



# What might I need to know about Managing a Crisis Situation?

Generally, when a child is engaged in the active, disruptive stage of a behavior, such as a tantrum or aggression, the essential focus has to be on the safety of the individual, those around them, and the protection of property. It is important to keep in mind that when he is in full meltdown mode, he is not capable of reasoning, being redirected, or learning replacement skills. However, this level of agitation does not usually come out of thin air. You can learn skills to help anticipate and turn around an *escalating* situation that seems to be headed in this direction.

*In case of emergency, call 9-1-1. Always take suicide threats seriously!*

*“Both my husband and I have thought of calling 911 before but we were too scared of the unknown. Finally one afternoon we were in a difficult situation with our son and we knew it was time to make the call. It was one of the hardest decisions we have ever had to make, but it was the right one – for our son’s safety and ours as well.”*

*–CH, Mother*

## Have a Plan

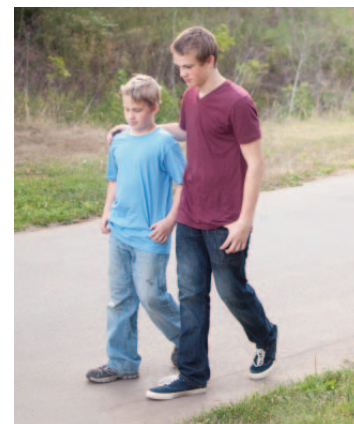
Preparation and strategies for coping and staying safe in these situations is essential and it is important for the team, including the family, to develop a *crisis plan* together. A well-designed plan will include:

- Defined setting events, triggers or signs that a crisis situation might develop
- Tools and strategies for keeping the individual and those around him safe in any setting (school, home, community)
- Intervention steps and procedures promoting de-escalation that are paired at each level with increasing levels of agitation
- Lists of things to do and NOT to do specific to the history, fears and needs of the individual
- Hands on training and practice for caregivers and staff
- Data collection and monitoring for continued re-evaluation of the effectiveness of the plan
- Knowledge of the best prepared facility if hospitalization or an Emergency Room visit might be necessary
- Secured guardianship if your child is above age 18 and you need to continue to make decisions for him (See the [Autism Speaks Transition Tool Kit](#) for more information)

Providers and families who have experienced crisis highlight the need to maintain safety first and foremost. This is not the time to teach, make demands, or to shape behavior.

### *Know Ways to Calm an Escalating Situation*

- Be on alert for triggers and warning signs.
- Try to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object.
- Remain calm, as his behavior is likely to trigger emotions in you.





- Be gentle and patient.
- Give him space.
- Provide clear directions and use simple language.
- Focus on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity.
- Praise attempts to self-regulate and the use of strategies such as deep breathing.
- Discuss the situation or teach alternate and more appropriate responses once calm has been achieved.
- Debrief with the individual, as well as the team, to prepare for increased awareness of triggers and strategies for self-regulation in future experiences.

### *In the midst of a Crisis Situation*

- Remain as calm as possible
- Assess the severity of the situation
- Follow the Crisis Plan and focus on safety
- Determine whom to contact:
  - Dial 211 for free, confidential crisis counseling
  - Dial 911 for an emergency: fire, life-threatening situation, crime in process, serious medical problem that requires mental health and basic life support ambulance services
  - Call local police for non-emergencies

### *Disclosure to a Police Officer:*

*“The decision to disclose your (or your child’s) diagnosis to a police officer will always be yours to make. If you have learned through experience that disclosure would be helpful in the particular situation, you may decide to disclose to a police officer. Law enforcement officers report that they make their best decisions when they have their best information. A good, strong autism or Asperger Syndrome diagnosis disclosure that includes the use of an information card, contact information for an objective professional, and proof of diagnosis should be considered.”*

*– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders*

When severe and dangerous behaviors pose a risk of physical harm to the individual or to others in the vicinity, physical restraints or seclusion as a brief intervention are sometimes necessary to maintain safety.

**Physical restraints** are physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely.

**Seclusion** (putting the individual briefly in a room by himself to ‘calm down’) is often employed in schools and other group environments. Seclusion can provide a quick halt to an immediate threat, but in the long run, seclusion is not a solution to the behavior itself, especially if the function of the behavior is to escape or avoid something. School programs should be focused on developing functionally based, positive behavior intervention plans to eliminate the need for seclusion practices all together.

It is important to note that while restraints and seclusion can serve to maintain safety, it is an intervention of last resort and should only be used when less restrictive and alternative interventions are not effective, feasible,





or safe. Improper use of these techniques can have serious consequences physically and emotionally. Parents and caregivers should seek out and receive professional guidance and training on positive behavior interventions and supports, crisis prevention, and the safe implementation of restraints and seclusion techniques when necessary.

## Managing a Crisis at Home

Having a Crisis Plan is an important step, and it might be helpful to create this with your team or behavioral provider. Some families have emergency information cards with vital information and signs posted to alert first responders. Strategies for keeping the individual with autism and other family members safe during episodes of aggression or self-injury are most important. Being prepared for an individual who is inclined to outbursts and times of aggression or property damage can help everyone feel safer. The strategies outline in [Making Homes that Work](#) might be helpful.

## Managing a Crisis at School

For school age children, there are protections under the *Individuals with Disabilities Education Improvement Act (IDEIA)* that pertain to behavioral considerations, functional behavior assessments, and positive supports. The school will need to have a behavior intervention plan (BIP), and your child's educational team should provide you with materials to explain your rights and your child's rights under educational law. You need to approve the plan, and the defined behavioral targets, expectations and interventions should be clear to you, your loved one and his entire team. If you need information or training, ask! Be persistent.

In the case of a significant aggressive or other concerning behavior at school, the staff or the family can call an emergency IEP meeting to discuss placement, BIP and other considerations. [Special Needs, Special Gifts](#) offers some insights into challenging behaviors in the school environment and the responsibilities and warning signs.

Your school team may suggest the use of seclusion and/or restraints, but these controversial interventions should not be undertaken lightly. It may also be helpful to know the regulations as they pertain to challenging behaviors and the use of suspensions and expulsions. There are certain protections afforded students with special needs under a provision in IDEA. The Wrightslaw page [Behavior Problems & Discipline: What Parents and Teachers Need to Know](#) contains great information on this topic.

## Managing a Crisis in the Community

*“My daughter has had quite a few tantrums in our community that have escalated. This encouraged my family and I to take steps to let my local neighborhood know about my daughter’s behavior — by posting autism cards, in my car window, on our front door, etc.*

*The other thing that really helps my family is that we travel in pairs. This means that someone is always around to help whomever my daughter is with. As a parent, I always worry about my child’s safety, so I try to find a “safe place” while I’m out to take her to when there’s a problem, Places like family bathrooms or even dressing rooms in clothing stores work when she needs to calm down or re-focus. I also spoke to our state’s DMV about getting a handicap placard for my car that I only use when my daughter is with us—so I can make that bee-line to the car even faster!*

*The other thing that helps a lot is placing a Family Emergency Kit in the trunk of each car we travel in. Much like the ones used during pregnancy and in Disaster Emergency Preparedness Kits, I add a comfortable change of shoes/clothes, personal items, an extra insurance card, her medic alert necklace info, even my CPI card—to show that I’m trained. I complete each kit with a few extra sensory items she might like and extra water and snacks, in case she might be cranky because she’s hungry and cannot say so. Also, in each kit, I started packing a few care items for myself, just in case we had to go to the hospital so that I would be more at ease, during our wait. The last thing I do very*





*frequently, is make sure I bring any medication for my child and for myself so that neither one of us get off our meds. One time my daughter's meds had changed recently, and my daughter had to go to the ER. As it turned out, I was the only one with the meds she needed, right there in my kit!"*

*– KV, a parent*

## Emergency Personnel Response and Interacting with Law Enforcement

Training in autism awareness is increasing, but has certainly not been universal across the United States. It is important that you understand that EMS personnel might not know that 'he has autism' means that he might have difficulty understanding directions, or respond poorly to flashing lights, a blood pressure cuff or other actions. It can be helpful to have information (on a card) ready to pass along or to find ways for your local responders to get to know your child. You might advocate for training in your local emergency departments. Visit the [Autism Safety Project](#) page for tools and more information for emergency personnel.

## Police and Law Enforcement Response, Judicial System

It is important to remember that police and law enforcement officers, such as security guards and TSA agents, often have little training in autism awareness and response. Sometimes a person with autism will appear to be dangerous or on drugs to a law enforcement officer. The unpredictable behaviors and communication challenges of autism, coupled with variable social understanding of authority have been known to have dire consequences. It is important to keep these factors in mind when [interacting with law enforcement](#).

You may encounter law enforcement when you are out in the community. If your loved one has especially troubling behaviors, you may have occasion to call them into your own home. It is important to get to know your local police department and have them get to know your child. Advocate for training and sensitivity concerns. Find resources and training information to pass along to law enforcement officers and other professionals on the [Autism Safety Project](#) page.

If police are involved and your loved one is charged with a crime, there are special considerations within the [legal system. Information for Advocates, Attorneys, and Judges](#) supplies additional background information and statistics on autism for legal representatives.

*"Persons with autism who are able to navigate the community without assistance should strongly consider developing personal handouts, along with the skills and resiliency to risk necessary to appropriately disclose their need for accommodations. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome. What's the best tool to use when you decide to disclose your autism or Asperger Syndrome to a police officer? A handout card:*

- *Develop a handout card that can be easily copied and laminated.*
- *Remember that the handout card is replaceable. You can give it away to the officer on the scene.*
- *Carry several at all times.*
- *The handout card can be generic or specific to you.*
- *Work with an autism support organization to develop a generic handout.*
- *Work with persons whose opinions you trust and value to develop a person-specific handout."*

*– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders*





## How do I know it is time to get more help?

Many families work diligently at home to help their children with autism negotiate the many challenges the world presents for them. However, it is important and necessary to seek professional help when:

- Aggression or self-injury become recurrent risks to the individual, family or staff
- Unsafe behaviors, such as elopement and wandering, cannot be contained
- A threat of suicide is made
- An individual presents with persistent change in mood or behavior, such as frequent irritability or anxiety
- A child shows regression in skills
- The family can no longer care for the individual at home

Sometimes this journey starts with a trip to the Emergency Room, when a person is in crisis and the caregiver or family needs immediate help. Sometimes it occurs in a more planned way, at the advice or urging of a doctor, mental health provider or other member of a team.

## What can I expect at the Emergency Room?

Whether it is for behavioral concerns or just necessary medical care, the emergency room can be a difficult place for people with autism. [Treating autism patients in emergencies presents challenges](#) describes some of the challenges and makes suggestions for medical staff regarding how they might be more accommodating. It might be helpful to pack this in your emergency prep kit and pass it along to ER staff upon your arrival. Be prepared to advocate yourself.

If you are requesting a *psychiatric evaluation*, it is important to bring documentation of the behaviors that are causing concern, information about psychiatric history, any previous psychiatric evaluations, recent FBA and/or BIP, a list of current and past medications and other relevant information. Names and contact information for doctors, your behavioral provider or other important team members will be helpful. Having all of this information in writing, in one place, will help you be prepared in the event of a crisis.

Alternately, a call to the police might trigger their concern for the person or those around him, and the officer might issue orders to have the individual transferred to the ER, even if that is not your wish. In either case, the police officer or the hospital staff can place the person on a *Mental Health Hold*. When a person is placed on a mental health hold, they can usually be held for up to 72 hours for a psychiatric evaluation. This does not necessarily mean that the person will be held for the entire 72 hours. The evaluation often takes place within 24 hours.

Before a psychiatric evaluation can occur, the ER staff must evaluate and medically clear the individual. In many cases, they are likely to do a drug screen and toxicology report. The process to get medical clearance may take several hours, and maybe longer based on the staffing and volume at the ER and the complexity of the medical situation. Then a psychiatric evaluation will be performed, and will include interviews, a record review and an examination. For more information, see [Psychiatric Evaluations in the Emergency Room](#).





Many trips to the emergency room will involve calming the individual, often with medication, and then releasing him and sending him home. Arriving at an ER does not necessarily translate into an admission to the hospital. Sometimes, the ER visit will turn into a longer stay of 1-2 weeks, with the length of stay sometimes a reflection of insurance issues.

If the hospital staff decides that the individual is at particular risk of harm to himself or others, they may recommend commitment to a mental hospital or psychiatric ward. It is important to know that if you or the adult patient does not approve, the law provides for a process known as *Involuntary Commitment* or *Civil Commitment*. This allows for court-ordered commitment of a person to a hospital or outpatient program against his will or protests.

## Psychiatric Inpatient Hospitalization: How do you choose a facility?

Often individuals are brought to the nearest hospital or the closest one that has an open bed. While this may be the fastest response in a crisis, it is best to be at a facility that can best respond to the needs of your child. If possible, discuss with your providers ahead of time if there is a preferred treatment setting for individuals with autism in the event of crisis. Some hospitals have a psychiatric emergency room.

In a few states, there are specialized hospital programs specifically designed for individuals with autism and other developmental disorders. These **Crisis Intervention Centers** can often provide more targeted treatment options and assessment expertise. Pre-planned stays in *bio-behavioral units* may be hard to arrange since so few of these facilities exist, but the length of stay is generally a 3 to 6 month period.

## What happens when you check into a hospital?

Just as you might do when planning a trip, it is important to remember to bring your loved one's necessary supports, including communication devices, visual supports, preferred toys and sensory items, as well as a familiar blanket or pillow. Entering a hospital can be quite stressful, so anything you can do to reduce anxiety and increase predictability should be considered.

If your child or loved one is placed in a psychiatric facility or ward, it will be important for you to help the staff understand his particular skills and challenges. You should be prepared for the fact that unlike many medical situations you may have experienced, a psychiatric ward is likely to have locked doors and may have stricter limits on visitation. You may not be able to be present during your child's entire stay or there to be his 'interpreter' of behaviors, food aversions, fears and anxieties as you might otherwise do. These facilities are not obliged to provide behaviorally-based treatments and interventions, though some do.

You may need to advocate for a role in helping the hospital to understand your child. In particular, it might be important to advocate against the use of restraints for your loved one, as this may increase anxiety and the intensity of negative behavioral responses. There are established policies on the use of restraints and seclusion in healthcare that you can read [here](#). You can also request that a medical provider who knows your child be involved with the hospital staff.





*“When Kevin ended up in the psych unit at our state hospital, it was incredibly valuable to have our autism doctor involved in his care. The hospital staff did not get it when it came to autism and Kevin, and our doctor was very helpful at running interference.”*

*– SB, parent*

Most hospitals are family-friendly and have extended visiting hours for children. Separating from your child can be difficult and leave you with feelings of guilt, but it is essential to remember that this is in the child’s best interest. He needs specific help, and you need an opportunity to recover from a challenging situation.

## Patient Rights

Patients receiving services in a hospital have the same human, civil and legal rights accorded all minor citizens (those under the age of 18) or adults. Patients have the right to a humane psychological and physical environment. They are entitled to respect for their individuality and to recognition that their personalities, abilities, needs and aspirations are not determined on the basis of a psychiatric label. Patients are entitled to receive individualized treatment and to have access to activities necessary to achieve their individualized treatment goals.

*Commitment–Involuntary vs. Voluntary:* As mentioned above, a psychiatric evaluation will be performed to determine if the individual is a danger to himself or others. If he is considered a danger, he can be committed against his (or your) will with a court order.

## Parent Rights

Parents (or guardians) retain their legal rights for decision-making regarding the health and welfare of their child under the age of 18. Parents have the right to informed consent to treatment, including notification of the possible risks and benefits of any treatment that is proposed. Parents have the right to be involved in the treatment that is provided to their child, which includes visiting their child during the course of their treatment, ongoing communication from the providers about the child’s progress, and copies of medical, behavioral and educational records.

If you feel your child would be better served in a different setting, you should engage the attending physician and other members of the hospital clinical team in a discussion of the risks and benefits of changing treatment programs. While you know your child best, it is important to evaluate the implications for safety and treatment in any setting being considered.

*Age of Majority and Guardianship:* For many years, you have been making decisions on behalf of your loved one with autism. But at the age of 18, the law says he gets to decide for himself and can give the required *‘informed consent.’* He can refuse treatment or be declared unfit to decide. Either way, unless you apply for and are granted *guardianship*, the decisions are now out of your hands. If you think your loved one will need your assistance in making medical, safety and/or financial decisions, it will be important for you to learn about and consider your state’s laws and procedures for obtaining guardianship status. This may take some time and the process involves a series of procedures, so it is important to consider this in advance of his 18th birthday, if possible. Sometimes there are allowances for temporary guardianship status while guardianship proceedings are in process. Guardianship is different from conservatorship, which allows for financial responsibility of another person. You can learn more in the Transition Tool Kit section on [Legal Matters to Consider](#).





## What happens when the Hospital Stay is over? What is a Discharge Plan?

When the hospital stay is complete, your child or loved one should leave with a Discharge Plan created by the hospital, ideally with the input of other team members. It is not necessary for you to agree to the terms or components of the plan, but the hospital is required to counsel you, your loved one and other relevant team members about the components of the plan. The hospital is also supposed to begin implementation of the plan and assist in the coordination and connection to local social services organizations, making referrals or transfers and forwarding information and records. Such a plan is not likely to occur after a brief ER stay, but should be developed for your child over the course of an extended inpatient hospitalization. A discharge plan should include:

- A statement of your child's need, if any, for:
  - Supervision
  - Medication (what, when, how much)
  - Aftercare services and supports
  - Assistance in finding employment
- Recommendation of the type of residence in which your child is to live and a listing of the services available to your child in such residence
- Lists of the organizations, facilities, and individuals who are available to provide services in accordance with each of your child's identified needs
- Notice to the appropriate school district, if relevant, regarding the proposed discharge or release of your child
- An evaluation of your child's need and potential eligibility for public benefits following discharge, including public assistance, Medicaid, and *Supplemental Security Income*
- Follow-up evaluation plans



For anyone who has been hospitalized for any reason, recovery is best when there is a solid support network. This network can be family, friends or team members, often working together. Involving others in the discharge process will help your loved one and support you in moving forward. To learn more, visit [Discharge Planning in Mental Health](#).

Contributions to this section were made by Matthew Siegel, M.D.

