have not begun the process of talking about their trauma may present with anxiety when talking to a medical professional for a variety of reasons. Talking about their prior history of sexual abuse may be triggering for the individual who may heavily avoid the topic, which can interfere with proper treatment or resources. For those individuals victimized by helping professionals or people they know, trusting medical professionals may be difficult, creating further anxiety for the survivor in crisis. Validating the person's feelings related to the trauma, affirming their unique intersectional identities, and providing choice can increase feelings of safety, control, and trust in the care process.

Reducing stimuli and creating a safe environment is essential for the survivor of sexual assault. Accordingly, they have a right as per Sexual Assault Response Team (SART) protocols, to a private room in the emergency room and accompaniment by trained professionals such as the SART members. SART is a multidisciplinary team trained to respond to and support victims of sexual assault and typically is comprised of advocates, law enforcement officers and sexual assault nurse examiners (SANEs). Part of or all the team may be activated to respond to the hospital to meet and provide support to the survivor of SA. Support may include providing information and resources to the victim, supportive counseling, specialized medical care and gathering of forensic evidence. Survivors of SA who develop PTSD need to have support and may benefit from either psychiatric or non-medical treatments that address trauma.

Department of Human Services: Adult Protective Services (APS)

Contact information for the county Adult Protective Services offices can be found in the fact sheet accessible via the following web link:

<http://www.state.nj.us/humanservices/doas/documents/APS%20flyer.pdf>

Support Coordinators Guide to Unusual Incident Reporting (DDD Circular #14):

Information about Unusual Incident Reporting (UIR) is available via the following web link: http://nj.gov/humanservices/ddd/documents/sc_guide_to_incident_reporting.pdf

Department of Children and Families:

Division of Child Protection and Permanency (DCP&P) Child Abuse Hotline (State Central Registry)

1-877-NJ-ABUSE (1-877-652-2873).

For more information, visit the following website: <http://www.nj.gov/dcf/reporting/how/>

Laws Protecting People with Disabilities

Danielle's Law

A New Jersey law designed to make sure individuals with disabilities are not harmed through neglect or failure to obtain needed care including medical and mental health services. Sometimes staff and service providers worry that if the person has acted in a difficult way that they (the staff/agency) will be fined or get in trouble for not acting with due diligence. However, if the person is not in danger, the appropriate

response to a behavior problem is not an emergency room visit, but an appropriate assessment and design of relevant behavioral supports.

More information: <https://nj.gov/humanservices/ddd/resources/info/danielleslaw2.html>

Megan's Law

New Jersey law authorizes the Division of State Police to make available to the public over the Internet information about certain sex offenders required to register under Megan's Law. The sex offender Internet registry law can be found in the New Jersey Code 2C:7-12 to -19.

More information: http://www.nj.gov/njsp/spoff/megans_law.html

Komnino's Law

Stephen Komnino's Law requires that the state make two unannounced visits a year to all group homes. Group home service providers must contact a parent or guardian within two hours following an injury or other critical incident. Group home workers will need to undergo drug testing before being hired and random testing if the employer suspects drug use. State officials will be required to invite parents or guardians to attend interviews of their children who are victims of abuse and notify parents if the group home employee deemed responsible for abusive or neglectful acts is placed on an offender registry.

More information: <https://www.state.nj.us/humanservices/home/skl.html>

STATE AND NATIONAL RESOURCES

Office of the Governor

P.O. Box 001
Trenton, NJ 08625
Phone: 609-292-6000
Email Form Available on Website:
www.nj.gov/governor/

NJ Department of Human Services (DHS)

Capital Place One
222 South Warren Street
Trenton, NJ 08625
Mailing Address: P.O. Box 700
Trenton, NJ 08625-0700
Phone: 609-292-3717
Email Form Available on Website:
www.state.nj.us/humanservices

NJ Division of Developmental Disabilities (DDD)

Mailing Address: P.O. Box 726
Trenton, NJ 08625-0726
(Physical Address: 222 South Warren Street, Trenton, NJ)
Toll-Free Phone: 800-832-9173
E-mail Form Available on Website:
www.state.nj.us/humanservices/ddd

NJ Division of Medical Assistance and Health Services (DMAHS)

P.O. Box 712
Trenton, NJ 08625-0712
Toll-Free Phone: (800) 356-1561
Email Form Available on Website:
www.nj.us.gov/humanservices/dmhas

NJ Division of Disability Services (DDS)

11A Quakerbridge Plaza
Mercerville, NJ 08619
Mailing Address: P.O. Box 705
Trenton, NJ 08625
Toll-Free Phone: (888) 285-3036
Website: www.state.nj.us/humanservices/dds/

NJ Department of Health (DOH)

369 South Warren Street
Trenton, NJ 08608
Mailing Address: P.O. Box 360
Trenton, NJ 08625-0360
Toll-Free Phone: (800) 367-6543
Website: www.nj.gov/health/

NJ Division of Mental Health and Addiction Services (DMHAS)

5 Commerce Way
Hamilton, NJ 08691
Mailing Address: P.O. Box 362
Hamilton, NJ 08691
Toll-Free Phone: (800) 382-6717
Website: <http://nj.gov/health/integratedhealth/>

New Jersey Department of Children and Families (DCF)

50 East State Street
2nd Floor
Trenton, NJ 08625-0729
Mailing Address: P.O. Box 729
Trenton, NJ 08625-0729
Toll-Free Phone: (855) 463-6323
Email: askdcf@dcf.state.nj.us
Website: <https://www.state.nj.us/dcf/>

PerformCare

300 Horizon Drive
Suite 306
Trenton, NJ 08691
Toll-Free Phone: (877) 652-7624
Email: solutions@performcare.org
Website: <http://www.performcarenj.org/index.aspx>

Alliance for the Betterment of Citizens with Disabilities (ABCD)

127 Route U.S. Highway 206
Suite 26
Hamilton, NJ 08610
Phone: (609) 581-8375
Email: Admin@abcdnj.org
Website: www.abcdnj.org

The Arc of New Jersey

985 Livingston Avenue
North Brunswick, NJ 08902
Phone: (732) 246-2525
E-mail: info@arcnj.org
Website: <https://www.arcnj.org/>

Asperger Syndrome Education Network (ASPEN)

9 Aspen Circle
Edison, NJ 08820
Phone: (732) 321-0880
E-mail: info@aspennj.org
Website and Email Form:
<https://aspennj.org/contact-aspen>

Autism New Jersey
formerly COSAC: The N.J.
Center for Outreach and Services
for the Autism Community
500 Horizon Drive
Suite 530
Robbinsville, NJ 08691
Phone: (609) 588-8200 or
Toll-Free Phone: (800) 4-Autism
E-mail: information@autismnj.org
Website: <https://www.autismnj.org/>

Disability Rights of New Jersey
(DRNJ)
210 South Broad Street (3rd Floor)
Trenton, NJ 08608
Toll-free Phone in NJ Only: (800)
922-7233, or
Phone: (609) 292-9742
Website: www.drnj.org
E-mail: advocate@drnj.org

New Jersey Chapter Healthcare
Financial Management
Association (HFMA)
Mailing Address:
Attention: Laura A Hess
PO Box 6422
Bridgewater, NJ 08807
908-963-2505
Website: <http://hfmanj.org>

National Assoc. of State Offices
of Minority Health (NASOMH)
3737 N. Meridian Street, Suite 300
Indianapolis, IN 46208
Phone: (317) 920-4928
Email: nasomh@gmail.com
Website: www.nasomh.com
NJ State Office:
NJ Department of Health
225 East State Street, 2nd Floor W.
P.O. Box 360
Trenton, NJ 08625-0360
Phone: (609) 292-6962

Autism Speaks:
New Jersey Regional Office
1060 State Road (2nd Floor)
Princeton, NJ 08540
Phone: (609) 228-7324
E-mail: newjersey@autismspeaks.org
Website: <https://www.autismspeaks.org/new-jersey-0>
Southern New Jersey Office
216 Haddon Ave, Suite 403
Westmont, NJ 08108
Phone: (856) 858-5400
Fax: (856) 858-5444
Email: southernnewjersey@autismspeaks.org

The Boggs Center on
Developmental Disabilities
-Rutgers Robert Wood Johnson
Medical School
Liberty Plaza
335 George Street (3rd Floor)
New Brunswick, NJ 08901
Phone: (732) 235-9300
Website: <http://rwjms.rutgers.edu/boggscenter/>

Mom2Mom Helpline
Rutgers/University Behavioral
Health Care
Phone: 1-877-914-6662
Website: www.mom2mom.us.com

National Association for the
Dually Diagnosed (NADD)
An association for persons with
developmental disabilities and
mental health needs
132 Fair Street
Kingston, NY 12401-4802
Phone: (845) 331-4336
Toll Free Phone: (800) 331-5362
Email: info@thenadd.org
Website: www.thenadd.org

Community Access Unlimited
80 West Grand Street
Elizabeth, NJ 07202
Phone: (908) 354-3040
Fax: (908) 354-2665
Email: info@caunj.org
Website: www.caunj.org

Family Support Coalition of New
Jersey
The Arc of New Jersey
C/o The Family Support Coalition
985 Livingston Ave., NJ 08902
Phone: (800) 372-6510
Website:
www.familysupportcoalition.org/
Email: fscnj.info@gmail.com

National Alliance on Mental
Illness New Jersey (NAMI NJ)
1562 U.S. Highway 130
North Brunswick, NJ 08902
Phone: (732) 940-0991
Website: <http://www.naminj.org>

New Jersey Association of Mental
Health and Addiction Agencies
(NJAMHAA)
3635 Quakerbridge Road
Suite 35
Trenton, NJ 08619
Phone: (609) 838-5488
Website: <http://www.njamhaa.org>
Email form available on above
website

**New Jersey Child Assault
Prevention (NJCAP)**

NJ CAP Regional Training Center
at Camden County College
200 College Drive
Blackwood, NJ 08012
Phone: (856) 374-5001
Website: www.njcap.org
Email form available on above
website (on Contact Us page)

**New Jersey Council on
Developmental Disabilities**

P.O. Box 700
Trenton, NJ 08625-0700
Phone: (609) 292-3745
Email: njcdd@njcdd.org
Website: <http://www.njcdd.org>

**Statewide Parent Advocacy
Network (SPAN)**

35 Halsey Street (4th Floor)
Newark, NJ 07102
Phone: (973) 624-8100
Toll Free Phone:
(800) 654-SPAN
Website: www.spanadvocacy.org
E-mail: span@spanj.org

The Family Resource Network

1 AAA Drive, Suite 203
Trenton, NJ 08691
Phone: (800) 372-6510
Fax: (609) 392-5621
Website: <http://www.familyrn.org>
E-mail: info@familyresourcenetwork.org

SUMMARY OF APPENDIX

The following additional information and materials are available for viewing, downloading and printing in the Resources section of Community Access Unlimited's website www.caunj.org:

- Full PDF version of the ***Revised Family Crisis Handbook***
- Individual Family Stories/Voices and Choices – 18 vignettes featuring learned experiences shared by individuals with a dual diagnosis and their families (coordinated and provided by Donna Icovino)
- Informational PowerPoints (provided by Dr. Lucille Esralew):
 - Ability to Launch (issues around youth with autism transitioning to adult services)
 - Aging with Disabilities
 - Borderline Personality Disorder and Intellectual/Developmental Disabilities (IDD)
 - Early Recognition of Dementia and Intellectual/Developmental Disabilities (IDD)
 - Everyday Supports for Adults with Dual Diagnosis
 - More Information on the NJ Department of Human Services – Division on Developmental Disabilities (DDD), the NJ Department of Mental Health and Addiction Services (DMHAS) and the NJ Division of Disability Services (DDS)
 - NJ Crisis Response – C.A.R.E.S.
 - National Task Group Early Detection Screen for Dementia
 - Overview of Mental Health Disorders and Intellectual/Developmental Disabilities (IDD)
 - Shared Decision-Making in Mental Health and Intellectual/Developmental Disabilities (IDD)
 - See Me for Me: Person-Centered Positive Supports for Individuals with Dual Diagnosis
 - Suicidality and Intellectual/Developmental Disabilities (IDD)
 - Voice and Choice in Wellness and Recovery
- Portable Emergency Plan (included at the end of the revised handbook, and also available in the Resources section of CAU's (www.caunj.org) and NJCDD's (www.njcdd.org) websites.

PORTABLE EMERGENCY PLAN

(This tool can be brought to the emergency room and updated as needed)

Section 1: Emergency Information

Call 911 if the person:

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

Individuals age 21 and older: Call CARES: 1-888-393-3007

Individuals under age 21: Call PerformCare: 1-877-652-7624 or the CMO Care Manager or on-Call Supervisor

Tell CARES, PerformCare or CMO Care Manager/Supervisor where your family member is being taken for emergency services:

Closest ER/Screening Center:

Phone No.: (____) ____ - _____

Behaviors Include:

- ☐ Non-compliant with routine task request 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: Personal Profile

Name: _____ DOB: ____/____/____

Street Address/Apt. #: _____

Phone: (____) ____ - ____ Insurance: _____

SSN: ____ - ____ - ____ Primary Diagnoses: _____

Guardian Name: _____

Street Address/Apt. #: _____

Home Phone: (____) ____ - ____ Cell Phone: (____) ____ - ____

Fax: (____) ____ - ____

Treating Psychiatrist Contact Information

Name: _____

Phone: (____) ____ - ____ Other Phone: (____) ____ - ____

Answering Service: _____

DDD Case Manager:/Support Coordinator _____

Phone: (____) ____ - ____

Recent (within the past year) relevant medical history, including allergies and adverse reactions to medication:

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: _____

Sensory Issues:

☐ Noise/sound

☐ Bright lights

☐ Textures

☐ Touch

☐ Other _____

What is helpful in engaging or calming?

☐ Music

☐ Stuffed animal

☐ Video game

☐ Books

☐ Preferred food _____

☐ Other _____

