

MICROPHTHALMIA



ANOPHTHALMIA



PARENT



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MAPS - Finding Our Way

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Sign, Sign, Everywhere a sign...

By, Jennie S.

Effective communication is such a critical skill for children to learn. We all communicate in a wide variety of ways. We use spoken words, different intonations in our voice, subtle gestures (raising our eyebrows, a sly smile, or a quick wink), and not so subtle gestures (waving our arms, stomping our feet, and clapping our hands loudly.) Some research studies say that over 80% of expressive communication is nonverbal. Have you ever noticed how many people talk while moving their hands? In some cultures, it seems impossible NOT to gesture while speaking! I remember being at a conference and we all had to sit on our hands and then engage in conversation with someone sitting nearby.

Within seconds, people were lifting their hands to gesture saying they simply could not keep them still while talking. Do you know anyone like that? Does this describe YOU?

For many children, especially those with disabilities, learning how to communicate effectively is extremely difficult. Using gestures and formal signs is a way to facilitate expressive language and opens doors to so many kids who, for whatever reason, simply have not yet been able to develop verbal skills. Almost ALL young children use gestures when learn-

ing to talk. They wave bye-bye, shake their little heads "no", and blow very wet kisses. Such actions clearly express a thought, an intention, or an emotion and all can be done without speaking. My son, Max, who is totally blind with bilateral anophthalmia, is one of those young children who is having a very difficult time learning to use verbal language. He is three years old and has four spoken words, two of



Max signing for "cracker"

which he is just beginning to use. However, Max can communicate twenty-seven things to us today because we have taught him how to use signs (that number is sure to be higher by the time you are reading this) Without signs, Max would only be able to say "mama", "dada", "night-night", and "ball". These are all great words to have, but not a very powerful way to make his needs known through out his day. LANGUAGE IS POWER! Using signs and gestures is lan-

guage. The use of signs does not prevent children from learning to speak. Research has proven this. In fact, there are studies that show children who used signs as babies actually have *more* spoken words as they grow than their non-signing peers.

A couple of months ago I wrote a post on the anophthalmia message board (Yahoo) about my experience with how our family taught Max to sign. I have included the post (on page 4) in hopes of sharing my strategies with a wider audience. There are many resources for learning how to make signs. Michigan State University has an on-line site that plays small video clips of common signs to visually demonstrate how to make signs. Their web address is: <http://commtechlab.msu.edu/sites/aslweb/browser.htm>

If you have questions about how to teach sign to your child, please e-mail the MAPS Moms and we will do our best to problem solve with you. If you have great strategies that you have already used to help teach your child how to sign, let us know so we can share them with others. Our e-mail is: owner@maparentsupport.com

Happy Signing!

*The family stories we print are **personal experiences** of members and **DO NOT** reflect the views of the entire MAPS group*

Transitioning to Pre-School

By, *Megan E.*

Sending your child to preschool is a huge transition for any family. It can be especially daunting if your child is blind. Typically motivating aspects of preschool – the colorful, cute classroom, the smiling teacher’s welcoming face, and the excitement of being with other rambunctious children – are sometimes lost initially on a blind child. This was no exception for our daughter, Ava, who was born in February, 2005 with isolated bilateral anophthalmia and recently began preschool at the Western PA School for Blind Children.

When Ava was born, we realized that we were lucky enough to have a School for Blind Children less than 15 minutes from our home. During her first two years of Early Intervention, Ava reached basic mobility, speech and O&M goals in the safety of our own home. When the time came to make decisions about preschool, we knew that the School for Blind Children would be the best environment for Ava, but we did have some unique issues to address. The first circumstance that presented a challenge in our minds is that, Ava, unlike most other people with a visual impairment, is totally blind, but she also has no other disabilities. Some may call her “vanilla blind.” In an article written in *The Braille Forum* (2001), Charles H. Crawford writes, “...there are people labeled by some professionals as the “vanilla blind,” meaning that they have no additional disabilities and blind people who have other disabilities to contend with as well, including hearing loss, cerebral palsy, and the inevitable physical side effects of just growing older. Add to that the range of visual impairment that is described as “legally blind,” and it’s understandable why some wonder about the existence of a community of people who are blind.”

Truth be known, most children who attend schools for the blind are *not* totally blind. The Western PA School for Blind Children’s own website cites that, “Many people assume that individuals who are blind have no vision

and thus live in a world of total darkness. In reality, only about 10 percent of all persons labeled blind are totally without sight.” When we visited the school, we wondered how Ava would fit in and how her needs would be addressed. We wanted Ava to continue to grow academically, as well as to learn the necessary Braille, O&M and social skills that would prepare her for a typical kindergarten experience.

Ava started preschool just six days after her third birthday. We had attended her IEP meeting at the school about 3 weeks before, so we were well aware of what her goals would be. The first



day was exciting and scary for all of us; my husband and I were asked to spend the entire day with Ava at school. We had talked to Ava for a long time about preschool, trying to prepare her for what was about to occur, but it’s not easy to explain the concept of “school” to a totally blind child. When we arrived, Ava was immediately overwhelmed with the voices of the five other children in her classroom, which we expected. Her teacher had prepared the class well; she reminded them that Ava was new and that she might appreciate it if they spoke and sang softly until Ava became more comfortable.

We spent the morning holding Ava on our laps, mostly staying across the room from the other children as they participated in their normal routine of morning circle time, snack, and transitions into other activities. Ava enjoys music and singing, so we thought that if

we recorded different songs throughout the day on her digital recorder, she could listen to them at home and learn them faster. We figured out that most of Ava’s early frustration would come from not knowing what was going to happen next. She is such a typical first-born child! Ava wants to be in control of her environment; she wants to know the words to every song, the directions of every activity and the steps of every process. This is also most likely a result of her blindness. Her world is largely unpredictable and she prefers very much to stay in her comfort zone.

Surprisingly, by the time lunch was over, she was moving closer and closer to the other kids and her teacher suggested that we go across the street to the main school building and have something to eat while Ava stayed and listened to a story. I thought for sure that she would cry the whole time, but when we came back and peeked in through the doorway, there she was, sitting in afternoon circle as quiet as a mouse. She looked comfortable and confident! This was the only time that I shed tears that day – I was so proud of Ava.

As I write this, Ava has been in preschool for four weeks and I can honestly say that there have been many more good days than difficult ones. For the first two weeks, I was able to spend time each morning at the school, getting to know the routine, the other kids and Ava’s teacher, aides and therapists and just being there to comfort Ava. Right now, Ava attends preschool only three days a week, a decision that I made before she began and am sticking to, for now. For a three-year-old who has previously spent every day at home, 40 hours a week at preschool just seemed like too much. So, Ava spends Mondays and Fridays with her 3-month-old sister, Lucie, and I, just playing and doing fun things. Something that I have compromised on is that Ava now rides a bus to school, provided by our local school district. I was determined to take her and pick her up every day, but with a new baby and a work-from-

home career, it was just too exhausting for me. I was really scared to put her on the bus, but as it turns out, she likes it. One of the lessons that I have learned about Ava during this transition is that, even though she can't see her world, she will adjust to it and thrive in it – and yes, that means the world outside our little, safe home!

Looking back on our first month of transitioning from home to preschool, here are some key issues that all parents making this transition should think about:

Placement

On a larger scale, this means choosing the right preschool for your child, especially if you don't live near a school for blind children. What kind of environment will your child thrive and feel comfortable in? If your child attends a "typical" preschool, how will the school work to accommodate the needs and goals of your child? On a smaller scale, the actual classroom that your child is placed in means a lot. For example, at the Western PA School for Blind Children, there are currently seven preschool classrooms, each very different from the next. When my husband and I initially visited the school, we were concerned that Ava would be placed in a classroom with kids who were all non-verbal or where a teacher was primarily focused on life skills and not academics. The director of the school heard our concerns and placed Ava in a classroom with three mobile and verbal children and two children who are largely non-verbal and use wheelchairs. This has been a wonderful combination for Ava, as she gets to know the verbal children by their voices and the non-verbal children by the switches and electronic devices that they use to communicate. Ava's placement is in the most traditional preschool setting available at the school – they start each day with a morning circle (Ava can already recite the Pledge of Allegiance!), work on the alphabet and phonics, create multi-sensory art projects, sing and read stories and practice hygiene skills. Ava also receives all of her therapies within the school day, in and out of her classroom. If your child has multiple disabilities, it might also be a good idea for them to also be in a mixed environment with children

who are up and down the spectrum verbally and physically. I have noticed that the kids in Ava's class who do speak often motivate the non-verbal kids to use their devices more to interact.

Mission: Independence

After I spent about three days with Ava at preschool, ducking in and out of the classroom as needed, I sat down with Ava's teacher and said, "I think



that Ava needs her own aide." I wondered how she would ever move around and participate without someone to help her at all times. I was concerned that Ava was the *only* totally blind child in her classroom. The other three children who are mobile have enough vision to move about independently and the two aides in the classroom seem to be pretty engaged with the two children who use wheelchairs, since they require so much



physical assistance. Ava's teacher understood my fears, but quickly offered me her opinion: she was willing to devote a lot of her energy initially to Ava during the school day until Ava learned her way around, but that *our ultimate goal for Ava was independence*. Having her own aide would definitely make her more dependent. She wanted Ava to function on her own, especially since Ava was about to

begin using a cane. When I think of my early request for an aide, I am so glad that Ava's teacher put it to me straight. After only four weeks, I now see that Ava does not need her own aide – she is becoming more and more comfortable with moving about and often uses a little shopping cart in and out of the classroom to help her feel more comfortable. And soon, she will be fitted for her first cane, the true sign of independence for many blind children.

Communication and Knowledge = Power

Every day, Ava's teacher sends home a folder that has some key details written about Ava's day. The next morning, I write a few things about Ava's evening and morning in the space provided for parents and any special concerns or directions that I may have for that day. Ava's teacher and I frequently talk on the phone and email and I truly do feel that all of the questions and anxieties that I have are addressed immediately. Communication is key when making the transition to preschool. It calms the nerves of uneasy parents and helps the teacher and staff to know your child better. Because our children with microphthalmia and anophthalmia will have IEPs for their entire school careers, preschool is the best time for you to practice the communication skills that will help you to obtain what is best for your child. At Ava's initial IEP meeting, her plan and goals had already been written based on her DART evaluation. (DART is an acronym that stands for Discovery, Assessment, Referral and Tracking and it is our local resource for eligible children, ages three to five, who have developmental delays or disabilities.) Since we had so much involvement in Ava's initial evaluation and great relationships with her Early Intervention therapists, we were fully prepared for what her goals would look like in preschool. However, should we want to revisit those goals, it is any parent's right to request an IEP review at any time throughout the school year.

The MAPS website (<http://maparentsupport.com>) lists a number of useful IEP resources that parents can become familiar with before this process begins.

Thoughts from a preschool teacher

One of our MAPS moms, Heidi S., interviewed her son's pre-school teacher, Ms. Louise Homstead. Heidi's son AJ has bilateral microphthalmia and is autistic as well. Here are Ms. Homstead's answers to the following questions:

1.) What thoughts did you have when you first learned you would have a child who was blind in your classroom?

I took great interest in finding out the ways this child learned. I attended several trainings and graduate level courses which helped me understand teaching approaches. Mostly, I collaborated with a team of people with equal interest (ie: parents, I/I, SP/L, OT, PT, VI, etc.) to build approaches.

2.) Once school got started and you got to know the child, were things different than you expected?

We saw so many great strengths (auditory perception, auditory memory, imitation) to tap into. We were a bit perplexed to comprehend the etiology and appropriate approaches to counteract weaknesses such as lack of exploration and delays in communication.

3.) What did you do to prepare your classroom for this child?

We rearranged furniture in consult with the VI to provide routes. We used auditory toys, developed as reinforcers to elicit responses. We helped peers to become "buddies."

4.) What things would you have liked to have known before the child started school?

How to overcome lack of initiative to try novel experiences and how to draw a team together with deficit of time to collaborate.

5.) What have you learned from having this child in your class?

More than words can tell. I have learned how incredible the human mind is. How people's efforts can make a tremendous difference and how well someone with a talent and eagerness to learn can produce.

6.) What advice would you give to a teacher who was going to have a blind child in their class for the first time?

Collaborate, Collaborate, Collaborate! Let successes move the child forward. Build social-emotional skills. Finally, friendships are vital!!



(continued from **Sign Language** story on page 1)
Jennie's post about teaching her blind son Max to sign:

Max just learned another new sign last night - "car" for his ride-on toy. It was the first thing he signed when he woke up this morning! The process for Max to learn sign has been VERY long and persistent. If my memory serves me correctly, I think I signed 3 signs with him many times per day for about 6 months before he began to show any attempt at doing a sign by himself. When I started, I was teaching in an intensive program for preschoolers with autism and using a strict ABA (Applied Behavior Analysis) method. This is what gave me the idea to just keep at it with Max. The basic principle is to choose an item that is HIGHLY preferred (for him it was his "lovie bear" he sleeps with and uses for general comfort). I would say AND sign bear EVERY time he came into contact with the bear. I took his hands and made the sign on his body 2 or 3 times and then IMMEDIATELY gave him the bear. I just used natural daily opportunities to work on signs versus a structured teaching setting where you give the item and then take it back to do it over again. I think kids learn faster with natural opportunities because it has everyday context. I think the other 2 beginning signs for Max were "milk" and "cracker".

My main points to teaching signs are the following:

1. Choose items that are extremely preferred - these are motivating. Most of us are not going to sign for Brussels Sprouts!

2. Start with no more than 3 signs - if you sign everything, it becomes overwhelming - kids will tune out and adults will lose interest. 3. Find several opportunities each day to use the sign - repetition is the key. 4. Give the item or do the activity (tickle game for example) IMMEDIATELY after making the sign. If you wait, even 30 seconds in the beginning, you are no longer reinforcing the gesture. 30 seconds is a long time and, within that time, the child has most likely done another behavior (turned his head, started to cry, waved his arms) - then you are reinforcing the wrong act of intended communication. I think I walked around my house with a bear in my pocket or within an arm's reach for 6 months! 5. Always use the word with the sign. Don't sign in silence. 6. Give verbal praise after the sign is made, even if it was done with hand-over-hand facilitation. I used to give physical as well as verbal praise - "Wow Max, you asked for your bear!" along with tickles as I gave him the bear. 7. Choose signs that are going to get the child something preferred - strong communication. It's nice if kids learn to say "please" or "sorry", but when you have a very limited vocabulary, each sign needs to be powerful. You can add the social "nice-nice" things later. 8. Accept a sign approximation as a success - most kids are not going to motor plan the sign perfectly, especially since they cannot see you doing it. Even verbal kids will say wa-wa before water. Later you can shape the "baby signs" into perfection if this is going to be a primary means of communication. As kids learn verbal language, signs naturally drop out. 9. Give it time! :)

Thoughts from a Kindergarten teacher

Another one of our MAPS moms, Michelle, interviewed her son's kindergarten teacher. Michelle's son Matteo is blind and has bilateral anophthalmia. Here are the answers from Nancy Kulis, a teacher at Mary Rowlandson Elementary School in Lancaster, MA.

1.) What thoughts did you have when you first learned you would have a child who was blind in your classroom?

At first I didn't think too much about the whole situation, because I had previously worked 6 years as a special needs aid with a child who is legally blind. I felt I had at least a little experience within the field and had so enjoyed the special friendship I developed with this child and her family over the years. I had also worked with an Optelec Machine and a vision specialist before, and had implemented modifications and accommodations when necessary. When I realized that the child in my classroom had Anophthalmia and had two prosthetic eyes, that's when I got a little nervous. Thinking about no light perception, and the thought that an Optelec type machine would never be an option I started to wonder how I would ever be able to teach



Matteo at the Braille in his classroom

Matteo. My next concern was with his communication difficulties. Would I be able to understand him? Would I remember how to say things? I had to change my language to be sensitive to his needs (ie: Turn your body towards my voice, Hi, Matteo, it's Mrs. Kulis on your right, and no more 1, 2, 3, eyes on me!)

2.) Once school got started and you got to know the child, were things different than you expected?

I was fortunate to meet Matteo early on. I had met both the vision specialist and Matteo in the early spring during an Orientation held at the school. I stopped into the school several times during the summer while he was attending summer school and spoke to both he and his aid. I think this helped with transitioning once school actually started. As I got to know Matteo, it became a little easier to understand him. It was necessary to use context clues, his voice intonation and information from mom, but these are all strategies that helped me. As far as remembering how to say things, the more I did it, the easier it was. I had to remember that this was a learning experience for all of us.

3.) What did you do to prepare your classroom for this child?

We had a team meeting to prepare many of us who would be working Matteo. We were taught and got to practice how to lead Matteo; we also learned how to approach and talk with

him. Matteo's mom had sent me some pictures of his summer kayaking experiences. Bingo! we had a connection! I too love to kayak! I made a little power point presentation which I forwarded to mom and then I put it in book formation and titled it, Matteo's Summer Vacation. This book helped when introducing Matteo to his classmates. Mom also wrote a letter introducing Matteo to our school. This letter was included in our Orientation packages for all Kinders and their parents, as we felt the information was valuable for all. A cubby close to the door, a mail box at just the right location, open and unobstructed pathways, audible signals such as a train whistle and chime, brailled name plates for cubby/mailbox/center tables, etc.

4.) What things would you have liked to have known before the child started school?

We met Matteo early on and I feel that we were fully prepared. It would have been reassuring to know that the vision specialist would meet with me weekly to go over lesson plans and make the necessary modifications and accommodations we needed.

5.) What have you learned from having this child in your class?

I have learned that it is best to explain things fully to the other parents and children so they know what to ex-

pect. This allows all to be very accepting of Matteo and his challenges. Many of the tactile strategies that are utilized with Matteo are beneficial to others children as well.

6.) What advice would you give to a teacher who was going to have a blind child in their class for the first time?

You can't do it alone! Accept and work with all team members. Try to show that even though the child is blind he or she is still a person with true feelings. As with Matteo, he can kayak and ski just like you and me! And, boy oh boy do we know that he loves music! God Bless America is a favorite of his! Don't be afraid to do something for this child that is different than the other children. Explain how he sees with his hands and you see with your eyes. A true example of this is our classroom birthday celebration. We usually have each child draw a birthday picture for the birthday child and it is put into a book formation. For Matteo, we took little glass marbles and made birthday wishes on them. We placed our marble wishes into a little snowman drawstring bag for Matteo to always have and cherish. If other children try to mother him/her, try a group discussion and ask the visually challenged child if they want help or if they want to do it themselves. Props for stories are very helpful too.

Teaching the Visually Impaired & Blind

By, Lisa La Due
Teacher for the Visually Impaired & Blind

Lisa is a friend of MAPS and is currently in the graduate program in Florida through FSU (online). She will receive her Masters degree next year, which will give her a specialization in early intervention for children with visual impairments. She has a supporting husband and a fun and loving year-old son named Keenan. When Lisa was in her twenties, she got in a car accident and lost her right eye. As a result, she wears a prosthetic eye. Because of her own personal experiences, Lisa feels like she is a better teacher for individuals who are visually impaired or blind. She wanted to share with us some of the questions she has received from some of our families and her answers to them:

Q: My son with monocular vision will start Pre-K next year. Is it necessary for him to sit in the front row to get the best view of the front board? Thank you, Maureen R.

A: He will receive a functional vision assessment (FVA) before entering Pre-K if he does not currently have one which is done by a Teacher for the Visually Impaired and Blind (TVI) and is required as part of his Individual Education Plan (IEP). The components of the functional vision assessment may include appearance of eyes, visual reflexes, visual responsiveness and perception, muscle balance, eye preference, oculomotor behaviors, field of vision, color vision, depth perception, figure-ground perception, light sensitivity and light-dark adaptation, contrast sensitivity, visual acuity, visual motor coordination, visual-cognitive skills and visual perceptions skills. All this information will assist the IEP team in determining if he will need any accommodations, such as sitting in the front row of the classroom. In addition, the TVI can observe him in the classroom at the beginning of the school year and note the approximate distances between his desk and the area where visual information is being presented and the distances from his desk to the area where the teacher typically provides instruction to the class. Other important factors that should be considered include the reflection of the light sources on overheads, dry erase boards, chalkboards, and other surfaces where he is expected to retrieve visual information. For example, he may need to be seated in the front row while the teacher is writing on the chalkboard so he can visually access the information. On the other hand, during circle time he may choose to sit anywhere he wants because the viewing distance is shortened so he can easily retrieve visual information. It is not always the best practice to assume that because a child is visually impaired he or she needs to be seated in the front row. This can lead to negative beliefs that all individuals who are visually impaired need to be seated in the front of the room. For instance, an individual with retinitis pigmentosa which can cause a decrease in both the peripheral and central vision also called "tunnel vision" would probably see better by sitting in the back of a room. In addition, if children who are visually impaired are always expected to sit in the front row, as they transition into higher grades, they may feel embarrassed or ashamed of their visual disability which can negatively impact social relationships and later lead to isolation.



Q: My daughter, Jadyn, is 7 months old. I was advised to get her in early intervention services as well as Orientation and Mobility early. The sooner the better. Her Early Intervention teacher comes to our house twice a month and so far Jadyn is developing just like any typical 7-month-old child, crawling, pulling herself up, etc. I asked about getting her O&M and was told because she is sighted and is not going to be caning she doesn't need services and therefore they won't refer me to an O&M specialist. We live in a small town and contract an O&M specialist from a larger city. I have noticed now, Jadyn, is running into walls when she is crawling now. So, do you think O&M is beneficial for my child who has monocular vision? Thank you, Jessica H.

A: Since I am not an O&M specialist, I consulted with one of my O&M colleagues. She suggested asking the case manager on Jadyn's team to ask the O&M specialists to come and do an evaluation. Furthermore, a child's vision can change over a short period of time therefore having Jadyn reevaluated by her primary eye care doctor may also be a good idea. Safety is very important and O&M specialists are trained to show the parents and child how to use specific strategies to maintain safety while exploring their environment. Even if a child will not be using a cane, he or she may need to be taught sighted guide procedures, trailing techniques, self-protection techniques, and basic cane skills. Learning these skills will teach the child to travel safely, efficiently, and gracefully, through any environment and in a variety of environmental conditions. All in all, independent movement plays a significant role in the child's overall growth and development.

Q: My son is 2 years old and totally blind from bilateral anophthalmia. When he was born we lived in a district the VI therapist came to the house 2X week. Then, we moved and in our new district the new VI therapist came about 1X a month or every other month. This VI was shared with another school district. Finally, the school found a new VI therapist. She is also with another school district. We are supposed to see her 1X week but she hasn't been in for the last 4 weeks. At 2 years of age...what are your thoughts on how often a VI therapist should work with a child? My son gets PT/OT 2X week (once during structured play group and another at home). I know he is getting enough PT & OT, but I am afraid about the lack of VI services. I am a little afraid for the present but more for the future and the actual learning of Braille, reading, and other things. I know he will need more than 2X a month, and I will insist on 2-3X a week, but what should I do when they just don't have a TVI available? Thank you, Janet G.

A: Part C of Individuals with Disabilities Education Act (IDEA), which became a law in July 1998, specified that services must be delivered to infants with disabilities and those who are at risk for developmental delay from birth through 36 months. Under this law, eligible infants and their families are required to receive a multidisciplinary assessment and to have an Individualized Family Service Plan (IFSP) developed. If it is stated on your son's IFSP that he is to receive vision services a certain number of minutes each week or each month then that is what he should be receiving. In my county, which may be very similar to many other counties, if a child is not receiving the services that he or she is entitled to by law then first the case manager is notified. If that does not work, the IDEA representative is contacted. If that fails, then the parent can contact the county Exceptional Student Education (ESE) supervisor. If that does not work then contact the Department of Education Office of Special Education and Early Intervention Services in your state. The special education consultant will probably advise you to file a complaint. DO IT! I'll bet that will get the ball rolling. If not, then you will be advised what the next step needs to be. It is a good idea to go through the proper channels first to see if a problem can be solved at a lower level instead of going straight to the top. It is very important that all parents under the IDEA law are familiar with their rights and what to do if those rights are violated. The case manager can provide you with a list of resources from the very beginning when services first begin. Among the resources should be a list of agencies and organizations that can assist families with situations similar to yours. Some of those agencies include, Citizen Alliance To Uphold Special Education (CAUSE) 800-221-9105 www.causeonline.org, which is an excellent resource for parent advocacy issues. Other great resources include, the National Association for Parents of Children with Visual Impairments (NAPVI) 800-562-6265 www.napvi.org that supports state and local parents' groups and workshops that educate and train parents about their children's rights and more. By becoming familiar with IDEA, agencies, and organizations, that support children with visual disabilities and their families, you will know what to do and who to report to in any given situation.

Q: My son's TVI insists that a child should never "win" when it comes to his not wanting to do something, even when it's something that he's tactually defensive about. For example, when he was suppose to be gluing on styrofoam peanuts onto paper to make a Christmas tree, he just wanted to squish the peanuts up but he was not allowed to. I don't believe he's ever felt styrofoam peanuts before. Thank you, Leanne M.

A: Maybe the TVI can collaborate with the OT and discuss what types of tactile materials he likes and dislikes. This way the TVI can plan to use materials that he enjoys touching to make art projects. If I have a student that is tactually defensive then I will collaborate ahead of time with the teacher about what types of tactile materials my students will be interacting with on that particular week. If it is something unfamiliar to my student then we practice using it and this allows my student to fulfill his or her natural curiosity about the object before he or she is expected to use it in the classroom. In this case, if he has never seen styrofoam shaped peanuts before then it may be best practice to let him explore and manipulate them so he can gather the information he needs to before he is expected to move onto the next step, which is to use them to make a Christmas tree. Through tactile exploration he is learning that if he squishes the peanut shaped styrofoam he hears a "crunchy" sound. He also learns about its temperature, weight, size, and texture, which are all additional concepts that describe things about the styrofoam. In turn, more than likely the next time he comes in contact with a piece of styrofoam he will automatically recognize what he is seeing. I wish I could send him a huge box filled with styrofoam shaped like peanuts. Teach him the TRUE purpose for using styrofoam so he learns and understands why styrofoam exists. Have him pack a box using styrofoam or visit a packaging store and discover the different types of styrofoam packaging materials. I'll bet a store like UPS would be glad to donate some styrofoam materials to you. I like my students to know the intended function of any objects and/or materials that I first introduce to them. Once they understand its function we think about other ways we can use the objects and/or materials. For example, uncooked macaroni is a food that we cook to eat but once they understand its initial function then we can use it to make an art project.



(Continued on page 8)



Please visit our site -
www.maparentsupport.com

MAPS needs YOUR feedback

We would like to encourage our readers to submit any ideas for articles, as well as their family stories for publication in a future issue of "Finding Our Way."

Please e-mail your ideas and family stories to owner@maparentsupport.com.

We look forward to hearing from you!

MAPS Mission Statement:

MAPS will provide...parent to parent support to others raising children with microphthalmia and/or anophthalmia.

By sharing a wide variety of information, MAPS strives to empower parents and reduce the overwhelming feeling of isolation that is all too common when a diagnosis of microphthalmia or anophthalmia is confirmed.

Teaching the Visually Impaired & Blind (continued from page 7)

Q: What are some alternative methods I can suggest to my son's therapists who seem to want him sitting in a chair while they have him "do" therapy? He seems to do a lot of sitting during school hours, including his therapy time with the exception of PT. (Leanne M.)

A: Positioning is very important because if children are sitting or lying in a position that is not comfortable for them then they may not be able to complete the activity that they are required to do. Here is one example of why positioning is so important. I worked with a child that had to be seated in her car seat in order for her to work on any activity because she experienced motor difficulties based on decreased postural tone. She needed to be able to have her head supported before I could expect her to use her visual skills to reach and grasp her toys. Because I collaborated with the entire team (OT, PT, SLP, and Parents) from the beginning I was able to have a complete picture of the "whole" child.

Q: What are some reasonable academic and life skills goals for my son in the classroom? (Leanne M.)

A: Without seeing his IEP, eye report, Functional Vision Assessment (FVA), observing him, interviewing you, consulting with a team members, and conducting a developmental assessment, it is impossible to give you specific goals. Look at the goals that are on his IEP and maybe observe him in his classroom working on those specific goals and objectives. Ask yourself, "Can I work on these same goals and objectives in the home?" If so, go for it! The more practice he gets the more independent he will become. Remember, work on anything that you feel he is capable of learning even if it is not listed on his IEP. One excellent resource that can assist parents and teachers to find what they need to ensure that their students and children are receiving an appropriate education in all of the Expanded Core Curriculum (O&M, Social skills, Career Education, Independent/Daily Living skills, Assistive Technology, Visual Efficiency, Recreation and Leisure skills) areas is the Texas School for the Blind and Visually Impaired (TSBVI) www.tsbvi.edu/recc, which lists documents, articles, books, videos, and other materials, that can be downloaded from the web or purchased from various sources.

Q: Should my son be learning Braille to some extent, even if in a very basic form? (Leanne M.)

A: Again, an assessment, such as a Learning Media Assessment could be done to determine that. Yet, if a child is totally blind then Braille will more than likely be the child's primary way for reading and writing. Not all children will use Braille. For example, if the child is severely mentally delayed or has a physical impairment that will not allow him or her to read or write Braille then another system for communicating will be used. I introduce Braille as soon as I can. If I have a small child that will probably be a Braille user, then I introduce the Braille immediately. For example, if the child is blind then he or she can begin to learn about Braille by exploring the Perkins Braille. In addition, so many items in the house can be labeled in Braille. Even before children can read or write Braille they can be introduced to the concepts related to Braille. In addition, become educated about Braille by going online to look at the Braille instructional resources. Some include, The American Printing House for the Blind (APH) www.aph.org, and The Texas School for the Blind and Visually Impaired (TSBVI) www.tsbvi.edu. In addition, order Braille books from the Library of Congress at 1-800-424-8567. They are the National Library for the Blind and Physically Handicapped and will send the books to your home at no charge.

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Lisa La Due would be happy to answer any questions that our readers might have, so if you have one for Lisa— please send your questions to owner@maparentsupport.com and we will see that she gets it. Your question and answer might be published in a future MAPS newsletter!