NATIONAL FRAGILE X FOUNDATION

Strategies for Addressing Aggressive Behavioral Outbursts in Adolescents and Adults with Fragile X Syndrome

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We encourage you to carefully review this information in the order presented, including why this behavior occurs in some individuals. Although this is primarily focused on teens and adults, some of the recommendations may also be helpful with younger children.

Some individuals with intellectual or developmental disabilities, including typically easy-going individuals with Fragile X syndrome, can have a behavioral outburst that includes aggressive behavior. These incidents can occur with little or no warning and can be quite disturbing or even traumatizing for everyone involved. Since aggressive behavior is only seen in a minority of teens and adults with FXS, there has been little practical information available that includes strategies for dealing with the more extreme situations.

There are many reasons why an individual might exhibit aggression, including lower cognitive abilities (which may include not understanding what is happening or is about to happen), anxiety, pain or injury, medication changes, or fear. Fear is related to the individual's perception of the threat or loss of the feeling of safety. This perceived threat can come from various external or internal sources such as sensory issues, interactions with others, or a perceived lack of control that can lead to a sense of unpredictability.

The most common aggressive behaviors reported include:

- Hitting.
- Scratching.
- Biting.
- Throwing objects, either randomly or intentionally.
- Hair pulling.
- Yelling, usually directed at a caregiver.

Aggressive behavior can cause problems with friendships, employment or day programs, living arrangements, or when participating in various recreational activities, including with typically developing peers. Further, it can negatively impact the family and their ability to have friends, travel, or find respite care. These are all important reasons to try and minimize aggressive behaviors.

Of note, in 2021, the National Fragile X Foundation worked with the Food & Drug Administration to develop the report, **Voice of the Patient Report: A Patient-Focused Drug Development Meeting for Fragile X Syndrome**.[1] Aggression is mentioned over 40 times in the report and 20 of the 137 respondents to an NFXF survey said aggression had a significant impact on their life or the life of the individual with FXS. That same document stated it is "important to consider that anxiety, communication, and sensory issues can also lead to behaviors, including aggression."

This article addresses how to deal with aggressive outbursts. While there is no single, simple solution, we present an introduction to the challenge of aggressive behavioral outbursts and some ideas to help prepare you for such an event.

Please review the ideas shared here with the understanding that all individuals and all incidents are unique and the issues discussed may not apply to all families or situations.

1 https://fragilex.org/research/articles/nfxf-led-pfdd/

When Aggressive Behavior First Appears

Ideally, caregivers should have an advanced understanding of intervention strategies and feel confident applying them when an individual becomes aggressive or shows signs of a possible outburst.

If you are concerned about a currently non-aggressive child someday developing aggressive behaviors, we recommend learning the early signs and watching for them carefully. The earlier the behavior is recognized, the better you (and appropriate professionals) can develop an intervention plan.

Understand the ABCs of Behavior

The ABCs of behavior include A for antecedent, B for behavior, and C for consequence.

- **Antecedent**: What occurs before the behavior.
- **Behavior**: The exact description of what the behavior looks like.
- **Consequence**: What occurs after the behavior.

The ABCs of behavior are a helpful framework to use with understanding aggressive behavior. The best path forward is to address what comes before the behavior by recognizing the antecedent as a real experience for the individual with FXS. This helps tune everyone into the why.

Possible Causes of Aggressive Behavior

In general, the underlying basic characteristics of FXS — sometimes referred to by scientists as the neurobiology of FXS — can contribute to behavioral outbursts. Features such as anxiety, hyperarousal, sensory processing issues, communication delays, and cognitive challenges can lead to or contribute to challenging behavior including aggression.

Daily Living Challenges

Day-to-day living, including typical activities, routines, and expectations, requires many skills. Individuals with special developmental needs often lack or have limited flexibility and difficulty anticipating and managing changes in their routines. In particular, one or more situations may result in behavioral responses:

- Being asked to do something they don't want to do.
- New routines or changes in routine.
- Looking forward to an upcoming activity.
- Anxiety about an upcoming activity.
- Having a busy day with little downtime.
- Not understanding what is going to happen.
- Something someone said about them.
- An activity a care provider will not let them do.
- Going through a transition.
- Feeling hungry or tired.
- Feeling embarrassed.
- Not being able to express needs or wants.
- Not being able to address any of these items immediately or fast enough.
- Having too many "unknowns" about an activity — When are you going? Who is going to be there? What are you going to do? How long will you be there? What will you do when you get home?

Importance of Feeling Safe: Not feeling safe, or a lack of predictability or control over typical daily activities may contribute to challenging behaviors.

An individual's ability to handle daily activities can vary. Some days may be manageable while others might lead to behavioral outbursts of varying intensity. The frequency of these behaviors may fluctuate from a few times a year to a few times a week or day.

Focus on analyzing what is happening just before a behavior and the reasons behind them to develop effective strategies.

Minimizing daily events can reduce behaviors, but may lead to new challenges such as becoming reluctant to leave the house. The ultimate goal is to create a productive day for the person with FXS while providing necessary support and training to navigate days involving activities outside the home.

Even with support in place, occasional behavior outbursts may still occur that require caregiver intervention. The key lies in finding strategies that help them handle daily activities while acknowledging the potential impact of the underlying features of FXS.

It's Not Your Fault: It is important to recognize that as a caregiver, you may do all the right things and the individual will still have a behavioral outburst. It does not mean a parent or caregiver is doing it wrong — it just means the individual had an outburst. Some aspects of their daily life may need to be adjusted, with the goal of milder and fewer outbursts.

Physical Pain or Discomfort

Some individuals with FXS have a high tolerance to pain and are not able to easily identify where the pain is located. If an individual is hurt, it can result in difficult behavior including aggression. Not only is it challenging for them to communicate what happened or what they are experiencing, but it's even more challenging trying to determine whether their pain is what's behind the behavior.

Preventing and Minimizing Aggressive Behavior

Develop Strategies to Address the Underlying Characteristics and Neurobiology of FXS

When developing a strategy, look at the various possible triggers:

Anxiety

Anxiety is a very significant symptom for many, if not most, individuals with FXS. It is also believed to be one of the most significant contributors to aggressive behavior. Anxiety management is an essential component of any plan for managing aggressive behavior.

Hyperarousal

Arousal refers to a general state of nervous system activation that is reflected in behavior, physiological activity, and emotional experience. One of the characteristics of FXS is that the internal control of arousal does not work in a typical way and there is a

heightened sensitivity to environmental and social stimulation, all of which leads to a "hyperaroused" state. While hyperaroused, behaviors can be unpredictable so addressing hyperarousal should be a component of a behavior management plan.

One aspect to consider is whether the person with FXS feels safe and connected with those around them or if they are becoming hyperaroused. If hyperaroused, they may shift from feeling safe to feeling a sense of threat. From threat, hyperarousal may produce the fight or flight response and lead to aggression. For some individuals, aggression may be followed by shutting down, crying, and a remorseful collapse.

Sensory Processing

Sensory processing issues can sometimes be a contributing factor to a behavioral outburst. Managing sensory overstimulation might include using sensory-based inputs to reestablish predictability and reset the arousal system following an aggressive episode.

Communication

Most individuals with FXS experience delays in developing expressive and receptive communication. Additionally, common issues like anxiety, hyperarousal, and sensory processing can further reduce language processing and problem-solving skills.

Having trouble understanding what's being asked of them or difficulties asking for what they want or need can contribute to aggressive behavior. When tensions increase, communication may become more challenging, so it is important to develop strategies for communication.

Reducing direct verbal communication and increasing non-verbal communication and cueing are often helpful.

Cognition

Individuals with FXS exhibit intellectual delays ranging from mild to severe. Males are more often in the moderate range, while females tend toward milder delays.

Depending on an individual's cognition, their response during a difficult behavioral episode can reach a level of arousal where they're no longer able to respond to de-escalation strategies. Because of this, it's important to take their cognition into account when developing a customized behavioral plan.

Tip: Social stories can be used to demonstrate appropriate behavior and the consequences of inappropriate behavior. However, do not attempt to use social stories during or too soon after an episode. Make sure everyone has had a chance to recover emotionally.

Tip: Side dialogue can help lead up to communicating a change that's likely to cause a behavioral episode. For example, you can talk about the upcoming change with someone else while the person with FXS is within earshot. This indirect exchange helps them process the information while still calm and makes for a smoother transition when they hear about it directly.

Create a Calm, Predictable Environment

Individuals with FXS are better at self-managing their anxiety and hyperarousal when they are in a calm and predictable environment. Predictability provides a sense of stability and control for individuals with FXS, reducing anxiety and uncertainty.

To achieve this ideal environment, clearly communicate schedules, transitions, and expectations whenever possible. This helps them anticipate an event and understand what is expected of them.

Clear boundaries and expectations about their behavior also create positive engagement, which is key in helping them feel safe and connected and can be an important aspect of managing aggression.

Not Always Predictable: While it is important to maintain a predictable environment, it is also important to have strategies for responding when unexpected situations arise.

Develop a Repertoire of Self-Calming Strategies

Self-calming and relaxation strategies can be taught to an individual with FXS, but should not be introduced during an outburst. However, if they have previously learned and practiced different techniques, they can be prompted to use their training at the first signs of agitation.

Caregivers can experiment with a variety of strategies to find out what is most effective based on the individual's preference, and how they best react to the cue. Individuals may respond to a single strategy or to a combination of strategies. Some ideas might include:

Listening to music, a meditation tape, or calming sounds like rain or the ocean.

- Deep breathing exercises.
- Time in a rocking chair.
- Taking a walk.
- Swinging.
- Petting a dog.
- Looking through a favorite book or photos.
- Accessing quiet time with low lights.

Self-Calming: Self-calming and relaxation strategies may only be effective with some individuals and only when they have had sufficient practice.

Have the individual practice their self-calming activity and go to their room during a calm time. Parents can also model this behavior. This allows the individual to see that it is not just them who sometimes needs to calm down.

Build a Relationship with a Fragile X Doctor and Other Specialists

Families are encouraged to develop a relationship with a doctor or other specialists who specialize in Fragile X. This is particularly important if the individual has a history of behavioral outbursts.

While wait times for a regular medical appointment can be 6-12 months, in a crisis, some clinics may be able to provide an earlier appointment. This is especially true when the family has an established relationship with the clinic team. Therefore, families are especially encouraged to develop that relationship during non-crisis times.

Over the past few years, many clinics have enhanced their online telehealth options, which can be an important option for parents in a crisis. In addition, the Fragile X clinic doctor may be willing to consult with your local primary care provider regarding medication adjustments.

Team Approach: When appropriate, a team approach to developing an intervention plan can be helpful because it brings in multiple perspectives. It is critical to include primary caregivers and — when possible — the individual with FXS in the team. In addition to physicians, the team might include special educators, occupational therapists, speech-language pathologists, behavioral therapists, and psychologists. These team members should draw from research and clinical and educational knowledge specific to FXS.

Consider the Use of Medication

This article is not meant to provide recommendations on the use or type of medications for individuals with FXS. That decision should be made between caregivers and, when possible, a Fragile X specialist doctor or other healthcare provider knowledgeable about Fragile X syndrome.

Supports: Medication should only be used in conjunction with environmental and behavioral supports.

The CDC-supported, long-term natural history study of FXS, called FORWARD, has collected data that address aggressive behavior. For example, **a 2019 paper covering all ages**[2] noted that over 40% of those with aggressive or self-injurious behavior were receiving medication-based treatment for those behaviors. As a result, there is an ever-growing body of knowledge about medication types, dosages, and frequency that have a beneficial impact on aggressive behavior while minimizing any side effects.

The **2021 Patient-Focused Drug Development report**[3] to the FDA contains many comments from parents about the beneficial role that medications play — in combination with other forms of therapy — in managing their child's aggressive behavior.

Examples of Strategies

One example is when there's a doctor's appointment coming up that the individual might not be happy about, all aspects of making the appointment should be thought through — from setting the time of day, to when to tell the individual, to traveling to the appointment and making it through the appointment, to receiving a reward, if appropriate.

Whenever several activities will occur within a short period, extensive planning is necessary to make sure everything goes smoothly.

Additional Thoughts

Here are additional aspects to consider when developing a plan to prevent or minimize aggressive behavior:

- **Understanding and Empathy:** Develop an understanding of the individual's needs, emotions, and past experiences. Practice active listening and feelings of empathy to establish meaningful connections.
- **Positive Reinforcement and Encouragement:** Utilize positive reinforcement and praise to acknowledge efforts and achievements. Celebrating small successes nurtures self-esteem and motivation to engage. For example, offer praise when the individual successfully makes or accepts an unexpected change to their typical routine, or calms down on their own.
- **Continuous Reflection and Growth:** Regularly assess the effectiveness of strategies and make adjustments as needed. Continuous learning and improvement are essential for maintaining a regulated and supportive environment.

2 https://link.springer.com/article/10.1007/s10803-019-04173-z

3 https://fragilex.org/research/articles/survey-treatment-priorities/

By incorporating the above, parents, caregivers, and educators can create an environment that promotes regulation, predictability, and a sense of safety to form the basis for strong connections and meaningful engagement with individuals.

Setting up such an environment can include:

At Home

- Have a routine and use a visual schedule.
- Use visual cues to move throughout the day and various activities.
- Give choices regarding activities and events.

Outside the Home

- Every environment outside the home may need to be considered — location, time of day, noise level, and number of people.
- Familiarity with an environment can help. If possible, use visual aids to introduce any new environment.
- When possible, try to introduce the individual to new places slowly and in phases or steps.

Parents should think about what would work best for them and their families. There is not a one-size-fits-all plan. Instead, a plan should take into account everyone's safety — the individual with FXS, parents, caregivers, siblings, and anyone else in their life.

Other suggestions and recommendations from caregivers and professionals include:

- Let the individual have a say in what they do and when they do it, "I will take my shower on Saturday before we go out."
- Respect the wants and needs of the individual, "I don't want to go to that restaurant, it is too noisy."
- Emphasize the positive, "You get to go see Eve tomorrow." (Not "You have to go to the dentist tomorrow.")
- Acknowledge when a lot is going on, "There are a lot of activities going on this weekend. Let's talk and I will write them down."

In summary, begin by trying to determine the causes or likely causes of a behavior and learn to address them. This will hopefully minimize or stop the behavior before it escalates to a more challenging outburst. However, keep in mind that the causes of a specific behavior may change over time.

Learn More

Observable Symptoms of Anxiety in Fragile X Syndrome: The information analyzed in this study will result in the development of a measure where observable and quantifiable data on anxiety in those with FXS can become an outcome measure to be used in future research.[4]

Managing Anxiety ... What Works and Why? Dr. Jennifer Epstein, a licensed clinical psychologist, has seen patterns develop among parents she works with in her practice. Parents can anticipate when difficult behaviors will emerge for their children, and they try many different strategies to support their children but sometimes feel that what they're doing is not helpful.[5]

Concept and Use of a Sensory Diet: Learn more about strategies used in combination with an overall sensory diet to integrate sensory-motor activity into an individual's daily life routine.[6]

4 https://fragilex.org/research/articles/observable-symptoms-anxiety/

5 https://fragilex.org/healthcare/managing-anxiety-what-why/

6 https://fragilex.org/healthcare/sensory-diet-concept-use/

Emotional Regulation in Fragile X Syndrome: Join Rebecca Shaffer in a webinar focused on signs of emotion dysregulation in Fragile X syndrome and ways to respond including practical strategies.[7]

Cincinnati Children's Hospital Caregiver Calming Toolkit: From CHOP, resources for breathing exercises, calming and relaxation tips, and the 5-point scale for children who understand numbers but struggle with communicating how they feel.[8]

Ready-Not-Ready Cueing: From Strategies for Day-to-Day Life by Tracy Murnan Stackhouse and Sarah Scharfenaker, "ready-not-ready cueing" can help children learn to identify their "state" of preparation or readiness for the next demands or challenges.[9]

Mindfulness and Me: Watch this short video with Tracy Stackhouse and Ruth Meissner on teaching one strategy for relaxation, plus links to additional resources.[10]

Find a Fragile X Clinic: Locate an NFXF Fragile X Clinical & Research Consortium (Fragile X syndrome) or NFXF International FXTAS Consortium member clinic.[11]

NFXF Treatment Recommendation on Medications: Learn more about medications, which are at times helpful to facilitate the individual's ability to attain optimal life skills and allow for better integration into educational, adult, and social environments.[12]

Develop a Response Plan

Plan in Advance

Developing a plan in advance is an important aspect of a behavior incident. This is especially critical if there is a history of prior incidents. The plan may include what each caregiver, sibling, or other family member should or should not do, and what should be said to any bystanders who try to intervene. The plan should also include what you expect the individual to do, which needs to be discussed and practiced ahead of time.

Reflecting on Prior Incidents: It is important to consider how the adult in a situation should respond when the behavior occurs. Prior responses can influence any later episodes, as the aggressive individual will expect the same or similar response. Because of the role it can play, stay aware of your responses and whether they contribute to or lessen the behavioral outburst. Of course, you'll want to repeat those that help to reduce their response.

When Behavior Starts to Escalate

Recognize the Warning Signs

Caregivers can often — but not always — recognize signs of an impending outburst. These signs might include:

7 https://fragilex.org/resources/webinars/emotional-regulation/

8 https://fragilex.org/wp-content/uploads/2025/06/fxs-conference-toolkit-shaffer.pdf

9 https://fragilex.org/healthcare/strategies-for-day-to-day-life/#readynotready-cueing

10 https://fragilex.org/resources/webinars/mindfulness-and-me-with-tracy-and-ruth/

11 https://fragilex.org/resources/clinics/

12 https://fragilex.org/resources/treatment/medications-fxs/

- Excessive pacing.
- Clenched fists or jaw.
- Speaking loudly.
- Verbal perseveration.
- Verbal refusal.
- Throwing items.
- Grabbing an arm.
- Biting hands.
- A red face or ears.
- Kicking.
- Spitting.

Once an individual's anxiety or frustration has increased, their needs will have to be met fairly quickly since they usually are not able to stop the situation from progressing themselves.

Where that point of no return lies is unique to each individual and situation, which makes planning and responding very challenging, but that is when you need to take action. At that point, the individual needs to engage in a planned calm activity or remove themself from the situation.

Signs of Escalating Behavior

When a caregiver sees signs of escalating behavior, the next step might be to:

- Ask the individual to do deep breathing.
- Ask the individual to go to their room to do self-calming activities until they feel calm enough to rejoin the group.
- Remove themselves (parent or caregiver) from the situation and seek a safe place, when the behavior calls for it.
- Tell the individual to go to their room.

In-The-Moment Responses and Interventions

Sometimes, even if you've already acted according to the suggestions above, you may find yourself dealing with a significant behavior outburst. Here are additional suggestions for dealing with more severe aggressive behavior:

At Home

Parents and Other Caregivers

At the first signs of aggressive behavior or before the behavior even starts, tell the individual to go to their room. If that hasn't happened or isn't possible, go to a separate room and lock the door if possible.

If that's not possible, protect yourself as best as you can. This can include putting a table or chair between you and the individual. In all instances, be sure to protect your face and head. You might need to break their grip if they grab you, however, it is never recommended for a caregiver to hit back.

Siblings

Siblings require special consideration, especially when they're younger or smaller than the aggressive individual. Protecting them from any physical risk should take precedence. Whenever possible, an adult known to the younger sibling should quickly remove them from the scene. If that is not possible, quickly direct them to a safe space.

In addition, a younger sibling will likely be frightened by their older sibling's behavior and the interventions used to manage their outburst. In this case, psychological risk needs to be addressed, especially if the outbursts are chronic in their lives.

Discussing the behavior with siblings in advance can help lessen their fear and confusion when they find themselves present during an outburst. If that's not possible, this discussion needs to happen as soon as possible.

Self-Defense Classes: Some parents have found self-defense classes to be helpful, especially classes that emphasize diffusing the situation, using evasive movements, and self-protection.

Groups and Counseling: Professionally run sibling groups or counseling can be very helpful. Siblings must learn that it is never okay to be hit — by anyone.

In a Car

If you find yourself in a car during a behavior outburst:

- Find a safe place to park, away from traffic.
- Encourage the individual to remain seated.
- Protect yourself.
- If the individual gets out of the car, you may need to lock the doors and remain inside to protect yourself and others.

Child Safety Locks: If it's safe to remain in the car with the individual, use the child safety locks (if available) to prevent the agitated individual from exiting the car into dangerous traffic.

In Public

If you find yourself in a public space during a behavioral outburst:

- Attempt to remove the individual from public view and have them sit down.
- If possible, quickly move away from the individual.
- If the individual starts to chase you, do whatever is needed to get them to sit down.

Bystanders

If a bystander wants or tries to intervene, thank them but make it clear you will handle the situation. If needed and possible, quickly explain that the individual has special behavioral challenges that you are experienced in dealing with, and their assistance may be counterproductive and could worsen the situation.

Calling 911

If the individual is in imminent danger of hurting you or anyone else, 911 may be the only option.

You might not be able to call 911, but if you do, be aware that the 911 dispatcher has likely never heard of Fragile X syndrome. Telling them the individual has a "disability" can be misunderstood as a physical disability. Or if you tell them the individual has a

cognitive disability, the responders may only hear the word "disability," without understanding it is cognitive. Keep in mind that the dispatcher also may not relate the situation correctly to the emergency responders. Or they may not get that message at all.

The critical point is that you may have only one chance to say what is going on with the individual, so be careful and thoughtful. You may need to use whatever language necessary to explain the situation, even if they're not technically accurate.

Helping Responders Understand: Use of the terms "intellectual disability," "cognitive delay," or "autism" may be necessary to ensure that law enforcement officers or emergency responders better understand the situation.

Someone Else Calls 911

If a bystander calls 911, ask that you or someone with you greet the responders when they arrive, so you can inform them of the individual's disability.

When Responders Arrive

When calling 911, in addition to police, an ambulance, and a fire truck may also show up. Tell them right away that the individual has an intellectual disability or cognitive delay and may not understand their instructions or commands. If it applies, tell them they have little or no verbal skills.

The responders may not all arrive at the same time, so you may have to repeat this information so everyone involved is on the same page.

Keep in mind that some law enforcement officers and other responders have had training to deal with individuals with intellectual disability. Others, though not formally trained, may have an innate sensitivity for people experiencing a mental health crisis and will work hard to de-escalate any behavior.

Unfortunately, some police officers lack both training and sensitivity and will not understand how stress, anxiety, and sensory challenges can affect behavior. In this case, they may respond in a more typical law enforcement manner including, in the worst-case scenario, physical restraint such as handcuffs or, in an even worse scenario, using a Taser.

Working With the Police

Law enforcement will most likely ask a series of questions. They will ask about medications and a possible drug overdose. And, since they are not familiar with the individual with FXS, they will also want to know if they are in danger from weapons in the house and ask whether there are weapons in the house or scene, such as guns and knives, including kitchen knives.

Be aware that even if the individual has been in this situation before, how they respond to law enforcement is unpredictable. They may become passive, or they may become combative. If law enforcement does not know the individual has a disability, their response may also be unpredictable.

Prepare for Possible Situations: It may be helpful for parents to contact their local police department and alert them to their child's needs and possible situations before an event arises.

Some districts issue voluntary wristbands or have systems in place to flag the individual as having an intellectual disability. Families may also want to consider whether their area has in-person events (such as touching a fire truck or meeting a police officer) to help make an encounter less frightening.

Hospitalization

What to Expect: Many hospitals are not equipped to deal with a crisis, particularly one that involves aggressive behavior. Instead, in many instances, the individual is sent to the emergency room and treated by emergency room staff. While the staff may do their best, this is not a good, long-term solution. This is a situation where having a relationship with a Fragile X healthcare provider will be invaluable. They may be able to guide you and the ER providers in treating the individual.

Emergency Room Treatment

Parents and caregivers should not assume that hospital staff, including nurses and doctors, have heard of Fragile X syndrome. Therefore, similar suggestions and precautions, as used when calling 911 also apply to visits to a hospital emergency room.

When available, nursing staff may request an appropriate, professional hospital social worker to get involved. A psychiatrist may be involved, though is less likely due to limited availability in many hospitals.

Learn More

Emergency Room Stabilization Protocol For Individuals With IDD: A guide for emergency room staff to utilize to better support individuals with intellectual and developmental disabilities.[13]

Post-Incident Responses and Interventions

Review the Incident

After a cooling off period, which could be an hour or even a day, families and caregivers should discuss the event amongst themselves including looking at the causes and what they can do differently next time. This is critical to ensure a healthy outcome for all involved.

The emotional fallout is critical and should not be seen as something to feel guilty about. The important point is that a discussion takes place.

The discussion might include:

- A review of the sequence of events that led to the incident in as much detail as needed.
- A discussion of different or better ways to address the underlying features of FXS that may be contributing to outbursts.
- A close look at changes to the environment that might help prevent future issues.
- Meeting with a Fragile X specialist healthcare provider to discuss possible new medication or existing medication changes such as type of medication, frequency, and dosage.
- A review of the response plan, focusing on antecedents, behavior, and consequences.

Incident Review Participants: In addition to the family and other caregivers, including a mental health professional in the discussion can be useful, particularly if a family member or other caregivers feel traumatized by the incident. When appropriate, including the individual with FXS in discussions about changes to the intervention plan may be beneficial.

13 https://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/er-idd-stabilization-protocol/

Consequences

Logical, age-appropriate consequences (punishment) may be considered as long as the individual understands the association between the behavior and the consequence. For example, when items are thrown around, have the individual pick them up and put them away. When something is broken, they would clean up the mess and possibly replace the item.

Lashing Out: Angrily scolding or criticizing the individual is not recommended and may result in further anxiety and a continuation or repeat of the behavior.

Talking with the Individual

Following an incident, the individual with FXS may immediately express remorse and sorrow. Likely, they'll also want to move on quickly to the next activity in their daily routine.

In this case, it may not be effective to belabor the incident. During a calm time, even the next day, discuss using more appropriate behavior. For example, "When you feel upset, I will ask you to go to your room, and I need you to do that."

Professional Counseling

In general, most individuals with FXS are better at receptive language (listening) than expressive language (talking). As a result, they may benefit from "talk therapy." Talk therapy or psychotherapy, refers to working with a mental health professional — who ideally has experience working with individuals with an intellectual disability — to help the individual think about and process their behavior.

The therapist may use visual supports and indirect strategies to help the individual absorb the shared information. Importantly, the discussion is done one-on-one as a sense of embarrassment could cause another episode. A therapist can assist them in thinking about things they might do differently to help them the next time they feel angry, anxious, or frustrated.

Challenges to counseling can include:

- The individual with FXS is non-verbal or has very limited receptive or expressive language.
- Talking makes them highly anxious.
- There are very few professional talk therapists knowledgeable about working with individuals with an intellectual disability.

If Injuries Occurred

If an incident results in an injury to anyone involved, it is important to seek treatment without delay. Depending on the injury and severity, a visit to a doctor's office, urgent care, or an emergency room may be necessary. If so, you need to understand that many medical professionals are "mandated reporters," which means they are required to report the incident to authorities including social services, child or adult protective services, or law enforcement. The mandates and the names of these organizations differ from state to state. The legal responsibilities of the mandated reporters also depend on the age of the individual and whether another child is present in the home.

Without delaying treatment for injury, if there is an established relationship with the individual's healthcare provider, consider immediately consulting with that provider.

Keeping in mind the possibility of mandated reporting in the treatment setting, you might also consider seeking professional advice on how to inform the hospital or other medical personnel about the circumstances of the injury.

In the very rare instance that a non-family member or bystander is injured, legal assistance may be necessary.

Beyond the medical aspects of an injury, family members, friends, neighbors, teachers, and others may wonder about or have questions about the injury. Depending on the nature of those relationships, parents will need to decide how much they want to share, if at all, the circumstances that led to the injury.

If you are doing all of these recommendations and still have a problem with aggressive behavior:

- Continue refining daily living strategies.
- Grow your relationship with your Fragile X healthcare provider and other specialists.
- Explore additional medication options including staying informed about the newest treatments.
- Find and work with other intervention and behavioral specialists as part of a plan to explore new approaches to daily living.

Conclusions, Summary and Resources

Most of the time, individuals with FXS are nice, easy-going, enjoyable, and often funny. However, aggressive behavior in some adolescents and adults with FXS has been documented.

Parents and caregivers may not want others to see or know about the problem of aggressive behavior since it does not — and should not — define the individual. They also tend to avoid talking about how intense the behavior outbursts are because they don't think there is an answer, they don't want to be judged negatively, or they worry someone might call social services or the police.

While behavioral challenges may be lifelong for some individuals with FXS, understanding the possible causes, taking proactive steps to minimize aggressive behaviors, planning the steps to take during an incident, and developing steps to take following an incident, we believe that incidents can be lessened, both in intensity and frequency.

Lastly, you should know that aggressive behavior is not a problem specific to FXS; it is associated with several disability conditions. Therefore, please know that strategies and help are available from a variety of sources both within and outside of the Fragile X community.

National Fragile X Foundation

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