

Understanding and Modifying the Behavior of Boys with XYY: **A Guide for Parents and Professionals**

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Individuals with XYY disorder have both a physical and developmental profile that is somewhat unique due to their genetic composition. The developmental profile will be the emphasis of this paper in how it relates to the behavior. It is important to note that as is the case with all neurodevelopmental disorders boys with XYY present with a spectrum of involvement. Typically these individuals have cognitive delays ranging from mild mental retardation to low average abilities, often with a characteristic learning disability split with verbal being lower than performance. They have speech and language delays including but not limited to auditory processing delays as well as expressive language issues. Gross and fine motor delays are also present including low tone and motor planning difficulties. Sensory integration dysfunction is also common as is ADHD and mood instability (Hagerman, 1999). This profile would suggest that these individuals would garner compassion and appropriate services. This is not always the case. As a result of these genetic characteristics these boys and young men often exhibit difficult and challenging behaviors. These behaviors often separate them from their peers both socially and academically and cause them and their families a great deal of concern. Understanding these behaviors is the first step to modifying them. The following paper will attempt to serve as a guide for those individuals who work with and care for individuals with XYY.

Questions regarding behavior posed by parents and professionals alike are typically phrased in the following format “What do I do when he *fill in the blank?*” This is a common thought and certainly reflects the manner in which we as a society view behavioral problems. This paper will address behavior from a different perspective. The emphasis will be on understanding the function of the behavior and then providing support in order to prevent the behavior from occurring in the first place. All behavior serves a purpose. The key is to understand that purpose and then to provide the child with an alternative means for meeting that need and/or the supports and abilities to get that need met in an appropriate manner. The body will do what the body needs, it is the job and the challenge of parents and interventionists alike to find a way for individuals with neurodevelopmental disorders to get their needs met in a way that is socially acceptable. The following paper will outline the characteristics of children with neurodevelopmental disorders that negatively impact behavior and the basics of understanding behavior, and will also cover how to develop an effective behavior plan including why most behavior plans fail. A short section will also be committed to the effective use of Time Out and a couple of sections are dedicated to specific issues posed in the proposal.

It is important to note that some of this work has been field tested with children with XYY but has also proven to be effective in working with children with other neurodevelopmental disorders including fragile X syndrome. It is also important to note

that although some of the questions/behaviors that were originally proposed will be mentioned in this paper it does not provide a recipe for specific behaviors. As you will be able to see after reading this paper, you need to have a great deal more information than the behavior in order to create an effective behavior plan.

Characteristics that impact behavior.

It is very important to understand the developmental characteristics that can impact behavior. Cognitive deficits can have a negative effect on behavior in a variety of ways. Children who have limited cognitive abilities may not understand the subtleties of various social situations, may not read social cues well or respond to rules and regulations. Not because they want to break these rules, but because they do not have the capability of understanding them. Cognitive delays can also contribute to behavioral issues in school. If the academic work is too difficult or presented in a way that is overwhelming children often become frustrated. This frustration leads to avoidance behaviors including leaving a situation physically, daydreaming or doodling which is in effect leaving the situation mentally. This frustration can also prompt an individual into doing something that he knows will result in being removed from the situation such as hitting, spitting, poking a friend or throwing his book.

Speech and language delays can also lead to disruptive behavior. Clearly if a child has difficulty expressing himself he will become frustrated. A person can only repeat themselves so many times before becoming frustrated and either give up or take physical action. However language also has a receptive component which is equally difficult for boys with XXYY. This involves auditory comprehension, verbal memory, and sequencing. So for an individual with these types of delays listening and following a string of directions can be very difficult. So what looks like naughty behavior can actually be an inability to remember or fully understand the directions.

Similar issues arise with delays in gross and fine motor delays. Fine motor delays are obvious sources of frustration in a school setting. Couple the above mentioned challenges with fingers that do not work efficiently or effectively and the result would lead a student to do anything to avoid note taking, including getting out of one's seat or even falling asleep. Low tone is the enemy of sitting up straight. For individuals with low tone do not have the strength or stamina to maintain an upright position for extended periods of time. As a result they can appear lazy or disconnected. Gross motor delays can also lead to disruptive behaviors. The playground and/or recess can be a competitive environment with strict social rules particularly with boys. Boys who struggle with low tone and gross motor delays are typically not picked to play touch football, soccer or basketball during unstructured outside time. These boys however often times want to play and to make friends with their peers, so if they are not picked to play they might run in the middle of the game and kick the ball down the hill. This is not really playing with the other boys, but it is better than being ignored.

Sensory integration dysfunction can also lead to behavioral challenges. Sensory integration is a difficult concept to understand. Jean Ayres book *Sensory Integration and*

the Child and *The Out of Sync Child* by Carol Stock Kranowitz are good resources for parents. Our world is filled with sensory stimulation. If an individual has difficulty accurately interpreting this information it causes distress. For example in schools the environment that is most filled with unpredictable sensory stimulation is the cafeteria. There are smells from the food, echoing loud sounds of children talking and moving about not to mention an occasional dropped tray and in order to get to the cafeteria one must stand in line where others are likely to bump into you. This is a sensory nightmare and so an individual would do just about anything to get away from this situation; even if it meant eating alone with the teacher in the classroom or losing recess.

Boys with XXYY have all of the above listed characteristics and challenges. For each of the above listed characteristics one could write an entire paper on effective interventions. The focus of this paper however is on their resulting impact on behavior. These characteristics need to be understood, but **CANNOT** be used as an excuse for inappropriate behavior. The presence of these characteristics is **NOT** a sentence for a life of isolation. These boys can learn and grow, but they need to be given the proper support and taught the necessary skills. In order to modify behavior we must understand the causes and contributing factors so that we can effectively change those behaviors. The overall goal of intervention at any age for individuals with disabilities is to help them to be functional contributing members of society. Remember it is typically not cognitive level that keeps individuals out of inclusive settings; it is behavioral issues that limit their opportunities.

Prior to developing any type of a behavior plan it is prudent to ask several questions. If and only if you are able to answer yes to one of these questions should you proceed with a behavior plan. There is nothing magical about these particular questions. They serve only as a guide to prevent developing plans for behaviors that might otherwise be ignored. It is very important when dealing with all children but particularly with children with neurodevelopmental disorders to ignore what can be ignored and to only address those behaviors that are worthy of the time and energy necessary for changing behavior.

Is the behavior disruptive to the home and/or school environment?

Does the behavior interfere with the child's ability to learn?

Does the behavior interfere with other's ability to learn?

Does the behavior present a danger to self or to others?

Does the behavior interfere with social acceptance?

Attempting to change any behavior is very difficult and requires a great deal of effort on the part of all involved. This approach has been used effectively within many different settings as well as with children with a variety of neurodevelopmental disorders. The expanded outline was originally published in by Epstein, Riley and Sobesky in Hagerman & Hagerman, 2002 and was based on the presentations that had been done by Dr. Rley to parent and professional groups. The information has been updated and modified to address the unique needs of this population. This approach can be used effectively with all age groups and with a variety of different types of behaviors. It is holistic in its

approach and as a result requires the interventionist to look at the individual himself as multifaceted and as a person who functions within a dynamic and changing environment.

Step 1 Identify one specific behavior to target. This seems like an easy task but can be overwhelming. The behavior needs to be specific and well defined. You can make many modifications to the environment, but you should only choose one behavior at a time to target. If you try to address more than one behavior at a time the behavior plan will not work. It could include hitting, screaming or breaking pencils. One possible down fall here is to choose something that is a construct rather than a behavior, for instance choosing aggression instead of hitting. Choosing the behavior that you would like to target is key. You may need help in determining the targeted behavior.

Step 2 Determine when, where and how often the behavior occurs. All behavior occurs for a reason and so to change any behavior one must first understand the function that that behavior serves. In order to understand the function one must first determine the antecedent, the action that occurs directly before the behavior as well as the consequence, what happens directly after the behavior. Behavior does not continue if it is not somehow reinforcing. The ABC (Antecedent-Behavior-Consequence) model of behavior management can be a useful way to both understand and modify inappropriate behavior. Modifying or eliminating the antecedent alone can change or eliminate the behavior (Braden 2000a, 2000b) see step 4. The consequence of the behavior is equally important as it is the consequence that maintains the cycle of the behavior and provides the reinforcement that the individual is seeking.

The only way to make sure that you really understand both the antecedent and the consequence of the behavior is to complete a Functional Behavioral Analysis. This is a form of data collection that allows the interventionist to look for patterns within the individual's behavior and thus hypothesize about the purpose or the function that the behavior serves. An FBA can be done at school and/or at home, and is simply a means for tracking when the behavior occurred, where it occurred, what happened prior to the occurrence of the behavior and then what happened immediately following the behavior. Gathering the data is not difficult, but it is important to remain objective during the process. This appears easy at first, but can be very challenging and often requires utilizing an outside observer to accurately document the occurrences of the behavior as parents and teachers are often too close to the situation. This observer could be a school psychologist or even a graduate student from a local college. Many FBAs are completed with a "theory" in mind regarding the purpose of the behavior. Be careful to let the data inform you rather than you informing the data. For instance a teacher may think that a student is leaving or acting up in her class because he does not get along with one of the students in the class. When an FBA is performed the teacher may be able to see that in fact he sits next to that same peer in a different class but does not have any problems. Once the data has been gathered the staffing team or the evaluation team should sit down and go over the information produced by the FBA in order to determine the operational definition of the behavior, a prediction of the times and situations when the behavior will and will not occur and the definition of the function (the maintaining reinforcers) that the

undesirable behavior produces for the person. This information can then guide the ensuing behavior plan.

Attached please find an example of a Functional Behavioral Assessment form. There are certainly other FBA forms that can be used. This too may be reproduced in order to be used to gather data for developing behavior plans. As consumers of behavior plans **do not** agree to any behavioral intervention with your child or a child in your class if an FBA has not been completed by the school or a representative.

It is important to note that with individuals with neurodevelopmental disorders the reinforcing quality of the behavior may be internal. For example when a child bites it is typically out of frustration or in order to avoid an uncomfortable situation. The biting will typically stop the situation even for a few seconds. For individuals with sensory integration dysfunction biting also provides input into the proprioceptors within the jaw, which is very organizing neurologically. Unless the interventionist is familiar with XXYY this part of the FBA may go unnoticed and as a result the rest of the behavior plan may not be effective.

Step 3 Examine and address any physiologic causes. Physiologic causes are anything that has to do with how the body itself is working; so these factors can range from low blood sugar in the morning to medication wearing off in the early afternoon. They can also include hearing and vision impairments as well as ADHD. Attempting to change a behavior that is based in biology will only serve to frustrate everyone. It would be silly to make a behavior chart to try to change someone's blood sugar or to improve their vision, however we still see behavior charts for not leaving one's seat. Addressing the physiological cause of a behavior may eliminate the behavior entirely. If you battle against biology you will always lose.

Step 4 Examine and modify the structure of the situation, when possible to decrease the opportunity for the behavior to occur. It is often easier to change the environment than it is to change the child. For example if the FBA shows that the targeted behavior increases during the afternoon and you know that he has difficulty with math then perhaps moving math to the morning would be a good idea. If a child has difficulty poking other children while standing in line then have him at the front of the line so that there is less opportunity for poking to occur. If a child has difficulty getting dressed in his room because he keeps playing with his toys, then have him dress in the bathroom.

Step 5 Provide the child with additional resources for dealing with the stressors associated with the behavior. An additional resource can be an intervention such as a social skills group to deal with interpersonal issues or it can be a physical aide such as wearing earphones to decrease the inconsistent and unpredictable noise in the school cafeteria. These additional resources are necessary and again are frequently left out of traditional behavior plans. If a child was able to function well without these supports then they would not be exhibiting these behaviors. Individuals with XXYY have a compromised system and as a result need a variety of external supports in order to

address the deficit areas caused by their genetic makeup. It only makes sense that they would need some external support to address these areas of weakness.

Step 6 Outline natural consequences for the behavior. This requires some forethought and some creativity. All individuals involved need to decide ahead of time what the response will be when the behavior occurs these consequences need to be specific and succinct. Learning from natural consequences is optimal; however when that cannot occur you must create a consequence that is naturally linked to the situation (Braden, 2000b). If a child misuses a toy, then the natural consequence is the loss of that toy for a period of time. For children with XYY is very important that the link between the behavior and the consequence be clearly linked. As previously stated they have some cognitive delays as well as difficulties with short term memory and impulsivity. So if the consequence is imposed several minutes or hours after the undesirable behavior it will be more difficult for the child to link the consequence with the behavior, and as a result the behavior will probably not change.

It is also important to remember that sometimes ignoring is the best consequence for the behavior if the purpose for the behavior is to gain attention. This is difficult to do, but truly the only way to address inappropriate attention seeking behaviors. If you are going to ignore a behavior make sure that you have shared that information with others who will be involved in implementing this plan. You will also need to plan for what will happen when the behavior escalates, because it will.

Although removing recess is a common occurrence in schools for inappropriate behavior it is **NOT** recommended for children with XYY syndrome or for any other child for that matter. Children with ADHD need to be able to move. If they have difficulty on the playground or during unstructured times, then it is the job of the interventionist to structure that time so that he can be successful.

Step 7 Be consistent. This is the shortest step and the most difficult to apply. Consistency is the most crucial component of an effective behavior plan. Consistency and predictability are calming and organizing for all children, particularly those who are disorganized internally. Individuals with neurodevelopmental disorders often have difficulty differentiating between subtle variations that may change the appropriateness of a specific behavior. They may also have difficulty reading a social situation. As a result, it is imperative to provide clear, and at times rigid, limits for behavior. The consequence for the targeted behavior should also be applied in a consistent manner. If it is not, it can actually increase the behavior. For example if you have determined that you will ignore grumbling behavior while the individual is doing his chores, and then sometimes you ignore it and sometimes you engage with him and give him attention for his comments, what he has learned is that sometimes when I complain I get attention and sometimes I do not. The child would probably not be able to verbalize this and it is not manipulation, it is simply how our brain learns. This is called *intermittent reinforcement* and actually serves to strengthen the behavior pattern rather than decrease it.

Step 8 Provide a substitute behavior. It is important to know what you want the individual to do rather than just focusing on what you do not want them to do. Determining what it is that you want them to do can be challenging and again sometimes outside support is necessary. A behavior should never be taken away without providing an alternate **appropriate** substitute. For example, instead of breaking a pencil when angry have him indicate that he is frustrated through signing, or utilizing a pact phrase such as “This makes me mad.” It is not that you do not want him to get frustrated, and if you have employed steps 1 through 8 you will decrease the likelihood that he will become frustrated, but he needs an appropriate way to express that frustration and anger.

Step 9 Reinforce positive behavior. It is important to identify the reinforcers that work for your child or the child that you are working with. All children are different. The most effective reinforcers are those that are naturally occurring, such as positive attention, receiving an item that is requested in an appropriate manner, sitting next to a friend during class because you are able to work together without being disruptive or participating in a group game because you were able to abide by the rules. Unlike typically developing children however children with XXYY may not respond well to simple social reinforcement. Many children may need external reinforcers such as stickers, small toys or extra TV time. It is important that children receive the reinforcer immediately following the desired behavior at the start of a positive behavior program. This allows them to clearly link the appropriate/desired behavior to the reinforcers. If the reinforcement regime does not work then return to step 2 and reassess the frequency of the targeted behavior so that the reinforcement schedule can be reassigned and/or you can reevaluate the purpose of the behavior. The use of reinforcers is effective with children, but can also be effective in working with adults with XXYY.

Step 10 Start in a controlled setting. The initiation of a behavior plan is very important for all involved. Initial feelings of success are important for the continuation of the program. It is easier for all involved to begin a plan at home or at school where there is more control over the environment. After everyone feels more comfortable, it is time to take the plan on the road, so to speak. Using the plan in a variety of settings including the grocery store and the mall clearly conveys to the individual that the same rules apply regardless of the setting.

Step 11 Provide opportunities for both success and for failure. Initially it is important for the child/individual to succeed and to be reinforced for the substitute behavior. In order for the child to succeed the substitute behavior or the desired behavior must be attainable for that particular child/individual. Setting unrealistic expectations is one of the most common reasons for ineffective behavior plans. Again that is why the FBA is so important. If the child is able to complete 3 math problems before getting up then an initial benchmark for success and reinforcement should not be set at finishing an unmodified homework sheet containing 20 problems. That is unrealistic and will result in failure.

After success it is important to plan for failure. For example, if the targeted behavior is begging for toys or treats at the store and throwing a temper tantrum when the child does

not get what he wants, initiate consequences for the temper tantrums at home, and reinforce positive behavior. Finally initiate a trip to the grocery store where the behavior is likely to occur. The key is to plan the trip as a part of the behavior plan, not as a true shopping trip. The trip will be geared so that you are prepared to follow through on the previously determined consequences when the target behavior occurs. This again reinforces the child's understanding that the consequences are real and the person imposing the consequences will follow through in all settings.

Why do most behavior plans fail?

Consumers of behavior plans include teachers, therapists, parents and children. Many parents have reported that they have created plans or followed plans that were created by others and that they have not been effective, or that they only worked for a while and then appeared to lose their effectiveness. The typical behavior plan is not holistic in its approach and assumes that the behavior occurs in isolation. Token economies are often used in schools, but if the child has difficulty sequencing and recalling the rules as well as the events of the day a system that employs stickers and daily tabulations can be too complicated. Often times these token economies also forget steps 1 through 5 and begin with consequences for the negative behavior. If the behavior plan does not address and provide supports for the causes of the behavior it will not be successful.

Attached is a *Behavior Plan Worksheet* and has been developed by myself and Dr. Marcia Braden. This worksheet is designed to be used in an IEP or review staffing. This worksheet can be duplicated as long as the citation is used. The title reflects the purpose. It is designed to guide a team or an individual in creating a behavior plan and clearly outlines all of the above mentioned steps. There are spaces to write down suggestions as well as who will be responsible for tracking and implementing that section of the plan.

Time Out

This section of the paper was originally written for the *Quarterly*, which is the journal for the National Fragile X Syndrome Association. Time-out has been an effective tool, used by parents and professionals alike, to change behavior for many years, even before it was called time-out. Research has supported its usefulness with typically developing children as well as those with delays such as ADHD. Families of children with disabilities say that they have tried time-out at one time or another, and frequently state that it did not work for them. This was often puzzling to me and so in an attempt to find effective intervention strategies I probed into how the families were using time-out and where the problems were occurring. I spoke with families and had them demonstrate their techniques for me. These conversations and observations revealed that it was not time-out that was not working, but that typical strategies did not work for children with fragile X syndrome and other neurodevelopmental disorders and that adaptations were needed for this to be a useful tool for families. It is important to note that behavioral strategies designed and implemented with children who are typically developing frequently prove ineffective for children with special needs **unless** adaptations and modifications are employed that address the specific profiles of these children.

In order to understand the adaptations one must first understand the original construct. Time-out is defined as time away from positive reinforcement. Many counselors, researchers and therapists use variants along this theme to define the process or the technique. It is typically used for young children, but I have found it to be successful for children with disabilities who range in age from preschoolers to tweens. Placing a firm age limit on this technique is difficult, as children are so different and individual strengths and challenges need to be considered.

Clinically time-out is considered to be a punishment for inappropriate behavior. This differs slightly from removal from a situation as a natural consequence. For instance a child who spits his/her food during dinner has lost the privilege of sitting with the family to eat. Or a child, who is generally acting out in circle time, may be asked to leave the group. This is a natural consequence for that particular behavior, and can be used effectively in many situations. Removal from the situation as a natural consequence can be very effective, as long as the original purpose of the behavior was not to avoid the group activity. Determining the function of the behavior is an additional topic that we do not have time to address here. Time-out as it will be outlined for the purposes of this article will be linked to one behavior and will actually be used as a punishment.

In working with many families with children with XXYY and other neurodevelopmental disorders I have found time-out to be an effective part of a comprehensive behavior plan, but only when I modified the process to fit the physical and developmental profile of the children with whom I was working. I have found the following guidelines to be the keys to success. These strategies are based upon the fundamental principles of time-out and incorporate adaptations that address the fact that children with XXYY have issues with language and attention and that they need and learn through repetition, consistency and predictability.

1. Time-out does not need to be a specific place. Time-out is a process rather than a location. The act of removing the child from your attention is, in the clinical sense a punishment, and as a result a deterrent for the behavior. Most children want attention. (Note: Although children with XXYY may exhibit some social anxiety and social inappropriateness they are social beings. For children with autism this presents an additional challenge and often times time-out is not effective for them. Consultation with a psychologist or behavioral interventionist is recommended.) If the process is linked to a specific place in the home or the classroom you are limited in both how and where you can use time-out. If you place your child on a kitchen chair or in their room for hitting, what are you going to do if they hit in the grocery store? My recommendation is to sit the child down right where the infraction took place or if they are already sitting, simply turn them around so that they are either not facing you or the group. They are now in time-out.

This differs from the information that is available in many parenting books and on the web and is an important modification for children with XXYY for several reasons. Many of which will be addressed in the following recommendations. The largest and most common obstacle that parents have shared with me around using time-out is getting the

child to the designated chair, corner or stair step. This step can be eliminated and the process can still be effective. It is a slight, but crucial change in thinking; the location is not what is effective it is the time away from your attention.

2. Time-out does need to be time away from your attention. This is the most fundamental part of time-out and one that appears to be the most difficult to implement. If you place a child in time-out and talk to them about what they have done and why they are there, they are not in time-out; they are simply on the kitchen chair getting a lecture or engaging in an argument and neither one of these strategies is effective in changing behavior. You will need to communicate with the child but in a very structured and routinized way.

3. Use a consistent phrase and decide what you are going to say before you start. The use of a consistent phrase serves several purposes in this process and should contain two basic components. The first part of the phrase lets the child know what they did and that it was wrong. The second part of the phrase lets the child know what is happening; it labels the process. So for a child that hits an appropriate phrase would be “No hitting, time-out.” This is very short for several reasons. Children with XXYY typically have language delays; as a result more language will actually lead to less understanding. Most parents feel it is necessary to explain and rationalize the situation with their child, however when you engage in discussion you delay the time-out which makes it more difficult for the child to link time-out with the undesirable behavior. By the time the child is actually in time-out they may have forgotten what they did to get themselves there.

Consistency of language allows you to change location without disrupting the routine. You cannot take the kitchen chair with you to Grandma’s house, but you can take your time-out routine and your phrase. “No hitting time-out.” It is important to choose the phrase that you want to use ahead of time so that you do not have to think about what you are going to say in the heat of the moment. All of the people that care about the child and are involved in changing his/her behavior should use the same phrase. Consistency, consistency consistency. Using this consistent phrase also keeps you from engaging in discussions and arguments. You have a set response to any comment “No hitting time-out.” Changing behavior is tough, particularly when you are initiating something new. Using this same phrase can be calming for you. “No hitting time-out”. Ultimately, this statement reminds you and your child what he/she did and why he/she is in time-out.

4. Time-out needs to be linked to a specific act or behavior. Time-out is not for generalized naughty behavior. We have all said “That’s it! You have been whining and grumpy all day. You can go to your room for time-out until you can come down and be nice.” or “You sit on this chair until you can calm down.” In order for the child to understand why they are in time-out it must be clearly linked to a behavior. Behaviors are things like hitting, kicking or biting. Time-out should not be confused with a time to organize oneself. It is not the same as going to the quiet corner for children with sensory integration issues. It is not part of a sensory diet; it is part of a behavior plan.

Implementing time-out effectively can be challenging and should be reserved for major offenses.

5. Time-out should be imposed immediately following the behavior. For time-out to be effective there needs to be a clear relationship between the undesirable act and time-out. This is particularly important for children with XXYY who have short attention spans and difficulties with sequencing and cause and effect. The shorter the time between the behavior and the time-out the more easily the child is able to understand the relationship between the two and the more effective time-out will be in decreasing the unwanted behavior.

6. Do not engage in repartee. On the way to time-out, or while a child is in time-out many children will attempt to get your attention by arguing. Children may deny their involvement “I didn’t do it”, blame another child “Liam hit me first” or comment on their feelings about you and/or your parenting skills “I hate you bad mommy”. If you address any of these comments prior to time-out or during time-out the child has your attention and they are no longer in time-out. It is very difficult not to comment on these statements, and that is why it is important to use the previously determined phrase. “No hitting, time-out.” This is your mantra. It keeps you from engaging with your child during the time-out process.

7. Do not address behaviors that occur on the way. As stated in #6 children will attempt to get your attention in anyway that they can. They will also attempt to delay time-out whenever possible. Hitting you, trying to bite you, knocking down the planter next to the couch are all attempts to engage you and consequently to delay or avoid time-out. If you address these behaviors the child will learn quickly that kicking or spitting will work in delaying the punishment and will consequently continue to use them. By implementing time-out in the manner outlined in step #1 you decrease the likelihood of additional behaviors. You are not dragging the child to their room or lifting them onto the second step, so they have less of an opportunity for these behaviors to occur, thus the focus remains on the original behavior – hitting.

It is important to note here that all children at sometime or another will attempt to use these strategies because they do not want time-out. It is not fun. That is what makes it an effective tool. It is also important to note that these are not bad children; they are not unusually manipulative or strategic. Our brains are simply designed to work this way. We all avoid things that we do not like and/or are unpleasant and we repeat things that work for us.

8. If he/she gets up put him/her back. Two commonly asked questions are “How long should the child stay in time-out?” and “How many times should I put him/her back.” Again we need to think about how the brain works and more specifically how a brain with XXYY works. The rule of thumb for time spent in time-out is 1 minute for every year, so a three year old child would spend 3 minutes in time-out. This works fine for typically developing children, but for children with XXYY I recommend cutting the time in half. Children with XXYY typically have attentional issues that need to be considered.

It would be unreasonable for them to be able to stay in one place for as long as a child their age without XXYY. We also want the time-out process to be successful for all involved. Setting the time too high will result in frustration for parents, teachers and children.

The second question is answered quite easily, but again can be quite difficult to put into practice. If the child leaves time-out you need to put him/her back as many times as it takes until the child stays for the predetermined amount of time. Remember, this is a punishment for a specific behavior. You put him/her in time-out and you need to tell them when time-out has ended. When the child attempts to leave the situation remember to use your phrase rather than commenting on their leaving. If he/she gets up or attempts to leave and you say “Now Justin, you need to get back in time-out.” or “I told you that you have 2 more minutes.” the child has your attention and is no longer “in” time-out. If the child attempts to get up or to leave, sit the child back down and say “No hitting time-out”. You have not engaged with the child and the focus is redirected back to the original offense- hitting.

9. This is one component of a behavior plan. Time-out in and of itself is not a complete behavior plan. It is an effective consequence for many behaviors, however to change behavior one must institute a complete plan that addresses the antecedents for the behavior including but not limited to appropriate medications, therapeutic and remedial interventions such as speech and occupational therapy and environmental modifications. Comprehensive plans by definition require the coordination and collaboration of parents and professionals.

10. Time-out needs to be used in a consistent manner. Consistency is the key to success in any behavior plan, and the most difficult to employ. If you decide that a child should go to time-out every time he/she hits, then you need to follow through, even when you are out in public or even when the child is tired. If you start making exceptions what you have actually taught the child is that sometimes you can hit and sometimes you cannot, which actually strengthens the behavior. Consistency is difficult to maintain, so do not be too hard on yourself. As I have advised many parents, do not try to implement any behavior plan when you are tired or when you are on a trip. Set aside a weekend when this is your priority. I know in our busy schedules this is easier said than done. But if you really need to address a behavior effectively, a comprehensive plan requires an initial time investment. It will payoff in the end.

It is also important to note that children, particularly children with XXYY do not understand this process the first time that you use it. You may need to practice time-out before it can be used successfully. It is also important to note that time-out expectations for a typically developing child may look very different from those for a child with XXYY. Remember the ultimate goal for the procedure. In other words do not get hung up on whether or not he/she is sitting or lying down. That is not the behavior you are trying to change, you are trying to decrease hitting.

Additional Notes

Oppositional Behavior

The best way to deal with oppositional behavior is to provide the child with choices. All children need to feel as if they have some control over their environment. Children with disabilities often have less control than their typically developing peers. Because of their disability they are physically handled more by medical and therapeutic professionals, have less “free” time because of appointments etc. and often have less independence. These situations often times cannot be changed, but the need for control continues to exist. It is important to recognize that they have this need and allow them to have control in areas that are appropriate for them or they will exert control through inappropriate means such as refusing to get dressed, do their homework or go to work. The key is to provide your son with opportunities to make decisions and have control over situations that are appropriate for him by giving him a limited number of choices. For example for young children, getting dressed is not the choice; however he can choose which shirt to wear. “Which shirt do you want to wear, the red one or the blue one?” or “Do you want to use the big plate or the small one?” These choices are finite and allow him an appropriate amount of control. Too many choices can be overwhelming and actually defeats the purpose. Remember to pick two choices that are acceptable to you. For older children and teenagers the same holds true, you simply need to adjust the types of activities. For example doing homework is not a choice, however he can choose where he wants to do it, in the kitchen or in the dining room. Doing math is not a choice, but using a marker or a pencil is a choice. If he does not make a choice or chooses something other than the two choices presented, then you need to make the choice for him, follow through on what you have chosen and let him know that he will be able to make a choice next time. A note here is to make sure that the task requested, ie. getting dressed or doing the math is within the individual’s ability level.

Situation Specific Behaviors

There are some behaviors that are okay in some situations and not okay in others. As previously stated it is difficult for these boys to determine when and where some of these behaviors are appropriate. When attempting to teach an individual about when and where a behavior is appropriate provide as many external cues as possible including changes of clothing and/or physical parameters. When discussing a behavior with the individual give directions that include the location for example “That’s not okay at school.” When moving from an environment where the behavior is okay into one where it is not, make the transitions clear using more than oral language; pictures are typically a good idea. When a behavior is okay sometimes, provide the individual with an alternative location “Putting your hands in your pants is not okay in the family room. If you want to do that you can do it in your room.” Again consistency is the key. These boys have enough difficulty reading cues without us changing the rules because we do not want to make a fuss this time or conversely because this was the last straw. Be consistent. If it is not okay to bring cars to the table then it is never okay to bring cars to the table and playing with cars needs to occur only in the family room. Carefully balance how many situation specific behaviors are allowed. These types of behaviors are confusing so proceed with caution. For example young boys like to wrestle and that is an okay thing to do with your father (or mother) at certain times. But it is not okay to wrestle at school, even with

people who you want to be your friends. It is okay at home in the family room but not on the stairs or when the boss is over for dinner. In order to make things clear you could make a wrestling mat out of an old sheet. When the boy wants to wrestle he can get out the wrestling mat and lay it on the floor in a specified room. When wrestling time is over put the mat away. This example illustrates consistency, physical cues and a clear transition. The key is then for the parent to stick with the rule so that wrestling only occurs on the mat.

Developmentally Appropriate Behaviors

Before beginning a behavior plan it is important to discuss the behavior with someone who is knowledgeable about development and developmental trajectories. This is crucial, because some of the behaviors that boys with XXYY engage in are developmentally appropriate and the behavior itself should not be changed. However where and when the behavior occurs might need to be modified. For example dumping blocks or baskets with toys in them is a developmentally appropriate phase that all toddlers go through. Boys with XXYY might still be in that phase when they are 3 or 4 years old. That does not mean that he should be allowed to dump all of the baskets in the house. It means that he is not trying to be naughty but needs a means for appropriately working on a cognitive skill. The same holds true for young men who are going through puberty. It is natural for them to have the same urges and curiosities as their typically developing peers. Again they may get stuck in stages that are below their chronological age. This is not an excuse for masturbating in public. It means that the individual needs very specific guidelines for when and where that type of behavior is appropriate. The National Fragile X Syndrome Association website has a good link for dealing with issues related to sexuality <http://www.fragilex.org>.

Notes regarding ADHD Behaviors

As has been stated earlier in this paper and is documented in the literature boys with XXYY often have ADHD. ADHD is an interesting disorder and I would recommend reading more about ADHD in order to understand some of the behaviors exhibited by individuals with XXYY. Some of the comments and questions posed for this paper included behaviors that were based in impulsivity. When children are young they have interests that are appropriate for their age. As a result their impulsive behaviors center around taking toys that they want etc. Unfortunately for individuals with developmental delays and ADHD the impulsive behaviors coupled with the inability to read social cues well often leads to inappropriate behaviors that can get a young man in trouble. Again this cannot be viewed as an excuse for any type of impulsive behavior. It is meant simply to shed light on why these boys might steal and touch inappropriately. These behaviors need to be addressed. Using the previously outlined behavior plan is a good start as it emphasizes a holistic approach which can include medication. This should be both discussed and monitored by a physician who is familiar with neurodevelopmental disorders. Knowing that this is a possibility with these boys, addressing these behaviors early could help diminish the frequency and severity during adolescence.

Telling Stories

This is a behavior that appears to be somewhat unique to this population of boys. Although there is not empirical data at this point to support this theory I think that the stories are based in their difficulties with language, executive function, social immaturity and some social anxiety. These stories are often produced when an individual is asked a question, particularly a question that is abstract in nature. For example when a boy or even a young man is asked “What would you like to do in the future?” rather than saying, “I don’t know.” or waiting while they sort out what they might do, they come up with an answer that they have either heard before or they think will satisfy the person who asked the question. “I want to go to college.” They have learned to provide an answer that will either take the heat off of them to come up with a plan and/or will appease the person asking the question. Creating a plan is a very difficult task and requires many steps as well as abstract thinking and self awareness. These are all areas that individuals with XXYY struggle with. This does not appear to be a manipulative tactic although all children, and adults for that matter, lie on occasion. I think that they know that they are supposed to answer and yet they cannot actually come up with an appropriate answer and so they come up with a story or phrase. They are also social beings and so through simple positive reinforcement, they have learned that when they talk, *about anything*, they have captured another person’s attention. This behavior, although more evident in the teenage years, has probably been developing over the child’s life span as a compensatory mechanism.

This can be very frustrating for parents. As stated with other behaviors, understanding possible causes for these behaviors should not be an excuse. There are a couple of strategies that have appeared to be effective. Remember that the person that you are talking to has a language delay. Speak slowly use simple language, repeat things frequently and rephrase statements to give additional vocabulary cues, and provide the individual with enough wait time to come up with an appropriate answer. When the individual fabricates an answer do not get into a battle about lying, but let them know that you would like to talk about it at a different time. Additional processing time seems to help get to the “real” story. Remember that they want to please you even if it does not appear that way. They might come up with a story, a goal, or a plan that is very elaborate because they think it is what you want on some level or because they think that this goal is what they are supposed to want as an adult. When the stories are clearly not real, simply stop that conversation and move onto a topic that is based in reality. This will decrease the attention gained for the story and will show the individual that he will get the attention that he needs when he talks about things that are based in reality. When the stories are related to plans that need to be made i.e. future goals, allow months of processing time. Help the individual sort out what he really wants. For this type of activity I would recommend employing a counselor or therapist who has experience in working with individuals with developmental delays. Family members are often times too close to the situation to be effective.

Summary

Changing behavior is not easy for anyone, but it can be done in a fair and effective manner. There are a few things that we need to remember prior to initiating a behavior plan. Only one behavior should be targeted at a time. Several modifications and adaptations can be employed at the same time; however when more than one behavior is being targeted the effectiveness decreases. Remember that the behavior will actually get worse before it gets better. This is referred to as an extinction burst and is actually a sign that the plan is working. Changing the rules for a child can cause frustration, which can lead to an increase in inappropriate behavior until the child becomes familiar with the new routine. Popular parenting advice whether it comes in the form of a television show, a self-help book or a prepackaged program can provide insight and applicable strategies, however this information can also be misleading and can cause additional stress, especially for families with children with special needs. The trick is trying to determine which programs can be helpful and which strategies should be adapted (Riley, 2006).

Biography: Karen Riley, Ph.D.

Dr. Riley is currently an Assistant Professor at the University of Denver in the Morgridge College of Educational in the Child, Family and School Psychology Program, where she is the CO-PI of Project InSPECT, a federally funded training program for school psychologists with an emphasis on early intervention. Her education includes a B.S. in Psychology from Colorado State University; a M.A. in Early Childhood Special Education from the University of Denver and a Ph.D. in Educational Psychology with an emphasis in Child and Family Studies from the University of Denver. She completed a post-doctoral fellowship at The Children's Hospital in Denver in the Fragile X Treatment and Research Center and subsequently worked at the Child Development Unit within The Children's Hospital. She has over 15 years of experience in teaching and administration of early childhood special education programs. She has an additional 10 years of experience working with children who neurodevelopmental disorders and their families. She has been involved in several psychopharmacological studies and other research projects related to fragile X syndrome and other neurodevelopmental disorders. Particular areas of interest and expertise include assessment and intervention of infants and preschoolers, curriculum development, school consultation, behavioral interventions and low incidence disabilities. Dr. Riley was instrumental in the initial development of the PLAY Based assessment with Dr. Toni Linder and has written a chapter in the revised version of PLAY Based Assessment. She lectures extensively throughout the US as well as internationally, on behavioral and educational interventions for children with neurodevelopmental disorders. Dr. Riley is married and has two children.

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Behavior Plan Worksheet

Name: _____ **Date Initiated:** _____

Parents: _____

Interventionist Involved: _____

Positive Behavioral Supports Employed: _____

1. Targeted Behavior: _____

2. When does it occur: _____

3. Where does it occur: _____

4. How often does it occur: _____

(Attach FBA data sheets)

5. What purpose does the behavior serve: _____

6. Physiological causes and interventions needed:

a. _____

b. _____

c. _____

d. _____

e. _____

f. _____

7. Structural and scheduling modifications:

a. _____

b. _____

c. _____

d. _____

e. _____

f. _____

8. Additional resources:

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____

9. Consequence of the behavior: _____

10. Substitute for the behavior: _____

11. Reinforcers for the behavior:

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____

12. Where the behavior plan will be initiated: _____

Date of review: _____

Monitoring parties:

Name	Responsibility

Post review modifications: _____

Plans for generalization: _____
