

Summer Camp for Your SMS Child

By Leah Baigell

Summer camp is a place to have fun. It's a place to have great experiences, meet new people and take a break from everyday life. When you have a special needs child, you have to carefully select where to send your child so as to maximize his or her experience, and you want to make sure the experience is as positive as can be. There are questions to ask yourself and camp staff as you make summer plans for your child. Sometimes your town has summer programming to offer that might be just right. In addition, there is always the question of how to fund summer programming. The bottom line is that you want your child to have an amazing experience, and you want to minimize the chance that you are going to get that phone call we've all gotten . . . "please come pick up your son/daughter . . .NOW." How do you set about doing this?

When thinking about summer camps for your SMSer, there are so many things you have to consider. Before hitting the road to look at camps, ask yourself the following questions: are you looking for day or overnight camp; mainstream (with inclusion) or strictly special needs camp; educational, recreational, or a combo camp. Think about location – is it far from home? In the case of a day camp, how much traveling is required each day? If overnight, is it too far for the emergency visit you might have to make? Think about the size of the camp, if it is co-ed, who is the staff comprised of – teens or adults, are they trained to work with special needs kids? Does your child have a medical need? If so, are there trained personnel to deal with daily and emergency medical needs? How do they handle a child who is raging out of control? What is their

restraint policy? Are the providers trained in proper restraint procedures?

It is helpful if you can see the camp in operation prior to sending your child there. That is not easy to do. It means thinking about camp well in advance. Maybe this is the summer you can explore some options in order to plan for next summer. It is helpful to see how counselors work with kids, and it is nice to see how your child might fit in. It is immensely helpful to get a sense of the physical layout to see if it can work for your child. In lieu of visiting a camp, you can explore websites, and you can ask the camp for a list of local families you can contact who have attended their camp. Do not forget the importance of talking to friends who have sent their children to camps – they can offer a wealth of information.

One place to start is your town. Does your district offer a summer program? According to the Individuals with Disabilities Education Act (IDEA), each state is required to provide a Free and Appropriate Public Education (FAPE). This can carry over to the summer if it can be demonstrated that without support there will be regression. In order for your district to support summer services, it has to be written into the Individualized Education Plan (IEP). The IEP must specify the need for extended school year services (ESY). Some districts have their own summer programs, others might be connected to private programs, and of course, many districts offer nothing.

Maybe you can piecemeal a summer together. Think about the activities your child loves to do. Does your local Special Olympics offer a program? Is there a week long art camp? Drama



camp? Sports camp? Are there adaptive sports programs? Are there special educational programs that run weekly sessions? Is there a children's museum, aquarium or science museum in your area that might have summer programs? Does your local recreation center offer something? Could your child attend any of these alone, with an aide, a friend, a sibling? Does your local Parent Advisory Council (PAC) offer a list of summer camps and programs? Usually around January/February there are camp expos that have information on all kinds of camps.

Communication is probably the most important advantage you can give your child to ensure a successful experience. If you are looking at a public camp (not school run where they likely know your child), it is very important to be forthcoming about your child's syndrome, and what support they will need. Little anecdote: One summer I signed my son, Zach, up for an inclusion summer day camp not far from home. He was familiar with it as his older brother had been a CIT there the previous summer. I had many conversations with the owners prior to signing up, describing all the parts that made up my child. The camp was willing to set things up so that Zach could attend camp. I signed him up and paid the non-refundable fee in full. That

spring, Zach had a major meltdown, the likes of which precluded him from being involved with any summer activity. I called the camp to let them know what happened, and that we were going to have to withdraw. Because I had honest up-front conversations with camp staff prior to signing up, I was able to get a full refund. They told me had I not explained my child, they would not have given me a refunded thinking I just found a better alternative and was bailing on them. That said, if Zach had been able to attend camp that summer, I have no doubt that he would have had an amazing experience. The staff knew all about him and what to expect. They were willing to hear what I had to say about my child, and in turn, they could be honest about whether or not they could handle him. It's all about being open and honest.

One thing I find helpful is to provide a one page (no longer) cheat sheet about my child. This gives providers, who likely will not read an entire IEP, some quick important information about my

child. Included might be things like a definition of SMS, things your child loves to do, things likely to cause an outburst, what can help when there is an outburst, emergency phone contacts, anything you think is important for providers to know in a nutshell.

How are you going to pay for all of this? All too often we empty our bank accounts providing for our special needs children, especially with all the therapies, tutoring, doctors, medications and supplies they need. Often we have to just pony up. You can look for scholarship money to help with summer camp. If your child's IEP indicates the need for extended year schooling (schooling can be loosely defined as academic, social, recreational), then you can petition your district to cover the cost of an outside camp for the amount they would have to spend on an inside program (or go for the whole thing – can't hurt to try!). Some other places to look for additional funding might be

your local chamber of commerce, fraternal organizations and other charitable organizations. Summer camp is a place to have fun and create wonderful lifelong memories. Help your child do that by doing your research, being honest and communicating with anyone who might potentially provide service for them. Our children are the most wonderful and the most difficult to work with. Their unpredictability makes them challenging, their wonderful love and concern for everyone makes them the best. If we do our job well, then we have the best chance for a successful summer. Good luck!*



A Letter to the Camp

By Mary Beall

Sample Letter I Give to Camp Counselors and Caregivers
(Feel free to use it to write one to fit your child's needs)

Notes on helping Laura Beall control her behavior:

Laura has a syndrome called Smith-Magenis Syndrome. It is rare, and you have probably never met someone who has it. She is extremely personable, cute and outgoing. She can do a lot for herself and is pretty easy to care for until she gets frustrated or loses her temper. She is a helpful, loving, sweet child, and most people who know her love her. But...

Behavior problems are a hallmark of Smith-Magenis Syndrome. Laura has to work very hard to control her outbursts, hyperactivity, mood changes, etc. You probably will see things she does that make you wonder why none of us ever worked on it...that's a common response the families of these children get. Most likely we/the school/the therapists/the doctors have worked on it a lot, and Laura is doing the best she can. Her IQ, her general knowledge and her sweet demeanor are very much more developed than her emotional self-control. This is not her fault, it is a trait she shares with everyone with her syndrome. So here are some suggestions on the best way to help her control her behavior

Best Approach to Discipline Issues (like if she is refusing to do what you ask):

Try to keep your voice neutral. Harsh tones and force can escalate a situation with Laura. She gets most angry when anyone tries to be really strict and authoritative with her. When possible, wait a minute and let her decide to cooperate, she loves to please others.

An example would be, you say “we’re going to the playroom” and she says “no!” You wait a few seconds and then start walking without saying anything, assuming she will comply.

A little freedom (or perceived freedom) is very important to her. It seems to help her to have control of things...maybe where to sit in a group, or whether or not she needs a jacket, or whether she wants to participate in something or just watch. She acts offended if she is micro-managed. Exaggerated praise works wonders with her. You sometimes can change her bad mood by telling her excitedly what you do like that she is doing.

Acknowledge/accept her fears and anxieties and give her a way to cope - even if it means she skips an activity or just watches.

If she needs to be given a consequence for something, make it pretty low-key and try not to show a forceful attitude. Say something like, “Ok, why don’t you sit out for awhile,” but make it short.

If possible, find a way to give her a “choice”. (eg., “Ok, I know you don’t want to go now, but I have a problem. I can’t leave the other kids, and they want to go....so can you think of a compromise? Could you come and help me watch them?”). You may have to get creative.

If you can tell she is beginning to be upset, try to distract her...that is successful most of the time.

She may be more moody in the afternoon, because her sleep disorder affects her most then.

Self-abuse

She is very anxious on the inside and will often show it on the outside by biting her palm and/or hitting herself. It won’t last, and she seems to need to do it. She even sometimes does it when she is very happy about something. Just let it happen. Don’t worry about trying to stop her, she’ll stop quickly, and doesn’t usually hurt herself badly (she may need a Band-Aid). It’s not helpful to interfere or to try to make her stop or even to talk to her about what she’s doing. It’s best to either say/do nothing, and just wait quietly by, or to comment on the situation she is facing, “You seem kind of worried about the slide. Is that right?” It’s fine to try to distract her by changing the subject or giving her a job to do or something if she just seems anxious but isn’t acting out.

She carries a small teddy bear in her purse; it is very soothing for her to touch it, and it calms her when she starts to feel anxious.

If Laura becomes very upset and starts a tantrum: (this is rare)

Although these tantrums appear to be “spoiled brat behavior,” they are actually caused by this genetic syndrome. Typical discipline techniques (punishment/reward) don’t help them through these “fits” because they lose control of themselves and actually CAN’T get themselves to stop. Parents and teachers have to work together to come up with a way to help her get control again.

During a tantrum she will seem quite defiant. It will remind you of a fierce two-year-old with no control over herself. She may threaten you and/or throw some things, but she has no history of hurting other kids, or even adults, unless they are trying to hold her down (generally makes her worse). Your goal should be to keep the environment and yourself calm enough that she can calm herself down.

Don’t get into a power struggle with her, she gets wrapped up in it and then can’t get herself out. A good analogy would be that of a cornered animal; they aren’t reasonable and logical, they just become panicked and reactionary. Stay calm and quiet. Waiting and not reacting at first usually works great. Give her some physical space. Ignore what she is saying; think of it as garbage that really means, “I’m frustrated and scared”. You can try talking to someone else in the room about something that might interest her, but don’t say it to her - sometimes she gets busy listening to your conversation and forgets she is angry. She may seem really mad and defiant, and even may be threatening you verbally, but if you give her time to get back control of herself she will be ok and remorseful. If you need to tell her something after she is already in a meltdown, write a note; often that gets less problem reaction than saying something. Sometimes she will need some time alone with her bear, or a chance to nap.

Special note to caregivers: having a tantrum does not mean she doesn’t like you or that you did something wrong...it usually means that she feels overwhelmed in some way and can’t contain herself.

Getting Laura involved if she doesn't want to be:

Ask her to help you with something. She will gladly run any errand or do whatever, she loves that. She also loves having a "buddy" with her. She's bribe-able, particularly with soda. Best to reserve this for emergency use.

Fears:

Loud noises like fireworks

Balloons popping

Having her picture taken (this is getting a little better, but if she refuses and starts to act agitated, it's best to give up or she will get really upset)

Surprises, or the kind of excitement that typical kids like...crazy loud skits, wild costumes...

Favorites/Interests:

Her bear, board games like Monopoly and checkers, card games, math activities, music, U.S. geography (where each state is), license plates, Dallas Cowboys (especially Troy Aikman #8, and Tony Romo #9)

Strengths:

Her endearing, bubbly, personality

Her reading skills

Her observational skills-she learns very complicated skills by watching, and she will know what everyone has on, and if you have lost something, ask her, she may have seen it

Willing and able to help others

Sleep problems:

All kids with Smith-Magenis Syndrome have a major sleep disorder. Their natural body clock tells them to be awake at night and asleep during the day. (It's a melatonin thing). Laura takes a medication at night to sleep, and it is usually very effective for her, but it wouldn't be unusual for her to wake up in the wee hours.

Soda obsession:

She is crazy about soda. Tell her ahead of time how many and when she can have them. Of course, we would like her to drink diet soda, but don't let that cause problems for you. You can use this obsession for a bribe if you are having a behavior problem.

Summary

*Keep yourself calm, non-reactive and positive with her.

*If she starts to get agitated, it's best to stay quiet yourself and wait a minute for her to calm down.

*Acknowledge/accept her fears and anxieties and give her a way to cope, even if it means she skips an activity or just watches.

*Accept that she is trying hard, and try to stay on her side.

*Give her freedom and choice when you can. Don't micro-manage her because it will add to her frustration. Remember that she is a young adult. ❄



This article is a reprint from Spectrum, the quarterly newsletter of PRISMS. PRISMS is the non-profit organization Parents and Researchers Interested in Smith-Magenis Syndrome. PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS. Please visit www.prisms.org for more information or to make a donation.