

AN ENHANCED  
**FAMILY SUPPORT**  
**CRISIS HANDBOOK**

A Behavioral Health  
Wellness Toolkit



Promoting voice and choice for New Jerseyans of all  
ages with intellectual and developmental disabilities,  
and all stakeholders who support them.

# AUTHORS

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## NOTE:

- 1. This handbook and additional resources are not for use during a crisis, but are meant to avert or mitigate a crisis. If you are currently experiencing a life-threatening crisis, please dial 911.*
- 2. The term Complex Severe Behavioral Health Conditions does not refer to individuals who are in continual crisis as a result of their significant disabilities and behaviors. Children and adults who experience ongoing severe and complex conditions may require stabilization and/or hospitalization that are not addressed in this Handbook since this population requires much more individualized attention within our service systems.*

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## A. Introduction

### A1: Why write an expanded update to the Family Crisis Handbook?

The purpose of this expanded version of the Toolkit is to empower individuals with disabilities and their family and professional caregivers by providing information to more effectively advocate for persons with complex severe behavioral health conditions (which we formerly referred to as “dual diagnosis”) for treatments, supports, services and the conditions that promote mental wellness. Individuals with diagnoses of developmental disabilities and behavioral health disorders face multiple challenges in their daily lives. Some of these challenges relate to the behavioral health conditions themselves. Other barriers include the shortage of qualified medical and non-medical behavioral health providers and the failure to give mental health and behavioral disorders the same attention as with medical disorders. Individuals of all ages with intellectual and developmental disabilities and behavioral health challenges, therefore, face the barriers of limited access to needed services, lack of equality and problems with obtaining and affording care.

When the original *Family Crisis Handbook (2010)* was developed, the co-authors envisioned this as a toolkit for family caregivers. This updated version expands to include the experiences of clinicians, direct service professionals and individuals with disabilities themselves. The concept of “it takes a village” is applied to the recognition, prevention or management of behavioral and mental health problems and functional deficits that if, unaddressed, lead to behavioral crisis. This concept is also applied to the aftermath of behavioral health crises among persons with intellectual disabilities and behavioral health challenges and beyond.

The authors believed it was time to update the *Family Crisis Handbook (2010)* and the New Jersey Council on Developmental Disabilities Council awarded a contract to Community Access Unlimited (CAU) to update the handbook. Unlike the *Family Crisis Handbook (2010)*, this revised Handbook includes something for all stakeholders involved in the behavioral health crisis of people with intellectual and developmental disabilities. Unlike its predecessor, this Handbook includes the perspectives of individuals, families, staff and service providers regarding crisis and the handling of crisis situations. This Handbook, reflects the issues faced by children, adults and older adults and therefore, takes a lifespan approach. There are many elements within this Handbook that are likely to reflect the experiences of individuals, their families and formalized support staff throughout the country; however, this Handbook specifically reflects the unique landscape of New Jersey services and resources.

### A2: How to Use this Handbook?

The authors designed this with a certain logic in mind beginning with the lived experience of individuals, looking at behavioral health wellbeing, complex severe behavioral health conditions, crisis and stabilization services, and advocacy resources. However, the reader can enter the material at any point that is most useful. We particularly want to direct your attention to the *Emergency Plan* in the Appendix Section, which is intended as a pull-out portion to be updated and kept in an area that is most easily accessible in the case of a behavioral health crisis. We suggest that you detach, make copies and laminate the Emergency Plan to include with other important information. It is meant to be shared with emergency responders, screeners, and members of the person’s interdisciplinary team (IDT) or family members who will be accompanying the person to the emergency room.

*We have additional resources that will be listed in the relevant sections and in the Appendices at the end of the Handbook.* PowerPoints have been developed to add pertinent information on topics for which there was not sufficient space in the Handbook. If a section has an accompanying Power Point you will be directed to follow a link to <https://njcdd.org/an-enhanced-family-support-crisis-handbook-a-behavioral-health-handbook> where this material is stored. Resources will also be posted and added to the dedicated webpage; ensuring that information remains current.

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### A3: Preface

Even as we wrote the concluding sentences of the original Handbook, published in 2010, Donna Icovino and Dr. Lucille Esralew, regretted that not have enough information was included about children in crisis. We knew that information became outdated even as the “ink dried” on the original Handbook. In part this was because our systems of care were configured differently. Furthermore, the New Jersey Department of Children and Families, Division of Children’s System of Care to not involve youth affected by complex severe behavioral health conditions at that time. Since then, the New Jersey Department of Children and Families has taken on the support of youth under the age of 21, with these types of behavioral health needs. It is now pertinent to write about these services, some of which are in the process of being strengthened and further developed.

We have also moved as a field of human services towards more person-centered and strengths-based thinking about the co-occurrence of mental health disorders and intellectual disabilities. The emphasis is more on building positive conditions for mental wellness through early intervention and working with families and school systems, provider agencies and work sites and less about remediating, rehabilitating and diagnosing individuals with mental illness. Although our services for persons with disabilities may be age-based, our thinking about developmental disabilities is across the lifespan. Disabilities, themselves, are life-long. Mental health disorders may also be life-long for many of the individuals with whom we work. Our thinking has also moved towards self-direction and empowerment of individuals and families and away from dependence upon specialists. Specialists are needed, but there is much that we can all do on an everyday basis to improve the quality of life for individuals with developmental disabilities and mental health disorders. We offered an updated version of the original Handbook with the release of the *Revised Family Crisis Handbook* in 2019 with to update the original Handbook. We hope that you find pertinent information, inspiration and value in our latest publication, *An Enhanced Family Crisis Handbook: A Behavioral Health Wellness Toolkit*.

#### a: Donna’s Preface



Co-authoring the Family Crisis Handbook (2010), The Revised Family Crisis Handbook (2019) and the newly published expanded version, *An Enhanced Family Crisis Handbook: A Behavioral Health Wellness Toolkit*, with my esteemed colleague and friend, Dr. Lucy Esralew, has been a very gratifying experience. Lucy originally proposed the idea for the first edition, after I lamented about how terribly blind-sighted I had been during my son, Michael’s behavioral crisis. Prior to Michael’s crisis episode, I had always prided myself on being very knowledgeable about the symptoms and treatment associated with his autism and bipolar disorder diagnoses. However, when Michael was unexpectedly thrust into the mental health system, I was equally as ill-prepared to advocate for him, as the local hospital and overall system was to address his emergency needs. Because the system lacked the necessary resources to serve someone with a developmental disability, Michael was automatically disqualified from receiving urgently required care and treatment.

Afterwards, I could not bear the thought of other families being caught in similar circumstances, as they attempted to help loved ones during their times of greatest need. I believed that the Family Crisis Handbook would serve to enlighten family members about navigating the broken service delivery system to avoid existing pitfalls, and to inform them about existing services, as limited as they were. Around the same time as we began developing the Handbook, the New Jersey Department of Human Services Dual Diagnosis Task Force was convened to examine and resolve the serious lack of services/supports, unmet service needs, and major obstacles to receiving developmental disability and behavioral health care services encountered by children and adults with complex severe behavioral health conditions. Back then I recognized that in order to generate real change, increased activism and utilizing a variety of methods was the only way to bring these issues to the forefront of people’s attention.

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I approached my work on *An Enhanced Family Crisis Handbook: A Behavioral Health Wellness Toolkit* with a greater understanding of the current issues facing individuals in emergency, and sometimes life-threatening situations. That knowledge has further increased my passion for sharing relevant information which can help produce better outcomes, regarding the overall quality of care and treatment necessary to create a life that is satisfying to the person with intellectual/developmental disabilities. In addition, my contributions to this expanded Handbook have been greatly influenced by my former role as Co-Chair of the Dual Diagnosis Task Force. The Dual Diagnosis Task Force Report, available on the New Jersey Department of Human Services website, contained priority recommendations, and furnished a blueprint for developing a quality-based, person-centered, accessible, cross-agency, and sustainable service delivery system. I am pleased to say that the New Jersey Department of Children and Families, Children's System of Care has implemented several of the task force recommendations by launching community-based short and long-term crisis stabilization/assessment/treatment programs, as well as expanding in-home behavioral support services, upgrading mobile response services, for individuals under the age of 21. These service and support initiatives are outlined in this edition of the Handbook. However, there is still a great deal more to be accomplished, particularly for adults (21 years of age and older) affected with complex severe behavioral health conditions, and served by the Department of Human Services. With that said, I invite readers to review the *Advocacy* section of this Toolkit.



I feel blessed to be the mother of two exceptional children who have greatly inspired my contributions to each Handbook. Michael, 36 years-old, has worked very hard and made significant progress. He has been effectively guided and supported by the care and expertise of many dedicated people. By all accounts, Michael is living the kind of happy, active and fulfilling life that is genuinely meaningful to him. His achievements have reinforced my unwavering belief in his potential for real growth, the power of advocacy, and the importance of developing a *Life Plan*, which I address in this publication. My daughter, Lauren is a thoughtful and compassionate young woman and mother. She formerly served in a supervisory position for a partial hospitalization program for young children with behavioral health challenges. Michael has clearly had a positive influence on Lauren's life and career choices, and he has benefited from the love and care she has always shown him. When they are together, I am always touched by the ease and comfort in the way they interact with one another. Their mutual affection is truly palpable. As a family, we take very little for granted. Our shared experiences have taught us what is truly important in life, and that understanding continues to shape our lives in valuable ways. We consider this to be an extraordinary gift from Michael. I have offered my thoughts and ideas in the chapter entitled "*Family Members Coping Together with Behavioral Crises*", based on my firm belief in the necessity to actively nurture family relationships in general, but particularly during times of great challenge.

For the past seventeen years, I have had the great privilege of counseling special needs families. For eight of those years, I served as a Peer Support Counselor for the Rutgers/University Behavioral Health Care, Mom2Mom Helpline. This telephonic and web-chat service is based on a best-practice reciprocal peer support model, which focuses on the behavioral health care needs of the caregiver. Drawing from the latest research and personal accounts from parents, I discuss the importance of self-care in the "Care for the Caregiver" chapter. In addition, counseling has given me the opportunity to work alongside family members as they attempt to address their loved ones' highly complex challenges within an ever-changing and often bewildering system of services. Just knowing that you are not alone can make a world of difference. Additionally, the more informed one is, the more effective their advocacy efforts become, which can lead to an improved quality of life for the family as a whole. I am forever changed by the remarkable resourcefulness and determination of the family members I have been fortunate enough to work alongside.



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Finding one's voice as an advocate is as unique a journey as the person themselves. When it comes to the driving force behind human rights activism, we are all united by a common goal. Simply stated, every individual on earth, regardless of their capabilities, deserves to be treated with dignity, compassion and respect. We should all have ample opportunities to engage in experiences, which can ultimately lead to a personally satisfying life. Most importantly, there is a place in society for each of us to share our natural and acquired gifts with others who might benefit from them.

As you read through the pages of An Enhanced Family Crisis Handbook, please keep in mind that the overall goal of this publication is to promote voice and choice. A person's complex severe behavioral health condition does not just profoundly affect the individual's life, it impacts everyone around them. With that in mind, I believe you will find the personal and professional narrative pieces appearing throughout this text to be exceptionally compelling and thought-provoking.

Finally, I encourage you to ask yourself, Am I willing to challenge the status quo? Am I willing to sacrifice to change things for the better? Wishing you success on your own personal journey, and I hope you never lose sight of the fact that...the power of the human spirit is truly indomitable.

### b: Lucy's Preface



It has been my pleasure to collaborate with my long-time friend, colleague and *Family Crisis Handbook* Co-author Donna Icovino on this revised and updated Handbook. It was my pleasure to work with newer associates on the Community Access Unlimited staff including Jeremy Lefever, Sarah Eibach, Carolee Marano, Tracy LeBaron, and talented and dedicated others.

Since the publication of the *Family Crisis Handbook* in 2010 much has happened for me both professionally and personally. In 2011, I transitioned from Program Director of Trinitas Regional Medical Center's Statewide Clinical Consultation and Training (SCCAT) to become Clinical Administrator for SCCAT and another Trinitas outreach program, S-COPE, designed for older adults 55+ living in Long Term Care. In 2015, SCCAT was renamed Crisis Assessment Response and Enhanced Services (CARES). At the end of 2017, after 20 years of working for Trinitas Regional Medical Center, my husband and I moved to California to be nearer to our daughters and grandchildren. I began working as a Behavioral Psychologist and Autism Clinical Specialist for Redwood Coast Regional Center which covers four northern California counties; I am currently living in Sacramento and working as the Senior Psychologist for the California Department of Developmental Services, which is California's equivalent of New Jersey's Division of Developmental Disabilities. In some ways the themes developed in this Handbook apply to individuals with disabilities regardless of their location in either New Jersey or in California. In other ways, this revised Handbook is uniquely New Jersey and a product of the service environment for New Jerseyans with disabilities.

Donna and I originally saw the offer extended to us by CAU through the New Jersey Council on Developmental Disabilities as a long-awaited opportunity to update the *Family Crisis Handbook*. The original Handbook was a labor of love that had been well-received but had become outdated and insufficient as a source of help for individuals who are dually diagnosed. However, as this material has taken shape it is clear this is less about crisis response, per se, but about averting crisis by promoting mental health wellness for individuals, regardless of age, with the dual diagnoses of Intellectual/Developmental Disabilities (I/DD) and a mental health disorder.

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My own thinking has evolved over the past 11 years. I am still (as I always have been) interested in finding ways to remove the barriers and reduce the everyday stressors for individuals with complex severe behavioral health conditions that affect their function and quality of life. My focus has shifted away from mental health treatment, per se, and towards the promotion of health and wellness skills. Since I have come to see mental health as part of overall well-being, I can no longer consider the treatment of one without the promotion of the other. I have also become more focused on the practical, everyday ways we can support people with complex severe behavioral health conditions and help them, their families and their staff feel empowered and better equipped. For me, it is a movement away from crisis response and the treatment of mental health disorders and towards increasing choices, increasing the “voice” of those being supported and promoting informed and shared/supported decision-making.

During my work in complex severe behavioral health conditions over the past twenty-three years, I had the good fortune of meeting hundreds of individuals, staff and family members at screening centers and inpatient and outpatient units, during crisis calls to family homes, group homes, and day programs and in my private practice, workshops and trainings. I am convinced that mental health wellness requires that mental health providers understand and respond to the unique needs of individuals and the families and staff that support them. Families need to familiarize themselves with their relatives’ mental health needs and available mental health resources. Most individuals with intellectual and developmental disabilities live in their own homes with their families. When delivering mental health services to individuals who reside with their families, both the individual and his/her family are our service recipients. While this remains as true, today, as it was when Donna and I wrote about this in our original *Family Crisis Handbook*, I have grown to see more interdependence among individuals, families, staff and providers and opportunities to help people at all levels become more skilled and effective. I have also come to see how individuals, themselves, can have more input and take more personal responsibility for their mental health wellbeing. Whether the point of contact is the individual with disabilities, the family, staff, and case management or provider agency, there are innumerable opportunities to promote mental health wellbeing on a daily basis, and avert full-blown crises or mitigate the more serious effects of crisis, should they occur. In my mind, that is both the rationale and the value of this updated Handbook. This Handbook encompasses the perspectives of multiple stakeholders in both the crisis response and stabilization process. Those of us responsible for service delivery to individuals with dual diagnoses of Mental Illness and Developmental Disability, need to facilitate and improve communication between service providers and service recipients. This Handbook is a way of resuming the work that was begun in 2010, contemporizing it and moving it forward.

#### **A4: Lived Experience: Voice and Choice Vignettes**

We think it is important to begin the Enhanced Family Crisis Handbook with the statements of individuals, advocates, families, crisis workers, direct support professionals and service providers that reflect their lived experiences as people who have been in crisis or supported someone in crisis. You will find other vignettes throughout the Handbook, which we placed to best match their statements to the topic being covered. To the extent possible, we have not edited the language of statements unless it was to make the material more understandable to the reader. The vignettes do not necessarily represent the viewpoints of the Handbook authors.

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## Family Member

*We've never known exactly what triggered my son's meltdown. When I arrived at his community group home to take him home for the weekend, the police had just taken him away. A phone conversation an hour earlier with my son and a staff person had no hint of trouble. The staff member said his coworker, who was in her first day on the job, had called the police when my son went out of control. A chair and bookcase in his room were overturned. In the living room, a VCR and tapes were scattered on the floor next to a broken picture that had been on the wall. The police had taken him to a locked psychiatric ward, where the staff kindly let me stay with him. He was chronologically in his 20s, but in fact far younger. He seemed a little scared, and somewhat confused about what had happened. He said he broke things but had not hit anyone. He had recently been hit and shoved by an untrained staff member at the group home and was fearful. I was told I could not take him home, which was upsetting to both of us.*

## Family Member: Reverend Joe Gratzel, M. Div. (Denise and Joe Gratzel and their son, Gavin)



*My 19-year-old son, Gavin, has been our great joy and our great challenge. Gavin has developmental disabilities, cerebral palsy and autism spectrum disorder as well as mentally ill. For many years, he would exhibit extreme violent and aggressive behavior at home and in the community. He is a big kid – six feet tall and about 185 pounds, and very strong. What we learned from our crisis experience was: First, don't be afraid to ask for help – even if it just means asking a bystander to hold a door, call a family member for you or dial 911. Second, when folks are helping you – whether first responders or helpful bystanders, be specific about what would be helpful. For example, you may ask them not to speak to your child directly, or may ask them to back away if they are making the situation worse. People are willing to help – bystanders and first responders alike – and they are looking to you to know how they can best assist you.*

*I am happy to say that Gavin is now residing in an out-of-state campus setting that is only an hour from our home. He goes to school every day, Boy Scouts each week, and enjoys a rich social life on campus. For the first time in his life he has friends his own age who “get him”. It was hard to let him go, but I sleep well every night knowing he is well cared for and thriving.*

## Self-Advocate: “My Perspective on Crisis Intervention”

*For me, being in a crisis means I am hurting myself or others, or wanting to do so. I might not be taking my medication. I may be manic or psychotic. I have Autism Spectrum Disorder, Bipolar with psychotic symptoms. First off, to help with crisis intervention, I gave my parents a Durable Power of Attorney, and signed a Psychiatric Advance Directive, so my parents are allowed to stay involved in my care.*

*When I have a crisis and need to be committed, I go by ambulance to the screening center. I have bad anxiety issues, and they get worse at screening, because I feel very uncomfortable in the locked screening unit. In a specific center, they prohibit you from turning out the lights to sleep, and I tend to get more over-stimulated from that. I don't like the noise level in a lot of facilities. There needs to be more units like the Trinitas-2-D complex severe behavioral health conditions Adult Unit. Sad to say, dually diagnosed patients do not get accepted regularly to transitional STCP. It goes on too long without a bed at Trinitas. A lot of times, screeners will call Centralized Admissions, and ask for a State Hospital bed, which is not always appropriate for someone with complex severe behavioral health conditions.*

*Trinitas 2-D is a model program, but their children's floor is so strict and inflexible with their rules. With a complex severe behavioral health conditions crisis, flexibility with medication algorithms, behavioral management plans, etc. is key. Without flexibility, crises escalate more and more, and the individual gets deeper into the mental health disorder. Trinitas 2-D behavioral specialists and staff are very coordinated. A lot of times in general facilities, especially MI/DD youth clients are isolated from the group, because they do not benefit from the treatment. A lot of times, I have been rejected from a lot of general facilities, because I have a dual diagnosis, and “my acuity level.”*

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*We tend to have a lot of medication changes. Medication is not always a solution. I need individual therapy. Talk therapy helps me express my feelings in an appropriate way and get solutions to problems I am having. Talk therapy on an individual basis needs to be more available in crisis settings. Also, Crisis Houses are excellent alternatives to the hospital. There needs to be some Crisis Houses specifically for complex severe behavioral health conditions. Positive Behavior Supports training for staff and families is really important to prevent further regression post-acute stage. Positive Behavior Supports and Behavior Plans, in general, need to be monitored for effectiveness. Sometimes an ineffective behavior plan can cause a crisis.*

*In general, good crisis intervention services mean there are ways to prevent a crisis. This includes early intervention practices before the crisis episode becomes dangerous to self, others, and property; as well as ways to intervene when it does become unsafe; and ways to deal with things after a crisis to recover losses.*

### **Self-Advocate Member of Community Access Unlimited: “My Personal experience with crisis.”**

*I had tried attacking my brother because he thought I was going to attack my mom. I don't remember why I was so upset at the time. My family called the police and I was taken to the hospital. I was really angry and frustrated with myself that I let things get so out of control. I felt bad that I had hurt my family. The nursing and psychiatric staff helped me by having me talk about what was happening. Since I was discharged, I have been trying to improve myself by working and trying to go back to school to be either a personal trainer or a golf professional. It is harder for me to change things because of my disability.*

### **Family Member**

*At the crisis screening center my son was cooperative with doctors and others who spoke with him and cheered when a group home staffer he'd especially liked came to visit. It was a hectic place. During our second night there, a woman began screaming. She cried out jumbled words and expletives in a torrent of anguish. “I keep coming here, I've come for years, and no one can help me,” she cried. “Why can't anyone help? Does anyone even care?” My son became panicky. He wanted to know what was wrong with the woman and what was making her cry like that. A nurse assured him that the woman would be OK. The nurse patted his hand and explained in a soft voice, “That's what happens when she goes off her meds.” The woman's screaming began splintering into deep sobs. “She is not happy,” my son said. “She's not really OK, is she?” The nurse looked weary and continued patting his hand. The nurse and I both felt he was glimpsing a sad adult reality that not everything can be fixed. After more doctor visits, another psychiatric stay, help from a psychologist, and considerable tinkering with his extensive regime of medications, my son was admitted to a campus environment operated by a community service provider, where he was initially safer and could start to get better.*

### **Direct Support Professional**

*The individual was being transported from his residence to a local Shop-Rite for food shopping. While staff was driving, the individual became aggressive and agitated and opened the back door of the van and attempted to jump out. Staff quickly observed it and pulled over the vehicle to the side of the road to stop. The individual jumped out of the vehicle after the van came to a halt and started running into the street towards oncoming traffic. Staff immediately called 911 for assistance. While waiting for the police, staff followed him and redirected him to return to the vehicle; the individual refused to adhere to all redirections. He ran back to the van and started causing damage to the vehicle. Staff kept on providing redirection but the individual kept breaking the windshield wipers and the side fenders to the vehicle. Staff kept ensuring the individuals' safety while waiting for the police to arrive by providing verbal prompts. The individual eventually calmed down and sat on the pavement along the street while staff watched him. The individual became agitated again when he saw the police arrive, picked up a huge stone and attempted to throw it towards the windshield of the van but staff quickly redirected him. The police then intervened and restrained him, cuffed him and called for an ambulance to transport him with*

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assistance of Emergency Medical Technicians (EMT) to the Trinitas psychiatric emergency room for an evaluation. The individual was monitored and evaluated for safety in the emergency room for 12 hours and was then discharged the next morning because the hospital psychiatrist stated he no longer met the criteria for admission. It was frustrating that the individual did not get admitted due to the nature of the behavior that had been exhibited. We continued to receive assistance from the behaviorist that works with the individual to learn how to better manage or minimize the risk of future behavioral outbursts.

### Family Member

When our son was in a community group home, he was punched and knocked down by a much larger resident the staff was not able to control. When I arrived at the group home to take our son home for the weekend, he was barricaded in his room with furniture pushed against the door. The other resident was kicking the door with his bare foot and yelling hysterical threats. Two staff members sat at the kitchen table looking scared. I asked the guy kicking the door if it was hurting his foot. He said it hurt very much. He agreed to go into his room, and began sobbing. The staff went to comfort him. My son let me into his room and we put the furniture back before leaving. Initially, our son was very angry and upset. When he had calmed down, he observed that his housemate was sometimes nice. "I guess I have liked him sometimes and kept away sometimes," he said. "I don't think he knows what he is doing or why he goes off." Hours later he said that sometimes he himself has "gone off" and that sometimes he knew why, and sometimes he didn't.

### Masters Level Crisis Assessment Response and Enhanced Services (CARES) Clinician: Ke'Nesha Jones

Although more Americans have access to mental health services there are still individuals not receiving the mental health care they need; this is, in part, due to the lack of knowledge in regards to where to find appropriate services. This becomes particularly problematic when working with individuals with a developmental disability and mental health diagnosis. A big part of what I am seeing is families struggle with finding a provider (psychiatrist and/or counselor) who will accept their insurance, and struggle with finding a provider who has the expertise to work with individuals who have an intellectual/developmental disability. The task of finding a provider can be daunting to families, leaving them to feel hopeless, at times. However, as a crisis worker for CARES it is part of my duty to ensure that the families feel as supported as possible during times of crisis, empower them to continue fighting for the care their loved one deserves, and networking with professionals in the field to expand my knowledge about services available to the client and their family. There are also aspects that families have expressed much happiness about, in regard to how quickly services have been made available (i.e. locating a day program and in-home behavioral supports). These services, along with the support provided from CARES, have helped provide individuals with disabilities with skills they need to be successful in the community and avert psychiatric hospitalizations. Families have reported significant improvements in their relative's day to day behaviors, with these services. We have come a long way in regard to being able to successfully serve individuals with disabilities and co-occurring mental health needs and are continuing to make great strides in doing so. As professionals, CARES clinicians are continuing to educate ourselves and develop a platform to share that information with others.

### Post-Script to Voice and Choice

The aforementioned vignettes indicate a range of experience by individuals, families, support staff and clinicians. The terms Voice and Choice indicate two fundamental premises to promoting the expression of lived experience with intellectual and developmental disability: access to a means for functional communication either through language or assistive augmentative communication technology (PECS®, Proloquo™, etc.) and our commitment to person centered thinking in helping individuals live the lives they want. For more on this topic, refer to the PowerPoint entitled: **Voice and Choice in Mental Health** in the Appendix Section.

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## B. What is Mental Health Wellness?

**Mental Health Wellness** is one part of overall well-being; it is more than the absence of mental illness or emotional distress. Wellness involves choices we make to advance our physical and mental well-being. It is a holistic, person-centered, individual-driven, strengths-based approach to our own care and the approach used by others to support us. It includes important life considerations: Does the person have meaningful connections to others? Does the person enjoy school or work? Does the person live in a situation in which he is getting along well with others? Does the person have access to leisure activities, family, faith-based community? Does the person have access to culturally competent supports? All these dimensions of well-being affect our mental wellness.

The Substance Abuse and Mental Health Services Administration (SAMHSA) defines wellness as consisting of eight dimensions including emotional, environmental, financial, intellectual, occupational, physical, social and spiritual areas of living. To learn more about SAMHSA, including wellness strategies <https://www.samhsa.gov/wellness/strategies>

When we refer to **Mental Health**, we do not usually mean **Mental Wellness**, 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 problems 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 is strengths-based, culturally competent, person-centered and holistic. It 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 he/she wants. We build on identified character and other strengths to help us address limitations. The person, not their 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, it is probably important to note that **mental health** and **behavioral health** are not interchangeable terms. In NJ, we usually refer to **behavioral health** as third party reimbursed outpatient services which may include mental health disorders but may also promote well-being. When we refer to mental health, we may be referring to inpatient or outpatient services used to treat significant mental health disorders, substance abuse or other addictions. For instance, the New Jersey Division of Mental Health and Addiction Services (DMHAS) oversees inpatient treatment and outpatient treatments of mental illness, <http://nj.gov/health/integratedhealth/dmhas/>, whereas 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 complex severe behavioral health conditions may access behavioral health services or mental health services depending upon their level of service need. When individuals are in crisis, they will often be accessing services that are managed through DMHAS.

## C: What is Complex Severe Behavioral Health Conditions (CSBHC) Formerly Referred to as Dual Diagnosis

Donna and Lucy struggled with this one for a while. How do we do justice to the complexity of the individuals on whose behalf this Handbook was written? We are interested in getting your feedback. We decided that "dual diagnosis" did not quite cover what we were looking to convey. Simply put, "dual diagnosis" refers to having two or more diagnoses at the same time; this term has been historically used to refer to people with mental health conditions and co-occurring substance use problems. In the original *Family Crisis Handbook*, we used this term to refer to persons with intellectual and developmental

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disabilities and co-occurring mental health and/or behavioral conditions (MI/DD or DD/MI). We have decided to rethink this as people with ***Complex Severe Behavioral Health Conditions (CSBHC)***, which may include persons with medical conditions such as seizure disorders, behavioral issues and mental health needs. So, who are the children and adults whom we are referring to, here, as having **Complex Severe Behavioral Health Conditions (CSBHC)**? These are individuals who have a developmental disability and a behavioral health condition which may be either a severe behavior disorder, a mental health disorder or a combination of both a psychiatric disorder (mental health condition) and severe behaviors. These are also individuals who are more likely to have medical conditions that may contribute to the complexity of their challenges. They may have seizure disorders, brittle diabetes that add to their challenges. It may be worth backing up to consider whom we mean when referring to individuals with developmental disorders. We are referring to persons who have an intellectual disability or a condition such as autism spectrum disorder, epilepsy, cerebral palsy or another condition that began during their formative years and has resulted in needing multidisciplinary support of an interdisciplinary team. Individuals with intellectual and developmental disabilities are more likely to need lifelong support and case management. We are concerned because individuals with these neurodevelopmental disorders may have a higher likelihood of having co-occurring behavioral health conditions, but a lesser likelihood of having their treatment and service needs related to their behavioral health conditions met.

### **C1: Obtaining a Thorough Assessment and Arriving at an Accurate Diagnosis**

The term “complex severe behavioral health conditions” (CSBHC), as used within this Handbook, refers to individuals with intellectual and developmental disabilities who may have either mental health needs or significant behavioral challenges that put them or others around them in danger. The term “MI/DD” is a shorthand way of referring to individuals who live with a Mental Illness and a Developmental Disorder. Individuals, Families and Staff may wonder whether unwanted behaviors are due to mental health problems, developmental disabilities, unsafe behavioral habits or a combination of all of these challenges. Unless the individual is thoroughly assessed by knowledgeable professionals, it may be difficult to know why people may act in unsafe ways and what to do in order to keep everyone safe.

Just as is the case for the general population, people with complex severe behavioral health conditions may live with such mental health problems as depression, mood disorders, thought disorders and anxiety disorders. However, unlike the general population, persons with intellectual and developmental disabilities may display their mental health needs in the form of unwanted and unsafe behaviors such as threatening behavior, assault, self-injury, property damage or elopement. These behaviors may be ineffective and interfere with the person pursuing independent living and self-determination. The person with a complex severe behavioral health condition may have extra difficulty in pursuing preferences, goals and valued outcomes at school, at work or within relationships.

Although individuals with developmental disabilities may exhibit behavioral problems, there is nothing about either an intellectual disability or a developmental disorder that automatically explains a person engaging in such unsafe behaviors as aggression, self-injury, property destruction, or elopement. Some people do have a developmental disorder that is associated with a higher likelihood of engaging in self-injury or other unwanted behaviors. While this is possible, it is not common. Some people may display unwanted behaviors that are associated with mental health problems. There can be as many explanations for problem behaviors as there are people who exhibit them.

The first step to getting a clearer picture of what is going on is to have the person with a question about mental health or behavioral issues thoroughly assessed. It is imperative that potential medical issues be identified when someone with a complex severe behavioral health condition is experiencing a behavioral health crisis. Some individuals exhibiting unwanted behaviors might also be suffering from health problems such as infections and pain. This is why it is important to have the individual comprehensively evaluated. This is the best way to attempt to identify all factors that relate to the individual’s behavioral issues.

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***The first step in obtaining treatment is to obtain an accurate diagnosis.*** Sometimes individuals with intellectual and developmental disabilities are difficult to diagnose because of their languages and cognitive challenges which may affect their ability to understand questions during assessment and may limit their ability to report distress. Individuals with disabilities may be non-traditional communicators. The clinicians who evaluate them may not be aware of these challenges and use assessment tools applied to the general population of individuals without disabilities. As a result, we see people who live with mental health needs that have never been properly identified and treated and we see people who are mistakenly diagnosed with mental health disorders although they do not suffer from a mental illness. The result can be either unaddressed mental health needs or people who are unnecessarily receiving medication or being hospitalized. It is important to be aware that some co-occurring diagnosis overlap in symptoms and as always, you should work with your medical providers to ensure integrated care.

***The first step in obtaining an accurate diagnosis is to see a medical doctor*** who can rule out any medical conditions that may be affecting thinking, mood or behavior. If there are no known medical problems that need treatment, referral to a psychiatrist or psychiatric advanced nurse practitioner with experience in assessment of psychiatric issues of persons with disabilities or referral to a psychologist or other non-medical clinician who is familiar with the diagnosis of mental health needs of individuals with disabilities.

***Even if someone displays behavioral outbursts, it does not mean that person meets criteria for a mental health disorder or that the individual requires medication or hospitalization.*** It is not uncommon for people who are on the autism spectrum to display significant behavioral outbursts in response to sensory overload or out of frustration over the failure of others to understand or meet their needs because of limited communication skills. When aggression and other types of behaviors are the individual's response to environmental stressors the best approach is to arrange an evaluation by a Board-Certified Behavior Analyst who is familiar with conducting functional behavioral assessments and can develop a behavioral shaping plan or support guidelines to address elimination of those conditions that lead to a behavioral outburst. This assessment is best accomplished within the person's natural setting and behavioral shaping plans are best implemented by the individual and his/her supports across all usual settings in which the behavioral outbursts occur.

***The following scenarios illustrate the importance of an accurate diagnosis that can help explain behavior and give a direction for treatment, services and supports:***

*Joe is a 16-year-old male who is high functioning on the autism spectrum with a co-occurring diagnosis of bipolar disorder. His developmental disability (autism) is associated with sensitivity to noise and his difficulties with change. His mental health issue (bipolar disorder) may cause sleep disturbance, mood changes, and increasingly impulsive and reckless behaviors. When he is depressed, he cannot get out of bed, he sleeps and does not eat on a regular basis. He has thoughts about being different and less adequate than his friends at school. When in a manic mood, he will stay up all night playing music, be on the computer or watch television all night. When in the active phase of mania, he may sleep no more than a half hour at a time. He can become more irritable and reactive. He sometimes destroys property and will become physically aggressive by pushing his mother or younger sister. When in either an actively depressed or actively manic phase of his illness, Joe is unable to maintain a schedule, go to school, complete his academic work or participate in chores. His parents sometimes worry about his ability to be safe. In addition to the challenges posed to him by his developmental disorder (autism), he experiences excess disability due to his mental health needs.*

*Jennifer is a 35-year-old female with a history of anxiety disorder, depression and borderline personality disorder. She resides in a structured community living arrangement. Although her anxiety and depression are adequately managed with medication, she presents on a frequent basis to Psychiatric Emergency Services because of her relationship problems with staff and other individuals. She is at risk for losing her residential supports and she has already had multiple short-term hospitalizations from which she does not appear to obtain benefit. Her mental*



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*health needs are disrupting her chances for community success. Although medication has addressed her anxiety and depression, there is no medication that addressed her borderline personality disorder. Her family and staff do not seem to know about non-medical ways to help her. As a result, she is not getting the best and most effective supports.*

*Fred is a 58-year man who has Down syndrome, mild intellectual disability and dementia. His family and staff have noticed changes in his behavior and personality. When he was last brought to his primary care physician who told his mother that there was nothing to be done about this and that this is what happens when individuals with Down syndrome are over the age of 59. His family and staff are discouraged because they witness his decline in cognitive, adaptive and behavioral functioning and do not know how to best support him within the community.*

*In all of these cases, individuals of different ages with intellectual and developmental disabilities have mental health needs due to psychiatric illness or a mental health condition. The best approach to support individuals with mental health needs is to understand their condition and the best practice is to provide both medical management and non-medical supports. Medical management often involves therapeutic medications that are prescribed for a mental health diagnosis such as antidepressants for depression, anti-anxiety medications (anxiolytics) for anxiety, antipsychotic medications (psychotropics) for psychosis, etc. Non-medical ways of addressing mental health needs may include lifestyle changes, psychosocial programs, therapy, behavioral approaches and environmental modifications. Best practice for the treatment of most mental health conditions involves both medication and non-medical approaches.*

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

- 1) If you notice change from what is characteristic and baseline in appetite, sleep, mood, activity level and behavior that persist for more than two weeks, bring the individual to the attention of his/her primary care physician to rule out medical problems that may affect mood, thinking or behavior. Please note that the severity and/or intensity of the observed change may require more timely or even immediate action. Call our PCP and seek advice as to whether this constitutes an emergency and how to proceed.
- 2) Collect information about changes leading up to the visit with a physician so that you dialogue with your health care provider about changes you have observed at home, school or work that may not be observable during an office visit
- 3) Obtain a mental health assessment from a clinician who is familiar with complex severe behavioral health conditions (developmental disabilities and mental health disorders)
- 4) Obtain a functional behavior assessment from a behaviorist (BCBA credentialed Behavior Analyst) to determine the role of environment, interpersonal relationships and everyday stressors in driving behavior change
- 5) Involve the multidisciplinary team in problem-solving changes that may support the individual and reduce depression, anxiety or stress-related behaviors
- 6) Involve PerformCare 1-877-652-7624 that can provide in-home supports and Mobile Response and Stabilization Services (MRSS) to youth under the age of 21 with intellectual and developmental disabilities and behavioral health needs.
- 7) Involve CARES 1-888-393-3007 as an outreach and engagement mental health team that specializes in adults 21+ with intellectual and developmental disabilities and behavioral health needs.

For more information about intellectual and developmental disability and mental health needs, see the PowerPoint: ***Overview of Mental Illness and Developmental Disability*** in the Appendix Section of the Handbook.

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## **C2: What is a Mental Illness or Psychiatric Illness?**

The following is intended to serve as general considerations for individuals, families and support staff who are involved in mental health care decision-making; the following does not substitute for the advice and recommendations provided to a person by his/her current practitioner, clinician or health care provider including a psychiatrist, advanced practice nurse, psychologist, social worker, professional counselor, behaviorist or other credentialed practitioner.

Mental illness (sometimes referred to as “mental health disorders,” or “psychiatric illness”) refers to long-term problems with mood, behavior and thinking. You may have heard about Major Depressive Disorder, Generalized Anxiety and bipolar disorder, which are mood disorders. You may have also heard about Psychosis, Delusional Disorder and Schizophrenia, which 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 with mood or thinking problems. However, people who display significant behavior issues may need special attention because they behave in ways that are unsafe for themselves or others.

**The state-of -the-art treatment for mental health disorders involves a combination of medication and psychosocial interventions.** If someone has Schizophrenia, that person can take medications called “antipsychotics” that help with hallucinations and disorganized thinking. People diagnosed with bipolar disorder can take mood stabilizers to help even out the ups and downs associated with cycles of mania and depression. If someone has a severe behavior problem, they may also be placed on medication; for instance, severe self-injury has sometimes been medically treated with Naltrexone or an antipsychotic. Many if not most mental health disorders have treatments associated with taking medication. However, the best practice treatment for most mental health disorders also involves non-medical practices including strengthening social supports, developing coping skills, and providing environmental and lifestyle changes.

**In addition to environmental factors that may contribute to and sustain mental health problems, we also need to consider the role of culture and individual values and belief systems** that can influence how one approaches 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 his or her life. It is also likely to affect others in the person’s surroundings such as family members, friends and other individuals who are in relationship with the person living with mental illness whether the setting is at work or home.

## **C3: What is the Relationship between Behavior and Mental Illness?**

Behavioral outbursts, which can take a variety of forms including (but not limited to) verbally threatening behavior, physical aggression, self-injury, property destruction, elopement, and/or inappropriate touching. These behaviors may be signs or symptoms of mental health problems.

When someone is experiencing an active episode of mental illness you may observe that he or she displays an increase in the frequency, severity or duration of unwanted behaviors. For instance, individuals may become more self-injurious when depressed, more aggressive during a manic episode, or more impulsive when anxious. In such cases, changes in the frequency, severity or duration of dangerous behavior may be linked to mental health disorders. It is important for people who know the individual to observe and report changes in behavior that is different from the person’s typical pattern. State-of-the-art treatments for mental health disorders consist of medication and psychosocial supports. This is as true for a person with complex severe behavioral health conditions as it is for anyone without disabilities.

Behavioral problems do not necessarily predict that an individual meets the criteria for a mental health disorder. Behavioral problems may arise from a variety of reasons that have nothing to do with psychiatric illness, among them lack of attention, boredom, overstimulation, lack of necessary support or meaningful activity, limited social connection and as a response to environmental stressors such as noise, task demands, pain or physical discomfort.

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While hospitals are not the preferred locations in which to effectively address behavioral problems, some individuals demonstrate behaviors that are too dangerous for them to stay at home. They may need to be hospitalized, in order to be observed and treated in a supervised setting. The understanding is that once they are no longer dangerous, they can leave the hospital and continue any needed treatment on an outpatient basis while returning to their home, work and usual routine. The purpose of hospitalization for a behavioral crisis is not to cure the person of a mental health problem or eliminate their unwanted behaviors, it is for the person to be safe enough that they are no longer dangerous to themselves and others; they are discharged at the point that it is safe for the person to continue getting the supports and services they need while they return to their natural settings where they can continue their recovery from their mental health or severe behavioral crisis.

#### **C4. What Does Intellectual/Developmental Disability have to do with a Behavioral Crisis?**

Intellectual disability, which is the most common type of developmental disability, is characterized by significant limitations to both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. Individuals with developmental disabilities 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. There may be a mismatch between the support and services a person needs and what is available to them. These are among the factors that may leave someone living with disabilities more prone to behavioral crisis than other individuals without disabilities.

#### **Behaviors may be linked with a specific developmental disability**

One of the things to consider while attempting to determine if a person's issues are driven by mental health or behavioral problems, is to identify any behaviors that might be linked to a specific developmental disability that is associated with behavioral problems. Certain types of developmental disabilities are associated with a higher risk of specific behaviors; we call these "behavior phenotypes" of the developmental disability. Screeners at emergency rooms or mental health practitioners who are not aware of certain behaviors, might mistakenly diagnose someone with a mental health disorder. The individual might not need to be medicated because the behavior is not the result of a mental health problem; it is associated with the person's developmental disability, here are some examples:

1. Individuals with Lesch-Nyhan syndrome or Cornelia de Lange syndrome are more likely to be self-injurious. Self-injury could be mistaken for depression or another mental health condition.
2. Individuals with fetal alcohol spectrum disorder are more likely to be impulsive and have limited attention span versus diagnosing individuals with fetal alcohol syndrome with Attention-Deficit/Hyperactivity Disorder or Impulse Control Disorder.

Individuals with Fragile X are more likely to have rage or anger issues as opposed to those with Intermittent Explosive Disorder.

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## D. Range of Services that Address Complex Severe Behavioral Health Conditions

### D1. Types of Professionals You May Encounter

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

#### Resource Coordinators

**Care Manager** – A worker from a Care Management Organization (CMO) serving individuals under the age of 21, and assigned by PerformCare, the Systems Administrator for DCF/Children’s System of Care (CSOC).

**Support Coordinator** – An individual who manages Support Coordination Services for individuals age 21+ by performing the following four general functions: individual discovery, plan development, coordinator of services, and monitoring.

**DCP&P Workers** - A bachelor’s or master’s level caseworker assigned through NJ Department of Children and Families, Division of Child Protection and Permanency. This professional’s role is designated based upon one of the following services: child protection, case management, foster care, adoption, family supports and services through community providers or information and referral.

**Medicaid Managed Care Manager**

**Special Child Health Case Manager**

**Private Insurance Case Management**

**Direct Support Professional** - Personnel possessing a high school diploma, GED equivalency or higher. This professional provides support to an individual with disabilities to lead a person-centered 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

**Psychiatrist** - An individual who has obtained a medical degree and has completed specialty training in mental and emotional disorders; a psychiatrist may prescribe medications for the treatment of psychiatric illness and mental health disorders.

**Physician** - An individual who has obtained an M.D. (Medical Doctorate) or D.O. (Doctor of Osteopathic Medicine) degree. Physicians can prescribe medications. Neurologists are another group of specialty medical-practitioners that are often consulted by individuals with developmental disabilities.

**Psychiatric Advanced Nurse Practitioner (A.N.P.)** - A nurse practitioner who specializes in the treatment of mental illness and can prescribe medications.

#### Non-Medical Practitioners

**Allied Professionals** Licensed practitioners who may offer non-medical rehabilitation services in a hospital or outpatient setting such as Occupational Therapy (O.T.), Physical Therapy (P.T.), Speech Therapist or Nutrition/Dietician.

**Psychologist** - An individual with a doctoral degree in psychology (Ph.D., E.d.D. or Psy.D.) from an accredited university or professional school; a psychologist may specialize in non-medical treatment of individuals with mental health or behavioral problems but cannot prescribe medication.

**Social Worker** - A master’s level clinician (Master of Social Work, M.S.W.) who may provide non-medical clinical services to individuals with mental health or behavioral problems.

**Professional Counselor (L.P.C.)** - A master’s level clinical who provides counseling and psychotherapy to individuals with mental health or behavioral problems. Some counselors are licensed professional counselors.

**Behaviorist (BCBA- new legislation prohibits ABA from being provided without the supervision of a BCBA in the home setting)** - A bachelor’s, masters or doctoral level practitioner trained in the use of learning techniques to assess behavior problems and develop approaches to teach individuals to replace

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target problems with adaptive skills. Behaviorists can have different types of training or certificates: some may be trained in Positive Behavioral Supports (PBS) techniques, while others may be certified in Applied Behavior Analysis (Board Certified Assistant Behavioral Analyst, BCaBA, at the bachelor's level and Board Certified Behavioral Analyst, BCBA, at the Master's and Board Certified Behavioral Analyst-Doctoral BCBA-D at the doctoral level).

### Registered Behavior Technician

#### ABA Therapist

**Screeners** - A clinician with a bachelor's degree who may also hold a master's degree and who has received basic training in psychiatric screening. Currently, screeners can receive both mandatory basic training and advanced training required for retaining Continuing Education Credits, through the Technical Assistance Center (T.A.C.) affiliated with Rutgers University.

## **D2. Obtaining a Comprehensive Evaluation**

A comprehensive evaluation may involve a number of professionals who assess the individual from different perspectives. A comprehensive evaluation might include a general medical exam, a neurological exam (particularly if your relative has a seizure disorder or a known neurological disorder), laboratory work, medical testing, a psychiatric evaluation, a psychological assessment, and a behavioral assessment.

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

Most individuals are challenged in obtaining a good mental health assessment because of problems regarding access, capacity, competency, and parity. There are widely reported problems in **availability** of trained professionals, **access** to qualified professionals and **parity** (or equality) of treatment for individuals with I/DD. The above mentioned may result in a significant gap of services for individuals who are in need of mental health treatment and should be reported to managed care organizations responsible for paying for the individual's behavioral health treatment such as Medicare, Medicaid, and the Arc of New Jersey Mainstreaming Medical Care. The lack of adequate mental health treatment, in general, but particularly for individuals with intellectual and developmental disabilities, constitutes an important issue to advance through advocacy. You will see ways in which you can advocate for mental health services later in the *Handbook*.

**If you or someone whom you support is prescribed medication for a mental health disorder, you will probably want to know the following information:**

1. What is my diagnosis?
2. What is the medication prescribed to medically treat my mental health needs? Ask the prescribing physician the reasons for the medication.
3. How will this medication address my problems? For example, can I expect that the medicine will reduce my mood swings, end my troubling hallucinations, help me better manage my anxiety or help me sleep?
4. How long can I expect that medication will take to work? How will I know that it is working?
5. Should I be looking out for any possible side effects or reactions to the medication? What should I do if I think I am having a reaction to the medication?
6. If I become concerned about anything (e.g. side effects, changes in behavior, over sedation) how can I best communicate this to the prescribing practitioner?

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## Additional Information to Consider about the Use of Medication(s):

**Pharmacogenetics** (also referred to as **Pharmacogenomics**) is the study of how genes affect your body's response to medications. Pharmacogenetic tests look for changes or variants in genes that may determine whether a medication could be an effective treatment for you or whether you could have side effects to a specific medication(s). This is a diagnostic tool that might help a physician determine the best medication for an individual. There are a number of companies that conduct Pharmacogenetic testing, which involves analyzing a sample of DNA taken from the person's blood or saliva. Additional information can be obtained by consulting a doctor and through your own research. Note: The following link contains a February 20, 2020, Food and Drug Administration (FDA) press release announcement, regarding a collaborative review of scientific evidence to support associations between genetic information and specific medications: <https://www.fda.gov/news-events/press-announcements/fda-announces-collaborative-review-scientific-evidence-support-associations-between-genetic>

**Medications should be prescribed according to a formal diagnosis** made by a qualified professional and include the person demonstrating symptoms that meet the criteria for that specific behavioral health disorder. Investing the necessary time and effort to arrive at a formal diagnosis helps to establish the primary cause of the individual's challenging behavior, and allows for more effective medication management to reduce or resolve their symptoms. Prescribing medication(s) solely on the basis of symptoms may place the person at risk by not addressing the root cause of their severe behaviors, and therefore, delaying the progress they could be making. This can also lead to prescribing more medications than are necessary, as well as unintentional, but inaccurate dosing practices.

**In addition to medical treatment, you may want to know the following, regarding non-medical treatments and approaches to mental health needs:**

1. What are my options for non-medical treatment for my condition?
2. How does therapy, counseling, or behavioral intervention work? What am I expected to do and what will the therapist/counselor/behaviorist be expected to do?
3. How will this treatment or approach address my problems?
4. If I follow the treatment guidelines, how long can I expect before I will feel better?
5. If I become concerned about anything related to my treatment (e.g. increased distress, thoughts about harming myself, lack of desire to continue treatment), how can I best communicate these concerns to the clinician?

If you are interested in additional information about complex severe behavioral health conditions, you may want to read about particular mental health issues within the **DM-ID-2** (Diagnostic Manual for Intellectual Disabilities), which is the companion volume to the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) especially developed for individuals with intellectual and developmental disorders. The **DM-ID-2** is available through the NADD bookstore (National Association for the Dually Diagnosed). The website for the national organization dedicated to persons with intellectual and developmental disability and behavioral health needs has many resources listed to help understand complex severe behavioral health conditions: [www.thenadd.org](http://www.thenadd.org).

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### D3. Types of Services that May be Useful

#### a. Adapted Counseling Approaches

When individuals receive supports that help them build coping skills and become more effective in their personal lives, they are less likely to experience behavioral crises. Many individuals with disabilities can benefit from talking to a trained professional. Among the factors to consider: 1) Does the individual have sufficient language skills to communicate thoughts, feelings, beliefs and to understand and follow work in verbal therapy? 2) Is the person motivated to better understand himself or herself and work on changing unhelpful patterns of relating to others? 3) Can the individual consistently get to appointments on a scheduled basis? There are several traditional counseling approaches that have been adapted for individuals with intellectual and developmental disabilities; among them are: Cognitive Behavior Therapy for individuals with Asperger's (Valerie Gaus, Ph.D.) that particularly addresses anger issues <http://www.drvaleriegaus.com/>; the Skills System (Julie F. Brown) a Dialectical Behavior Therapy (DBT)-informed skills training curriculum <http://www.skillssystem.com/> ; a strength-based approach based on Positive Psychology <https://www.viacharacter.org> and a promising modification Exposure Response Prevention(ERP) for individuals with Obsessive Compulsive Disorder (OCD) and intellectual disability. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3710662/>

A comprehensive review would be beyond the scope of this Handbook. Interested readers may want to consult NADD for guidelines on best practice for counseling and psychotherapy for children and adults with intellectual and developmental disabilities. NADD does sponsor a clinical certification program which is one way to know if the clinician has experience and is recognized for their ability to work with individuals with disabilities and behavioral health needs.

#### How to work with a Therapist/Counselor

Therapists and counselors are non-medical mental health practitioners. These professionals include Psychologists (Ph.D.), Licensed Professional Counselors, Licensed Social Workers, marriage and family therapists, and pastoral counselors. They will usually have a license or certification that acknowledges they have received training and pass standards. Although NJ does not require that someone have a license to provide therapy, you are better off seeking this type of support from someone who has been credentialed in their field. These practitioners cannot prescribe medication, but they can help individuals to better understand their thoughts, feelings and behaviors and can help people develop better coping skills to handle the hassles and stressors of everyday living as well as large life challenges.

When working with a counselor or therapist, be sure to share the issues that are interfering with your goals at work, in relationships, within your family and in the community. Ask the professional to tell you how he/she is thinking about your situation and the specific ways in which that professional can help you. It is also helpful to ask about the frequency and format for sessions including how billing for services is handled and what may be the expectations for the individual. Some therapists/counselors offer homework assignments, readings, or work with family and staff to promote skills development.

Success within counseling presumes the individual has sufficient verbal skill to be able to communicate ideas about what is going on and process information, presumes the ability to tolerate 30-60 minutes of interaction with a counselor and sufficient curiosity about oneself and desire to change including persistence to exert effort to change. Family members and staff, albeit well-intentioned, are not doing an individual a favor by volunteering the person for therapy who lacks the motivation or skill set to benefit from this kind of work. Counseling may be in private practice or within an outpatient setting. Outpatient settings, or clinics, may be within hospitals or may be free-standing community behavioral health centers.

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## Family Member

*Our son has been a long-time patient of Dr. Lucille Esralew, a psychologist. She has detected patterns we as his parents had not recognized and made many helpful recommendations for addressing behavioral issues. A caregiver asked why he saw a psychologist and what he thought he got out of that. He said later he thought the question was strange. 'I like to see her,' he said, 'because I can tell her things and she listens to me. And I listen to her too. She helps me think about things.'*

## b. Behavioral Approaches

When people with disabilities learn skills to manage their own behaviors, they are more likely to feel confident and in control and less likely to experience behavioral crises. When the individuals who support the person with disabilities learn more effective ways to support an individual, that individual is less likely to have a behavioral crisis and that person's support team are more likely to feel equipped to respond (should there be a behavioral outburst) within the person's natural settings without utilizing the Emergency Room, hospitalization or medications unnecessarily. There are two main approaches that are recommended to address behavioral problems which will be briefly overviewed in this section.

## Best Practice Behavioral Strategies and Services for Individuals with Complex Severe Behavioral Health Conditions, including Self-Injurious Behavior

*Written by: Virginia Kaufmann, M.Ed., BCBA*

Many families of adult children with developmental disabilities are familiar with **applied behavior analysis (ABA)**, a treatment approach that uses behavior-based technologies to affect behavior. The research discussing the use of ABA to treat individuals with a behavioral health issue is somewhat new (see Harvey & Luiselli, 2010 for a more in-depth read on applying ABA to behavioral health issues). However, practitioners often use ABA to work with individuals who have complex severe behavioral health conditions. These strategies can be helpful in preventing behavioral crises and can also help to minimize the impact of crisis behaviors should they occur. It is strongly recommended that any family interested in using ABA as a treatment strategy contact a Board-Certified Behavior Analyst (BCBA) to help develop an individualized plan to provide the greatest benefit to their loved one.

One of the things that separates ABA from other treatment approaches is that it focuses on measurable, observable behaviors. This means we can identify if the treatment is actually working by tracking those behaviors before we start intervening to gather a baseline and then continuing to collect data as we intervene to determine if the behavior increases or decreases. While ABA is a very effective intervention strategy, an interdisciplinary treatment approach is frequently used effectively with the complex severe behavioral health condition population. The interdisciplinary team can be made up of family members, behavior analysts, psychiatrists, psychologists, and any other discipline or important party who hopes to make a positive impact on the individual.

An example of an interdisciplinary approach can be seen with the many individuals with co-occurring behavioral health issues who are treated with medications. While medication can help to reduce the impact of problem behaviors, it doesn't tell us why the behaviors are occurring. Without knowing the why, it's really hard to put an effective intervention in place to prevent those behaviors from occurring in the future. A BCBA can conduct a functional behavior assessment which could include a functional analysis (the clinician assessed how often a behavior occurs in a variety of conditions, such as giving demands, or providing attention when the behavior occurs). Once the function of the behavior is determined, a function-based treatment plan can be developed. An ABA-based approach would also include systematic tracking of the problem behavior(s), which is often helpful to other disciplines. By tracking interventions, including pharmacological interventions, the family can determine if any changes are occurring and make objective decisions about on-going care, including the possible reduction in psychotropic medications.



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## Preventing Problem Behaviors

A key to preventing problem behaviors is to understand why the behaviors are occurring. Behavior analysts will tell you that behaviors occur for the following reasons: to access attention, access some kind of tangible item, escape demands or aversive stimuli, or because the behavior provides some kind of sensory or internal input. As previously discussed, behavior analysts assess problem behaviors to determine why they are occurring and then identify interventions that prevent the behavior or provide an appropriate response to the behavior. Some of the strategies listed below could be helpful for an individual with a complex severe behavioral health condition, but they are provided with the caveat that without knowing the function that maintains a behavior, it is difficult to identify which strategies will be most successful.

Strategies that prevent a problem behavior from occurring are called *antecedent modifications*, and they might include things like putting a structured schedule in place, ensuring that your family member has the opportunity to make choices, or providing an *enriched environment* (i.e., making sure your family member has access to items that keep him/her calm, such as music, headphones, preferred items to hold, etc.). With a *structured schedule*, we make sure that there is routine in the individual's life and that he or she knows when events may be different. This provides reassurance and can help to decrease some of the anxiety that an individual may be experiencing, especially when the schedule is posted. For individuals who cannot read, a visual or picture schedule can be significant in maintaining calm behavior. Providing as many choices as possible gives an individual a sense of control over his or her life. Choices can be simple, such as giving a few choices for a snack, choosing what order chores can be completed in, or what route to take on a walk. In addition to these antecedent modifications, some *adjustments can be made to the environment* to ensure that your family member is safe and supported. This might include changes like putting chimes on windows or doors if your family member often elopes, identifying a space for your family member to go to cool down or have time alone, or minimizing the amount of furniture in a room if your family member needs room to move around.

Some other preventative strategies include *functional communication training*, *non-contingent reinforcement*, and the use of first/then strategies. If the problem behavior is serving as a form of communication, it is important to teach the individual a better way to communicate. We want to make sure we are not giving a pay-off to problem behaviors, because they will then continue to occur. However, if an individual is able to appropriately request access to what he or she wants and we honor that request, we eliminate the need to engage in problem behaviors.

If we have determined why a behavior is occurring, providing the individual with access to what he or she wants prior to the problem behavior occurring is another strategy for preventing those behaviors. For example, if an individual is engaging in problem behaviors in order to get a snack, you may want to provide a few snacks throughout the day regardless of any behaviors the individual engages in. These "freebees" remove the need to engage in problem behaviors since the individual is already getting what he or she wants. In an effort to prevent or minimize problem behaviors, family members may hold back on presenting demands. While this may prevent some issues in the short term, the fact is that demands are going to be placed on us whether we like it or not. Using *first/then strategies* (e.g., "First let's go to the grocery store, and then we can stop to get ice cream"), can be one good way of presenting demands to an individual and decreasing any resulting problem behaviors.

Family members can easily conduct *simple preference assessments* by asking an individual what he or she wants to earn or providing a choice between a few options (e.g., "What do you want to do after wiping the table?" or "Would you like to watch some TV or go for a walk outside once we're done with brushing your teeth?"). Doing this before presenting a demand can provide motivation and an idea of the good things to come once the demand is completed. If your family member cannot answer verbally, a visual choice board can also be effective.

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## What do we do in a crisis?

Ideally, intervening early in a crisis situation may help prevent problem behaviors from escalating further. Identifying precursors to crisis behaviors will allow family members to try de-escalating the individual before high rates of aggression, self-injury, property destruction, or other harmful behaviors occur. For example, your adult child may tend to make a certain facial expression or make specific comments prior to engaging in crisis behaviors. Intervening at the time when the pre-cursors occur may prevent escalation to crisis. In the event that crisis behaviors occur, *maintaining safety* is most important. If possible, ensure that the individual is in a safe place and remove 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.).

Attempt to minimize the behavior by prompting the individual to tell you what is upsetting and through the use of calming strategies. *Calming strategies* may include deep breathing, counting, positive self-talk, taking a walk, or getting some form of physical exercise. These strategies should be taught to the individual when he or she is calm and accessible for learning. Mental health counselors can be very helpful in identifying what calming strategies would work for the individual and how to best teach those strategies. It is important to note that crisis situations are never a good time to teach a new skill.

Another way to minimize crisis behaviors is to not verbally respond to the behaviors. For example, if the individual is engaging in property destruction, avoid saying things like, “Don’t throw that” or “You’re going to break things”. Making comments about the problem behavior may actually increase that behavior over time. Instead, attempt to *redirect the individual* to what you want him or her to do. This might include telling the person, “Come sit in the chair” or “Let’s take deep breaths together”. If the individual does not de-escalate and problem behaviors escalate to a point that safety cannot be maintained, family members should contact emergency services.

If the crisis behaviors tend to cause significant physical harm, family members may want to consider getting 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, Crisis Prevention Institute’s Nonviolent Crisis Intervention®, JKM Training Inc’s Safe Crisis Management®, or Professional Crisis Management Association’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 behavioral health issues such as anxiety disorders, bipolar disorder, or depression. Physically managing a crisis situation while waiting for emergency services may prevent injuries to the individual and/or family members.

## Focus on: Self-Injurious Behavior

As a family member, one of the hardest things to witness is your own child or sibling harming him or herself. Unfortunately, self-injurious behavior (SIB) may occur when the individual is in crisis. There is no simple answer to preventing SIB – the intervention used is going to depend on why the individual is engaging in SIB, as discussed above. Preventative measures may include providing reinforcement for the absence of any SIB, functional communication training, or redirecting the individual to an item that might compete with the self-injury (such as a massage tool if the individual engages in self-injury to access some form of sensory stimulation). Family members can follow some basic strategies when or if self-injury occurs. Any SIB that is to the head (e.g., banging head on hard object or hitting self in head with a fist, etc.) or causes significant harm to the body (e.g., redness, broken skin, etc.) should be immediately *blocked*. This can be done by placing a pillow, gardening mat, or another soft object between the individual’s head and whatever object or body part is being used to engage in the SIB. When blocking self-injury, stand behind or to the side of the individual, not directly in front. This positioning helps to prevent aggression. Generally, *redirecting* the individual to another activity

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or conversation topic is partnered with blocking. Family members should also *avoid verbally responding* to the behavior when redirecting the individual from engaging in SIB, as this may cause an increase in SIB.

References:

Harvey, M.T. & Luiselli, J. (2009). Application of applied behavior analysis to mental health services. *Psychological Services*, 6(3), 212-222.

### Applied Behavior Analysis (ABA)

Practitioners of applied behavior analysis (ABA) aim to improve socially important behavior by using interventions that are based upon principles of learning theory and that have been evaluated in experiments using reliable and objective measurement. ABA is a science that uses principles of behavior to increase prosocial behavior and decrease maladaptive behavior. Through the use of ABA, we aim to make a meaningful change in people's lives through the use of reinforcement.

### Positive Behavior Supports

Positive Behavior Support (PBS) is a behavioral approach which utilizes a variety of strategies with the aim of increasing quality of life and decreasing problem behaviors by teaching new skills and making changes in a person's environment. When individuals feel supported and they are in situations and surrounded by people who value their preferences and help teach them how to cope with their everyday stressors, they are less likely to experience behavioral crises.

Positive behavior support combines an emphasis on several areas: 1) **Valued Outcomes**, which are based on the individual's needs and preferences and are linked to positive lifestyle changes and an increase in social belonging; 2) **Behavioral and Biomedical Science**, which refers to assessment and interventions which are supported by research and are applicable to the everyday settings of the individual; 3) **Validated Procedures**, including strategies for behavioral data collection and evaluation of interventions; 4) **Systems Change**, which include interventions that address everyday settings and consider the family home, school and agency setting to ensure that a support plan is effective across all settings.

For more information: [www.apbs.org](http://www.apbs.org)

### Positive Behavior Supports in the Schools (PBIS)

Schools in New Jersey that utilize PBIS do so to focus on building supports and preventing problems. Students who are involved in PBIS, learn about what behavior is appropriate, just like they would learn about other subjects. Students are taught social skills, including how to act in different school settings such as the classroom, on the bus or with friends. They may learn through role-playing or through actual lessons. PBIS is based on several important principles: 1) Every child is capable of learning socially acceptable behavior; 2) Early intervention can prevent more serious behavior problems from developing; 3) Since each child is different, a variety of approaches need to be used in school for behavior support; 4) Schools should base the teaching of behavior on methods that are research-informed; 5) Schools need to base decision about behavior supports on data collected through observation and interaction. For more information about the use of Positive Behavior Supports in New Jersey schools and how this approach might be helpful for your child with disabilities, please follow the link to the site: <http://www.njpbs.org/>

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## How to Work with a Behavioral Consultant

A behavioral consultant may be a Board-Certified Behavior Analyst (BCBA), Licensed Behavior Analyst (LBA) or it may be someone who has knowledge of Positive Behavior Supports (PBS). You may also come across a registered behavior technician (RBT). An RBT directly implements plans that are written by a BCBA. Applied Behavior Analysis is an approach to learning new skills and reducing or eliminating maladaptive behaviors using empirically-based learning principles. Both ABA and PBS require an assessment and design of a program based upon assessment. Staff and/or family members are trained on the implementation of the plan and ways to measure if the plan is effective in increasing adaptive behaviors and reducing unwanted behaviors. Most consultants share responsibility with others for data collection and implementation of a behavior plan across settings. Usually, family or staff are involved in the implementation of plans.

Assessments usually take the form of a functional behavior assessment (FBA) or a functional analysis (FA), both of which are conducted by a BCBA or BCaBA. An assessment involves observation of individuals across settings and anecdotal information collected from staff and family. During this assessment, people close to the individual may be asked specific questions about the behavior that they observe. This is done to help the clinician to determine the function of the behavior. For additional information about the FBA, Autism New Jersey has created a Functional Behavior Assessment Frequently Asked Questions (FAQ) document available online at <https://www.autismnj.org/article/functional-behavior-assessment-faq/>

Behavior plans consist of strategies and opportunities to teach adaptive behaviors and replace unwanted behaviors. For instance, a plan might be devised to decrease the frequency of hitting others or self-injury. Some plans involve rewards and other incentives. Every behavioral plan should include opportunities to learn adaptive or coping skills as well as to reduce unwanted behavior. Every plan should include clear expectations regarding what the individual needs to do in order to earn rewards and incentives, if those are included. Additionally, there should be clear expectations and training on any plan that involves the assistance of family members or staff.

Every behavioral plan should include evaluation of that program's effectiveness so that the interdisciplinary team can determine whether a plan needs to be ended, continued or modified. Every plan should include the time frame in which behavioral strategies will be applied with clear expectation of what the individual or other will do in order to follow the plan. If changes in behavior such as the reduction of unwanted behavior or learning of adaptive/coping behavior do not occur within the specified time within the plan, the plan needs to be re-evaluated. Perhaps there are different strategies that are needed to be put in place, or adjustments to the incentives being used with the individual. Also, it is not the expectation that the individual will not remain on this plan for a long period of time. The end goal is that the plan will be faded out over time while a clinician works to increase the skill level of that individual.

### Family Member

*I noticed at some point that when I tell people my son lives in a group home, I say that he was sixteen and a half when he moved in, as if that extra half a year makes it sound way better, like I should be apologizing for doing such a horrific thing. My husband and I are nice people, loving parents. How could we have done such a thing? You'd need to have some background to understand.*

*Matthew or Matt, which is how we usually address our son, had developmental issues early on. By eighteen months I told the skeptical pediatrician Matt had autism. By twenty-three months, two developmental pediatricians agreed with me.*

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*Treatment with ABA therapy began immediately with Matthew having Early Intervention Services, and then continuing his education at one of the finest private schools for children with autism in the state. Progress with Matthew was always slow, and he often had terrible temper tantrums. But at age nine Matt had the most rapid period of learning and best behavior he had ever had. Unfortunately, that progress was short-lived, because at age nine and a half Matt developed self-injurious behavior (SIB) concurrent with a gastrointestinal ailment.*

*Out of the blue Matt started to slap his face so hard that his skin immediately opened and started to bleed. We treated Matthew's gastrointestinal problem right away, and the very hard slapping stopped for the most part. But for reasons we don't fully understand, the self-injurious behavior (SIB) has remained even though Matt is happy most of the time. Matthew's SIB has included slapping, scratching, pinching, punching, biting himself, and pulling out his own hair, and he does it "compulsively." My husband and I started ordering wound care supplies in bulk, and every night after Matt's bath we went through the painstaking process of cleaning out Matthew's wounds, applying antibiotic ointment, bandaging, and wrapping the affected areas.*

*When Matthew was twelve years-old we decided to request a change in educational placement, and the Child Study Team agreed to move Matthew to a program that serves children with more significant behavioral problems. Matthew's overall behavior has improved, but he has had two stays at an inpatient facility for children with autism, several emergency room visits, as well as surgery on his ear and lip due to the damage he has caused himself.*

*By the time Matt reached his mid-teens, we had tried many different behavioral plans and medications. Our home was in complete turmoil. Thank goodness my son Adam was such a loving son, independent person, and terrific student, because we weren't doing that much parenting when it came to him. My husband and I consulted with staff at our son's school. It was clear that Matt's SIB rates were always lower at school than they were at home. When Matt was about fifteen years old, the school staff, my husband, and I came to the conclusion that a structured out of home placement was Matt's only hope for making any progress in decreasing the SIB. Matthew's case manager agreed.*

*I felt that this was the best thing for Matthew, but I had unbelievable anxiety. It was so bad that I actually became ill over a period of months leading up to Matthew's move. I realized that I needed to examine and address each of the points that made me anxious. From there I came up with a document I called, "All about Matthew." I wrote up a document to try to communicate the things that Matt couldn't express to the group home staff himself, but that I wanted them to know. The headings in the document were: food, activities, hygiene and toileting, communication, cognitive skills and abilities, and difficult behaviors. I encourage other parents preparing for this transition to do the same.*

*In January of 2013, Matt moved into a lovely group home near his school. My husband and I have had great communication with the staff who know Matt well. We see Matt frequently, and he is happy in his home as well as at Mom and Dad's house. We know when Matt is ready to go back to his group, because he will say "go in the car." When he gets out of our car, he has a big smile on his face as he runs up to the door of his house. Best of all, Matt's behavior plan is in effect 24/7. We have seen a decrease in his SIB, and he is able to enjoy being out in the community doing the things he likes to do.*

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## c. Programmatic Approaches: Partial Care and Partial Hospital Programs

### Programs Designed to Meet Behavioral Health Needs

There are psychosocial rehabilitation programs that have been designed to assist individuals with behavioral health needs. These programs either serve for people to step-up to a higher level of behavioral health support than is available in typical day programming or they can serve as a step-down from hospitalization. Many of these are offered as partial care or partial hospitalization programs as a step-down from hospitalization or a step-up from counseling but more intensive to avert hospitalization.

These programs usually provide group skill building sessions regarding lifestyle factors relevant to behavioral health, medication management, stress and coping skills groups. You may learn about specific mental health disorders. Many of these programs are meant to be time-limited until the individual is sufficiently stable and can move onto work or generic day programming.

There are programs available throughout the state. Some have developed specialized tracks for individuals with developmental disabilities with a 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. Most of these programs are funded through Medicaid reimbursement. Those programs are not typically designed for individuals with significant behavioral problems.

### d. Psychoactive Medication

#### What is the role of Psychoactive medication?

If diagnosed with a mental health disorder, an individual may be prescribed a psychoactive medication designed to address mood or thinking problems associated with that person's mental health disorder. Individuals who need medication, are on the correct medication and have the signs and symptoms of their mental health disorder well managed by their medication, are less likely to experience behavioral crisis.

A psychiatrist might recommend an anti-depressant medication to address signs and symptoms of depression, or an anti-anxiety medication for anxiety disorder, or an anti-psychotropic to address signs and symptoms of a thought disorder. The psychiatrist may also prescribe several different medications that are thought to work well with one another.

The treating doctor will determine dosing of medication and review and adjust medications based upon the individual's report and may ask family and staff for additional information. This is particularly important if the person is a non-traditional communicator and may not be able to make his experience with medication or other problems known to the doctor without the assistance of family and/or staff. It is extremely important to keep records regarding behaviors to see if there are changes that coincide with beginning new medications or are associated with medication adjustments.

A comprehensive list of medications is beyond the scope of the Handbook. The best way to obtain information is to look up the information about the particular medication prescribed on the internet and to ask the medical doctor to supply information. We list the main classes of psychoactive medications that are usually used to address mental health needs. Remember, if you do not know why a medication has been prescribed to you, ask the prescribing doctor.

Redundant

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## Classes of Medication Prescribed for Mental Health Disorders

### Antidepressants

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

### Anti-anxiety

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

### Mood Stabilizers

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

### Antipsychotics

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

### Psychostimulants

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

## How to work with medical practitioners who prescribe medication for mental health disorders

These practitioners may include M.D.'s (psychiatrists, neurologists, primary care physicians), or nurse practitioners. You would consult a medical professional for the medical management of signs and symptoms of mental health disorders. In preparation for a visit, collect data over a period of 2 weeks regarding sleep, appetite, energy level/activity levels, mood and thinking or behavioral issues that are different than usual or since your last appointment. Mention non-medical ways in which you have been helping yourself and any recent stressors that may be affecting how you feel such as the death of a relative, a recent move or change in staffing or day program.

If the medical practitioner determines that the individual meets the criteria for a mental health disorder he/she may prescribe psychoactive medication. Ask the practitioner about the diagnosis that is the basis for prescribing medication. This diagnosis is listed in the Diagnostic Statistical Manual of Mental Disorders (DSM-5) or the Diagnostic Manual for Intellectual Disability (DM-ID-2). These are medications that have been designed to particularly target the signs and symptoms of specific mental health disorders. For instance, an antidepressant for depression, an anti-anxiety medication for anxiety, a mood stabilizer for bipolar disorder or an antipsychotic for Schizophrenia. Ask the doctor to tell you why the medication is being prescribed and what you can expect. How long will it take to see some benefit? What should I be looking for regarding side effects? How should I follow up with the doctor if I see there is some unpleasant or troubling result of taking the medication or if I have any questions.

Take notes of questions you have prior to your visits, during the visit and following the visit-particularly if you notice an increase in unpleasant side effects that could affect your motivation to continue taking the medication and may prompt you to stop. Never stop or decrease prescribed medication without consulting the prescribing physician. Sudden changes in dosage can lead to seizures and other difficulties.

Medications should be prescribed according to a formal diagnosis made by a qualified professional and includes the person demonstrating symptoms that meet the criteria for that specific behavioral health disorder. Investing the necessary time and effort to arrive at a formal diagnosis helps to establish the primary cause of the individual's challenging behavior, and allows for more effective medication management to reduce or resolve their symptoms. Prescribing medication(s) solely on the basis of symptoms may place the person at risk by not addressing the root cause of their severe behaviors, and therefore, delaying the progress they could be making. This can also lead to prescribing more medications than are necessary, as well as unintentional, but inaccurate dosing practices.

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#### **D4. Wellness and Recovery**

Later in this Handbook (Under **Special Topics**), we will share some of the tools that individuals with intellectual and developmental disabilities, their families and support staff can use to promote behavioral health wellness and help persons of all ages and abilities move past the barriers of complex severe behavioral health conditions to go on to the lives they want and deserve.

The Wellness and Recovery movement comes out of the field of mental health and embraces the following key concepts: 1) Hope – that people who experience mental health difficulties get well, stay well and go on to meet their life dreams and goals; 2) Personal Responsibility – that it is up to the individual, with the assistance of others, to take action and do what needs to be done to stay well; 3) Education –the person with a complex severe behavioral health condition benefits from learning about his/her disorder so that he/she can make good life decisions; 4) Self Advocacy – learning how to effectively reach out to others, accept help and have what you want and need to maintain wellness; 5) Support – While working toward your wellness it is up to you, receiving support from others, and giving support to others will help you feel better and enhance the quality of your life.

(Based on Key Concepts of Wellness and Recovery posted by [mentalhealthrecovery.com/info-center](http://mentalhealthrecovery.com/info-center))

When individuals with complex severe behavioral health conditions and those who support them embrace these wellness and recovery principles, those individuals are less likely to experience behavioral crises.

#### **D5. The Role of Systems Collaboration in Support of Persons with Complex Severe Behavioral Health Conditions**

The following section will describe the role of systems in addressing the needs of persons with complex severe behavioral health conditions. Specifically, the role of the Children’s System of Care (CSOC) through the New Jersey Department of Children and Families (DCF) in responding to behavioral crisis among youth under the age of 21, as well as the role of the Department of Human Services (DHS), Division of Developmental Disabilities (DDD), and Division of Mental Health and Addiction Services (DMHAS) in addressing the behavioral health care needs of adults (Age 21+). A summary outlining the responsibilities of the DHS, Division of Disability Services (DDS) is also provided for your review.

##### **a. The Role of CSOC in Support of Youth with Complex Severe Behavioral Health Conditions**

The Department of Children and Families (DCF) through the division known as Children’s System of Care (CSOC), formerly the Division of Child Behavioral Health Services (DCBHS), serves youth with intellectual and developmental disabilities; emotional and behavioral health care challenges; substance abuse issues, and 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. The division offers a variety of services to address the intellectual/developmental and behavioral health challenges of youth up to the age of 21, including community-based and in-home services; out-of-home residential treatment services; and family support services.

##### **Determining Eligibility for Services for Youth Affected with Complex Severe Behavioral Health Conditions**

The Children’s System of Care (CSOC) is responsible for determining eligibility for intellectual/developmental services provided by the state of New Jersey for children, adolescents, and young adults under age 21.

**Please Note:** For individuals over the age of 21, the New Jersey Department of Human Services, Division of Developmental Disabilities (DDD) is responsible for determining eligibility. For additional information, contact DDD at 1-800-832-9173, or explore the following DDD website: <http://www.state.nj.us/humanservices/ddd/home/index.html>



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It should be noted that DDD funded services are not available until the individual is 21 years old. However, the eligibility determination made by DDD for youth age 18 and older will be honored by the CSOC for youth. CSOC still assumes responsibility for providing services and support for youth until the day before an individual's 21st birthday.

### **Initiating the Eligibility Determining Process Through PerformCare N.J.**

**PerformCare New Jersey** is the Contracted System Administrator for the Children's System of Care (CSOC). PerformCare (PC) manages the State of New Jersey's service delivery system, and was established to provide a single point of entry for youth to obtain existing developmental disability, behavioral health and substance abuse services and supports. PerformCare applies their knowledge, and integrated technologies to register, authorize, and match services and supports for youth diagnosed with the afore-mentioned challenges.

Information about eligibility, including applications can be found on the **PerformCare website**: <http://www.performcarenj.org/families/disability/determination-eligibility.aspx> A hard copy application can also be sent to your home via postal mail. The eligibility determination application on behalf of individuals who have turned 18 years old or older must be submitted to the Department of Human Services (DHS) Division of Developmental Disabilities (DDD), as per application form instructions.

**PerformCare can be reached toll-free, 24 hours a day, 7 days a week, at 1-877-652-7624.**

### **Assessment Tools Utilized by CSOC to Develop an Individual Service Plan**

The CSOC employs the **Child and Adolescent Needs and Strengths Assessment (CANS)** tool, developed by Dr. John Lyons, Ph.D., which is a multi-purpose communication tool that comprehensively assesses the needs of children/adolescents, as well as their parents or caregivers. The CANS tool was also designed to identify the strengths of the individual and their family, to build upon them. The results of the CANS are utilized to create individual service plans (ISP), determine the intensity of care, and it offers a built-in quality improvement and assurance component for keeping watch on intervention outcomes.

In addition, the CSOC has adopted the use of the **CANS-Crisis Assessment Tool**. Similar to the CANS version for children and youth with developmental disabilities, the CANS-Crisis Assessment Tool (CAT) supports individual care planning and the planning and evaluation of service systems. However, the CANS-CAT additionally focuses on addressing the behavioral health needs of youth and their families.

For more detailed information, regarding the CANS-Crisis Assessment Tool, a manual developed by CSOC can be accessed at <https://www.nj.gov/dcf/about/divisions/dcsc/Crisis.Assessment.Tool.pdf>

### **Care Management Services**

Most individuals and their families served by the CSOC do not require an assigned care manager. However, families should inform PerformCare (PC) of any unmet needs or challenges that their child is experiencing, so that these issues can be properly assessed and addressed. On a case-by-case basis, CSOC/PC can authorize the assignment of an individual to a local Care Management Organization (CMO), particularly when their challenges are considered highly intensive and complex. The CMO Care Manager provides person and family-centered service and support coordination. Note: Perform-Care will request that the family member/legal guardian contact their private health insurance company to determine if recommended in-home clinical services are reimbursable through their health insurance plan.

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## **Behavioral Stabilization Programs**

Typically, behavioral stabilization programs are composed of professionals specializing in behavioral psychology, psychiatry, neurology, pediatrics/primary care, nursing, social work, speech/language pathology, education. Challenging behaviors are identified and evaluated, including the existence of possible psychiatric disorders. A treatment plan is developed to decrease these behaviors and foster more desirable behaviors in their place. The necessity to utilize medication as an intervention is examined, as well as the need for possible current medication adjustments. 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, 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 youth under the age of 21. There are three such programs overseen by the Department of Children and Families, Children's System of Care (CSOC). Each program is operated by a different community service provider, and 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.

## **Out-of-State Neuro-Behavioral Stabilization Program:**

Kennedy Krieger Institute (KKI)

Neurobehavioral Unit (NBU)

Baltimore, Maryland

<https://www.kennedykrieger.org>

Toll-Free: 844-334-3211

Serves individuals up to 21 years of age, but periodically the KKI NBU admits individuals over 21.

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## Short-Term Developmental Disability Crisis Stabilization and Assessment Centers?

The Department of Children and Families, Children's System of Care (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 individuals in urgent need of out-of-home services and support due to severe challenges (behavioral, emotional, co-occurring medical issues, or abuse/neglect) and a family member/caregiver's inability to safely and effectively care for the individual.

This program offers community-based, person-centered care and treatment, including stabilization, assessment (medical, psychiatric, biopsychosocial, etc.) and developmentally appropriate services, skill-building opportunities, and coordination in maintaining current educational services, or other school options. A Board Certified-Behavioral Analyst (BCBA) will generate an Individual Service Plan (ISP), which includes a Functional Behavior Assessment (FBA) and Behavior Support Plan (BSP), utilizing Applied Behavior Analysis (ABA) practices to decrease problem behaviors.

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 may be provided for the youth and their family to avoid future hospitalizations and longer term out-of-home placement.

The DD Crisis Stabilization and Assessment Centers are not considered to be respite placements, and alternative resources should be trialed before exploring this option. Admission to this program is coordinated by a Care Management Organization (CMO), Mobile Response and Stabilization Services (MRSS), the Division of Child Protection, and Permanency (DCP&P), and Adult Protective Services (APS).

(Please refer to the Children's System of Care (CSOC) and Division of Developmental Disabilities (DDD) sections of this publication for more detailed information about the transition to adult services process. The Life Plan section also contains relevant information about planning for your loved one's future.)

Please Note the Latest Announcement Regarding the Establishment of a New Behavior Stabilization Program for Youth as follows:

Article: "Children's Specialized Hospital, Rutgers Center for Autism Research Announce Creation of Severe Behavior Program."

<https://www.roi-nj.com/2021/04/07/healthcare/childrens-specialized-hospital-rutgers-center-for-autism-research-announce-creation-of-severe-behavior-program/>

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## Family Member: Kathy H. Her Son Brandon is Pictured



*Our loving 18-year-old son, Brandon, who was diagnosed with autism and other neurological impairments, had endured a severe behavioral crisis when he was only 9 years-old. Brandon had become self-injurious, banging his head on the floor and biting his arm. He lashed out aggressively toward us and others, and he destroyed furniture and objects in our home. Up to that point in time, he had already been enrolled in three different special education school programs, suffered from Post-Traumatic Stress Disorder (PTSD), and he had been through numerous behavioral medication trials. Even though we tried our best to address his many challenges by providing a caring, supportive home, as well as specialized education programs and therapeutic treatment, he was, nonetheless, suffering. Our once happy-go-lucky boy (before his crisis) seemed to have fallen deeper through the cracks, which we feared he wouldn't be able to climb out of. His cheerful smile and infectious laugh faded. It was a very stressful and dismal time, but we weren't going to give up on him. Not then, not ever.*

*Through pure love for Brandon, and a belief that he deserved a better quality of life, we summoned up the courage to develop a plan on how best to help him. Although we were emotionally drained and frustrated, we persistently advocated for services and supports through state agencies, such as, the Division of Developmental Disabilities (DDD), Children's System of Care (CSOC), numerous doctors, school staff, behavioral specialists, and many others. It was, undoubtedly, exhausting and intense at the time, but our unwavering commitment and love for our son was steadfast. Eventually, we were able to obtain a lifeline for our son, and his journey out of the abyss became possible.*

*At first, Brandon was admitted to an inpatient psychiatric unit to stabilize his behavior with medications. This was not ideal, because they weren't really equipped to handle a child with autism, severe aggression and limited language. Afterwards, we were fortunate to work with both excellent DDD case managers, and our local school district who helped to secure intensive in-home behavioral supports for Brandon (funded by DDD and the school district). Brandon made progress, but when he entered puberty around 12 years-old, he regressed. It became very unsafe for him at school and at home. It was a gut-wrenching decision, but we knew that our son needed a much higher level of care than we were able to provide for him at home. We recognized that an out-of-home placement would best meet his needs.*

*Ultimately, the Children's System of Care agreed to fund an out-of-home behavioral stabilization program for Brandon. Fortunately, he has made much progress. After an extended lapse in classroom educational instruction, Brandon is returning to school, and he is preparing to transition to a community-based residential program. He is even enjoying going on short outings with our family. Because Brandon's program provides a continuum of care to meet his current and long-term needs, we are finally able to have some hope for him. Seeing Brandon, once again, smiling and laughing more and more, is encouraging and we never take it for granted!*

### **b. The Role of the DDD in Support of Adults with Complex Severe Behavioral Health Conditions**

The New Jersey Department of Human Services, Division of Developmental Disabilities (DDD), funds services and supports to help individuals diagnosed with intellectual and developmental disabilities, 21 years of age and older, to live as independently and productively as possible. The majority of DDD eligible adults reside with their families at home. Other residential options include community-based residences such as group homes, supervised apartments, a Community Care Residence overseen by a family caregiver, or Developmental Center. According to the Division's mission statement, "DDD assures the opportunity for individuals with intellectual/developmental disabilities to receive quality services and supports, participate meaningfully in their communities, and exercise their right to make choices."

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## **MEDICAID**

In order to receive services and support funded through DDD, an individual must first be determined eligible for Medicaid. Applying for Medicaid requires an in-person visit to your local Social Services office. To ensure that you have the mandatory documents when applying, consult the Medicaid Document Verification Checklist available online: [https://nj.gov/humanservices/ddd/documents/medicaid\\_document\\_verification\\_checklist.pdf](https://nj.gov/humanservices/ddd/documents/medicaid_document_verification_checklist.pdf)

For additional information and support contact the DDD Medicaid Eligibility Helpdesk at [DDD.MediEligHelpdesk@dhs.nj.gov](mailto:DDD.MediEligHelpdesk@dhs.nj.gov) or phone: 609-631-6505

## **SUPPLEMENTAL SECURITY INCOME (SSI)**

The Supplemental Security Income (SSI) program pays benefits to individuals with disabilities who have limited income and resources following their 18th birthday. New Jersey residents who have been deemed eligible for SSI, will also be entitled to receive New Jersey Medicaid. For additional information, the Supplemental Security Income (SSI) Fact Sheet can be accessed online: [https://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Medicaid\\_Fact\\_Sheet%20SP.pdf](https://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Medicaid_Fact_Sheet%20SP.pdf)

## **DETERMINING ELIGIBILITY FOR DDD-FUNDED SERVICES AND SUPPORTS**

To attain eligibility an individual is required to meet the functional criteria of having a intellectual/developmental disability that is evident before the age of 22, is lifelong in nature, and significantly limits the individual in at least three of the following areas:

- Self-Care
- Learning
- Mobility
- Communication
- Self-Direction
- Economic Self-Sufficiency
- Ability to Live Independently

## **INITIATING THE ELIGIBILITY DETERMINING PROCESS: DDD INTAKE APPLICATION**

Individuals may apply for DDD eligibility at 18 years of age. However, eligible individuals will only begin to receive DDD-funded services when they turn 21 years of age. Once Medicaid eligibility has been established, the DDD Intake Application, available online at <https://www.nj.gov/humanservices/ddd/individuals/applyservices/> in both English and Spanish, can be completed. Naturally, proof that New Jersey is the person's primary residence is required. A parent or legal guardian of the individual may apply for services on the person's behalf. The completed application forms can be submitted in person, by postal mail or by email to the Community Services Office serving your county. There are nine Community Services Offices serving all 21 counties. Check the DDD online site entitled "DDD Community Services Offices" at <https://www.state.nj.us/humanservices/ddd/about/contactus/communityservices/> to locate the appropriate office. In addition, if you have any questions simply click on the Community Services Structure table for the name and contact information of the respective Directors. For email submissions, the scanned copy can be sent electronically to [DDD.NJApply@dhs.nj.gov](mailto:DDD.NJApply@dhs.nj.gov). Make sure to include the following in the email subject line: Intake Application - Individual's Initials - County of Residence (SAMPLE: Intake Application JS Mercer County).

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## NEW JERSEY COMPREHENSIVE ASSESSMENT TOOL (NJCAT)

The NJCAT is a mandatory needs assessment survey utilized by DDD to decide an individual's eligibility for DDD-funded services. The NJCAT is completed in conjunction with the DDD Intake and Application process. The NJCAT evaluates a person's support needs focusing on self-care, behavior, and medical issues. A DDD facilitator will schedule a face-to-face meeting with the individual, family member, or someone who is the designated caregiver, and is very familiar with the person's special needs, for example, a service provider representative. The DDD facilitator sends the score to the Developmental Disabilities Planning Institute (DDPI) of Rutgers University for analysis. The results of the NJCAT are used to assign a tier, which is associated with an individualized budget.

## FEE-FOR-SERVICE IMPLEMENTATION

DDD has transitioned from a contract-based system of service reimbursement to a Medicaid-based, Fee-for-Service (FFS) reimbursement system. Detailed information about FFS and resources can be found on the DDD website: <https://www.state.nj.us/humanservices/ddd> or by contacting the Fee-for-Service Help Desk (DDD.FeeForService@dhs.nj.gov). Some of the FFS online resources include:

- Graduates Aging Out of the School System Timeline, <https://nj.gov/humanservices/ddd/documents/graduates-timeline.pdf>
- Supports Program Policies and Procedures Manual, <https://www.state.nj.us/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf>
- Community Care Program Policies and Procedures Manual, <https://www.state.nj.us/humanservices/ddd/assets/documents/community-care-program-policy-manual.pdf>
  - Supports Program and Community Care Program Policies and Procedures: A Quick Guide for Families, English: <https://www.state.nj.us/humanservices/ddd/assets/documents/quick-guide-for-families-english.pdf>
  - Spanish: <https://www.state.nj.us/humanservices/ddd/assets/documents/quick-guide-for-families-spanish.pdf>

## SUPPORTS PROGRAM

The DDD Supports Program funds services and supports for individuals, 21 years of age and older, diagnosed with intellectual and developmental disabilities who reside in a non-licensed setting. Once Medicaid and DDD eligibility has been confirmed (see application process previously outlined), the individual will proceed as follows:

- Complete the Support Coordination Agency Selection Form
- Be assigned to a Support Coordination Agency
- Sign the Supports Program Participant Enrollment Agreement form
- Work with their Support Coordinator on the Person-Centered Planning Tool (PCPT)
- Work with their Support Coordinator on the Individualized Service Plan (ISP)

Support Program services and supports include employment/day program services, individual and family supports, and supported employment. For more details and to obtain answers to your questions, consult the Supports Program Policies and Procedures Manual, including A Quick Guide for Families, and/or contact the Supports Program Help Desk on the following DDD website: [DDD.SuppProgHelpdesk@dhs.state.nj.us](mailto:DDD.SuppProgHelpdesk@dhs.state.nj.us) or by phone: 800-832-9173.

## COMMUNITY CARE PROGRAM

The Community Care Program (CCP) is funded by both the State of New Jersey, and the federal government's Medicaid program. The CCP is available to individuals, 21 years and older, affected with intellectual and developmental disabilities, and pays for community-based services and supports. The federal government approved the use of waivers to give people with intellectual/developmental disabilities the choice to reside in a community setting instead of living in an institution. Gaining access to the CCP can occur either chronologically on the CCP Waiting List or the individual's status can be deemed an emergency by DDD. It is important to note that the individual must meet all functional criteria, be covered by Medicaid, and

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meet the CCP level of care standard. For additional information, including a Frequently Asked Questions (FAQ) section, go to the DDD website: <https://www.nj.gov/humanservices/ddd/documents/community-care-program-faqs.pdf>

### **DDD-FUNDED SERVICES AND SUPPORTS**

A list of DDD-funded services and supports under the Supports Program (SP) and Community Care Program (CCP) can be accessed via A Quick Guide for Families: Supports Program and Community Care Program Policies and Procedures at:

English: <https://www.state.nj.us/humanservices/ddd/assets/documents/quick-guide-for-families-english.pdf>

Spanish: <https://www.state.nj.us/humanservices/ddd/assets/documents/quick-guide-for-families-spanish.pdf>

### **TRANSITION OF DDD CASE MANAGEMENT SERVICES TO A SUPPORT COORDINATION MODEL**

DDD Case Management Services began changing to Support Coordination as a result of the transition from a contract-based service delivery model to a Medicaid-based, fee-for-service system. All DDD eligible persons will either choose or be assigned to a Support Coordination Agency (SCA). The SCA will assign a Support Coordinator to complete the Person-Centered Planning Tool (PCPT), and create the Individualized Service Plan (ISP) with the individual and their family.

The Boggs Center on Developmental Disabilities has created the following guide books to aid individuals and their families in this process:

- Selecting a Support Coordination Agency: A Quick Guide for People with Disabilities
- Selecting a Support Coordination Agency: A Quick Guide for Families

These publications are available on the DDD website: <http://nj.gov/humanservices/ddd/> in the Support Coordination section.

### **FAMILY SUPPORT SERVICES**

In the Fee-For-Service (FFS) system, the “traditional” family support services, such as assistive technology, respite, home and vehicle modification, can be purchased through “Individual/Family Supports Budget.” Camp can be billed as “day habilitation” or “respite” depending on the nature and time of service rendered. The amount of Individual/Family Supports Budget is determined by the individual’s tier.

For both Supports Program and Community Care Program, Individual/Family Supports Budget is:

- \$ 5,000 for Tier A
- \$10,000 for Tier B & C
- \$15,000 for Tier D & E

The following list of services that can be purchased using Individual/Family Supports.

Services written in red can be purchased only through Individual/Family Supports. Others can be accessed through either “Employment/Day” or “Individual/Family Supports” budget. Employment/Day budget is significantly larger than Individual/Family Supports. Please see the DDD Budget Summary Chart.

Services can be purchased using Individual/Family Supports Budget

- Assistive Technology - Individual/Family Supports
- Behavioral Supports – Employment/Day or Individual/Family Supports
- Career Planning\*\*\* - Employment/Day or Individual/Family Supports
- Cognitive Rehabilitation (\*SP only) - Individual/Family Supports
- Community Based Supports (\*SP only) - Employment/Day or Individual/Family Supports
- Community Inclusion Services - Employment/Day or Individual/Family Supports
- Community Transition Services (\*\*CCP only) - Individual/Family Supports
- Environmental Modification - Individual/Family Supports

- Goods and Services - Employment/Day or Individual/Family Supports
- Individual Supports (\*\*CCP only) - Employment/Day or Individual/Family Supports or Individual Supports (supports provided residentially)
- Interpreter Services - Individual/Family Supports
- Natural Supports Training- Individual/Family Supports
- Occupational Therapy- Individual/Family Supports
- Personal Emergency Response System (PERS) - Individual/Family Supports
- Physical Therapy- Individual/Family Supports
- Respite - Individual/Family Supports
- Speech, Language, and Hearing Therapy- Individual/Family Supports
- Supported Employment\*\*\* - Employment/Day or Individual/Family Supports
- Supports Brokerage- Individual/Family Supports
- Transportation- Employment/Day or Individual/Family Supports
- Vehicle Modification- Individual/Family Supports

\*\*\* EMPLOYMENT SERVICES (Career Planning, Prevocational Training, Supported Employment) must initially be accessed through the NJ Division of Vocational Rehabilitation Services (DVRS) or Commission for the Blind and Visually Impaired (CBVI). If employment services are not available through DVRS or CBVI, or if employment services through DVRS or CBVI have been exhausted, DDD funding will be made available.

There is a “quick reference guide” in the manual to show the type of services and their budget component (For SP, see pages 189-191; for CCP, see pages 209-211).

- Supports Program Policies and Procedures Manual:  
<https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf>
- Community Care Program Policies and Procedures Manual:  
<https://www.nj.gov/humanservices/ddd/assets/documents/community-care-program-policy-manual.pdf>

## **SELF-DIRECTED SERVICES**

For some individuals diagnosed with intellectual/developmental disabilities, self-directing their services and supports is a way to exercise their right and desire to make choices about how they wish to live in the community. Self-directed services adhere to the principles of person-centered planning, with a strong focus on a person’s strengths, abilities and preferences. For more details, including eligibility key points check the following DDD website:

<https://www.state.nj.us/humanservices/ddd/individuals/community/selfdirected/>

An online Self-Directed Services Policies and Procedures Manual is also available on the same website.

## **ADULT DAY SERVICES**

Adult Day Programs offer opportunities for employment, day program, self-directed day services, or a blend of these service models. The New Jersey Division of Vocational Rehabilitation Services (DVRS) help individuals with intellectual/developmental disabilities who are in search of employment by conducting an evaluation to determine if a person is eligible for DVRS services. Access related links on the DDD Home Page: <http://www.nj.gov/humanservices/ddd/>

## **RESIDENTIAL SERVICES**

Group homes, supervised apartments, supportive housing, community care home are some of the residential options available to persons with intellectual/developmental disabilities when the need becomes apparent. Individuals transitioning to a residential placement will be required to contribute to the cost of their care, including food, shelter, etc. This is known as the “contribution to care” and is summarized in NJAC 10:46D within the Division Circular 3A, which can be accessed at <https://www.state.nj.us/humanservices/ddd/providers/providerinformation/circulars/>



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## **CRISIS RESPONSE SYSTEM (CRS)**

The Crisis Assessment Response and Enhancement Services (CARES) provides statewide crisis response and stabilization services to individuals, age 21 and older, affected with intellectual and developmental disabilities, who are experiencing mental health or behavioral crises. CARES staff provide mobile response in an effort to avoid unnecessary hospitalizations. Technical support, training and connecting individuals, families, and service providers to pertinent resources are some of the services offered by CARES, which can be reached at 1-888-393-3007, 24 hours a day, 7 days a week.

## **THE DDD OFFICE ON AUTISM (OOA)**

The DDD Office on Autism (OOA) established in August 2010 provides a centralized location for DDD staff to address challenges associated with autism. Additional information, related links, as well as an autism guide (Autism: A Family Guide to Navigating NJ Service Systems for Individuals with Autism Spectrum Disorder and other Developmental Disabilities) can be accessed on the following website: <https://www.state.nj.us/humanservices/ddd/individuals/autism/>

## **CONTACTING DDD**

To email DDD, go to <https://www.state.nj.us/humanservices/ddd/about/contactus/emailus/> to access the email form.

Toll Free Number: DDD Information: 800-832-9173

Mailing Address: P.O Box 726, Trenton, NJ 08625-0726

For information on DDD eligibility or to access services contact the DDD Community Services Office, which serves your county.

## **HOW TO RECEIVE DDD UPDATES AND ANNOUNCEMENTS**

To subscribe to the DDD e-news bulletin, entitled Division Update, send an email to DDD. [Communications@dhs.state.nj.us](mailto:Communications@dhs.state.nj.us) with Division Update Subscribe in the subject line.

### **c. The Role of the DDS in Support of Individuals with Disability**

The New Jersey Department of Human Services, Division of Disability Services (DDS) provides access to information and services for all people affected with various disabilities throughout the state. DDS annually publishes a directory of available disability-related services and supports entitled, “New Jersey Resources,” as well as the “New Jersey Guide to Accessible Parking.” These guides, available in English, Spanish and audio, can be obtained in hard copy print by calling 1-888-285-3036, or electronically on the DDS website:

<http://www.state.nj.us/humanservices/dds/home/>

## **DDS SERVICES AND SUPPORTS**

- Information and Referral Services
- Traumatic Brain Injury Services
- Managed Long-Term Services and Supports (MLTSS)
- Personal Preference Program (PPP)
- Personal Assistance Services Program (PASP)
- NJ Workability
- NJ Achieving a Better Life Experience (NJ ABLE)
- Disability Health and Wellness Initiatives
- NJ Nurse Delegation Project

\* More detailed information about these services and supports is available on the DDS website listed above.

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#### **d. The Role of the DMHAS in Support of Adults with Complex Severe Behavior Conditions**

The NJ Division of Mental Health and Addiction Services (DMHAS) is the state mental health authority (SMHA) and the Single State Authority on Substance Abuse (SSA) that plans, monitors, evaluates and regulates New Jersey's mental health and substance abuse prevention, early intervention, treatment and recovery efforts. DMHAS is responsible for the operation of three regional adult psychiatric hospitals (Ancora, Greystone Park and Trenton), and one specialized facility providing maximum security (Ann Klein). All Hospitals are accredited by The Joint Commission on Accreditation of Healthcare Organizations (JCAHO). All three regional adult psychiatric hospitals are also certified by the Centers for Medicare & Medicaid Services (CMS).

In addition to the hospitals, DMHAS oversees New Jersey's adult system of community-based behavioral health services which is currently provided through the administration of third-party and fee-for-service contracts with private non-profit agencies and governmental entities. These agencies provide a full array of services, including substance abuse prevention and early intervention, emergency screening, outpatient and intensive outpatient mental health and addictions services, partial care and partial hospitalization, case management, medication assisted treatment for substance abuse, and long and short term mental health and substance abuse residential services, in addition to other evidence-based practices such as the Program for Assertive Community Treatment (PACT), supported employment and education, and supportive housing. DMHAS is in the process of moving to a managed care environment.

The DMHAS has primary screening centers and affiliated psychiatric screening centers in each of the 21 counties throughout the state. In order to be admitted to an inpatient short-term facility inpatient psychiatric unit the individual needs to be screened at a screening center and committed. There are no direct admits to inpatient involuntary units from the community. DMHAS and DDD provide braided funding for Crisis Assessment Response and Enhanced Services. More detailed information about DMHAS can be found on their website: <https://www.state.nj.us/humanservices/dmhas/home/>

#### **D6. The Role of the Valued Team in Support of Persons with Complex Severe Behavioral Health Conditions**

##### **a. How Can the Individualized Education Program (IEP) be Utilized to Help Children with I/DD?**

The purpose of the IEP is to identify school-based supports that children need in order to be successful in the classroom. For children who have special needs, there are particular protections to make sure that they receive evaluations, proper classification and necessary services. For the child with complex severe behavioral health conditions, this may include support 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 [https://www.nj.gov/education/specialed/form/prise/RevisedParentalRights\(PRISE\).pdf](https://www.nj.gov/education/specialed/form/prise/RevisedParentalRights(PRISE).pdf)

Note: As of July 10, 2021, the Parental Rights in Special Education (PRISE) is available in the following languages: Spanish, Arabic, Chinese and Portuguese. <https://www.nj.gov/education/specialed/form/prise/>

##### **b. The Individualized Service Plan (ISP) and Interdisciplinary Team (IDT) in Support of Individuals with Complex Severe Behavioral Health Conditions**

Adults who are eligible for the Medicaid-based, fee-for-service system and wish to access Division-funded services can select or will be assigned to a Support Coordination Agency (SCA). To assist individuals and families in selecting a SCA, the Boggs Center on Developmental Disabilities has created two helpful guides: "Selecting a Support Coordination Agency: A Guide for People with Disabilities" and "A Guide for Families," available on both the DDD website: <https://www.nj.gov/humanservices/ddd/>

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and Boggs Center On Developmental Disabilities website: <https://rwjms.rutgers.edu/boggscenter>, along with related forms. The Support Coordination Agency assigns a Support Coordinator to work with the individual and his/her family to ensure completion of the Person-Centered Planning Tool (PCPT) and to develop the Individualized Service Plan (ISP).

Every individual also has an Interdisciplinary Team (IDT) that consists of the individual receiving services, the plan coordinator, the legal guardian, and may include the parents or family member, advocates, staff and other service providers and friends at the preference of the person served who are relevant to the identification of the individual's needs and preferences and the design and evaluation of programs to meet these needs and preferences.

The IDT can convene to develop an Individualized Support Plan (ISP) or they can be convened to discuss changes in supports when the need arises. The ISP is based upon individual values and preferences and meaningful activity. Utilize the ISP to identify and support behavioral health needs and utilize the IDT to respond to the person's changing needs. Behavioral health challenges can produce added stress and anxiety for the individual and interfere with school, work or relationships--utilize the ISP to address all of the person's needs.

Before and after a behavioral crisis, the IDT can meet to coordinate relevant resources and advance the best needs and interests of the individual.

### **D7. Everyday Supports for Individuals with Complex Severe Behavioral Health Conditions**

There are things that we can do on an everyday basis to support individuals with complex severe behavioral health conditions. Among the more important things is that we all need to feel control over our lives (choice), we need to feel understood (voice), we need opportunities for meaningful activity (school, work and recreation) and we need personal connections (family and friends).

Individuals without disabilities can often access these basics on their own. Many individuals with disabilities do not have ready and easy access to the basics. How can we support individuals on a daily basis who live with disabilities and mental health needs? Consider the following:

- **Functional Communication**

If the person is a non-traditional communicator, has there been an assessment to determine if there is augmentative assistive technology and augmentative and alternative communication (AAC) devices, visual communication systems such as Picture Exchange Communication System (PECS)<sup>®</sup>, sign language or some other way in which the person can learn how to indicate needs and preferences, let others know that he or she needs help or is in pain?

- **Establish Positive Routine**

Individuals feel secure and less anxious when there is a daily schedule of meaningful activity and contact with others.

- **Increase choices**

- **Provide opportunities for work and play**

- **Ensure opportunities to remain connected to family, friends and community**

- **Offer skills building to increase personal confidence and effectiveness**

For more information, see the PowerPoint: Everyday Supports of Individuals with Dual Diagnosis in the Appendix Section

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## E. Crisis Assessment

The following section contains general considerations about behavioral crises.

### E1: How to Assess if this is a crisis situation

#### a. What is a Behavioral Crisis?

Crises occur when an individual and/or a system of care are overwhelmed. This is not “business as usual;” it is when the individual can no longer effectively cope with stressors and his supports can no longer effectively support his behavior. This section defines behavioral crisis and reviews the elements that contribute to crisis such as 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 complex severe behavioral health conditions.

A person is in a behavioral crisis when he/she acts in a way that is unsafe and he 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 “normal” behavior, in other words, behavior that is normal for them.

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

Because of this severe 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 your relative will lose his/her job, school, day program, or residence. People around your relative are likely to become concerned about his/her lack of self-control and may worry about someone getting hurt.

#### Ask yourself the following questions:

1. Has the individual lost control?
2. Is he/she unable to follow instructions to calm down?
3. Is there a strong possibility that someone could be hurt physically?
4. Is someone in immediate danger because of this out-of-control behavior?

*If the answer to any of these questions is “Yes”, the person may be experiencing a serious behavioral crisis and you should seek assistance in handling the situation.*

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

- A strong demonstration of non-compliance with routine task requests, such as refusing to take the usual, prescribed medications, taking medication inconsistently or “checking” medication to avoid swallowing it;
- Sleeplessness or dramatic changes in appetite compared with usual, characteristic patterns sleeping and eating;
- 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 violent physical action;
- Changes in the person’s emotional and/or physical demeanor that might indicate anger, frustration, confusion, fear, or a general threat;

- Displays of violence such as biting oneself or others; hitting, kicking, or punching another person or the wall; or, pulling hair or another similar attempts to cause harm to oneself or others;
- Any type of inappropriate behavior that appears to be a departure from the characteristic baseline, becomes more frequent and intense than usual.
- To address individuals of all subsets, many additional examples would need to be included.

### Prevention is the Best Intervention for Behavioral Crisis

The best way to manage behavioral crises is to prevent their occurrence (or if the individual has already been in crisis) prevent its recurrence. 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 different services and supports might be relevant to different stages of development during childhood, adolescence (transition age), adulthood and old age. To avert crises, the individual, his family, school personnel, employers, direct support professional, service providers and healthcare professionals need to be equipped with the knowledge, attitudes and skills needed to advance the quality of life despite behavioral challenges. This may include learning skills, understanding the unique challenges of developmental disabilities, understanding the unique needs of someone with a complex severe behavioral health condition, 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 youth (under 21 y/o) contact Mobile Response Stabilization Services (MRSS) by dialing PerformCare at 1-877-562-7624.**

For adults (21 y/o +) contact **Crisis Response and Enhancement Services (CARES) at 1-888-393-3007**. For more information about CARES please follow the link to the PowerPoint: ***NJ Crisis Response for Adults with Intellectual and Developmental Disabilities*** in the Appendix Section of this Handbook.

### Master-level Clinician for CARES: Helen McGhee

*I have been working with individuals with Intellectual and Developmental Disability and Behavioral Health challenges for fourteen years and after speaking with clients, their families and agencies it seems to be increasingly difficult to consistently provide the same level of quality services. Families, service providers and clients report a lack of appropriate day programs, recreational activities and mental health professionals, particularly psychiatrists. As resources continue to shrink it has become increasingly important to maintain good lines of communication among all parties involved in providing care as “brainstorming” can often provide leads and help resolve some of the challenges. The following example illustrates this:*

*“J” was referred to the crisis team due to concerns about his safety in the community. This individual lives in his own apartment without supervision and has a history of depression and of making suicidal comments in the past. There is also a recent history of suicide in the family. He works one day a week in the community and does not attend a day program. He tends to isolate, does not always take his prescribed medications and does not always respond to phone calls. The crisis response team worked with him, his Support Coordinator, and mother to identify and address his needs and identify relevant resources in the community. The crisis clinician is working with “J” on developing coping skills to use when he becomes frustrated (rather than making suicidal comments) and makes recommendations to his Support Coordinator regarding specific mental health day programs that she was not aware of. The clinician also recommended a higher level of support to ensure “J’s” safety. The Support Coordinator is currently working on having a support person visit him daily and will explore the possibility of “J” attending a mental health program four days a week. “J” has mentioned wanting to move to a supervised apartment program (he has a specific program in mind) and the Support Coordinator will look into this option as well. “J’s” mother is in support of this plan and will encourage him to attend the day program and to accept in-home supports.*

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## **b. How to Assess the Severity of the Crisis?**

At the onset of a behavioral crisis, you must assess the level of danger to the individual and to others in the environment.

## **c. When to call 911 or a clinical crisis team?**

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

When usual containment methods and approaches are not working and the individual behaves in a way that is dangerous to themselves (self-injurious, attempting suicide, eloping) or others (assault, property destruction), it is time to call 911 to make sure the individual and other can be safe. You should not call 911 about something that has happened hours ago and is not an active issue and do not call 911 because you are worried something might happen. This is an emergency response for when someone is behaving in a dangerous way and needs further assessment within a supervised setting.

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

**For adults over the age of 21 who are clients of the N.J. Department of Human Services (DHS), Division of Developmental Disabilities (DDD) or have intellectual and developmental disabilities:**

**Contact Case Assessment Response and Enhancement Services (CARES): 1-888-393-3007**

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), or you can call CARES to report an individual’s crisis regardless of where or when the crisis is occurring. This service is for adults 21+ years old who have an intellectual or developmental disability and behavioral health challenges.

Taking this step might help to avoid an unnecessary emergency room visit. The CARES clinician can assist the family through telephone support as well as through face-to-face intervention. CARES also responds to crisis calls when the situation does not involve imminent danger.

If the individual is behaving unsafely and you have called for emergency assistance by dialing 911, you can also call CARES and inform them that your relative is en-route to the emergency room or crisis center. A CARES clinician can become involved in your relative’s care soon after he/she arrives at the hospital, can interact with emergency room and crisis center personnel, and can begin planning for future behavioral health management. CARES is funded by the New Jersey Department of Human Services Division of Developmental Disabilities (DDD) and the Division of Mental Health and Addiction Services (DMHAS) to provide clinical outreach and crisis response and follow-along.

**For individuals under 21 years of age who are served by N.J. Department of Children and Families (DCF), Children’s System of Care (CSOC):**

**Request Mobile Response Stabilization Services (MRSS) by calling PerformCare at 1-877-652-7624.**

If the person has already 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.

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If your relative resides in a group home or receives residential support, staff may call 911 in the event that your relative behaves in a dangerous manner. This is the legal responsibility of the provider agency according to Danielle's Law.

#### **d. Danielle's Law**

Danielle's Law (see Appendix for more detailed information) was designed to make sure individuals with disabilities are not harmed through neglect or failure to obtain needed care. It was originally designed to ensure that individuals receive needed medical care but has been extended to behavioral health services, as well. 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. Many people are presented to the emergency room each year unnecessarily because of this misunderstanding. You should do something if someone has a behavioral problem but going to the emergency room is not the only response or necessarily the best response. Offering people relevant supports works better than unnecessary emergency room visits.

### **F. What to do in the Event of a Crisis?**

#### **F1. You Have Called 911, 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, try to 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. This will alert the police, who are usually the first responders, to avoid unnecessary force. This includes not having weapons drawn upon arrival, if they know the person is aggressive. If a relative is available to meet the emergency personnel before entering the home, restate that the person in crisis has developmental disabilities.
- 4 Other individuals who do not need to support the person in crisis should leave or be moved to a safe area.
5. If the individual in crisis needs emergency medical services, ambulance transportation will be arranged. You can follow the ambulance to the hospital in your own vehicle.
6. If you have already filled out the **Portable Emergency Plan** template located in the Appendix Section of this Handbook, or if you already have an Emergency Plan notebook or folder, take it with you to the hospital. **(Detailed information about how to create an Emergency Plan can be found in the Planning for the Future section of the Handbook.)**
7. The individual may calm down before the police arrive, or when they arrive. However, it is also possible that he or she may become even more distressed or agitated at the sight of first responders. The police will assess the situation and if they believe your relative does not present a danger to self or other, they will not transport your relative to a hospital.

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## F2. What Strategies May be Helpful to You if You are Dealing with a Crisis?

Working with a behavior specialist to identify the precursor signs of a person's challenging behavior is a good place to start. This approach includes exploring; developing and implementing strategies to decrease these severe behaviors and increase appropriate behavior. It is equally important to take a close look at how behavior management plans are carried out to ensure that there is consistency across all environments, and that the caregiver's own behavior is not reinforcing the inappropriate behavior. The following strategies might prove effective in helping maintain control:

1. *Do your very best to remain visibly calm.* Any type of overreaction, for example, yelling, crying, fearful expressions, unexpected quick movements, etc., can intensify the individual's loss of control. In addition, assigning blame; 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.
2. *Use of a time-out procedure* giving the person the opportunity to calm down, and regain his/her composure. It also might provide the family/caregiver with a chance to regroup, and consider the next steps to take.
3. *Teaching the individual breathing exercises* to reduce their anxiety can be an effective coping skill for them, and at times help defuse a tense situation. Remember to teach these skills when the person is calm and not upset.
3. *Changing the environment* by going out for a walk, taking a soothing bath, or providing any type of preferred activity opportunities, prior to the exhibiting of challenging behavior(s) can help reduce an individual's stress/anxiety level. This strategy can also serve to address a person's frustration from boredom, an often overlooked contributing factor for the onset of severe behavior.
4. *Ignoring certain inappropriate* behaviors and not calling attention to them, 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, (for example: 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 which previously might have resulted in very aggressive behavior. In order to learn more about this approach, you can take a course on approaches to everyday management of difficult behaviors or seek the advice of a behaviorist. *Keep in mind that challenging behavior is being ignored, not the person.*

### Additional Techniques and Methods:

Teaching individuals coping skills to avoid the escalation of severe behavior is an ideal goal. Labeling feelings so that the individual develops a better understanding of their emotions is key, combined with providing the person with appropriate ways to express their anger and/or frustration. In some cases, this can be accomplished through the use of social stories, professional counseling, behavior therapy, a customized augmented communication device (For example- iPad, communication board, etc.).

It is important to make sure that the individual has meaningful preferred activities to participate in on a routine basis (For example- social, educational, physical fitness, vocational training, employment opportunities, and community service participation). Understandably, boredom can be a contributing factor to an individual's acting out. Keep in mind that a person's demonstration of inappropriate behavior can be a means of drawing attention to themselves as a sign that they wish to be engaged in some favored activity.



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### F3. 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 and to complete a general information form. This part of the emergency room visit will be easier if you have a Family Emergency Plan with you. (The Plan is described more fully in the Appendix Section of this Handbook)
2. You will be required to provide information regarding the person's health insurance, including Medicaid and/or Medicare.
3. If you are the legal guardian for your family member, you should be prepared to produce a copy of the official court document.
4. It will be helpful if you can provide updated contact information for your relative's professional support team including doctors, therapists and staff from the community provider organization.
5. The emergency room physician will inquire about the individual's official diagnosis and medical history.
6. The emergency room physician probably will ask you about the circumstances that led to the emergency room visit. It also will be helpful if you can share pertinent information about recent changes including 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 or change in medications, any significant events at work or at home including the deteriorating health or death of a family member or the loss of a well-liked neighbor, co-worker or direct care staff person.
7. The emergency room physician will conduct a routine physical exam to rule out major medical problems that might be contributing to your relative's behavioral crisis. Inform the doctor of any changes in your relative's medical condition, including dental-related issues. Remember to discuss the potential need for conducting blood work.
8. You may want to remain with the individual through all the examinations in the emergency room, especially if he/she is non-verbal, minimally verbal, or has communication problems.

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

### F4. Why is a Medical Evaluation Needed?

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

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

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

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## **F5. Why Must You Wait in the Emergency Room?**

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

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

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

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

If possible, while waiting in the emergency room, contact your 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.

## **F6. What to Expect at a Psychiatric Screening Center?**

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

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

A crisis screening clinical 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.

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

## **F7. What are the Criteria for a Psychiatric Hospitalization?**

The criteria used to determine the need for psychiatric hospitalization is based on whether or not the individual presents a danger to themselves, others, and/or property.

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

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## Medication to manage the crisis

- Your relative may be given a short-acting psychiatric medication often referred to as a “PRN.” PRN refers to a medication that is given on an as-needed basis to help an individual become calmer and less agitated while in the emergency room.
- It is possible that as the PRN’s sedating effects wear off, your relative may feel confused and disoriented and become agitated again.

## Mechanical restraints to ensure safety

- If your family member is exhibiting extreme agitation or dangerous behavior, emergency room staff may place him/her in mechanical restraints.
- It is true that 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, especially if your relative is unfamiliar with hospital settings, uncomfortable around strangers, or unfamiliar with restraints.
- In lieu of mechanical restraints, you may request that trained security staff be added to your relative’s care as support to the hospital staff.
- At any point that you feel confident that your loved one has gained a more subdued demeanor and is in control of his/her actions, you may ask the ER staff to remove the mechanical restraints.
- In all cases, however, the decision to use mechanical restraints ultimately rests with the hospital personnel.

## F8. What if an Individual Needs to be Hospitalized?

### a. Levels of Hospitalization

If it is determined that the individual will benefit from psychiatric hospitalization, he/she will be assigned to a level of hospitalization based on treatment needs. Adults, 21 years of age and over, 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, he/she may then be transferred to a county or state hospital. While treatment in a county or state hospital is not always a family’s first choice, it will permit your relative to receive longer-term care than that is available on an STCF unit.

### b. 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 a STCF. Adults who are their own guardians can sign themselves into treatment and court-appointed guardians can sign-in their ward for voluntary admission. However, Bureau of Guardianship Services workers, who are employees of the Department of Human Services, are able to serve as court appointed guardians for individuals’ eligible for DDD services, and are not able to sign-in individuals. These options do not apply to children under the age of 21.

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

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### **c. 2D - The Specialized MI/DD Unit at Trinitas Regional Medical Center**

Trinitas Regional Medical Center has a specialized inpatient psychiatric unit (2D) for adults (21+) with developmental disabilities as well as behavioral health conditions. This 10-bed unit, which is located in Elizabeth, is the only community hospital-based short-term, acute care psychiatric unit in New Jersey dedicated to the treatment of adults with complex severe behavioral health conditions. The individuals who are admitted often cannot be treated successfully on an outpatient basis because of the severity of their behavior. Individuals must meet criteria for hospitalization based on dangerousness to self or others. Individuals can enter the unit from any crisis or screening center in New Jersey. As of this writing, the average length of stay on the specialized Mental Illness/Developmental Disabilities (MI/DD) unit at Trinitas Regional Medical Center is approximately 15 days.

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

Children (under the age of 21) also are screened for hospitalization at their local screening and crisis centers. The commitment law does not apply to children, so they are not committed to treatment. If they are eligible for hospitalization, there is a statewide search for an available placement in Children's Crisis In-Patient Services (CCIS). Trinitas currently has eight beds on its Child and Adolescent In-Patient Unit that are dedicated to short-term treatment for children with developmental disabilities and behavioral health challenges. CARES is not involved in the hospitalization or follow-up of children or adolescents who are under the age of 21. Screeners can obtain information about the availability of MI/DD beds for children and adolescents by contacting Trinitas' psychiatric screening services.

### **d. What If Your Insurance Company Will Not Pay?**

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

### **e. Diverting Your Relative from a State Psychiatric Hospital**

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

Recently, the state psychiatric hospitals have given priority to taking individuals from the STCF units who need longer-term care in order that people in the emergency rooms can be directly admitted to STCFs for observation. This lessens the likelihood that someone will be transferred to a state hospital directly from the screening center. It also reduces the likelihood of a state hospital admission for someone experiencing their first hospitalization. This creates an opportunity for determining if an individual can be stabilized on a short-term care unit without being transferred directly to a state hospital from the emergency room.

### **f. How is an Individual Committed to Involuntary Care?**

Involuntary psychiatric commitment is a legal status. The first step towards that legal status is taken when a

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certified screener and psychiatrist separately conduct face-to-face evaluations of an individual. Based on these evaluations, a determination is made whether the individual has a mental illness and/or may be dangerous to self, others or property. If so, the screener and psychiatrist complete certifications and the individual is sent to in-patient psychiatric care, usually a short-term care facility (STCF).

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

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

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

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

The law states that at least 10 days before the full hearing, the patient or the patient's family, guardian or legal representative should receive notice of the date, time and location of the court hearing and with copies of the clinical certificates and supporting documents, the temporary court order, and the statement of the patient's rights at the hearing. These hearings are held at the facility to which the individual has been committed.

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

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

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

#### **g. What To Do If You Object**

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 inpatient care or 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.

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

Once a date has been set for a full hearing, you can call the county adjuster and obtain the name and telephone number of the attorney who will be assigned to represent your relative. Contact 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.

### **Self-Advocate: Christopher and his Sister/Legal Guardian, Donna, Comment Following Christopher's Crisis and Subsequent Admission to a State Psychiatric Hospital:**

*Christopher: "It felt like a bad dream you could not wake up from."*

*Donna: "Heart wrenching that there wasn't any way to help him in there. It was the worst feeling ever."*

#### **h. Alternatives to Hospitalization**

No one disputes that psychiatric hospitals are important resources for individuals who need in-patient management of a severe psychiatric illness. Hospitalization, however, is not always the appropriate response to a behavioral crisis. If your relative is displaying behavior problems that do not constitute a danger to self or others, the best place to manage the crisis may be at home or in a specialized community-based program.

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

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

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

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

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

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### i. What if an Individual Does Not Need Hospitalization?

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

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

### Additional Options

At the point of the writing of this Handbook, there are limited but growing numbers of relevant supports available through DDD and DMHAS.

Although CARES is the only statewide crisis response program, several programs in the state offer local crisis support services.

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

### j. What if You Are Not Able to Support Your Relative at Home?

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

1. If your family member is eligible for services from DDD, notify your family member's DDD case manager or 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. Planning is essential. It is wise to avoid seeking a permanent, out-of-home placement for your relative during times of crisis. Because of the emotional distress you and your relative will be experiencing, the middle of a crisis, it is not the best time to make such long-term decisions. Placements should be developed based on your relative's long-term needs, not just on what is immediately available.
3. **For adults (21 and over) 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 provide information to help families recognize the symptoms of mental health and behavioral disorders. They also can help caregivers create an individualized response plan.
4. **For youth, 21 and under, at risk, PerformCare may authorize Mobile Response Stabilization Services (MRSS) to come to your home within one hour of notification to provide face-to-face crisis services.** The goal is to stabilize behavior(s) and keep your child at home. Mobile response is available 24 hours a day, seven days a week, and can offer up to eight weeks of stabilization services. Contact PerformCare at 1-877-652-7624 to discuss if mobile response stabilization services are an appropriate next step for your child.

Crisis Assessment Response and Enhanced Services (CARES), which is the state-funded clinical outreach team for crisis response and clinical follow-up for adults (age 21+). The CARES team can become involved with the individual with mental health needs before it reaches a point of crisis and the team can follow the individual whether a mental health crisis is averted or not for 120 days. Call the toll-free hotline 1-888-393-3007 in order to receive further guidance. For additional information refer to the PowerPoint: *CARES: NJ's Crisis Response for Adults with Intellectual and Developmental Disabilities* in the Appendix Section of the handbook.

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## Family Member: Debbie

*When Paul would go into crisis our biggest fear was about keeping him safe. We knew we needed help. We couldn't do it alone. The most painful and hardest decision we have ever had to make was to place Paul in a residential behavioral stabilization program. But we knew it had to be about Paul...and getting him the help he needed with trained professionals to monitor his behaviors 24/7 in a safe setting. He needed an intensive treatment plan to get him back on track again, so we could once again see his face break into his beautiful smile. Our dreams and goals for Paul are rooted in our deep desire to see him happy, and living his life to its fullest potential. We will always be there for Paul...every step of the way...loving and supporting him. He is the best son a mom could ever have...and he deserves every opportunity that life has to offer to make a better life a genuine reality for him.*

## G: After the Crisis is Over

Whether the individual with disabilities is hospitalized or not and whether the crisis was related to behavioral health issues or not, all stakeholders can learn from the experience of crisis to fashion better supports and services in the aftermath of a crisis. This section will overview how to evaluate what has been missing in the support of the individual to better inform planning and delivery of supports and services and avert future crises. Crises affect everyone involved with the individual in crisis. There must be ways to support housemates, friends, family members and staff who have witnessed and were impacted by the individual's crisis. The section will also overview the supports needed by families, direct support professionals, school personnel and service providers to manage their own response to better cope in the aftermath of a crisis.

### Steps to take following a crisis

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

1.If the individual is eligible for services from the New Jersey Department of Human Services, Division of Developmental Disabilities (DDD), request an emergency interdisciplinary team (IDT) meeting from the DDD Case Manager or Support Coordinator. If the person is served by the New Jersey. Department of Children and Families, Children's System of Care (CSOC), request that the assigned Care Management Organization (CMO) Care

Manager schedule an emergency Child and Family Team (CFT) meeting, including school program personnel if possible. After a crisis event, it is essential for you to work closely with the individual's support team of doctors, therapists, teachers, direct care support professionals, et.al.

- 2.Take the lead in suggesting a re-evaluation of the person's behavior plans, medication regimen, and current supports; encourage the IDT to explore new therapeutic options and untried resources.
- 3.Share information among the various support services specialists. This is ultimately the caregiver's responsibility. 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 21-year-and-over 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 under 21-year-old 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 the individual appears to need a change for some other reason such as difficult side effects.



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- B. New medication can initially be sedating. This does not necessarily mean that the person is over-sedated. Medications can take time to reach optimal effectiveness.
  - C. There occasionally may be problems caused by the interaction of multiple drugs. The caregiver should keep a log of what appear to be the side effects from medications and share this information with the provider who prescribed the medication.
  - D. Medications should be prescribed according to a formal diagnosis made by a qualified professional and includes the person demonstrating symptoms that meet the criteria for that specific behavioral health disorder. Investing the necessary time and effort to arrive at a formal diagnosis helps to establish the primary cause of the individual's challenging behavior and allows for more effective medication management to reduce or resolve their symptoms. Prescribing medication(s) solely on the basis of symptoms may place the person at risk by not addressing the root cause of their severe behaviors, and therefore, delaying the progress they could be making. This can also lead to prescribing more medications than are necessary, as well as unintentional but inaccurate dosing practices.

## G1. Stabilization

Stabilization refers to the period following a crisis when an individual can return to their usual activities and behaviors. They are no longer actively in a crisis situation, and the danger has passed. Many individuals are able to return to school, work, and their usual activities, responsibilities and interests at this time. 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 Complex Severe Behavioral Health Conditions?

#### Donna offers a family member's perspective regarding this important decision-making process:

There are circumstances when a loved one affected with complex severe behavioral health conditions, regardless of their age, requires an out-of-home intensive therapeutic treatment program to address the highly complex and severe behavioral challenges she or he is facing on a routine basis. But how and when does a parent/legal guardian know when this is the appropriate next step for their relative? Of course, every individual's special needs and environmental situation are as unique as themselves. However, there is still a common thread of behavioral experiences that connects our children, including what is sometimes required to more effectively deal with acute and persistent problem behaviors such as:

- Aggression
- Self-injurious behavior
- Disruptive and destructive behavior
- Restrictive and repetitive behavior
- Pica
- Elopement

*The best advice and guidance that I can provide is based on my own personal experience with my son, Michael, now thirty-six years old, as well as the countless numbers of families I have worked with over the past seventeen years. A few months after Michael's ninth birthday, he began exhibiting mild aggression, coupled with a moody demeanor, and an increased level of anxiety and frustration which he had never demonstrated before. It appeared that the more we proactively tried to manage Michael's problem behaviors, utilizing recommended techniques from behavior therapists, the more demanding Michael became, and the more likely he was to utilize aggression to obtain what he wanted. The power struggle that ensued produced no winners. As Michael's non-compliance increased, and he attempted to control multiple situations throughout the day (not getting out of bed for school, not wanting to get dressed, obsessively demanding food, refusing to engage in activities he previously enjoyed, etc.), we continued to prompt him to comply, and limit what we felt were his unreasonable demands. Unfortunately, his aggressive acts became more severe, longer in duration, and frequent.*

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*Within a year, my husband, daughter, and I had tried numerous behavioral strategies, jointly developed by his school and in-home behavior therapists, to help Michael gain control of his problem behaviors. Michael was taught relaxation exercises. We made recommended changes to his diet and tried vitamin therapy. I conferred with trusted Psychologists, Psychiatrists, Neurologists, Behaviorists with expertise in the field of autism, as well as his Pediatrician, and Dentist to make sure that his issues were not related to an undiagnosed health issue.*

*Just about everyone I spoke with explained that it was common for individuals with autism to begin exhibiting aggressive behavior around the time of puberty, and Michael was already showing signs that he had entered that phase of his physical development. But my instincts told me that there had to be more to it than that, particularly when no one seemed to know how to respond when I asked, "Will Michael's aggression subside when he gets through puberty?" Unfortunately, what was becoming more evident was that the severe behaviors he was exhibiting were becoming deeply entrenched, and therefore, increasingly harder to change.*

*Initially, I was not at all in favor of placing Michael on medication. But as our treatment options began to dwindle, I knew that I had little choice but to explore this option for Michael who was obviously suffering. His and our lives had been turned upside down. So out of sheer desperation, I agreed to place him on medication. Long story short, during the next three years, our son underwent a number of medication regimens under the care of a Psychiatrist, as well as one additional Psychiatrist who played a consulting role. The first medication prescribed had no effect on reducing Michael's aggressive behaviors. The second trial of two medications worked relatively well. However, before we knew it, the medication dosages needed to be increased periodically, and as a side effect our son's weight climbed to an unhealthy high level. Unfortunately, his substantial weight gain contributed to increased strength, which only served to further intensify his aggression. Not one of his physicians ever witnessed his extremely severe and unsafe behaviors. They relied solely on the accuracy of my detailed accounts during what felt like countless clinical appointments and phone calls.*

*Additional medications were tested to address Michael's symptoms, sometimes exacerbating his behaviors to crisis-level. I was advised by his Psychiatrist to call 911 in those instances. He explained that our son would be taken by ambulance to the local hospital, sedated with medication, possibly placed in mechanical restraints, and eventually discharged back home. I was alarmed that during a crisis, Michael's greatest time of need, that a hospital could offer him nothing in the way of assessment or viable treatment. So, we decided as a family not to enlist the help of emergency services. Looking back, we certainly took a tremendous risk in attempting to handle Michael's explosive behavior on our own. I believe we were just trying to do the very best we could under extraordinary circumstances that no one could control, least of all Michael, who suffered the most.*

*It took some time to come to the conclusion that Michael would be more effectively served by an out-of-home, longer-term behavioral stabilization program. It seemed that the more we tried to help Michael, the more we seemed to fall behind in resolving the behavioral issues that plagued him. These strategies were always well thought out and implemented as best as we possibly could under the circumstances. But they were also unsuccessful in providing a practical and sustainable solution to the debilitating behavioral challenges that were destroying the once good quality of life Michael had achieved within the circle of support, we had so diligently worked to create for him.*

*I finally saw the writing on the wall when Michael's Psychiatrist recommended that we begin to wean Michael off of his current medications, and trial a brand new one. In that exact moment, it was clear to me that Michael needed the type of clinical oversight and care that we could not provide in our home. I began to understand that by continuing down this path of endless medication trials, that the dangers and risks would be a great deal higher than we were prepared to handle. Despite our unwavering love and devotion to Michael, we were no longer equipped to help him after exhausting all other treatment options and resources.*

*My immediate refusal to put my son through another medication change, prompted the same Psychiatrist to inform me about the Children's Hospital of Philadelphia Bio-Behavioral Inpatient Unit (Please note: this program is no longer in existence). Michael's admission to this inpatient behavioral stabilization program at the age of thirteen was*

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*a life-changing experience for him. He was safely weaned off of all medications, evaluated and closely studied and monitored by a medical and behavioral team, who diagnosed Michael with bipolar disorder within his five-month inpatient stay. He was placed on the proper medication to address bipolar disorder, and an effective (thoroughly trialed) behavior management plan was implemented, which our family and Michael's out-of-home step-down behavioral stabilization program staff were trained to skillfully administer.*

*All in all, Michael spent a year away from home at two behavioral stabilization programs which offered an intensive, integrated, applied behavior analysis (ABA), data-based approach to decreasing his acute challenging behaviors that were extremely resistant to less intensive and comprehensive interventions that we tried in our home.*

*In retrospect, as difficult as it was to have Michael living away from home during this treatment period, the time and expertise invested in his treatment far outweighed the related emotional aspects we experienced. I now recognize in Michael's case that attempting to treat the symptoms he displayed without a definitive diagnosis was destined to fail. I have also found this to be true in my efforts to counsel families during their determined efforts to ease the overwhelming struggles of their cherished loved ones with complex severe behavioral health conditions, in order to maintain the overall well-being of the entire family. There are times when our children need more than what we can offer. Recognizing this and taking the appropriate solution-focused steps might make all the difference in moving their lives forward in a respectful and compassionate way that achieves not only positive but sustainable outcomes.*

**Please Note: Information about short and long-term Behavior Stabilization Programs for individuals up to the age of 21 can be found under the CSOC section of this Handbook. Information about the 2-D specialized MI/DD unit at Trinitas Regional Medical Center for persons, age 21 and over, can be found under the Hospitalization section of this Handbook.**

## **G2: Family Members Coping Together with a Behavioral Crisis**

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

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

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

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 toward developing strategies for helping your family member in crisis:

1. A family can work together to build a solid foundation of trust and mutual understanding. Exploring new strategic opportunities together can empower all family members and strengthen a family's resolve to face its problems together by identifying and obtaining needed supports.
2. All members of the family should be reassured that they are not alone in dealing with their loved one's challenges. Finding solutions will be a family effort, and families will become even stronger as their coping skills improve.

3. Seeking qualified 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 skillful professional resources. Your relative's wellness and recovery will best be achieved through a collaborative therapeutic treatment approach involving professionals and family members.
4. There is no shame or failure in seeking help from people outside your family. Sometimes neighbors, fellow congregants at your place of worship, or friends can be helpful in providing another perspective or actual support to you and your relative. **It is also advisable for families to contact their local police department to inform them about a loved one's behavioral challenges in the event 911 assistance is required during a crisis episode. This would help to avoid any unnecessary confusion and promote a more sensitive and successful de-escalation of the crisis situation.**
5. 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 crisis situations. Family-centered problem solving is an invaluable skill that siblings 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.
6. Families can "track behaviors" in a journal, which can serve as a great tool in evaluating medications (are they working or not?) and identifying trends, triggers or antecedents to problem behaviors.
7. By openly discussing the difficult challenges your loved one and each family member is experiencing, you have an opportunity to lessen a sibling's confusion and fear with sensitive and age-appropriate explanations.

### **G3. 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 Individualized Education Program (IEP) or Individual Support Plan (ISP) to make sure it reflects the individual's needs.

## **H. Planning for the Future**

### **H1. 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.

### **H2. The Ultimate Goal is to Prevent a Crisis**

By developing an individualized, practical plan for maintaining safety in an emergency, and by implementing the strategies outlined in the plan when a crisis arises, families and caregivers can lessen the negative impact of these events for individuals as well as for everyone present.

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

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, neighbors, etc. **Include the contact information for the local Police Department and police officers whom you have previously informed about the individual's behavioral challenges, in the event you need to enlist 911 assistance.**
2. A contact list of all the individuals who contribute to the care of the individual; for example, doctors, therapists, teachers, social workers, his/her DDD Case Manager or Support Coordinator, CMO Care Manager/Supervisor/Director, the provider agency management team, and direct support professionals.
3. All telephone and address information for the people listed above.
4. A list of any outreach support services that might be needed during an emergency situation. (i.e. CARES 1-888-393-3007, Mobile Response Stabilization Services (MRSS)/PerformCare 1-877-652-

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#### 7624 or CMO Care Manager/Supervisor.

5. Up-to-date medical information about the individual, including current daily medications, the reasons they were prescribed, the doctor(s) who prescribed them, dosages, special medical needs, allergy information, etc.
6. A one-page summary about the individual and his/her special needs. Include current program information, prior hospitalizations, and any important details that would help acquaint someone with the person's preferences, dislikes or fears. Include all information that you think you might need in an emergency.

#### Additional Suggestions:

- Make copies of the Emergency Plan notebook or folder so that it can be with you and the individual at all times.
- You may wish to also give copies of the Emergency Plan 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 or ISP.
- If the person no longer lives in the family home it is still advisable to establish an individualized emergency plan for his or her full-time residence. It is advisable to be prepared, because a crisis can take place anywhere, and at any time.
- 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 and items, 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 Guardianship, etc. (See Appendix for more information about Legal Guardianship)
- **The Portable Emergency Plan template can be found in the Appendix Section of this Handbook and should be included in the "Emergency Plan" notebook or folder.**
- **A copy of the NJ Department of Health (DOH) "Hospital Visitation Policy" pertaining to individuals with intellectual/developmental disabilities can be found in the Appendix Section of this Handbook and should be included in the "Emergency Plan" notebook or folder.**

Once you have developed the Emergency Plan it is recommended that you review it with members of the individual's interdisciplinary and/or child study team, clinicians involved in the person's treatment, in order to incorporate their suggestions. 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 effectively follow its instructions 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 Information can be accessed online at <https://www.autismspeaks.org/tool-kit-excerpt/planning-crisis>

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## Family Member

*When our son was in his teens, he watched as his father cut limbs and pulled at the roots of invasive mimosa and mulberry trees. They take over quickly and are hard to remove. One mimosa had a tangled root system nearing the foundation of the house. His father observed that you have to admire the tenacity of this very hardy plant. Our son said, 'I'm like a mimosa. I just keep living and growing no matter what happens.'*

### H3. A Life Plan

Sometimes families put off making future plans for a loved one affected with complex severe behavioral health conditions, 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 also serve as a painful reminder to a parent or guardian about their own mortality, producing dreaded thoughts 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. They might 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 (for example, family; friends; educators; instructors; clinicians; community service provider personnel; direct support professional; 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. The following are some recommended preliminary questions that can be explored as the individual and his or her support team begins creating future plans:

- 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:

1. Employment opportunities, including supported employment (i.e.: job coach or crew), vocational training and job sampling.
2. A residential setting that is considered the most appropriate for the individual.
3. Social activities, including joining clubs, attending creative skill-based classes, special community events, dances, etc.
4. Day and overnight trips, exploring a local or nearby town or city, attending local festivals, sightseeing bus or walking tours, etc.
5. Educational and instructional courses and classes (i.e. college-level, computer science, dance, music, art, etc.).
6. Physical fitness activities, exercise programs, participating in the Special Olympics Program, etc.
7. Participation in a faith community, and regular attendance at religious services.
8. Increasing and refining self-help and daily living skills (i.e. cooking, chores, etc.).
9. Developing a hobby or other special interests.
10. Community service projects and other volunteer opportunities.
11. Pursue an interest in Self-Advocacy (Self-Advocacy Resources listed below and be sure to review the Advocacy Section of the Handbook beginning on page 64).

Keep in mind that a life plan should reflect the desires and interests 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. But 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

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had ever imagined possible for your loved one...all because you seized upon the opportunity to creatively and respectfully help them plan their future.

## Self-Advocacy Resources

*Autistic Self-Advocacy Network (ASAN): “A Self-Advocacy Guide to Managed Long-Term Supports and Services.”* <https://autisticadvocacy.org/policy/toolkits/mltss/>

*“An Advocate’s Guide to the NJ Legislature” (Self-Advocacy Series)* <https://disabilityrightsnj.org/> under Publications. Developed by Disability Rights NJ (DRNJ), this self-advocacy guide was created to assist and inform individuals with disabilities, their family members, and other persons, and organizations interested in working with the NJ Legislature.

*“Self-Advocate’s Guide to Choosing a Post-Secondary Program: Charting Your Course Through a New Landscape”, published by The Boggs Center on Developmental Disabilities (English and Spanish)* <https://rwjms.rutgers.edu/boggscenter/publications/Self-AdvocatesGuidetoChoosingaPost-SecondaryProgram.html>

*“Voting: It’s Your Right”* is a guide developed by the Boggs Center on Developmental Disabilities about voting rights and the voting process in NJ for People with Intellectual and Developmental Disabilities <https://rwjms.rutgers.edu/boggscenter/products/VotingItsYourRight.html>

## Life Plan Resource: Charting the LifeCourse Framework and Tools

In 2019, New Jersey joined the *National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities*, a national initiative to develop systems of support for families across the lifespan of their loved one. **Charting the LifeCourse framework and tools** were created by the University of Missouri-Kansas City Institute for Human Development in partnership with families. The goal is to empower people with disabilities and families to communicate their vision for a good life and to help professionals and systems to ask the right questions, listen, and act on strategies that support reaching this vision.

The New Jersey Division of Developmental Disabilities (DDD), New Jersey Council on Developmental Disabilities (NJCDD), and the Boggs Center on Developmental Disabilities are collaborating to increase awareness in our state of the Charting the LifeCourse framework and tools. A cross-system stakeholder group was convened to develop strategies for educating stakeholder communities and instilling the core principle that *“all people have the right to live, love, work, play and pursue their life aspirations in their community.”*

Various tools and publications are available in the follow link: <https://www.lifecoursetools.com/>

The first edition of the *Charting the LifeCourse New Jersey Newsletter*, was published in Spring 2021 via the following link: <https://rwjms.rutgers.edu/boggscenter/publications/documents/ChartingtheLifeCourseNJNewsletterSp21.pdf>

### **MY GOAL AUTISM**

My Goal Autism offers grants to support families caring for loved ones affected with autism who are residing at home. The “enrichment grant program” helps families take advantage of socialization and educational opportunities designed for individuals with special needs. The “Family Grant Award Program” is a need-based grant for covering medical, nutritional, or personal need expenses. For more information about grant applications, please consult the My Goal Autism website at <https://mygoalinc.org/> or call 1-877-886-9462, or write to the organization: MY Goal Autism, P.O. Box 531, Monmouth Junction, NJ 08852.



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## Ten Things I Know for Sure About Raising a Multiple-Disabled, Medically Fragile Child into Adulthood

*Written by: Linda Zani Thomas*

The needs of children/adults with ID/DD/MI who have medical challenges are complex and require careful planning and watchful oversight. Some of the medical conditions these individuals may experience may include: seizures that are uncontrolled by medications, the need for tube-feedings, or breathing through tracheostomies and/or with the assistance of ventilators. Nevertheless, with appropriate supports and services, children and adults with ID/DD/MI who have medical challenges can thrive and attend day activities/programs, and live in a variety of housing situations, including their family homes. They are true survivors, warriors, who enjoy life and enrich the lives of those around them.

### **1. No Doctor Can Predict your Child's Future**

Only you can. Sure, the CAT scan may look bleak or statistics may lean toward a bad outcome, but I have seen even the sickest child not just survive, but thrive and live with happiness and joy.

### **2. Be Careful of the Company You Keep**

Be aware that others – even your closest friends and family members – will look at your situation from their own perspective. They may advise you based on what they think they could handle, not what you CAN handle. You and your family have been given this child because you've got this.

### **3. Do the Research**

Become an expert in your child's condition. The doctors you meet over the next many decades will most likely ask you for advice, especially if your child is nonverbal.

### **4. Explore all Alternative Treatments**

Medical marijuana has a profoundly positive effect on the developmentally disabled, especially those with seizures, pain and gastrointestinal problems. Nutrition, music and companionship of animals have also improved our children's lives. No matter what your religion, reach out to local churches to have your child's name included in their prayer groups.

### **5. Get a Babysitter...**

...and always have the next one ready to step in. Neighbors, teens and college students have all rotated through my daughter's life for the past 27 years, many staying on for years until school or college takes up their time. Force yourself to go out with your spouse or friends at least once a week not matter what.

### **6. Plan their Lives around their Intellectual Age**

Some children will stay children in terms of their IQ all their lives. Gear their activities to their developmental age not their chronological age, and then adapt the activity to their physical abilities and medical needs. Some adults will prefer Barney to Beyonce or Sponge Bob to Game of Thrones. Go with what they like.

### **7. Be a Problem Solver, Not a Problem Creator**

Always approach those who care for or teach your child in a positive, supportive manner and calmly handle problems that arise. This is going to be a challenge, I know, but trust me, it works. If you complain or bring a problem to people's attention, always present at least one solution for discussion. Ask if you can be part of the solution. Keep a written record of all interactions

### **8. Accept that your Child will be Naughty Sometimes**

All children – even those with severe intellectual and physical disabilities – will still go through the terrible twos and try to manipulate their way out of situations! Really look at your child's behavior to distinguish what is related to the disability and what is just good old refreshing, typical-child hijinks. Use safe timeouts and gentle talking to set limits and let them know you're on to them.

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## 9. Be Sure your Child is Well Dressed and Groomed

Professionals, doctors and other adults will judge your child's worth with their eyes. Be sure they are clean, well-groomed and as stylish as possible. Others see that your child is well cared for and will then tend to follow suit. The child will also take great pride in their appearance, adding to their self-esteem.

## 10. Choose Happiness

For yourself, for your family and for your multiply-disabled, medically fragile child or adult. They will lead you there.

## H4. Advocacy

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

The following are some ways to begin advocating on behalf of people with complex severe behavioral health conditions (CSBHC):

### 1. Familiarize yourself with the current system of crisis intervention services and share your findings

- a. Research all options; available resources, outreach services, state agency programs, and state legislative reform packages. Some of this information can be found in this publication.
- b. Discuss your findings with Paul Aronsohn, Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families. This office is responsible for the following:
  - Assisting individuals and families to navigate New Jersey's system of care to get the services and supports they need and deserve.
  - Working with individuals and families to identify opportunities for improving the system.
  - Helping to ensure that the voice of individuals and families is heard in a meaningful way in decisions that directly affect them as well as in larger policy discussions

**The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families website link: <https://www.disabilityombudsman.nj.gov/>**

Contact Information for Ombudsman, Paul Aronsohn: Email Address: [Paul.Aronsohn@treas.nj.gov](mailto:Paul.Aronsohn@treas.nj.gov)  
Office Phone: 609-984-7764, Mobile: 201-213-1811

Contact Information for Associate Director, Christine Bakter: Email Address: [christine.bakter@treas.nj.gov](mailto:christine.bakter@treas.nj.gov),  
Office Phone: 609-984-3981

The following link contains Ombudsman Paul Aronsohn's 2020 Annual Report, which was submitted to New Jersey Governor Phil Murphy, and State Legislative Leadership on April 12, 2021:  
<https://www.disabilityombudsman.nj.gov/documents/2020-Annual-Report.pdf>

***Mr. Aronsohn welcomes your comments and questions, regarding the annual report, as well as your recommendations.***

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- c. **Susanne Mills, Mental Health Ombudsman:** dmhas.ombudsman@dhs.nj.gov Office Phone: 609-438-4321.

## 2. Begin writing letters

Draft a letter describing your personal experience dealing with the present crisis service system.

- a. Include a summary of your family's crisis experience and highlight unmet needs and service gaps.
- b. Be sure to include suggestions you have about how to improve the current crisis service system.
- c. It is important for the letter to be written in an informative, courteous, and constructive manner. Abusive language or other expressions of anger may not be taken as seriously as constructive criticism aimed at improving the current system of care.
- d. This letter can be sent to any number of individuals including the Office of the Governor, State Government agency officials at the New Jersey Department of Human Services (DHS), New Jersey Department of Children and Families (DCF), the Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families, the Mental Health Ombudsman, and Outreach Organizations for People with Intellectual and Developmental Disabilities.
- e. A copy of your letter can also be forwarded to the hospital Crisis Screening Center management team; your DDD Case Manager or Support Coordinator, CMO Care Manager, and to State Government Representatives in the Assembly and Senate. Information about the State Legislature can be found at [www.njleg.state.nj.us](http://www.njleg.state.nj.us)
- f. Submit an Op-Ed letter to local newspapers.

**New Jersey Department of Human Services (DHS) oversees the following Divisions:**

- Division of Developmental Disabilities (DDD)
- Division of Medical Assistance and Health Services (DMAHS)
- Division of Disability Services (DDS)
- Division of Mental Health and Addiction Services (DMHAS)

**New Jersey Department of Children and Families (DCF) oversees the following Divisions/Offices:**

- Children's System of Care (CSOC)
- Division of Child Protection and Permanency (DCP&P) formerly DYFS
- Office of Advocacy (OOA)
- Institutional Abuse Investigation Unit (IAIU)

## 3. Address the issues facing individuals with intellectual/developmental disabilities in a public forum:

- Provide testimony at New Jersey State Government Public Hearings

Throughout the year, New Jersey citizens are given the opportunities to voice their concerns and to make recommendations in a variety of public forums. These may be sponsored by the Senate and Assembly Budget Committees, State Senate and Assembly Human Services Committees, the Departments of Human Services and Children and Families, and state convened task force, advisory, and workgroup committees. It is essential that the New Jersey State Legislature and State Department officials hear from stakeholders, in order to develop a better understanding of the systemic challenges faced by individuals with complex severe behavioral health conditions. After all, the State of New Jersey is offering its citizens an opportunity to make a difference in the lives of one of the most vulnerable populations of individuals in the state...and they in turn are depending on resourceful and determined advocates to work with state leaders to generate needed service, system and policy reforms.

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#### 4. Meet and speak to the Governor of New Jersey at scheduled Town Hall Meetings

To participate in one of Governor Murphy's upcoming virtual town hall meetings, which can host 1,000 participants for each event, complete a Town Hall Sign-Up Form available online at <https://covid19.nj.gov/forms/townhall>

Consult the State government website at [www.njleg.state.nj.us](http://www.njleg.state.nj.us) for scheduled event notices.

#### 5. Contact outreach service organizations and support groups for people with special needs

Ask about their interest in discussing issues related to people with complex severe behavioral health conditions as part of their regular meeting agendas. Volunteer to speak. Please review the Resources listing in the appendix section of the Handbook.

#### 6. Encourage and support a person who shows an interest in self-advocacy

This can be a very productive and rewarding experience for your relative, and an effective means of having their voices heard. Sharing their experiences and recommendations in various venues, including testifying at public hearings, participating on task force/advisory committees and workgroups, joining self-advocacy groups or initiatives, can serve as a true catalyst to improving the quality of care and services for people affected with intellectual/developmental disabilities. (Self-Advocacy Resources can be found on Pages 62-63 in the Life Plan section of this handbook)

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

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

### H5. Strategies to Improve and Maintain Your Effectiveness as an Advocate

"That which we persist in doing becomes easier, not that the task has become easier, but that our ability to perform it has improved." - Ralph Waldo Emerson

By definition, an advocate is "a person who pleads another's cause; a person who speaks or writes in support of something". When you take on the responsibility to advocate on behalf of persons with special needs, including oneself, the definition of advocate takes on a very powerful and awareness-raising meaning. Moreover, when the subject of your advocacy is yourself, your child or relative, the significance of assuming this advocacy role is monumental in scope, and driven by boundless passion, resourcefulness and unyielding determination.

The following recommended methods are offered to help you create a foundation for building and maintaining the necessary skill set to become an effective advocate, regardless of the cause you are attempting to advance.

**1. Raise Your Expectations:** It is essential that you develop and uphold a strong belief in what is possible for you or a person(s) with complex severe behavioral health conditions to achieve, regardless of your or their challenges. It is certainly wise to take into account the thoughts and opinions of qualified professionals. However, it is equally important to acknowledge the person's capabilities from their own or their family's/caregiver's perspectives. Cultivating a perspective based on experience and facts, combined with raised expectations of what might be possible for you or the individual to accomplish, is a crucial first step toward becoming a successful advocate. This firm belief in your or the person's ability to progress in both anticipated and unexpected ways will serve as the motivating force to advance your cause.

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2. **Become an Expert:** Expertise involving a particular cause comes in multiple forms. Individuals, parents/guardians often consider themselves experts when it comes to understanding the special needs to be addressed, and there is great truth in this assertion. However, it is still important to educate yourself about specific topics related to the cause you are undertaking. Whether you are attempting to obtain access to crisis response/stabilization services for yourself, a relative or client, or trying to establish preventative measures to avoid a crisis situation, you will need to become familiar with how the service delivery system works. Online information, webinars, workshops, conferences, publications, are just a few of the available options to becoming a more knowledgeable advocate. Share your expertise by volunteering to serve on organization advisory committees or school boards, presenting to state legislators, or state human service agencies.
  3. **Be a Savvy Consumer:** Effective advocacy and being a savvy consumer of special needs related services and supports just naturally go hand in hand. Productive advocates understand that their primary responsibility is to obtain the best quality services they can identify to efficiently manage their own or an individual's special needs. Research existing resources according to your or the person's needs and utilize your advocacy skills to obtain the services/supports deemed most appropriate. Do not forget to utilize the documented professional opinions and recommendations of those with expertise in their practice field to support your advocacy efforts.
  4. **Manage Your Advocacy Cause(s) Like A Business:** The key to successful advocacy is being diplomatic, articulate, concise, and practical-minded in your approach. Think about handling these advocacy interactions as if they were business transactions. It is completely understandable when an individual and/or parent/caregiver becomes emotionally frustrated when advocating for themselves or their child/client. Unfortunately, more times than not, the person on the receiving end will write-off the individual/family/staff member as being overly emotional, and simply dismiss the advocate's argument or request no matter how valid it might be. When emotions take over the focus of your advocacy mission can get completely side-tracked, and any momentum gained might be lost. You will get greater mileage out of your advocacy efforts if you approach every opportunity in a professional business-like manner. Before exiting a meeting, insist on a proposed next step action plan and timeline for implementation. Be sure to send all meeting participants a detailed follow-up communication to document in writing all agreed upon measures. This strategy serves to keep everyone on the same page, and avoid future roadblocks that might slow down the process toward achieving your advocacy goals.
  5. **Exercise the Human, Civil, and Legal Rights of Citizens with Disabilities:** Educate yourself about the human, civil and legal rights of people with disabilities at both the state and federal levels. There is tremendous power in applying this knowledge as a resourceful advocate. It can save you much time and energy, because the legal system has already done the hard work to enact these essential privileges. You will just need to figure out how best to apply them. You might want to begin by exploring the disability rights resources listed below in the highlighted section.
  6. **Never Stop Networking:** It is amazing what you can discover and uncover when you are open to networking with professionals, friends and family, educators, service providers, direct support professionals, outreach organizations, state representatives, etc. Be sure to obtain the names, affiliations, contact information and/or business cards of the people you meet, and do not hesitate to connect with them as needed. In return, remember to offer your assistance to them, including facilitating connections among those in your network whose expertise and opinions are valued.
  7. **Do Not Be Afraid to Take it to the Top:** You have a right, as a citizen of the State of New Jersey, to advance your cause up the ladder to those persons in top leadership positions. Keep requesting help to move your cause forward, and do not stop until someone finally agrees to support your cause.

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8. **Remain Solution-Focused:** It is very useful to bring an issue to light, and all the more constructive if you couple a concern or complaint with a recommended solution. Starting off by citing something positive pertaining to the subject or service is a great way to break the ice, before moving on to presenting the problem, and your practical and creative solutions.
  9. **Be a Team Player:** You will accomplish your advocacy goals much quicker if you embrace the team spirit mentality. Being adversarial will only work against you. Being open-minded, respectful, and grateful to the other team members (For example- Child Study Team, Adult Interdisciplinary Team, Advisory Committee, etc.), does not mean you have to alter your convictions to appease other members. You can be firm and convincing without being argumentative. So do your best to maintain a pleasant and optimistic demeanor... all the time keeping your eye on the prize.
  10. **Trust Your Instincts:** Be open to compromise as long as it does not jeopardize your core values or interfere with attaining your ultimate goals as an advocate. Do not back down from your cause, because of applied pressure and/or fear of retaliation. Stay strong... in the end your persistence will pay off in meaningful ways.
  11. **Do Not Give Up:** There will be times when you feel extremely discouraged, and your goals seem to be completely out of reach. Opposing parties will try to convince you that what you are proposing is not needed; or cannot be done; or it has never been accomplished; or there's no money to fund it. Do not be swayed... persist in your efforts... see yourself as pioneering this initiative. Be creative. Keep in mind that pessimism is a misuse of the imagination.
  12. **Take a Moment to Pat Yourself on the Back:** It is not enough to simply believe in your cause. You also will need to firmly believe in your ability to make this happen. In many cases, an advocate working on behalf of an individual(s) with complex special needs serves as their eyes, ears and voice. In a sense, people with special needs are depending on skillful advocates to improve the quality of their overall care/support, and their lives. Needless to say, when progress is achieved the personal rewards are truly priceless. So take a moment to feel good about your accomplishments. This will go a long way in keeping you resilient and motivated to take on the next phase of your endeavor or subsequent worthwhile causes.

Note: “NJ Partners in Policy Making” is a leadership development and advocacy education program for adults with developmental disabilities (over age 21) and family members of young children and transition age youth available through The Boggs Center on Developmental Disabilities and Disability Rights NJ. The goal of this program is to prepare the next generation of disability advocates to work toward meaningful change in our state. Additional details available online at <https://rwjms.rutgers.edu.boggscenter/projects/njpartnersinpolicymaking.html>

### Family Member: “My Journey to Advocacy” by Tara Montague



Photo of Tara Montague and her daughter, Mary

*I never thought of myself as an advocate. I've always just been “Mary’s mom.” But there is no roadmap for raising a multiply-disabled, medically-fragile child and the road can get pretty bumpy. I had to learn to navigate my way through local, state, and federal agencies and organizations to get her the things she needs--not just to survive, but to have a happy, fulfilled life.*

*It’s a miracle that Mary has made it to the age of 20. Spinal Muscular Atrophy Type I is typically fatal during infancy or toddler age. Having the right services and supports for her has made all the difference. She has a tracheotomy and uses a ventilator, oxygen, feeding tube and wheelchair. Mary is also non-verbal, but does her best to communicate her wants and needs to us by using yes and no eye blinks. Except for needed hospitalizations, Mary has lived at home with her dad and me since she was two months old.*

*My first big step into advocacy came as I realized that I needed information – information about services, information about systems, about school, about patient rights, educational law, medical knowledge- the list goes on and on. As I became better educated, it became easier for me to advocate for what Mary needed. If I know what she's entitled to and can point it out, it's hard for someone to refute those hard facts. As I learned more, I started to become the go-to person for friends when they had questions or needed advice on how to advocate for their own child. The internet, and then Facebook, made it so much easier to gain valuable knowledge and to share it with other parents and professionals. As we seemed to repeatedly come up against the same types of issues, I began to explore systems-wide advocacy. Getting Mary what she needed was of utmost necessity. But what about the other kids out there who needed the same thing? I felt it was part of my responsibility to help them too. I had become an advocate without even knowing it.*

*I learned that at the heart of the matter was the necessity for government reforms. Many of the programs and supports that we use for our family members are government-funded, such as Medicaid. Getting further involved in understanding government funding, the laws that regulate services and supports, and how many agencies function was the next step. I was appointed by the Governor to the New Jersey Council on Developmental Disabilities in 2011. I get to work with self-advocates, other family members, and many of the state agencies that serve children and adults with disabilities, to develop a coordinated social policy for advancing the rights and opportunities of New Jersey residents with developmental disabilities.*

*My advocacy led me to a professional career in BAYADA Home Health Care, which also provides most of Mary's nursing care. In my role as the Manager of Client & Family Advocacy, I help educate clients and families on the issues that can affect their lives and give them a platform to interact with their elected officials to share their stories. Our lawmakers need to understand the significant needs of disabled children, adults, and seniors and their desire to remain in their homes with loved ones. Stories and experiences shared by constituents are frequently cited as having substantial influence on the decision-making of legislators. As family members and friends, it is our responsibility to stand up for what is needed. We must raise our voices as one and advocate for a better tomorrow for all.*

*Advocacy doesn't need to become your full-time job in order for you to make a difference. Even if you don't want to testify in front of a legislative committee meeting, or even share your struggles with your local legislator, there are smaller, but still significant ways to begin advocating. Consider taking five minutes to log onto an advocacy website you are interested in and sending a pre-written email to your legislators. For example, BAYADA's Hearts for Home Care keeps community members informed about legislative issues at the state and federal level that can impact the home health care industry and access to care.*

*Stay informed, network, ask questions, voice your concerns and ideas, and you too will create a path toward your own meaningful journey into advocacy*

## **Disability Rights Resources**

- “A Guide To Disability Rights Laws” : U.S. Department of Justice, Civil Rights Division, Disability Rights Section – <https://www.ada.gov/cguide.htm>
- “New Jersey Special Education Advocacy Guide” : developed by Disability Rights New Jersey – <https://disabilityrightsnj.org/resource/advocating-for-special-education/>
- “Voting: It's Your Right” : Voter rights policy for people with disabilities, developed by the Elizabeth Boggs Center/Rutgers Robert Wood Johnson Medical School in collaboration with New Jersey's Administration on Developmental Disabilities Partners, Disability Rights New Jersey, and the New Jersey Council on Developmental Disabilities. – <http://rwjms.rutgers.edu/boggscenter> or <https://disabilityrightsnj.org/> (Under Publications)
- “An Advocates Guide To The New Jersey Legislature” (Self Advocacy Series): developed by Disability Rights New Jersey, “This self-advocacy guide is to assist and inform persons with disabilities, their family members, and other persons and organizations interested in working with and influencing the NJ State Legislature”. <https://disabilityrightsnj.org/wp/content/uploads/Legislative-Advocacy-Guide.pdf>
- “Institutional Rights Resources” developed by Disability Rights New Jersey: Institutional Rights Resources - ([disabilityrightsnj.org](https://disabilityrightsnj.org))

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## Wellness and Recovery

Wellness and Recovery approaches are individual-oriented, person-centered and holistic behavioral health approaches. Those approaches combine skills building with education about mental wellbeing in order to better equip individuals with disabilities and behavioral health needs. Among the areas that are emphasized is identifying a support network, identifying activities and items associated with positive feelings and hopefulness, considering lifestyle choices in terms of how those options support well-being.

### H7. Wellness and Recovery Tools

#### Motivational Interviewing

Motivational interviewing is a psychotherapeutic approach that attempts to move an individual away from a state of indecision or uncertainty and towards finding motivation to make positive decisions and accomplishing established goals. Motivational Interviewing is a clinical approach that helps people with mental health and substance use disorders and other chronic conditions such as diabetes, cardiovascular conditions, and asthma make positive behavioral changes to support better health. The approach upholds four principles—expressing empathy and avoiding arguing, developing discrepancy, rolling with resistance, and supporting self-efficacy (client’s belief that she or he can successfully make a change). <http://www.motivationalinterviewing.org/>

#### Wellness Recovery Action Plan

The Wellness Recovery Action Plan® or WRAP® is a self-designed prevention and wellness process that anyone can use to get well, stay well and make their life the way they want it to be. It was developed in 1997 by a group of people who were searching for ways to overcome their own mental health issues and move on to fulfilling their life dreams and goals. It is now used extensively by people in all kinds of circumstances, and by health care and mental health systems all over the world to address all kinds of physical, mental health and life issues. WRAP® has been studied extensively in rigorous research projects and is listed in the National Registry of Evidence-based Programs and Practices. <http://mentalhealthrecovery.com/wrap-is/>

#### Zones of Regulation

The Zones of Regulation is a curriculum geared toward helping students gain skills in consciously regulating their actions, which in turn leads to increased control and problem-solving abilities. Using a cognitive behavior approach, the curriculum’s learning activities are designed to help students recognize when they are in different states called “zones,” with each of four zones represented by a different color. In the activities, students also learn how to use strategies or tools to stay in a zone or move from one to another. Students explore calming techniques, cognitive strategies, and sensory supports so they will have a toolbox of methods to use to move between zones. <https://www.socialthinking.com>

#### The Incredible 5-point Scale

The Incredible 5-point Scale (Buron & Curtis, 2003) introduces the use of a scale to teach social and emotional concepts to individuals who have difficulty learning such concepts, but who have a relative strength in learning systems. Using a scale to further break down the expectations might be helpful. The first step is to decide how you want to break down the concept. <https://www.5pointscale.com/>

#### Social Stories™

Carol Gray developed Social Stories™, a respected evidence-based practice used worldwide with people with autism of all ages. Carol was the first teacher for students with autism at Jenison Public Schools in Jenison, Michigan 1977-2004. In 1989, Carol began writing stories for her students to share information with them that they seemed to be missing, information that so many of us take for granted. Many of the stories resulted in immediate and marked improvement in her students’ responses to daily events and interactions. <https://carolgraysocialstories.com>



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## The Circles® Program

The Circles Program® is an innovative way to teach children and adults about the appropriate degree of closeness they have with other people as demonstrated by how they touch, talk and trust others, depending on the kind of relationship they have with them.

## The Circles® App

Circles® App is a tool for social skills learning based upon the Circle Program®. The tool helps with learning about appropriate social boundaries and interactions (touch, talk and trust). By working on intimacy boundaries, individuals of all ages are in a better position not to be the victims of abuse and exploitation.

<https://www.circlesapp.com/>

## Escape NOW Curriculum

*ESCAPE-NOW: The Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment for Individuals with Developmental Disabilities - NOW (Khemka & Hickson, 2015) is the culmination of a series of research and curriculum-development efforts by Ishita Khemka, Linda Hickson, and their colleagues. ESCAPE-NOW, based on current research and theory in abuse prevention and decision making, is designed to meet the need for an up-to-date, effective, evidence-based abuse prevention curriculum to teach women and men with intellectual and developmental disabilities to make effective, self-protective decisions in a wide range of sexual, physical, and verbal abuse situations.*

The staff of Finding Your Individuality in New Jersey worked with participants with developmental disabilities to implement the field test of this curriculum. <https://findingyourindividuality.com/>

## Family Member

*First of all, I am thankful that our son, Peter, is now able to shine in so many ways. His behaviors, due to his autism diagnosis, were very, very challenging for our family, especially when he reached the age of puberty. He began exhibiting severe aggression, and his hygiene and toileting skills regressed. He became withdrawn and was eventually diagnosed with depression. It was impossible to take him for an outing, even going to McDonald's was a major struggle.*

*My husband and I knew we needed more help. While awaiting an out-of-home placement, Peter was moved to a state psychiatric hospital for several long months. During this difficult time, the Rutgers Mom2Mom Helpline was (and continues to be) a blessing for me. We continued to advocate for Peter, seeking a group home placement. The state psychiatric hospital was definitely not where he belonged. Finally, our long wait ended when Peter was moved to a wonderful group home! At his new home, he received the care, understanding, and expertise of trained staff, with the goal of his becoming fully engaged in his community once again. Peter attends an awesome day program designed for adults with autism. He engages in activities such as yoga, soccer, and lunch outings. With support from his group home staff, he participates in many activities such as Special Olympics, parties (he loves music and dancing), and therapeutic horseback riding.*

*We feel so fortunate to have these supports in place so that Peter, just like the majority of people residing in the community, can enjoy all that his town has to offer. He now experiences such pleasure from a variety of activities, which has contributed to his overcoming the depression that once plagued him. Despite his autism and depression diagnoses, promoting and maintaining his overall wellbeing through 24/7 supervision is successfully achieved in his residential and day program settings. He independently picks out his clothes, dresses himself, can prepare part of a meal (like buttering his bread), makes his bed, and he likes to read books that he chooses. He also brushes his teeth, washes his face, and gets his pajamas on independently. Peter's episodes of frustration and aggression are very minimal. His group home provides a nurturing environment for Peter. Recently, Peter came home for an overnight Easter visit. He joined us for meals, said grace, colored Easter eggs, enjoyed watching his videos, slept in his bed both nights, took his medication, and most importantly, he was happy! Similarly, he smoothly transitioned back to his group home.*

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*We are immensely proud and grateful for the tremendous progress Peter has made to overcome the mental health and behavioral challenges that had once turned his life, and ours as a family, completely upside down. Earlier in Peter's life, living away from our home was not something we had ever imagined, let alone planned. We are fully aware that nothing is perfect. However, we never take for granted the hard work of all those who have supported him throughout his life. Peter was afforded an opportunity to achieve wellness and recovery, because of our strong, and unwavering belief in him. But in the end, it was Peter who showed us that these goals were always achievable, because of the amazing man and son that he is.*

## **I. Special Topics in Behavioral Health**

The following is intended to alert the reader to important issues and invite you to obtain more information. It is not meant to be a comprehensive discussion of complex behavioral health issues.

### **I1: Children with Complex Severe Behavioral Health Conditions**

Children in behavioral crises are often children who have not had their behavioral health needs addressed. Children with complex severe behavioral health conditions can work therapeutically to address their specific needs. Therapy may need to be modified in order to make these approaches accessible and useful to youth with disabilities. Several techniques used with children without disabilities can be applied to work with children with complex severe behavioral health conditions. Important factors to consider include- age, language and attention span. Children with complex severe behavioral health conditions are more likely to exhibit difficult to manage, sometimes dangerous behaviors because of their limited coping skills, communication challenges and limited resources. Children benefit from early intervention that addresses their behavioral health needs. In some cases, timely intervention can eliminate the need for psychoactive medication.

Children with limited language use may be able to participate in expressive arts including art and dance therapy. Children may benefit from play therapy, particularly sand therapy. For more information about transitioning youth on the autism spectrum you can access the link to the Power Point: *Ability to Launch (issues around youth with autism transitioning to adult services)* under the Appendix section of this Handbook.

For children that have been exposed to traumatic events, there are techniques that are used including Trauma Focused Cognitive Behavior Therapy (TF-CBT), expressive arts and sand play. Consult the National Child Traumatic Stress Network website: <https://www.nctsn.org/> which lists extensive resources and opportunities to receive training in the area of trauma-informed care for children.

## **I2. Trauma and I/DD**

### **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 it can be experienced over a period of 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, beating, slapping, shaking, kicking, biting, strangling, burning, or physically restraining an individual against their will. (This does not include the use of interdisciplinary team approved physical restraints

- safely implemented by properly trained individuals, as part of a person's behavior management plan.)
- **Sexual abuse** is a form of physical abuse which is sexual in nature and is placed in a category of its own. It is a secretive and isolating act that 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 harmful 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 affected with a disability. 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 caregivers. Abusers take advantage of children and adults with intellectual/developmental disabilities who are non-verbal or have difficulty communicating, as well as those who lack understanding in social situations. According to researchers (Sullivan, 2003), a person's disability can often indirectly increase their vulnerability to abuse, because of society's reaction to disability in general, not due to the disability itself. For instance, a parent may decide not to report signs of abuse suffered by their loved one if they are residing in a group home. Because if the service provider agency discharges their child from the program, suitable community-based housing is typically extremely limited. Abusers also fear legal and other consequences being brought against them, so they remain secretive, as do those who suspect or witness abusive acts.

The severe repercussions for people with disabilities who are abused or neglected are many. Beyond the results of physical abuse such as fractures, injury to the central nervous system and internal organs, burns, malnutrition, 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 their safety. Unfortunately, these behavioral changes are often 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. This is just one of the many extraordinarily harsh realities that surface when acts of abuse or neglect are finally revealed.

### Responding to Sexual Trauma

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

Research has suggested that more than ninety percent (90%) of people (both male and female) with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent (49%) will experience ten or more abuse incidents. (Valenti-Hein, D. & Schwartz, L. (1995). *The Sexual Abuse Interview for Those with Developmental Disabilities*. James Stanfield Company. Santa Barbara: California). Therefore, 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. These symptoms may include 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. Sexual trauma and the symptoms that occur as a result can significantly impact a person's daily functioning. Survivors who have not begun the process of talking about their trauma may present with anxiety when in a medical environment or when talking to a medical professional for a variety of

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reasons. Talking to or being confronted by medical professionals about the patient's prior history of sexual abuse may be triggering for the patient and heavily avoided which can interfere with proper treatment or resources. 44% of survivors of sexual abuse with I/DD had a relationship with the perpetrator specifically related to their disabilities. For those individuals victimized by helping professionals or people they knew, trusting medical professionals or the hospital setting may be difficult, creating further anxiety for the survivor in crisis. Reducing stimuli and creating a safe environment is essential for the survivor of sexual assault who 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. Validating the person's feelings related to the trauma, affirming the individual's unique intersectional identities and providing choice can increase feelings of safety, control, and trust in the care process.

#### **Mental Health Professionals You May Encounter:**

Sexual Assault Response Team (SART) is a multidisciplinary team trained to respond to and support victims of sexual assault. The SART team is typically 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 survivors of sexual assault. Support may include providing information and resources to the victim, supportive counseling, specialized medical care and gathering of forensic evidence. Although abuse is the most common cause of trauma, anyone can develop Post-Traumatic Stress Disorder (PTSD) as a response to events in which they believe their own lives or the lives of others are in danger or in danger of harm. Individuals who have been exposed to trauma whether as a result of abuse, witnessing natural disasters, having been in accidents (fires, earthquakes, motor vehicle accidents, etc.) need to feel safe, need to have support and may benefit from either psychiatric or non-medical treatments that address trauma. Trauma-focused clinical interventions may include- Eye Movement Desensitization Response, Dialectical Behavior Therapy + Prolonged Exposure (DBT + PE), Trauma-Focused Cognitive Behavioral Therapy (TF-CBT).

**Please Note: More detailed information about the topics of Abuse and Neglect, and Trauma, including Related Resources can be found in the Appendix section of this Handbook.**

### **13. Personality Disorders**

Personality is the way we view ourselves, others and the world. We each have a unique and individual style of relating to others. Personality Disorders affect the daily lives of individuals. These disorders such as borderline personality disorder, dependent personality disorder or antisocial personality disorder occur when we develop unhelpful patterns of relating to others. These problems related to personality style can result in our being less effective in our relationships and less able to pursue our life goals. Personality disorders are not considered psychiatric illnesses such as depression, anxiety, bipolar disorder or schizophrenia. Medication does not help people learn to be more effective. Hospitalization does not help people learn how to be more effective. However, people can receive counseling, learn behavioral strategies and coping skills that will lead to more adaptive living. For more information about Borderline Personality Disorder and Intellectual Disability, refer to the PowerPoint: *Borderline Personality Disorder and IDD* under the Appendix section of this Handbook.

### **14: Suicidality and I/DD**

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 it is by understanding the emotional or physical pain that might cause one to want to end their lives. There are no standardly used assessments for individuals with developmental disabilities. However, there is a tool that is generally used and can be applied to assessment for individuals with developmental disabilities. For more information about assessments used to identify suicidal risk consult Columbia Suicide Severity Scale (CSSS-R) for a video covering this topic.

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If you have reason to believe that 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, referral to a counselor.

For more information on this topic, please follow the link to the PowerPoint: *Suicidality and IDD* under the Appendix section of this Handbook.

### **15: Non-Suicidal Self-Injury and I/DD**

People do engage in non-suicidal self-injury. This means that they potentially hurt themselves without the intent of dying but may still may sustain injury or even die because of their pattern of self-harm. For some people, this pattern of self-harm (head-banging, skin picking, scratching and biting oneself) is linked to their developmental disability (see the earlier section on Behavioral Phenotype). 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, such as Applied Behavior Analysis (ABA) and Positive Behavior Supports (PBS), are approaches of choice for self-injurious behavior not thought to be caused by mental health disorders. For mental health issues, there may be medical ways of treating self-injury.

### **16: Substance Use and I/DD**

Individuals with disabilities can become addicted to substances such as alcohol, painkillers, marijuana 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.

### **17: Dementia and I/DD**

Individuals with down syndrome past the age of 50 and individuals with non-down syndrome disabilities past the age of 65 may 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 <https://www.the-ntg.org/> 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).

For more information, please follow the links to the following PowerPoints: *Early Recognition of Dementia and Intellectual and Developmental Disability and Aging and Disabilities* can be found in the Appendix section of this Handbook.

## **J. Emerging Issues**

### **J1. The Impact of the COVID-19 Pandemic on Individuals with Complex Severe Behavioral Health Conditions (CSBHC) and Those Who Support Them**

The COVID-19 pandemic has been challenging for everyone. Just about every aspect of our lives have undergone changes so abrupt that no one could have anticipated or have prepared for what was to occur; sheltering in place, social distancing, mask wearing, tele-health appointments, administering of COVID-19 testing and vaccines, remote instruction and employment, the cancellation of activities, as well as limited opportunities for social engagement. The unknowns associated with the virus have also greatly contributed to our stressors, because we wonder if our lives will ever be the same.

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No one understands better than individuals with complex severe behavioral health conditions (CSBHC), their families, and those who play a supportive role. Regardless of what is going on in the rest of the world, the challenges faced by people with CSBHC are ongoing and cannot be placed aside for any amount of time. Unexpected changes can be destabilizing to individuals, causing anxiety, and the regression of skills, etc. Disrupting a person's behavior management plan, for example, increases their risk of exhibiting severe behaviors, such as aggression, self-injury, and property destruction, impairing their ability to adequately function.

## J2. Coping Strategies During a Health Crisis

How do we help people with CSBHC adapt to significant drawbacks and limitations experienced during a health crisis, so that their overall well-being can be maintained, and individuals can continue to make progress toward achieving important goals? How do we address the needs of family members and professionals to avoid caregiver burn-out and build necessary resilience, in order to stay the course? It is important to pose these questions together, because the answers are very closely aligned and interconnected. Therefore, the following ideas illustrate ways for everyone to explore, in order to prevent or reduce pandemic fatigue, and other related issues during times of great change:

- **Make Connections:** Identify ways to communicate at a distance with all those in your social circle who have been important and supportive of you, and vice versa. There are countless ways to communicate, but the increased popularity of video chat services like Zoom, Google Hangouts and FaceTime, have demonstrated our strong desire for face-to-face contact. Sometimes it is assumed that individuals with intellectual/developmental disabilities (I/DD) who have limited conversational skills might not benefit from video technology. However, that's where you can get creative and engage the person by reading illustrated and/or audio illustrated/animated books, playing music, showing music videos, doing art projects, exercising, or just simply sharing a meal or favorite snack virtually. These are just a few examples of how to keep connected, but there are many ways to feel less isolated, and detached. You just need to reach out and make it happen. Try to keep in mind that those who maintain a strong circle of social support are more inclined to be happier and healthier throughout their lives.
- **Stay the Course:** If prior to the start of the COVID-19 pandemic you were advocating for changes that would better address your special needs or those of another individual, do not assume that the service delivery system and those who approve, manage and implement its operation have stopped fulfilling their job responsibilities. Addressing the needs of people with I/DD cannot and should not be placed on hold. Therefore, we must continue to advocate to ensure that essential services and supports are not jeopardized in any way. That is not to say that during times of great change and uncertainty that upholding or improving your or another person's acceptable standard of care and support will not be very challenging. However, there is no excuse for the system nor your advocacy efforts to lie dormant during these times. It might take more creative-thinking and persistence to attain short and long-range goals. Whether you are a self-advocate, parent/legal guardian, clinician, service provider or state entity, keep focused and confident knowing that you, or the individual you hope to better serve will reap the benefits of your tenacious advocacy efforts.
- **Build Resilience:** Resilient people tend to be self-aware, realistic, empathetic, motivated, optimistic, and they remain calm under stress, exerting self-control. Resilience is not a trait that people either have or don't have. Resilience is a skill that can be developed. Because stress and change is a part of life, there are plenty of opportunities to practice resilience building. Try not to view life's challenges as unbeatable problems, and respond with action instead of assigning blame, feeling fearful or victimized. Optimistic self-talk can help reinforce a positive view of your strengths and abilities to cope with adversities. Keeping a journal can also be very therapeutic and potentially enlightening. Remember that although there are circumstances out of the realm of our control, but how we react to difficult circumstances can really make a difference. Maintain your sense of humor. Preserve good health with exercise and consuming nutritious foods. Never give up on resolving the problems presented by life, because that is exactly what will nurture your resilient capabilities.

- **Identify and Generate Needed Reform:** The COVID-19 pandemic has brought forward some serious new challenges for people with disabilities. Besides the abrupt change in routine causing impaired functioning, the introduction of new routines can be equally destabilizing. For instance, moving to school or day program video instruction, remote employment options, tele-health medical and counseling appointments, virtual socializing and preferred activities, etc. These are issues that need to be addressed in a well-thought-out global manner to achieve positive outcomes for the greatest number of individuals. A real-life example of this occurred in the spring of 2020. Self-advocates, parent advocates, and outreach organizations joined forces contacting Governor Murphy’s office to request the drafting of a Department of Health (DOH) policy which would allow individuals with I/DD to be accompanied by a parent/legal guardian/direct support professional if they required hospitalization for any reason, including a behavioral health crisis. The NJ DOH Hospital Visitation Policy was enacted on April 25, 2020. This reform movement proved that there is “Power in Numbers” and “There’s No Time Like the Present.”

Please take a moment to review the NJ DOH Hospital Visitation Policy, enacted on April 25, 2020, which is also included with the “Portable Emergency Plan” in the Appendix Section of the Handbook for easy access and printing:



PHILIP D. MURPHY  
Governor

SHEILA Y. OLIVER  
Lt. Governor

JUDITH M. PERSICILLI, RN, BSN,  
Commissioner

April 25, 2020

**TO:** Acute Care Hospitals Licensed Pursuant to N.J.A.C. 8:43G

**FROM:** Judith M. Persichilli, R.N., B.S.N., M.A. *[Signature]*  
Commissioner

**SUBJECT:** Support Person Permitted for a Patient with a Disability

On March 9, 2020 Governor Philip D. Murphy issued Executive Order 103, declaring the existence of a Public Health Emergency, pursuant to the Emergency Health Powers Act, N.J.S.A. 26:13-1 et seq., and a State of Emergency, pursuant to the Disaster Control Act, in the State of New Jersey for Coronavirus 2019 Disease (“COVID-19”). In recognition of the fact that the virus that causes COVID-19 is easily transmitted, especially in group settings, it is prudent for hospitals to implement restrictions on visitors to the facility. Such limitations must take into consideration patient care and well-being.

The Department of Health (Department) considers a designated support person essential to patient care for patients with disabilities where the disability may be due to altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns. Therefore, hospitals are required to allow a designated support person to be with the disabled patient during hospitalization. This designated support person can be a family member, personal care assistant or another disability service provider knowledgeable about the patient’s care and must be allowed to remain with the patient while in the hospital, subject to the restrictions set forth below. The restrictions must be explained to the patient’s support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patient’s support person fully understands the restrictions.

The disabled patient’s support person must be asymptomatic for COVID-19 and must not be a suspect or recently confirmed case. Additionally, hospital staff must screen the support person for symptoms of COVID-19 (e.g., fever, cough, or shortness of breath), conduct a temperature check prior to entering the clinical area, and every twelve hours thereafter, and screen for potential exposures to individuals testing positive for COVID-19. Personal Protective Equipment (PPE) should be given to and worn by the designated support person. Once in the unit, the designated support person must have extremely limited access to other areas of the hospital and not be permitted to leave and re-enter the hospital.

Hospitals may restrict the presence of a designated support person should, in the Hospital’s judgement, a shortage of PPE require use of the resources by direct patient care givers.

Additionally, if the hospital determines that a second support person is necessary for the disabled patient, and PPE availability permits, hospitals are permitted to have a second designated support person and may permit either designated support person to be present with the disabled patient. The screening requirement above is to be followed for both designated support persons.

If you have any questions concerning this matter, please contact Ms. Jean DeVitto, Executive Director, Certificate of Need and Healthcare Facility Licensure program, at [jean.devitto@doh.nj.gov](mailto:jean.devitto@doh.nj.gov).

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- **Stay Well Informed:** “Knowledge is Power” is an old saying that has certainly taken on greater significance during the COVID-19 pandemic. However, what resources can you place your faith in when it comes to overly abundant and frequently changing information about the coronavirus? The answer is simpler than you might think. Empowering yourself with accurate information can help to dispel misinformation about the disease, improve your decision-making abilities, and reduce your feelings of stress and confusion.

### **J3. Where to Find Accurate Information to Assist in Identifying, Preventing and Managing COVID-19:**

**Centers for Disease Control and Prevention (CDC)** provides the most current scientifically-based details about COVID-19 symptoms, testing, as well as guideline instructions for specific groups such as schools, workplaces, healthcare service providers, etc.

**The World Health Organization (WHO)** offers detailed information on COVID-19, as well as an up-to-date global view of the pandemic’s status. Instructions for hygiene and respiratory care can be accessed on their website.

**The National Institutes of Health (NIH)** issues scientific knowledge (clearly defining scientific terminology) about COVID-19, including the latest research, treatments and the status of vaccines.

**State Departments of Health** has established a variety of communication approaches (webpages, public media announcements, etc.) to educate residents about state policies and guidelines focused on preventing and containing COVID-19 outbreaks in all areas of the community. This information gives citizens an opportunity to participate in keeping our communities healthy and safe. (**NJ Department of Health contact information listed below**)

**Centers for Disease Control and Prevention (CDC): “Guidance for Direct Service Providers, Caregivers, Parents, and People with Developmental and Behavioral Disorders”:** <https://www.cdc.gov/coronavirus/2019-ncov/hcp/developmental-behavioral-disorders.html>

**Communications First: “COVID-19 Communication Rights Toolkit”:** <https://communicationfirst.org/covid-19/>

**National Alliance for Direct Support Professionals (NADSP): “COVID-19 Toolkit for Direct Support Professionals.”** Resources to help DSPs take care of themselves during the health crisis. <https://nadsp.org/covid-19resources/>

The “Health Passport” in English and Spanish was adapted with permission from the “About Me”- “My Hospital Passport” from the **Treat Me Right Campaign**. <https://spanadvocacy.org/download/health-passport-for-youth-english-spanish/?wpdmdl=52108&refresh=5cfe6ab0d8f1b1560177328>

To explore additional information that The Arc of New Jersey has distributed about COVID-19, please go to: <https://www.arcnj.org/information/covid-19-updates-information/covid-19-updates-information.html> or <https://www.arcnj>

*The Handbook authors wish to express our appreciation to The Arc of New Jersey for granting us permission to reprint the above COVID-19 pandemic-related resource information.*



**For up-to-date COVID-19 pandemic-related information for New Jersey visit the following websites:**

The State of New Jersey:

- <https://nj.gov/> or [COVID19.NJ.gov](https://www.nj.gov/covid19/)

New Jersey Department of Health (DOH):

- New Jersey Department of Health COVID-19 Hotline: 1-800-962-1253 or
- Communicable Disease Service/NJ COVID-19 Dashboard: [https://www.nj.gov/health/cd/topics/covid2019\\_dashboard.shtml](https://www.nj.gov/health/cd/topics/covid2019_dashboard.shtml)
- New Jersey Interim COVID-19 Vaccination Plan: <https://nj.gov/health/legal/covid19/NJ%20Interim%20COVID-19%20Vaccination%20Plan%20-%20Revised%2012-15-20.pdf>

The New Jersey Council on Developmental Disabilities, in partnership with Disability Rights New Jersey, The Boggs Center on Developmental Disabilities, along with the Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families host virtual town hall meetings. Meeting announcements and additional COVID-19 resource information can be found at: <https://njcdd.org/covid-19-resources/>

The following information contains a small sampling of the many communications which The Arc of New Jersey's Beverly Roberts, Director, Mainstreaming Medical Care, has distributed in an effort to help individuals with I/DD, their families, service providers, and direct support professionals (DSP) remain safe and healthy throughout the COVID-19 pandemic:

Colleague,

*The Arc of New Jersey distributed the information below in the summer of 2020. We have received very positive feedback from families who had a phone conversation with local Social Security employees using the Office Locator. But we recognize that some families are not aware of an easy way to speak to a local Social Security employee during the coronavirus pandemic. Therefore, we are redistributing the information below. Please share it with others who may also be interested.*

Please see the Social Security Office Locator information below, which explains three ways to obtain information from Social Security during the COVID-19 pandemic:

The screenshot shows the Social Security Office Locator page. At the top, there is a yellow banner with a warning icon and the text: "We are OPEN to receive your calls! On Tuesday, March 17, 2020, we suspended face-to-face service to the public in our field offices and hearings offices nationwide until further notice. However, we are still able to provide critical services via phone, fax and online." Below this, there are three main sections: 1. "Find the Office for this ZIP Code." with a "ZIP:" input field, a "Locate" button, and a link to "Zip Code Look Up Services Outside the United States". 2. "Using our online services, you can:" with a list of services: "Apply for most types of benefits", "Estimate your future benefits", and "Do so much more". A link "To learn more, visit What You Can Do Online." is provided. 3. "National 800 Number" with "Toll-Free: 1-800-772-1213". At the bottom, there are links for "Privacy Policy", "Website Policies & Other Important Information", "About Us", "Site Map", and "FAQs".

1. You can enter your personal zip code into the Zip code lookup box, and click "locate". The address of the local Social Security office will appear along with the phone number for that office. This is the link to use to access the look-up feature. <https://secure.ssa.gov/ICON/main.jsp>
2. You can click on the "What you can do online" link <https://secure.ssa.gov/ICON/main.jsp> to access Social Security information online.
3. You can call the national 800 number: 1.800.772.1213. Please note that there may be a very long wait to speak to a representative at the national Social Security center phone number. I have heard from families who used the look-up feature explained in #1 above, and they were able to speak with a Social Security representative without a very long wait.

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#### J4. PowerPoint Presentations Relevant to COVID-19 Presented by Dr. Lucille Esralew

- a. Psychological Factors in Pandemic Response
- b. Psychological Response to COVID-19 and COVID-19's Impact on Daily Routine
- c. Coping During a Pandemic
- d. 10 Tips for Addressing COVID-19 with your Clients
- e. 10 Tips for Addressing COVID-19 with your Kids

#### J5. Psychology Corner Posts Relevant to COVID-19 Written by Dr. Lucille Esralew

- a. Promoting Healthy Brain Aging in a Time of Pandemic
- b. Vaccine Hesitancy
- c. Family Stress and COVID-19 Lockdown
- d. Behavior and Natural History of Infectious Disease
- e. The Enduring Impact of Coronavirus
- f. Heuristic Health Care Decision Making
- g. Pandemic Burnout-Cabin Fever and Zoom Fatigue

### K. Appendices

#### K1. The Transition Process to Adult Services

##### Donna shares her thoughts and ideas as a family member:

*Prior to and following the birth of a child, it is quite natural for parents to begin envisioning all types of wonderfully exciting experiences that they hope will enrich their son or daughter's life. Their imaginings can run the full gamut from being completely fantastic to the more realistic and ordinary. Regardless of where our creative imaginations take us early on as family members, what we all have in common is the ultimate desire for our children's lives to be happy, fulfilling, and safe from any harm. The simplicity of this hope lies in the belief that it is attainable if we work our hardest to ensure that our children's overall wellbeing remains our greatest priority throughout their developing years and beyond.*

*When a child is diagnosed with an intellectual/developmental disability, a parent's frame of reference begins to shift, because previously held assumptions, beliefs, preferences, values come into question. Our understanding and judgment as parents is challenged in a totally unexpected and often disorienting, and emotionally overwhelming way. Families go through a period of adjustment that varies from family to family and from person to person, which can include a mourning process for what their loved one might not be able to achieve or derive pleasure from during their lifetime. However, most special needs families find their way back to their initial goal, which was to provide the best care and support they can possibly garner to address the needs of their child to promote wellness, protection, and a life that is happy and meaningful to their child.*

*When we are dealing with an inevitable systemic change, such as the transition from schooling through the age of 21 to potentially less structured adult services, it can feel extremely unsettling. Part of it may be the fact that parents grow comfortable over the years, as far as the relative psychological safety offered by the education system. Naturally, no special education program is perfect, but the time and energy devoted to customizing the classroom environment to best serve a loved one is a great achievement, and not easily relinquished. By this time, we have also gotten very familiar with and skilled at navigating the education system. The many unknowns associated with the adult services world can certainly appear quite daunting.*

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*As your adult child reaches this important milestone in their life, it is a time to celebrate their accomplishments. We might reflect on the past, including thinking about those challenges that were overcome, as well as chronic conditions that have influenced the course of their life. We might even find ourselves consumed with thoughts about our own health and/or mortality. Who will be there for our cherished loved one when we are no longer able to be there for them?*

*As the mother of a young man whose life is affected by autism and bipolar disorder, I have always believed that it is important to remember what has been learned through past experience before taking any necessary steps forward to enhance my son's life. That brings me back to my opening remarks about how we learn to adjust our perspectives and subsequent actions based on our commitment to surround our children with quality services and supports. The same philosophy applies during the transition to adult services.*

*The following suggestions might help parents and legal guardians more effectively plan and direct the course of their loved one's future:*

- Be sure to involve your child in the transition planning process according to their individual capacity to make informed decisions about their future.
- Creating a strong circle of support (family members, friends, neighbors, teachers, clinicians, service coordinators, etc.) can be very helpful as the individual and their parent(s)/guardian(s) begin to think about interests and goals as the transition plan begins to take shape.
- Begin the future planning process early by exploring existing services, supports, and overall possibilities. (i.e.: 15-16 years of age)
- Be sure to ask a great deal of questions about available community-based options.
- Become acquainted with the application process, including eligibility criteria, and supportive documentation requirements.
- Consider all available adult services and supports options. The choices are numerous and varied according to the individual's interests. For example: attending college/vocational/technical school, supported employment, prevocational services, employment training, residential supports for community-based living, behavioral health resources, assistive technology supports, community service opportunities, participation in creative arts, music, dancing, physical fitness programs, social activities, etc.
- Try to maintain a positive attitude during the transition process, by thinking back to how you felt entering the adult world. It might have been a bit scary, but you were probably also filled with great excitement and anticipation about all the career and lifestyle possibilities before you. The same is true for our loved ones with special needs.
- Planning for their future will take more creative thought and strong advocacy on your part. However, the opportunities for growth are there if you keep an open mind, raised expectations, and an unwavering determined commitment for your loved one to succeed in their own unique and personally gratifying way.

Please refer to the **Children's System of Care (CSOC) and Division of Developmental Disabilities (DDD) sections** of the handbook for more detailed information about the transition to adult services process. The **Life Plan section** also contains relevant information about planning for your loved one's future.

For additional information about transition age youth on the spectrum, follow the link to *Ability to Launch* at the end of this Appendix section.

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## Family Member: Rommy Delvecchio and her son, Jake



*Our son, Jake, had turned 21, and as others are usually celebrating independence and adulthood, we were working on adjusting to the reality that Jake would need to be on the emergency list for residential placement. We had been working with DDD, the CEO of the special services school program that he had attended for most of his life, and the coordinators of their adult day program. It was decided that after graduation, Jake would transition to this day program, which he had been visiting/trailing for the past year. Transportation would be provided to the day program site, and his behavior plan which addressed his severe aggressive and self-injurious challenges would continue to be implemented, supported by a one-to-one direct care staff member. DDD sent out a residential placement e-Blast communication. We were confident that we would find Jake an appropriate community residence that would effectively serve his needs. Nothing could have adequately prepared us for what occurred a couple months later.*

*Five days before Jake's graduation, we received a text from his school's education coordinator stating that the new CEO wanted to meet with us that same day. My husband and I thought it would be good news, perhaps a possible opening in the organization's adult residential program. As we drove to the meeting, I was flooded with memories of when Jake's journey first began at this school program. Back then this special services provider was known for welcoming and being skillfully prepared to serve some of the most challenging individuals affected with special needs. Additionally, this provider had a great reputation for working well with families, which ultimately benefited their students in terms of progress they were able to achieve.*

*As we were greeted by the CEO's broad smile, he began to say, "Everyone wants what's best for Jake, and that while we all like to think that the program accepts everyone, I feel that we need to challenge DDD (to come up with alternative options). Therefore, Jake will not be accepted to our adult day program following graduation." I literally stopped breathing. I only resumed breathing, when I felt a stabbing pain in my chest. I pleaded with the CEO not to do this, that without structure and an established routine Jake would regress and suffer. The CEO was unmoved by my desperate and frantic appeal and remained completely firm in his decision.*

*For the next 105 days, Jake remained at home with no day program or structure, receiving daily respite services for a total of two hours. DDD reported that there was no availability as far as adult day programs because all existing openings were filled. Jake became more disoriented and anxiety-ridden with each passing week. His routine had drastically changed. His self-injurious behaviors were non-stop, and were accompanied by aggressive acts toward my husband, myself, and our two daughters. His sleep pattern became highly erratic, attacking all of us for hours. He would pound his body on the walls and floor, leaving himself with bloody bruises. I felt like such a failure as a parent. My husband was barely able to hold onto his job, as he tried his best to help me at home with Jake's unyielding aggression and self-injury. Several times, I was forced to send our 11-year-old daughter to live with family in New York, in order to keep her safe. I understood Jake's feelings of rejection, and I prayed that G-d could reach him in a way that I couldn't.*

*Out of total frustration and despair, I began videotaping some of Jake's crisis behavior episodes, in order to provide evidence to DDD about his rapidly deteriorating condition. After touring a clearly unacceptable residential placement for my son, I began researching day/residential placements on my own, while working closely with Jake's DDD funded Support Coordinator. I steadfastly documented everything that was taking place at home, including all Jake's doctor appointments, and ER visits. I forwarded copies of this documentation to his Support Coordinator and worked my way up the DDD chain of command, following up with multiple phone calls.*

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*Presently, we are approaching one year since Jake found his home away from our home. By all accounts, his departure has been an enormous adjustment for our entire family. However, it has also represented the answer to our constant hopeful prayers. The door that was closed so abruptly on our son's future has been replaced by an open door of genuine acceptance and respect for who Jake is, and all that he can accomplish over the course of his greatly valued life. He has been given the opportunity to thrive and progress in ways that will take a great deal of planning and hard work by Jake, and all those who are responsible for his care and support. I also believe that he will surprise us by achieving the unexpected. My determined advocacy efforts are never ending, in the most positive sense possible. For me, it began with a call to the Rutgers University Behavioral Health Care Mom2Mom Helpline, where I found my voice so that others could understand what Jake needed for them to know about his desire to live a truly happy, fulfilling and productive life.*

## **K2. Questions to Ask a Community Service Provider During an Out-of-Home Placement Tour and Accompanying Assessment of a Relative with a Complex Severe Behavioral Health Condition**

A time could arrive when the highly challenging needs of a loved one affected with a complex severe behavioral health condition might be better addressed in an out-of-home community-based treatment program. Once this has been determined and approved by working with the respective New Jersey state agency serving the individual (For example: Division of Developmental Disabilities (DDD) Case Management or Support Coordinator; or the Children's System of Care (CSOC) Care Manager from the assigned Care Management Organization (CMO)), there is a great deal to consider throughout this decision-making process.

The questions and advice, outlined below, can serve as a guide to obtaining relevant information. Making an informed decision is key to surrounding the individual with the appropriate services and supports, in order to promote the principles of wellness and recovery, as a means of improving their overall quality of life. This type of preparation may also help to reduce some of the stress and apprehension associated with this life changing choice for both the individual, and his/her family.

Note: Please keep in mind that some of these questions might be automatically answered by the service provider's admissions and clinical team members during the tour (often referred to as a "meet and greet") and assessment process. Either way, the following information is important to discuss with the service provider agency:

1. What is the overall goal of the community service provider, in terms of addressing an individual's identified strengths and needs? Does the service provider adhere to the principles of person-centered planning? If so, ask the provider to provide examples that support this claim.
2. Has the service provider instituted accepted best practice therapeutic strategies in the treatment and support of the individuals they serve? (For example- Applied Behavior Analysis (ABA); Positive Behavior Supports (PBS); Natural Supports; Medication Management; etc.).
3. What are the credential qualifications of the professionals assigned to work with individuals accepted into the program? (i.e.- Psychiatrist; Psychologist; Nurse or Nurse Practitioner; Board Certified Behavior Analysis (BCBA); Speech Therapist; Occupational Therapists; Licensed Social Worker (LSW) or Licensed Clinical Social Worker (LCSW); Teacher; etc.). What are their specific job responsibilities?
4. Who is responsible for overseeing the school or day program; pre-vocational/vocational program; supportive employment; and residential program? How is the management team set up? What are their specific responsibilities?

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5. How does the service provider's communication system operate? Who specifically will call the family with progress reports? What is the process for family members meeting with the individual's interdisciplinary team (IDT) to review the current status of their child's treatment, as well as the development of a target-dated next steps plan?
  6. What is the typical coverage, in terms of Direct Support Professional (DSP) to the individual served ratio? What type of training do DSP members receive? Is this training ongoing and person-centered specific? Does the service provider offer parent training in respect to their loved one's Behavior Support Plan (BSP)?
  7. What are the individualized and group security and safety measures, the community service provider has in place? Does the provider draft an Emergency Plan for each person, in the event of a behavioral crisis? What mechanism is in place for family members and provider management and/or DSP personnel to report incidents of abuse and neglect?
  8. Upon admission to the program, what are the typical protocols followed? For example, what happens first, and so on? Will the individual's current Individualized Education Program (IEP) / Individualized Support Plan (ISP) goals and Behavior Support Plan and/or Medication Management Plan be followed until revised plans are drafted? What roles does a family member/legal guardian play in terms of the individual's treatment plan? In other words, does the service provider consider the family an integral part of the decision-making process?
  9. Will the individual have opportunities to participate in preferred activities? Who is responsible for planning the individual's activities? (Parents should make a list of these activities to share with the service provider). Will the individual be given ample opportunity to engage in community-based activities? For example- opportunities that promote education, skill building (social, technical, etc.), physical fitness (individualized fitness activities or organized programs like Special Olympics), creative art and music exploration, special event activities, etc.
  10. Is the service provider agency involved in community service projects where those they serve can be offered a chance to give back to the community and achieve recognition as a valued citizen. (Meals on Wheels, Food Banks/Pantries, Habitat for Humanity, etc.)
  11. What is the service provider's home visit policy? For example, is there a maximum number of out of program days that must be adhered to? What is the family/friend visitation policy in respect to perspective programs?
  12. Are there family members whose children are currently being served by the designated program who would be willing to speak about their loved one's experience with a prospective client's parent/guardian?
  13. When does the service provider anticipate getting back to you with a decision as to whether or not your loved one will be offered the placement? Is there an existing waiting list in effect? What is the anticipated wait list duration?

#### **SOME ADDITIONAL ADVICE...**

A parent should ask the service provider admissions representative if there is any additional information needed, in order to complete the application and intake evaluation process.

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If a family member is firmly convinced of the overall merits of a community service provider's program(s) in serving their loved one, they should consider communicating the following points:

- It is important to inform the service provider that you will be actively involved in the person-centered development and implementation of your loved one's plan (i.e.: academic, vocational/employment, social, medical, physical fitness, preferred activities, etc.).
- It might also be helpful for you to let the service provider know that you would be interested in participating as a member of agency-convened committees, boards, as well as fundraising events to support their mission to improve the overall quality of life for all persons they serve.

### **K3. Abuse and Neglect**

#### **a. Potential Signs That an Individual with Disabilities Is Being Abused and/or Neglected**

The following list compiled by the [Child Welfare Information Gateway](#) contains potential signs of abuse and neglect for children, in general. However, these guidelines can certainly be applied to children, adolescents and adults affected with intellectual and developmental disabilities.

##### **The Child:**

- *Shows sudden changes in behavior or school performance*
- *Has not received help for physical or medical problems brought to the parent's attention*
- *Has learning problems (or difficulty concentrating) that cannot be attributed to specific physical or psychological causes*
- *Is always watchful, as though preparing for something bad to happen*
- *Lacks adult supervision*
- *Is overly compliant, passive, or withdrawn*
- *Comes to school or other activities early, stays late, and does not want to go home (if abuse/neglect at home)*

##### **The Parent:**

- *Shows little concern for the child*
- *Denies the existence of — or blames the child for — the child's problems in school or at home*
- *Asks teachers or other caregivers to use harsh physical discipline if the child misbehaves*
- *Sees the child as entirely bad, worthless, or burdensome*
- *Demands a level of physical or academic performance the child cannot achieve*
- *Looks primarily to the child for care, attention, and satisfaction of emotional needs*

##### **The Parent and Child:**

- *Rarely touch or look at each other*
- *Consider their relationship entirely negative*
- *State that they do not like each other*

#### **i. Signs of Physical Abuse**

##### **Consider the possibility of physical abuse when the child:**

- *Has unexplained burns, bites, bruises, broken bones, or black eyes*
- *Has fading bruises or other marks noticeable after an absence from school*
- *Seems frightened of the parents and protests or cries when it is time to go home*
- *Shrinks at the approach of adults*
- *Reports injury by a parent or another adult caregiver*

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**Consider the possibility of physical abuse when the parent or other adult caregiver:**

- *Offers conflicting, unconvincing, or no explanation for the child's injury*
- *Describes the child as "evil," or in some other very negative way*
- *Uses harsh physical discipline with the child*
- *Has a history of abuse as a child*

**ii. Signs of Neglect**

**Consider the possibility of neglect when the child:**

- *Is frequently absent from school*
- *Begs or steals food or money*
- *Lacks needed medical or dental care, immunizations, or glasses*
- *Is consistently dirty and has severe body odor*
- *Lacks sufficient clothing for the weather*
- *Abuse of alcohol or other drugs*
- *States that there is no one at home to provide care*

**Consider the possibility of neglect when the parent or other adult caregiver:**

- *Appears to be indifferent to the child*
- *Seems apathetic or depressed*
- *Behaves irrationally or in a bizarre manner*
- *Is abusing alcohol or other drugs*

**iii. Signs of Sexual Abuse**

**Consider the possibility of sexual abuse when the child:**

- *Has difficulty walking or sitting*
- *Suddenly refuses to change for gym or to participate in physical activities*
- *Reports nightmares or bed-wetting*
- *Experiences a sudden change in appetite*
- *Demonstrates bizarre, sophisticated, or unusual sexual knowledge or behavior*
- *Becomes pregnant or contracts a venereal disease, particularly if under age 14*
- *Runs away*
- *Reports sexual abuse by a parent or another adult caregiver*

**Consider the possibility of sexual abuse when the parent or other adult caregiver:**

- *Is unduly protective of the child or severely limits the child's contact with other children, especially of the opposite sex*
- *Is secretive and isolated*
- *Is jealous or controlling with family members*

**iv. Signs of Emotional Maltreatment**

**Consider the possibility of emotional maltreatment when the child:**

- *Shows extremes in behavior, such as overly compliant or demanding behavior, extreme passivity, or aggression*
- *Is either inappropriately adult (parenting other children, for example) or inappropriately infantile (frequently rocking or head-banging, for example)*
- *Is delayed in physical or emotional development*
- *Has attempted suicide*
- *Reports a lack of attachment to the parent*



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## Consider the possibility of emotional maltreatment when the parent or other adult caregiver:

- *Constantly blames, belittles, or berates the child*
- *Is unconcerned about the child and refuses to consider offers of help for the child's problems*
- *Overtly rejects the child*

### b. Reporting Abuse and Neglect

People with disabilities often do not report abuse, because they may not understand what abuse is. Communication problems can serve as a major obstacle for the individual, in terms of verbalizing occurrences of abuse and neglect. In addition, some individuals are viewed as very impressionable and unreliable when it comes to sharing information in general. As a result, their attempts to report abuse are quickly dismissed as being untrue or exaggerated, particularly because the nature of these accounts can initially appear highly doubtful. These are just a few of the many reasons why we need to be extra vigilant when it comes to overseeing all aspects of an individual's care, particularly the people responsible for providing this support. If possible, it is important to question the person about any safety issues they are experiencing.

### If abuse or neglect is suspected contact 911 or the local police immediately

If the maltreated person is served by a community service provider, Developmental Center or hospital setting, contact 911 and/or one of the State of New Jersey protective service divisions listed below. To access the Adult Protective Services (APS) and Division of Child Protection and Permanency (DCP&P formerly DYFS) Fact Sheets can be found via the following websites, which describe how and when to report abuse and neglect to the appropriate authorities:

**Department of Human Services: Adult Protective Services (APS)**

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

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

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

[http://nj.gov/humanservices/ddd/documents/sc\\_guide\\_to\\_incident\\_reporting.pdf](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)**

<http://www.nj.gov/dcf/reporting/how/>

### c. Preventing Abuse and Neglect

Overall, the most prudent course of action to preventing abuse and neglect involves the promotion of individuals with disabilities as valued and respected members of the community. This requires a multifaceted approach, so that preventative measures are comprehensive in scope, producing effective and sustainable outcomes.

- **Raising Awareness:** It is vitally important that we educate the general public not simply about the challenges faced by people with intellectual and developmental disabilities, but also about their significant personal accomplishments, as well as the positive impact their contributions and lives have on our society.

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- **Creation of Safer Services and Environments:** The State of New Jersey's human service delivery system must continue to improve and consistently enforce higher standards of care and support for children and adults affected with disability. State agencies need to maintain and protect their safety, overall well-being, and rights as valued citizens. Adopting policies and implementing mandatory practices that prohibit all types of abuse and neglect, including restrictive behavior techniques, must be closely monitored. In addition, it is important to make sure that school programs, workplaces, state and private hospitals, and service provider-operated day and residential programs are respectfully and effectively serving people with disabilities. Competently and compassionately meeting an individual's needs prevents abuse.
  - **Recruitment and Training of Management Personnel and Direct Support Professionals:** The recruitment process for identifying those individuals who are best suited to work with children and adults with disability should adhere to a higher standard, because of the vulnerability of the persons being served. Salaries need to be commensurate with experience and required job responsibilities. Initial mandatory training on intellectual/developmental disability, psychiatric and behavior disorders is an absolute necessity, as well as training about the signs of abuse and neglect, and how to respond by reporting these incidences to the appropriate persons without fear of retribution or repercussions. Moreover, mandatory training should be ongoing and specific to the individuals under service provider management or the support person's care.
  - **Community Integration:** Increasing community-based housing options for people with disabilities fosters inclusion and reduces the risk of abuse and neglect. Creating opportunities for individuals to build relationships in the community through meaningful employment, volunteering, and participation in a wide range of activities, including community service projects will enhance the quality of life for the community as a whole.
  - **Education:** State and local community education campaigns are essential to abuse prevention. Knowing the warning signs of abuse and neglect, and how to seek assistance, motivates individuals with disabilities, their families, and others to take the appropriate steps to prevent and address it. Being properly informed also helps to avoid some of the common barriers to getting involved, such as concern that the report will not be believed, confidentiality breaches, or fear of personal or legal repercussions.
  - **Fostering a Person's Confidence:** It is essential to educate individuals with intellectual and developmental disabilities about their rights as citizens. Training programs and the dissemination of information to increase knowledge and opportunities for skill-building encourages self-advocacy, and greater independence. Individuals also need to be afforded increased support, in order to more freely participate in their communities, according to their personal choices. These steps can help reduce the chances of victimization. However, the right cultural and environmental supports must be in place to promote opportunities for self-empowerment, as well as the enforcement of necessary protective measures against abuse and neglect.
  - **Supporting Families and Caregivers:** The high levels of stress experienced by family members, legal guardians and caregivers of individuals with disability can be the cause of abuse, but it is also considered a related symptom. It is essential that appropriate support be provided to both the person with disability, as well as his/her caregivers. Fostering resilience is key to reducing the risk of abuse and neglect. Better access to respite care; improved services and supports; case management oversight; establishing risk assessment and intensive support measures for families at risk; improving communication mechanisms so caregivers can voice their concerns; are just some of the specific actions that could be taken to prevent abuse and neglect.

Reference: Sullivan, P.M. (2003). Violence Against Children with Disabilities: Prevention, Public Policy, and Research Implications. Conferenced Commissioned Paper for the National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities (May 6-7, 2002) SUNY Upstate Medical University, NY.

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#### **d. Existing and Pending New Jersey Legislation to Help Protect People with Intellectual/Developmental Disabilities:**

##### **Danielle’s Law**

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

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

1. This act shall be known and may be cited as “Danielle’s Law.”

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

2. As use in this act:

“Commissioner” means the Commissioner of Human Services

“Department” means the Department of Human Services

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

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

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

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

3. a. A member of the staff at a facility for persons with developmental disabilities or a facility for persons with developmental disabilities or traumatic brain injury, shall be required to call the 911 emergency telephone service for assistance in the event of a life-threatening emergency at the facility or the public or private agency, and to report that call to the department, in accordance with policies and procedures established by regulation of the commissioner. The facility of the public or private agency, as applicable, and the department shall maintain a record of such calls under the policy to be established pursuant to this section.  
b. The department shall ensure that appropriate training is provided to each member of the staff at a facility for persons with developmental disabilities or a facility for persons with traumatic brain injury or member of the staff at a public or private agency, who in either case works directly with persons with developmental disabilities or traumatic brain injury, to effectuate the purposes of subsection a. of this section.

##### **C.30:6D-5.4 Violations, penalties**

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

##### **C.30:6D-5.5 Record of violations**

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

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

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

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

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

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

**Danielle's Law approved October 26, 2003**

**New Jersey Department of Human Services Division of Developmental Disabilities  
Identifying Life Threatening Emergencies**

- You must call 911 in the event of a life-threatening emergency.
- **Ask yourself:**
  - Could this condition be potentially fatal?
  - Could the condition get worse and become life threatening if you drove the person to the hospital on your own
  - Could moving the person on your own cause further injury?
  - Does the person require the skills/equipment of emergency medical personnel?
- **Life-threatening emergencies may include:**
  - Unconscious, unusual confusion/disorientation or losing consciousness
  - Difficulty breathing, not breathing, or breathing in a strange way
  - Having persistent chest pain, discomfort or pressure which persists for more than 3-5 minutes or that goes away and comes back
  - Severe bleeding from a body part
  - Broken bone that is showing through the skin or severe disfigurement of body part
  - Severe headache with slurred speech
  - Seizures that are not typical or back-to-back (3 in a row)
  - Seizures lasting longer than 5 minutes
  - Seizure resulting in serious injury; seizure in someone who is pregnant; seizure in someone who is pregnant; seizure in someone who is diabetic; seizure in someone for the first time
  - Serious injury to the head, neck or back
  - Call 911 first before your supervisor in a life threatening emergency.
- If you are unsure whether a situation is a life-threatening emergency, call 911. If the situation is not life-threatening, call your supervisor and provide appropriate care, including obtaining medical attention.

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### **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.  
[http://www.nj.gov/njsp/spoff/megans\\_law.html](http://www.nj.gov/njsp/spoff/megans_law.html)

### **Stephen Komninos' Law**

The Stephen Komninos' 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, as well as 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 are placed on an offender registry.

<http://www.state.nj.us/humanservices/documents/Stephen%20Komninos%27%20Law%20agency%20overview%2005-01-18.pdf>

### **Legislation Currently Under Consideration by the New Jersey State Legislature:**

#### **Billy Cray's Law: Bill A4013 (Pending Legislation)**

The Billy Cray's Law, Bill A4013, has been passed by the NJ Assembly Human Services Committee, and will move on to be voted on by the General Assembly and Senate. The bill would provide requirements for the use of Electronic Monitoring Devices (EMD) in group homes that serve individuals with intellectual and developmental disabilities (I/DD). The bill would enable but not require group home residents or their authorized representatives to cooperatively and collectively decide whether to allow for the installation and use of the EMD in the common areas of the group homes, and to decide on an individual basis whether to allow for the installation and use of the EMD in private residential bedroom areas. The bill includes a provision that grandfathers in and examines from the bill's provisions those service provider organizations that have already installed and are utilizing the EMD as of the bill's effective date. The bill accounts for residential facilities that serve multiple persons with I/DD, as well as facilities commonly referred to as supervised apartments for a single person. The use of the EMD would be a choice, not mandatory. To review the Billy Cray Law Bill A4013, click on the following link: [https://www.njleg.state.nj.us/2020/Bills/S3500/3301\\_I1.PDF](https://www.njleg.state.nj.us/2020/Bills/S3500/3301_I1.PDF). For up-to-date information on the status of Bill A4013 via Facebook: <https://www.facebook.com/1449104231/posts/10219187289420273/?d=n>

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## **K4. Support-Related Resources**

### **STI TESTING & SCREENING**

CDC-INFO/GET TESTED (NATIONAL HIV, STD, AND VIRAL HEPATITIS TESTING RESOURCES) 1-800-CDC-INFO WWW.GETTESTED.CDC.GOV, GET YOURSELF TESTED WWW.GYTNOW.ORG

### **PLANNED PARENTHOOD**

1-800-230-PLAN, WWW.PLANNEDPARENTHOOD.ORG

### **PREGNANCY TESTING & EMERGENCY CONTRACEPTION**

BEDSIDER (888) 321-0383, [HTTPS://WWW.BEDSIDER.ORG/WHERE\\_TO\\_GET\\_IT](https://www.bedsider.org/where_to_get_it)

### **THE EMERGENCY CONTRACEPTION WEBSITE**

1-888-NOT-2-LATE, [HTTP://EC.PRINCETON.EDU](http://ec.princeton.edu)

### **LGBTQ**

LGBTQ HOTLINE: 1-800-850-8078

### **GLBT NATIONAL HOTLINE**

1-888-843-4564 WWW.GLBTHOTLINE.ORG

### **TRANS LIFELINE**

1-877-565-8860 WWW.TRANSLIFELINE.ORG

### **THE ANTI-VIOLENCE PROJECT**

(LGBTQ+/HIV+) 1-212-714-1141 WWW.AVP.ORG

### **SEXUAL VIOLENCE & INTIMATE PARTNER VIOLENCE**

NATIONAL DOMESTIC VIOLENCE HOTLINE 1-800-779-SAFE 1-800-787-3224 (TTY) ONLINE CHAT [HTTP://WWW.THEHOTLINE.ORG/WHAT-IS-LIVE-CHAT/](http://www.thehotline.org/what-is-live-chat/) WWW.THEHOTLINE.ORG

### **LOVE IS RESPECT**

1-866-331-9474 / 1-866-331-9474 (TTY) ONLINE CHAT WWW.LOVEISRESPECT.ORG  
THE RAPE, ABUSE, & INCEST NATIONAL NETWORK  
800.656.HOPE (4673) ONLINE HOTLINE //OHL.RAINN.ORG/ONLINE/

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## **K6: Person-Centered Thinking and Decision-Making**

### **a. Shared and Supported Decision-Making**

Although it is not until age 18 that one formally becomes a self-guardian, individuals become decision-makers long before they become adults. We begin to make decisions in childhood when we indicate our choices and preferences in our daily lives. Parents should provide their relatives with disabilities with ample opportunity to obtain experience as decision makers, individuals with disabilities should have their opinions and values elicited and supported during family decisions and for issues that directly impact upon them such as where to live, where to go to school, where to work and what employment to pursue, medical care, and relationships. Even individuals who need extensive supports to complete activities of daily living can make decisions about their own lives. Individuals should have the opportunity to express their values and preferences with regard to all aspects of their lives. Everyone should have the ability to voice their preferences about their own lives. If the individual with disabilities is a non-traditional communicator, he or she may need a form of functional communication to have a “voice” in decision-making. If an individual does not have the ability to formulate or communicate their decisions, they may need individuals who can serve as their “voice”. These individuals should be chosen by the individual with disabilities to serve as a proxy or substitute for them by conveying their values and their input.

In New Jersey, we promote the concepts of supported and shared decision-making. supported decision-making provides the individual with disabilities with guidance, prompts and assists so that they can make decisions. shared decision-making is entered into by both the individual with disabilities and others who offer support or services. For more information about this topic, see the PowerPoint: Shared Decision-Making under the Appendix section of this Handbook.

### **b. Guardianship**

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

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

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

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

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

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

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

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

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

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

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

- Guardianship Assistance Program: [www.gapservices.org](http://www.gapservices.org)

Family Resource Network: <http://www.familyresourcenetwork.org> or 609-392-4900

Guardianship Services of NJ, Inc.: 1-888-340-9799

SCARC Guardianship Services, Inc.: [www.scarc.org](http://www.scarc.org) or 973-383-7442

- New Jersey Department of Human Services Bureau of Guardianship Services: <https://www.state.nj.us/humanservices/ddd/individuals/guardianship/>
- PLAN/NJ at: [www.plannj.org](http://www.plannj.org) In addition, the New Jersey Judiciary publishes a “Manual for Guardians” that can be obtained from your county Surrogate's Office. In at least some counties, this manual is automatically mailed to new guardians. It is only available in hard copy.



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### **c. Psychiatric Advance Directives (PADs)**

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

More detailed information about this option and forms that can be used to create a psychiatric advance directive or appoint a mental health care representative, can be found on the New Jersey Department of Human Services, Division of Mental Health and Addiction Services website: <https://www.state.nj.us/humanservices/dmhas/resources/mental/pad/>

In addition, Disability Rights New Jersey has created a webinar presentation entitled, “Healthcare Directives and Advance Care”, downloadable at <https://disabilityrightsny.org/resource/advance-directives/>

**K7. Listing of State Offices/Departments/Divisions and Outreach Organizations for Children and Adults with Intellectual and Developmental Disabilities**

<p><b>Office of the Governor</b>  P.O. Box 001  Trenton, NJ 08625  Phone: 609-292-6000  Email form available at:  <a href="http://www.nj.gov/governor/">www.nj.gov/governor/</a></p>	<p><b>Department of Human Services (DHS)</b>  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 at:    <a href="http://www.state.nj.us/humanservices">www.state.nj.us/humanservices</a></p>	<p><b>Division of Developmental Disabilities (DDD)</b>  Mailing Address: P.O. Box 726  Trenton, NJ 08625-0726  Toll-Free Phone: 800-832-9173  Email Form Available at:  <a href="https://www.nj.gov/humanservices/ddd/about/contactus/emailus/">https://www.nj.gov/humanservices/ddd/about/contactus/emailus/</a></p>
<p><b>Division of Medical Assistance and Health Services (DMAHS)</b>  P.O. Box 712  Trenton, NJ 08625-0712  Toll-Free Phone: 800-356-1561  Email Form Available at:  <a href="http://www.state.nj.us/humanservices/dmahs/">Department of Human Services   Division of Medical Assistance and Health Services Home (state.nj.us)</a></p>	<p><b>Department of Health (DOH)</b>  369 South Warren Street  Trenton, NJ 08608  Toll-Free Phone: 800-367-6543  <a href="https://www.nj.gov/health/">https://www.nj.gov/health/</a></p>	<p><b>Division of Disability Services (DDS)</b>  11A Quakerbridge Plaza  Mercerville, NJ 08619  Mailing Address: P.O. Box 705  Trenton, NJ 08625  Toll-Free Phone: 1-888-285-3036  <a href="https://nj.gov/humanservices/dds/home/">https://nj.gov/humanservices/dds/home/</a></p>
<p><b>Division of Mental Health and Addiction Services (DMHAS)</b>  5 Commerce Way  Hamilton, NJ 08691    Mailing Address: P.O. Box 362  Trenton, NJ 08625-0362  Toll-Free Phone: 800-382-6717    <a href="http://nj.gov/health/integratedhealth/">http://nj.gov/health/integratedhealth/</a></p>	<p><b>New Jersey Department of Children and Families (DCF)</b>  50 East State Street  2<sup>nd</sup> Floor  Trenton, NJ 08625  Mailing Address: P.O Box 729  Trenton, NJ 08625-0729  Toll-Free Phone: 1-855-463-6323  Email: <a href="mailto:askdcf@dcf.state.nj.us">askdcf@dcf.state.nj.us</a>  <a href="https://www.nj.gov/DCF/">https://www.nj.gov/DCF/</a></p>	<p><b>PerformCare</b>  300 Horizon Dr  Suite 306  Robbinsville, NJ 08691-1919  <b>Toll-free phone</b>  1-877-652-7624    <a href="http://www.performcarenj.org/index.aspx">http://www.performcarenj.org/index.aspx</a></p>
<p><b>ABCD: Alliance for the Betterment of Citizens with Disabilities</b>  127 U.S. Highway 206  Suite 26  Hamilton, NJ 08610  Phone: (609) 581-8375  Website:  <a href="http://www.abcdnj.org">www.abcdnj.org</a></p>	<p><b>The Arc of New Jersey</b>  985 Livingston Avenue  North Brunswick, NJ 08902  Phone: (732) 246-2525  E-mail: <a href="mailto:info@arcnj.org">info@arcnj.org</a></p>	<p><b>ASPEN: Asperger Syndrome Education Network</b>  P.O. Box 109  Oceanport, NJ 07757  Phone: (732) 321-0880  E-mail: <a href="mailto:info@aspennj.org">info@aspennj.org</a>  <a href="https://aspennj.org">https://aspennj.org</a></p>

<p><b>Autism New Jersey</b> 500 Horizon Drive Suite 530 Robbinsville, NJ 08691 Phone: (609) 588-8200 or 1-(800) 4-Autism E-mail: <a href="mailto:information@autismnj.org">information@autismnj.org</a> <a href="https://autismnj.org">https://autismnj.org</a></p>	<p><b>Autism Speaks New Jersey Regional Office</b> 1060 State Road (2<sup>nd</sup> Floor) Princeton, NJ 08540 Phone: (609) 228-7310 E-mail: <a href="mailto:newjersey@autismspeaks.org">newjersey@autismspeaks.org</a> <a href="https://www.autismspeaks.org/">https://www.autismspeaks.org/</a></p>	<p><b>Autism Speaks Southern New Jersey Office</b> 216 Haddon Ave, Suite 403 Westmont, NJ 08108 Phone: 856-858-5400 Fax: 856-858-5444 Email: <a href="mailto:southernnewjersey@autismspeaks.org">southernnewjersey@autismspeaks.org</a></p>
<p><b>Disability Rights New Jersey</b> 210 South Broad Street (3<sup>rd</sup> Floor) Trenton, NJ 08608 Phone: (800) 922-7233 Website: <a href="https://disabilityrightsnj.org/">https://disabilityrightsnj.org/</a> E-mail: <a href="mailto:advocate@drnj.org">advocate@drnj.org</a></p>	<p><b>Boggs Center on Developmental Disabilities Rutgers Robert Wood Johnson Medical School</b> Liberty Plaza 335 George Street (3<sup>rd</sup> Floor) New Brunswick, NJ 08901 Phone: (732) 235-9300 Website: <a href="http://rwjms.rutgers.edu/boggscenter/">http://rwjms.rutgers.edu/boggscenter/</a></p>	<p><b>Family Support Coalition of New Jersey</b> Phone: 1-(800) 372-6510 Email: <a href="mailto:fscnj.info@gmail.com">fscnj.info@gmail.com</a>: <a href="https://www.familysupportcoalition.org/">https://www.familysupportcoalition.org/</a></p>
<p><b>HFMA: New Jersey Chapter Healthcare Financial Management Association</b> Mailing Address: Attention: Laura A Hess PO Box 6422 Bridgewater, NJ 08807 908-963-2505 Website: <a href="http://hfmanj.org">http://hfmanj.org</a></p>	<p><b>Rutgers University Behavioral Health Care</b> <b>Mom2Mom Helpline (under 21 y/o)</b> Phone: 1-877-914-6662 <b>Mom2Mom Adult Helpline (over 21 y/o)</b> 1-833-652-3858 Website: <a href="http://www.mom2mom.us.com">http://www.mom2mom.us.com</a></p>	<p><b>NAMI New Jersey: National Alliance on Mental Health</b> 1562 U.S. Highway 130 North Brunswick, NJ 08902 Phone: (732) 940-0991 Email: <a href="mailto:info@nami.org">info@nami.org</a> Website: <a href="http://www.naminj.org">http://www.naminj.org</a></p>
<p><b>NASOMH: National Association of State Offices of Minority Health</b> 3737 N. Meridian Street Suite 300 Indianapolis, IN 46208 Phone: (317) 920-4928 Email: <a href="mailto:nasomh@gmail.com">nasomh@gmail.com</a> Website: <a href="http://www.nasomh.org">www.nasomh.org</a></p>	<p><b>National Association for the Dually Diagnosed (NADD)</b> An Association for persons with developmental disabilities and mental health need 321 Wall Street Kingston, NY 12401 Website: <a href="http://www.thenadd.org">www.thenadd.org</a> Email: <a href="mailto:info@thenadd.org">info@thenadd.org</a> Phone: 845-331-4336</p>	<p><b>NJAMHAA: New Jersey Association of Mental Health and Addiction Agencies</b> 3635 Quakerbridge Road Suite 35 Trenton, NJ 08619 Phone: (609) 838-5488 Website: <a href="http://www.njamhaa.org">http://www.njamhaa.org</a> Email form available on above website</p>
<p><b>New Jersey Council on Developmental Disabilities</b> P.O. Box 700 Trenton, NJ 08625 Phone: (609) 292-3745 Email: <a href="mailto:njcdd@njcdd.org">njcdd@njcdd.org</a> Website: <a href="http://www.njcdd.org">http://www.njcdd.org</a></p>	<p><b>SPAN: Statewide Parent Advocacy Network</b> 35 Halsey Street (4<sup>th</sup> Floor) Newark, NJ 07102 800-654-SPAN (7726) Phone: (973) 624-8100 Website: <a href="http://www.spanadvocacy.org">www.spanadvocacy.org</a> E-mail: <a href="mailto:info@spanadvocacy.org">info@spanadvocacy.org</a></p>	<p><b>The Family Resource Network</b> 50 Millstone Road Building 300, Suite 201 East Windsor, NJ 80520 Phone: (800) 372-6510 Fax: (609) 392-5621 Website: <a href="http://www.familyresourcenetwork.org">http://www.familyresourcenetwork.org</a> E-mail: form on above website</p>

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## K8. Portable Emergency Plan and NJ Department of Health Hospitalization Visitation Policy Pertaining to People with I/DD

### Section 1: Emergency Information

#### Call 911 if the individual:

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

Individuals 21 y/o and older: Call CARES: 1-888-393-3007

Individuals under 21 y/o: 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, for example: refuses medications
- 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: Individual Profile

Name: \_\_\_\_\_ DOB: \_\_\_\_/\_\_\_\_/\_\_\_\_

Address \_\_\_\_\_

Phone: (\_\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ Insurance: \_\_\_\_\_

SSN: \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Primary Diagnoses: \_\_\_\_\_

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**Guardian**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

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:**

Requires 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 preferred food, video game books,

other \_\_\_\_\_

**IMPORTANT NOTE: AFTER COMPLETING THE PORTABLE EMERGENCY PLAN REMEMBER TO ATTACH A COPY OF THE NJ DEPARTMENT OF HEALTH HOSPITAL VISITATION POLICY PERTAINING TO INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PRINTED BELOW FOR YOUR REVIEW AND CONVENIENCE.**



State of New Jersey  
DEPARTMENT OF HEALTH  
PO BOX 360  
TRENTON, N.J. 08625-0360  
[www.nj.gov/health](http://www.nj.gov/health)


PHILIP D. MURPHY  
Governor

SHEILA Y. OLIVER  
Lt. Governor

JUDITH M. PERSICILLI, RN, BSN, MA  
Commissioner

April 25, 2020

**TO:** Acute Care Hospitals Licensed Pursuant to N.J.A.C. 8:43G

**FROM:** Judith M. Persichilli, R.N., B.S.N., M.A.   
Commissioner

**SUBJECT:** Support Person Permitted for a Patient with a Disability

On March 9, 2020 Governor Philip D. Murphy issued Executive Order 103, declaring the existence of a Public Health Emergency, pursuant to the Emergency Health Powers Act, N.J.S.A. 26:13-1 et seq., and a State of Emergency, pursuant to the Disaster Control Act, in the State of New Jersey for Coronavirus 2019 Disease ("COVID-19"). In recognition of the fact that the virus that causes COVID-19 is easily transmitted, especially in group settings, it is prudent for hospitals to implement restrictions on visitors to the facility. Such limitations must take into consideration patient care and well-being.

The Department of Health (Department) considers a designated support person essential to patient care for patients with disabilities where the disability may be due to altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns. Therefore, hospitals are required to allow a designated support person to be with the disabled patient during hospitalization. This designated support person can be a family member, personal care assistant or another disability service provider knowledgeable about the patient's care and must be allowed to remain with the patient while in the hospital, subject to the restrictions set forth below. The restrictions must be explained to the patient's support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patient's support person fully understands the restrictions.

The disabled patient's support person must be asymptomatic for COVID-19 and must not be a suspect or recently confirmed case. Additionally, hospital staff must screen the support person for symptoms of COVID-19 (e.g., fever, cough, or shortness of breath), conduct a temperature check prior to entering the clinical area, and every twelve hours thereafter, and screen for potential exposures to individuals testing positive for COVID-19. Personal Protective Equipment (PPE) should be given to and worn by the designated support person. Once in the unit, the designated support person must have extremely limited access to other areas of the hospital and not be permitted to leave and re-enter the hospital.

Hospitals may restrict the presence of a designated support person should, in the Hospital's judgement, a shortage of PPE require use of the resources by direct patient care givers.

Additionally, if the hospital determines that a second support person is necessary for the disabled patient, and PPE availability permits, hospitals are permitted to have a second designated support person and may permit either designated support person to be present with the disabled patient. The screening requirement above is to be followed for both designated support persons.

If you have any questions concerning this matter, please contact Ms. Jean DeVitto, Executive Director, Certificate of Need and Healthcare Facility Licensure program, at [jean.devitto@doh.nj.gov](mailto:jean.devitto@doh.nj.gov).

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## **K9. List of Additional Information and Materials Available in the Resources Section of the New Jersey Council on Developmental Disabilities (NJCDD):**

*The following information and materials are available for viewing, downloading and printing in the Resource section of the New Jersey Council on Developmental Disabilities website: [www.njcdd.org](http://www.njcdd.org)*

- **Full PDF version of the Enhanced Family Crisis Handbook**
  
- **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: Council Emerg Prep FINAL1 (njcdd.org)**
  
- **The NJ Department of Health Hospital Visitation Policy Pertaining to Individuals with Intellectual and Developmental Disabilities: Hospital-Visitor-Policy-UPDATED-5-12-2020.pdf (njcdd.org)**

AN ENHANCED  
**FAMILY SUPPORT**  
**CRISIS HANDBOOK**

A Behavioral Health Wellness Toolkit

Promoting voice and choice for New Jerseyans of all ages with intellectual and developmental disabilities, and all stakeholders who support them.

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AN ENHANCED  
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