

Appendix to The Revised Family Crisis Handbook (April 2019):

Lived Experience – Real Life Stories Provided by People Living with Dual Diagnosis, their Families and their Support Professionals

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

Recognition and appreciation is given to Donna Icovino for coordinating these interviews and valuable stories, with many thanks to the individuals and families who have shared them.

Lived Experience: Voice and Choice Vignettes

As an Appendix to the Revised Family Crisis Handbook (2019), we have made available valuable insights and experiences shared by people with disabilities, advocates, families, crisis workers, direct care staff and service providers that reflect their lived experiences as people who have been in crisis or who have supported someone in crisis. 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 and contributors.

Family Member

We've never known exactly what triggered my son's meltdown. When I arrived at this 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 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.

My 19-year-old son, Gavin, has been our great joy and our great challenge. Gavin has a developmental disability with cerebral palsy and autism spectrum disorder as well as mental illness. 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 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 Dual Diagnosis 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 dual diagnosis.

Trinitas 2-D is a model program, but their children’s floor is so strict and inflexible with their rules. With a dual diagnosis 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 DD/MI 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.”

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 on 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. Crisis Houses specifically for dual diagnosis are needed. Positive Behavior Supports training for staff and families is 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 and 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 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 Service Professional – Support Worker

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 assistance of 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. He was discharged the next morning because the hospital psychiatrist stated he no longer met the criteria for admission. It was frustrating that the individual was not 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 keep 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 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 regards 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 in making great strides in doing so. As professionals, CARES clinicians are continuing to educate ourselves and develop a platform to share that information with others.

Family Member: Kathy H.

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 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 had 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 of 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 the DDD and 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 extending 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.

Family Member: Donna Icovino

I suppose that the best advice and guidance that I can provide is based on my own personal experience with my son, Michael, now thirty-three years old, as well as the countless numbers of families I have worked with over the past fourteen 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 behavior therapist recommended techniques, 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 saw as unreasonable demands. Unfortunately, his aggressive acts became more severe, and frequent. Within a year, my husband, daughter, and I had trialed 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 and practiced 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, as well as his pediatrician, and dentist to make sure that his issues were not related to an undiagnosed health problem.

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.

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 them to the point of crisis. I was advised by his Psychiatrist to call 9-1-1 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.

That brings me to how I came 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 good intentioned. 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 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. Regardless of our deep

love and devotion for 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 a life changing experience for him. He was safely weaned off all medications, evaluated and closely studied and monitored by a medical and behavioral team, who diagnosed Michael with bipolar disorder within his five-month stay. He was placed on the appropriate 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 on. 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 trialed 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 dual diagnosis. In order to maintain the overall wellbeing 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 in a respectful and compassionate way that achieves the best possible outcomes for your loved one.

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.'

Family Member: "My Journey to Advocacy," by Tara Montague

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 wheel-chair. 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, education all 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 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 to the Governor's 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.

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), make 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.

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.

Self-Advocate: “My perspective on crisis intervention,” by Autumn Matacchiera

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 Durable Power of Attorney, and signed a Psychiatric Advance Directive, so my parents are allowed to stay involved in my care.

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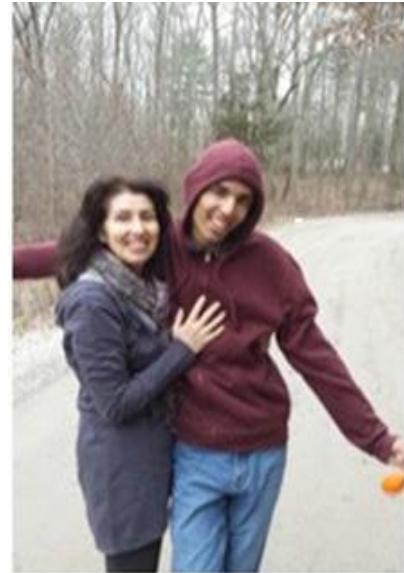
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Family Member: Rommy Delvecchio and her son, Jake

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 being 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. 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/UBHC Mom2Mom Helpline, where I found my voice so that others could understand that Jake needed for them to know about his desire to live a truly happy, fulfilling and productive life.

Master level Clinician for CARES: Helen McGhee

I have been working with individuals with ID/Mental health for fourteen years and after speaking with clients, their families and with 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:

Client J was referred to the crisis team due to concerns about his safety in the community. J lives in his own apartment without supervision and has a history depression and of making suicidal comments in the past. There is also a recent history of suicide in the family. J works one day a week in community and does not attend a day program. J tends to isolate, is not always med compliant and does not always respond to phone calls. The crisis response team worked with the support coordinator, J and his mother to identify and address J's needs and identify 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 made recommendations to his Support Coordinator (SC) regarding specific mental health day programs that SC was not aware of. Clinician also recommended a higher level of care to ensure J's safety. The SC is currently working on having a support person scheduled to visit J daily and will explore the possibility of J attending day program four days a week at a mental health day program. Client has mentioned wanting to move to a supervised apartment program (he has a specific program in mind) and SC will look into this option as well. J's mother is in support of this plan and will encourage client to attend day program and to accept in home supports.

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.

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 behavior 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 knows Matt well. We see Matt frequently, and he is happy in his home as well as at Mom's 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.

Post-Script to “Voice and Choice Vignettes”

These vignettes indicate a range of experience by people with disabilities, families, support staff and clinicians. The terms Voice and Choice indicates two fundamental premises to promoting the expression of lived experience with developmental disability and co-occurring mental health needs: access to a means for functional communication either through language or assistive augmentative communication technology (PECc, Proloquo, etc.) and our commitment to person centered thinking in helping individuals live the lives they want to live.