

Prevention Versus Intervention: Effective Behavioral Strategies for Children With Smith-Magenis Syndrome

By Barbara Haas-Givler

Children with Smith-Magenis syndrome (SMS) often present challenging behaviors at school and in the home. Traditional strategies for addressing behavioral issues include the use of positive reinforcement for good behavior, sticker charts to earn rewards, timeout, loss of privileges, and ignoring negative behavior. Such strategies are widely used in educational and vocational settings as well as at home. These approaches are "consequence-based" in that they are implemented after a behavior has occurred. While useful in shaping, reinforcing, increasing, or maintaining positive behaviors, they are often ineffective for decreasing inappropriate behaviors for individuals with SMS.

Parents, teaching staff, and caregivers often question, what is the "SMS" piece of the behavior? When is it just "bad" or unacceptable behavior? If this is a genetically driven behavior, then what can be expected of a child with SMS in the home or the school? Another common question relates to consequences. If children with SMS are to function within their family, school, and community, they are often in the midst of a consequence based system. Should children with SMS be held accountable for their behavior?

Brenda Finucane, MS, CGC, and I have provided educational consultation services through *Genetics at Elwyn*, Elwyn Inc., for individuals with SMS for over ten years. In our experience, behavior in students with SMS is often influenced more by the antecedents and settings, than by the consequences that occur. Even highly motivating positive reinforcers or reward systems may not be enough to prevent an outburst if certain "triggers" are pushed or if the environment is not "friendly" for children with SMS. Identification and avoidance of triggers are frequently more effective for these students than consequence-based behavior modification approaches. Behaviors such as seeking adult attention, task refusal, property destruction and aggression are extremely disruptive and often result in loss of valuable instruction time and social opportunities. Preventative or antecedent strategies, when successful provide more time to learn new skills rather than ad-

ressing behaviors that have already occurred and been practiced by the student with SMS.

BEHAVIOR BASICS

Behavior is NOT ALL BAD! Reading this newsletter is behavior. Raising a hand for attention, turn-taking, and following instructions, are sought after school behaviors.

Behavior is simple yet complex because it is dynamic. In a classroom, the educational staff and other students are interacting with the student with SMS and the environment. It is very challenging to teach a class and at the same time observe and record behavior of the often subtle triggers or "under the radar" interactions that occurred just prior to a challenging behavior. Daily and weekly classroom schedules are generally very busy with opportunities for the student with SMS to interact with a variety of staff and classmates in different rooms in the school. Even with the best of intentions, education team members and parents of a student with SMS may not have the time to relay the many events of the day. These events may appear to be minor incidents but could in fact be slow triggers or have a cumulative effect. As consultants, Brenda and I have the vantage point of focusing on the student with SMS in the dynamic natural environment of the classroom. We advise that when it comes to a student with SMS, consequences should be a part of the entire program, just NOT the emphasis.

Behavior is communication and serves a function. Whether the behavior is exhibited to gain something (e.g., seeking attention, preferred activity and/or sensory input) or escape/avoid something (e.g., an activity, person or sensory input), it serves a function for the person engaging in the behavior. The same behavior may be used for different functions. You cannot just get rid of a behavior! You need to replace it with another behavior that works for the same function for the same child. For example, handing a teacher a break card rather than getting up and leaving the area.

In the midst of a tantrum, or a meltdown, teachers

and/or parents need to keep in mind that it is NOT the function that is inappropriate but rather the behavior that the person is doing to communicate (e.g. hitting, dropping to the ground). Students with SMS, who usually seek an inordinate amount of adult attention, often get a “bonus” since most inappropriate behaviors will gain attention. Children with SMS may engage in inappropriate behaviors to escape or avoid a trigger or non-preferred activities (e.g. fine motor or handwriting) but generally, the challenging behaviors are attention seeking in function.

Furthermore, the sleep disturbance that is part of the “biology” of SMS, results in a student who may be fighting the urge to sleep due to their chronic sleep debt that “accumulates” from disrupted nighttime sleep pattern (i.e., decreased total sleep and frequent nighttime arousals). In addition to this sleep debt, their bodies produce the hormone melatonin during the daytime (rather than at night). This is analogous to taking a sleeping pill during the school day, which only further compounds/impacts the student’s ability to function during the school day, especially in the afternoon.

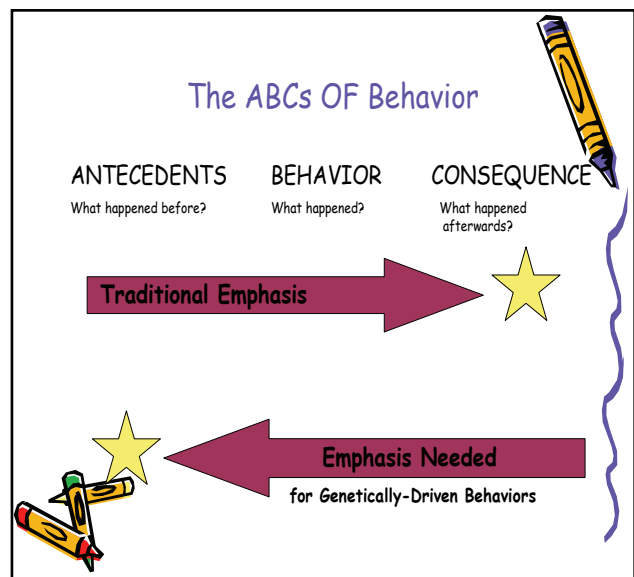
FBA and the ABCs of BEHAVIOR

A Functional Behavior Assessment (FBA) is a way to collect data and observe a student. It is a tool, often completed by a school team, and can be conducted in a variety of ways, but is best conducted by direct observation of the student. The FBA is generally conducted around target behaviors that are challenging, inappropriate or problematic. Staff collect and record data to document the ABCs of the behavior for the student.

A stands for the *antecedents* or setting events. These include what happened immediately before the behavior(s), what triggered the behavior(s) ...person, place, activity, demand or request?. Slow triggers or events that occurred in a cumulative effect that led up to the incident would be noted. What are possible establishing or motivating operations...hunger, thirst, pain or exhaustion?

B is the *behavior* or the response. It is observable, recordable and clearly defined for data collection.

C stands for the *consequences*. What happened after the behavior? Did the child receive attention from the staff or classmates? Did the staff remove the task demand? Did the child get removed from the classroom? Did the teacher get visibly upset? Was the student told “Good, but you can do better than that” or “Great job.”?



A Functional Behavior Assessment done successfully, will usually have the following outcomes:

- Identification and clearly defined behavior of interest
- Function (Assumed** unless proven by structural analysis?)
- Strategies to prevent or antecedent strategies
- Strategies for alternative or replacement behaviors
- Consequences that will not maintain inappropriate behaviors

Most parents and educators working with children with SMS are not surprised that the function and consequence of many challenging behaviors are attention, particularly from an adult. ABC data collection is helpful to identify the probable function(s) of the behavior and maintaining consequences.

Data collection and analyses are a process that often yields valuable insight and information about the antecedents/setting events and the consequences. The analysis for a challenging behavior exhibited by a student with SMS may bring to light that the behavior in question occurs most frequently when the preferred staff talked to another student, when there was a demand for specific non-preferred tasks, or that it occurred most frequently in the afternoons when effects of poor sleep and/or melatonin also may be factors. Staff may note that there was a cumulative effect and this behavior did not come “out of the blue”. The FBA process and data analyses are most useful in the development of behavior support plans, individualized behavior management systems, and the specially designed Instruction section of the Individualized Education Program.

CONSEQUENT STRATEGIES

Most people are familiar with consequent strategies based on the principles of reinforcement and punishment procedures. Behavior management is not just for special education. Weight loss programs, smoking cessation programs, and bonus incentives are prevalent in the community or workplace. Advantages of consequent strategies are that they are fairly well understood with readily available books, and resources for implementation.

Despite research in the past 15 years supporting the importance of antecedent strategies, behavior management systems in schools are often consequent based. In my experience when it comes to the student with SMS, behavior management programs based on reinforcement or punishment are less effective for the student with SMS than for classmates.

The disadvantages of consequent based strategies, when it applies to challenging or problem behaviors, are directly connected to timing. Reinforcement or punishment occurs after a behavior and increase or decrease the future occurrence of the behavior. The problem behavior has occurred, and the behavior has been practiced. Additionally, the behavior interrupted instruction, was witnessed by classmates and the student has not learned a replacement behavior. When it comes to significant problem behaviors such as aggression, self injury, property destruction, it is clear that the damage has been done by the time the intervention is to take place.

ANTECEDENTS VS CONSEQUENT STRATEGIES

There may be resistance and confusion with regard to the use of antecedent strategies in when it comes to classroom or individual behavior management systems. Some argue that this is just “walking on eggshells”...the student will never learn...if the student is included then the same system should be in place for all students...it isn't fair! Or is it?

Most students with SMS are motivated by a variety of positive reinforcers such as stickers, computer time, jobs, time with staff, or special DVDs. Despite their motivation for the consequences (e.g. tokens, classroom job) for students with SMS, the antecedents or setting events, many of which are directly related to the SMS and genetically driven behaviors are more powerful. Children with SMS often exhibit strong reactions when excited and may destroy the very prize they had been worked so hard to earn or drop to the ground on the way to a special event.

GENETICALLY DRIVEN BEHAVIORS

An example of the relationship between a genetically driven behavior and the relationship in function and consequences is noted with nail yanking, which is observed in some students with SMS. SMS is associated with signs of a peripheral neuropathy, that is, abnormal nerve sensation / function in the hands, lower legs, and feet; consequently individuals with SMS have a relatively high pain threshold. There may be decreased or abnormal sensation, poor fine motor function, decreased pain sensation, increased dryness and cracking of the skin of the hands and feet, and a tendency to severely pick at or bite the skin as well as finger- and toenails.

Nail yanking starts as a genetically driven behavior stemming from a response to probable uncomfortable feelings. Then it is given a great deal of attention not just for medical intervention, but also from children and adults who are in proximity. This behavior and other impulsive behaviors, when followed by a great deal of attention, are strongly reinforced for the student with SMS. Even if the adult remains calm and gives a no-nonsense response, there are often classmates or well-meaning bystanders who show reactions. Unlike access to toys or stickers you seldom can control the amount of attention given by others.

Slow or quick triggers of problem behavior are observed with students with SMS in response to fine motor or handwriting tasks. Challenging behaviors are further exacerbated by the chronic sleep disturbance. These examples illustrate the connection between SMS and behavior.

SETTING THE STAGE



Antecedent or setting events are critical for setting the stage for individuals with a genetic predisposition towards challenging behaviors. These strategies take into consideration what is known about what the student with SMS brings to the table (e.g. peripheral neuropathy, sleep disturbance; hypotonia; hearing loss, etc.). It makes sense to spend more energy teaching and engaging in positive interactions than dealing with behaviors as they occur. Remember BEHAVIOR CHANGE is not just for the child. Familiar strategies include:

- Structure, Routine, and well-defined limits
- Consistency
- Minimize triggers and distracters
- Preferential Seating
- Visual schedules
- Preferred items as reinforcers
- Preferred adult places demand for non preferred activity

- Acceptable way to request/protest
- Choices whenever possible
- Alternatives for fine motor or handwriting
- Allow brief nap or rest period

ADULT ATTENTION AND SUPPORT

Staff needs to pay attention to the early, subtle physical and verbal signs that a student with SMS is getting agitated. Redirection and distraction work best when initiated early, at the first signs that signal that behavior is escalating towards an outburst. There needs to be a shift in thinking and strategy selection when working with students with SMS.

Past Spectrum articles in Spectrum are well-received by parents and educators of students with SMS. Specifically: **“What’s a Teacher to Do?”** [Spectrum, Volume 2 (1), Winter/Spring 1995] and **“Observations on the Behavioral and Personality Characteristics of Children with Smith-Magenis”** [Spectrum, Volume 1, (2), Summer 1994]. In retrospect, these offer successful strategies that have an emphasis on prevention versus intervention.

Behavior is dynamic! Parents and teachers of children with SMS know how much their own behavior has been shaped and changed by the SMS student. The bar has been raised for us. We need to continue honing our skills and finding ways to set the stage for success for the child with SMS, while spending more time enjoying life and learning. ✱

An ounce of prevention is worth a pound of cure. Ben Franklin

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In addition to her work as a behavior specialist and teacher for school districts in the Allentown, PA area, **Barbara Haas-Givler, MEd, BCBA** serves as a consultant to Genetic Services at Elwyn. She has over 30 years' experience in special education, serving in many different capacities over the course of her career, including classroom teacher, administrator, educational consultant, and behavior analyst. She is a member of the PRISMS Professional Advisory Committee. Ms. Haas-Givler has authored several publications on topics related to genetic syndromes and frequently presents at local and national conferences.

Barbara is a member of the Professional Advisory Board of PRISMS.

What Is Smith-Magenis Syndrome?

Smith-Magenis syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann CM Smith, MA, a genetic counselor, and Ellen Magenis, MD, a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

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