

Parent to Parent

For Parents and Families of Students in
Kentucky who are Blind and Visually
Impaired

Summer 2007

Kentucky School for the Blind

Family Support Center, Member of Parent Resource Centers of KY



Blindisms—What are they? What can be Done to Correct Them?

By: Family Support Specialist Mitch Dahmke

The passage below is taken from a chat room:

Hi all,

On the topic of stereotypes, I wanted to share a different perspective on rocking habits and other "blindisms". I personally have been struggling with rocking and eye poking for as long as I can remember. I was told that I poked my eyes chronically as an infant, which seems to occur with almost everyone I have met who has my eye condition. I also developed other habits in early childhood such as jiggling my fingers and toes and, yes, rocking when I was bored or excited. And, like most well-reared blind children, I was admonished by parents and teachers regularly whenever I was seen doing any of these things, and I was assured repeatedly that these habits looked inappropriate to the sighted and that I had to do whatever I could to stop. I understood that these habits were undesirable, and eventually learned to become more aware of my rocking and eye poking and to limit its frequency.

But today I am almost twenty-one years old and I still catch myself rocking, jiggling my feet, and occasionally even poking my eyes. Usually I catch myself in private, but my mother has sometimes told me that she saw me rocking while having a conversation with another person (which, I might add, is quite embarrassing).

So I believe I understand that rocking and eye poking are unacceptable-looking to the sighted, and I also believe that I really want to look professional when I need to and also to look appealing to sighted men. And I

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Blindisms, continued from page 2:

really, really don't want to appear like I have a cognitive disability or bad blindness skills. But yet, despite my training while I was growing up, these habits still sometimes escape my awareness. I hope to someday develop the willpower or whatever it is I need to totally stop rocking and poking my eyes in all circumstances. But this just hasn't happened yet.

I feel that so-called "blindisms" like these are really a complex phenomenon with both biological and social aspects. Yes, proper training and skills do matter, and I will not say that my background or current skills are perfect. But there are probably also other elements relating to one's cause of blindness that may make a person more likely to develop blindisms or make those habits harder to overcome. There really needs to be more research done on the causes of blindisms so we can find more effective ways to help blind children stop these habits early. Then we can really weaken those stereotypes and especially help people who struggle with blindisms even though they may have good skills.

*Just my thoughts,
Beatrice*

**What are the facts concerning blindisms?
Are they behaviors that are learned from others?
Are they opportunities to satisfy the need for
movement?**

The preceding were questions I had concerning blindisms when I began reading on the topic. What I found was very informative, so I decided to share it in *Parent to Parent*.

All of the articles I read stressed that opportunities to satisfy the basic need for movement and activity must be provided from infancy, otherwise the child with severe visual impairment will seek to satisfy these needs within himself rather than outside himself and will gain satisfaction from seemingly aimless physical activities, or stereotypical behaviors called blindisms. These blindism behaviors include body rocking, head swaying, eye rubbing and finger flicking. They are characterized as being repetitive and not directed toward the attainment of any specific goal.

Geraldine T. Scholl lists many of the theories concerning the cause of blindism in the book *Foundations of Education for Blind and Visually Handicapped Children and Youth*. These include:

- The lack of adequate sensory stimulation so the child uses his own body for stimulation and activity.
- Limited motor and physical activity, so the child cannot easily change his environment by moving to another place to maintain and satisfy the need for physical activity.

- Social deprivation resulting from long periods of hospitalization where there is limited interaction with others.
- Inadequate primary caregiver-child relationships that do not provide opportunities and encouragement for the child to engage in a variety of behaviors.
- Lack of ability to imitate others in the environment and learn a variety of socially acceptable behaviors.

Teachers and parents working together should attempt to determine which of the above causes for the blindness is most relevant and then decide upon a

Blindism behaviors may lead to teasing by other children and may leave the blind child socially isolated.

plan of action to eliminate the undesirable behavior. One of the best and most successful interventions is keeping the child busy, physically active, interested and moving about in the environment as much as possible.

The effects of blindisms can be serious if it is not corrected. Blindism behaviors may lead to teasing by other children and may leave the blind child socially isolated. The majority of people with good vision are not accepting of the blindism behaviors and do not wish to be socially interactive with people who exhibit these behaviors.

Constant eye poking and rubbing can discolor the skin around the eye and cause it to become callous-like. Children may also become increasingly withdrawn from reality. Blindisms may also interfere with the child's ability to learn.

As parents and teachers, how do we redirect the inappropriate and socially unacceptable behavior of blindisms? One preventative measure that jumped out at me while reading was early intervention. Visually impaired children and their parents should receive instruction from a qualified Orientation and Mobility Instructor that is knowledgeable in early childhood education when they start to walk, if not before walking occurs. An early education program should be planned by a qualified teacher of the visually impaired to develop efficient, accurate, and effective use of the child's senses. Also, the parents should be included in the visually impaired child's program. Because the majority of parents of the visually impaired are ignorant of techniques used to teach visually impaired children, they too need to be instructed on how to help their child learn. *It's not all up to the teachers!*

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Blindisms, continued from page 3:

V. J. Eichel wrote an article for the *Journal of Visual Impairment and Blindness* entitled "A Taxonomy for Mannerisms of Blind Children," saying that when visually impaired children swing on swings, they do not rock and recommended that children who rock be given rocking furniture and swings to use.

In 1963, A. Sandler recommended that visually impaired children observed engaging in an inappropriate, stereotypical behavior be diverted to a meaningful activity. He stated that the same parts of the body used in the appropriate behavior should be used in the substitute activity. For example, eye rubbing or hand flapping can be substituted with meaningful object manipulation activities such as playing with a xylophone, pots and pans, or plush toys.

By providing children who are visually impaired with early intervention programs, encouraging meaningful play, many of the blindism issues may be avoided. If blindism issues do arise, a behavior modification plan should be developed.

Behavior modification programs use token reinforcers, peer pressure, praise and encouragement, point systems, and food reinforcers. Some programs combine positive reinforcement with additional strategies such as the introduction of alternative behaviors and reprimands and punishments.

It is important that whatever strategy is used to correct blindisms, that it should be consistently followed at school and in the home. It is not the sole responsibility of the teacher to correct the behavior. There must be a combined approach between home and school to confront blindism behaviors.

***Parent to Parent* is a quarterly publication containing information relevant to Kentucky parents and families of children who are blind and visually impaired.**

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Comments on Blindisms from Educators of the Visually Impaired

Teachers of the visually impaired at the Kentucky School for the Blind share these helpful comments regarding blindisms.

- Providing sensory stimulation doesn't mean providing lots of toys or background noise. Your child with a visual impairment, minus other disabilities, should be playing and investigating their surroundings in the same manner as would a child who is sighted.
- The best time to address blindisms is when your child is an infant or toddler. Generally, these behaviors are the result of a lack of sensory stimulation.
- You must re-direct the child as soon as the behavior begins, and you must be **CONSISTENT**. If your child is not in your care all day, communicate with the other caregiver.
- Do not draw attention from others to the blindism. Use a cue word that is known by only you and your child to make your child aware that the blindism is occurring and needs to stop. If the blindism is persistent and recurring, take a more dictatorial stance on the subject.

Graduation Day 2007

A Parent's Reflection

By: Mitch Dahmke

As I sit here working on this issue of *Parent to Parent*, I do so with many thoughts running through my head. For those of you who know me, you are probably surprised that I put these thoughts down on paper and why? It is because my youngest son will graduate from the Kentucky School for the Blind on May 24.

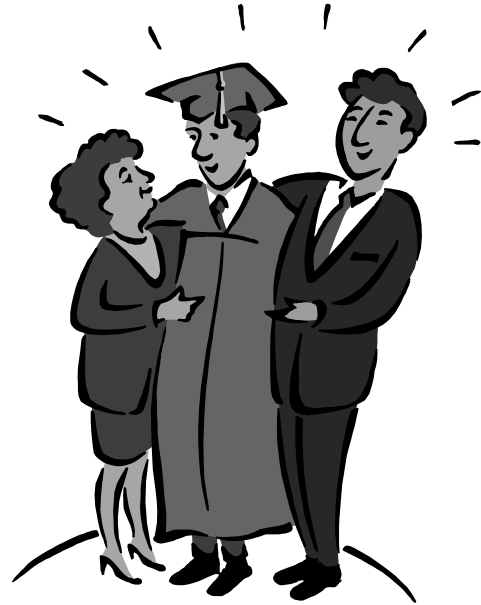
For those of you who may not know, I have three children and a son-in-law, Ashley Erwin and her husband Rob (who this past fall presented me with my first grandson), Chris who graduated from KSB and now is attending the University of Louisville, and Bret, who is 18 and the baby of the family.

I look over the past 23 years of their young adult lives and I am overwhelmed with the hardships, sacrifices, emotional ups and downs, successes and failures that my family has endured. The goal has been achieved and that goal was to provide our kids with the best education we could.

You may ask, "Why would anyone be thinking of anything other than successes at graduation time?" The reason is that many of you are or will be going through some of the same experiences my family has endured through the years. Hopefully, by putting my thoughts to paper, something that we have experienced will help you deal with a visual disability a little better.

When Ashley was in sixth grade, Chris in the fourth, and Bret in first, my wife and I made the decision that in order for the boys to get the most out of their education, we needed to do something different for them educationally and socially, or else we would lose them in both areas. At the time, the Department of Education in Nebraska was attempting to close the deaf school in Omaha and was considering closing the school for the visually impaired in Nebraska City in order to educate these young people in their home districts. This is a terrific idea in theory, but it is not the solution for all young people and it was these young people that I considered were my sons. The state had a vision itinerant (VI) teacher with a very large caseload that saw them for half an hour, once a year. After the VI teacher observed each of my sons, we had their ARC meetings to determine their IEPs for the next school year. If the special education teacher had any questions, she could call to receive guidance during the school year. I might also add that the VI teacher had approximately 60 other children she was responsible for in the Nebraska panhandle. Essentially the same happened for deaf children.

The department of education succeeded in closing the deaf school and essentially closing the school for the visually impaired and reopening as a



part of an education service unit and different name. This was back in the day when full inclusion was beginning and "granny bar the door," Nebraska was going to see this done no matter what the people who lived with these disabilities had to say. Needless to say, both the deaf and blind communities were not pleased. Since both communities were small in number, especially the blind community, their voices went unheard.

This was not the environment that I wanted my sons to receive their education. My wife and I looked at three schools for the visually impaired. They were Kentucky, Tennessee, and Indiana. We felt that the best we could do for our children was Kentucky. We knew that there had been many families that had relocated to Kentucky just for the school for the blind because of the support from the state of Kentucky and community of Louisville and the education the school provided.

Near the end of November in 1995, I resigned my teaching position and many other community positions, and decided that it was time to make the change. As the school year ended, my wife closed her bustling day care business and began the long task of packing a five bedroom house for a 1000 mile journey. I began job hunting in Kentucky in June and was followed by the rest of the family in August, including three dogs and a cat. It was a stressful time with so many changes and adjustments for all of us. The move was great for the kids and after eight years and a lot of stress, Carol and I can say the same. As for the three dogs and the cat, they are all dead now, nothing to do with Kentucky though!! Old age took them.

Why the move?

What were the outcomes for each family member?

The first family member I will discuss is Ashley. Many of you may wonder why she is included in this article, as she is not visually impaired. Well, the reason is that a nondisabled family member is affected in ways not always thought about by those outside of the immediate family.

Ashley handled the discussion of a possible move to Kentucky very well on the outside. I think deep down she too knew that her brothers needed more than they were getting in school. Even though, as the announcement was made of our moving, she was greatly upset that she would be leaving her friends. With goodbyes said, she entered seventh grade in Spencer County



The author's youngest son Bret is a 2007 Kentucky School for the Blind graduate.

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A Parent's Reflection, continued from page 7:

Middle School and became very active in band and soccer. The trauma of moving eventually passed!

Chris, who would be entering fifth grade and Bret, who would be entering second spent one month at Spencer Elementary before we had the first IEP meeting. Little did we know when we moved to Kentucky that different states handled placement decisions differently. For those of you who are unaware, placement is a decision of the ARC in Kentucky. In Nebraska, school choice was available so parents made the final decision at that time. At our first IEP

The goal has been achieved and that goal was to provide our kids with the best education we could.

meeting, placement was discussed and Kentucky School for the Blind was selected for our sons.

At this juncture, I must give Nancy Nusz and the Spencer County Special Education Department a pat on the back. Always, during the time the boys attended KSB and Spencer County, Carol and I felt that our concerns were important and we were heard when we had something to contribute. Our lack of understanding concerning the differences between the way Nebraska and Kentucky conducted education business was met with patience and explanation. Good communication seemed to be the key to this successful working relationship.

Chris had built up what I call a "chip" on his shoulder, which sometimes happens to children concerning their visual impairment. He seemed to have a lot of anger and he had trouble expressing it appropriately. The chip was built up by little comments made by peers in his classroom about the adaptations he needed to see and learn. Chris tried to play football on the playground, but would get hit in the face because he couldn't see the ball coming at him. He tried to play baseball, but could not see it either. Activities such as these enlarged the chip. Because he started refusing technology aids and large print materials (he wanted to be like everyone else), he fell behind in his education. Enter KSB!

Chris entered KSB and began to catch up to his grade level in most areas. Language arts was and has been a weakness, but his teachers gave extra assistance when needed. In dealing with his anger issues, Chris, our family,

and I want to offer our gratitude to Dr. Bill Greenlee. He counseled and worked with Chris to chisel down the chip. While there was still some work to be done at the time of his graduation in 2004, without Dr. Greenlee's help, we all wonder where Chris would have ended up. He is now attending the University of Louisville working on a degree in education.

Bret was a somewhat different story. We left Nebraska before he built a chip. While you wouldn't know that Bret has a visual impairment unless you observed him, he has the same condition as his older brother, cone dystrophy. Bret had not fallen behind in academics and was allowed to attend an elementary school in Louisville half days and KSB half days. By his seventh grade year, his vision had improved and he did not have any academic weaknesses. He returned to Spencer County to attend his middle school years.

He kept up academically, but had a problem turning in his homework, which he had up until this past year. Everyone accepted Bret and seemed to work with him well, but the refusal to use any technology or large print materials surfaced. He too, wanted to be like the other kids and did not want to look different. He also entered the fledgling Spencer County football program and had much success until his sophomore year when a comment was made about his vision that led him to shut down. Another comment surfaced from a teacher not believing Bret when he said that he couldn't see the overhead. This did nothing to help his self esteem. Bret's vision worsened and he became eligible again for special education services. He expressed the desire to go back to KSB where he wouldn't have to worry about being different. The assessments were done and placement was made at KSB.

Now here we are, Graduation Day 2007. MOM AND I MADE IT (and so did Renee Farrell, Bret's advisor)! We have a happily married daughter and a (perfect) grandson, two sons, one attending U of L and the other one looking to attend a college. Everyone is healthy.

In the case of my family, the successes have far outweighed the failures. I guess the feelings at this time are ones of normalcies. The visual impairments of the boys did not stand in their way of being like the other kids. They were normal boys, did normal boy things, but just happened to be visually impaired. A great sense of accomplishment is felt by both of the boys and their parents.



Mark Your Calendar

November 2-3, 2007

A Parent Conference for Kentucky Families with Children who are Blind and Visually Impaired will be held on November 2-3, 2007 at the Kentucky School for the Blind. Keep watching for more information. *This will be a conference you want to attend!*



When Should a Child Begin Working with a Cane?

By Renee Farrell, Orientation and Mobility Specialist and Jennifer Stocker, Occupational Therapist R/L, SIPT Certified

Thinking has changed about when to give blind or visually impaired children a cane. Now it is more and more acceptable to give preschoolers a cane as soon as they can walk. Having a cane and being able to use it in a safe and acceptable manner gives young children opportunities to socialize with their young friends. It gives them the opportunity to do something for and by themselves that helps them to feel good about themselves. However, age should not be the sole determination of whether or not a young child should be introduced to a cane. The first step in this determination is an orientation and mobility (O&M) evaluation by a qualified O&M specialist, preferably one who is familiar with young children and how they develop, preferably one who is familiar with young blind or visually impaired children. An evaluation plan that dictates that an O&M evaluation is to be completed must be signed by the parents or guardian before such an evaluation can be accomplished.

The results of the O&M evaluation should determine whether or not the child is ready for a cane. If it is determined that the child is not ready for the cane, it is important that the reason for this be clearly stated to the parents. This allows the parents to focus and work with the child in that area(s) so that he/she is ready for a cane and cane instruction in a relatively short time span. It may be determined that another O&M evaluation should be completed. If this is the case, request that the area (s) that had determined that the child was not ready for the cane be given special attention. Again, make sure any reason that is given for the child to not have a cane, be clearly and specifically stated in the report. If there are not any valid reasons for the child to not have a cane, then have IEP goals and objectives written so that instruction may begin. The goals and objectives should address the child's specific and individual needs.

Factors that should be considered when determining if the child is ready for a cane include body image and body awareness, strength, hand and shoulder development, walking gait, and balance. Being ready for a cane is important to the instruction and learning of how to use a cane in a safe and age appropriate manner. Consistent practice of the skills and how they are to be used is important for the young child to reduce the possibility of poor cane habits that may affect the child's safety. Practicing the cane skills in a consistent manner will enable the child to generalize the skills to a variety of environments and to be able to use the cane with their family, not just in school or with the O&M specialist. It is extremely important that when the child gets a cane, he/she receives instruction from a qualified O&M instructor and is given a variety of environments to practice the skills for its safe and appropriate use.

Families Connecting with Families



IN THE HEARTLAND OF AMERICA

July 13–15, 2007 ☼ Omaha, Nebraska



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A national conference covering all aspects of raising and educating a child with a visual impairment, the 2007 FCF conference will include:

- > Interactive sessions and panel discussions to address parents' most pressing interests: braille, social skills, college preparation, getting a first job, children with low vision or additional disabilities, & much more
- > Networking with other families and professionals
- > Daycare for children
- > Activities designed especially for teens
- > Fun for the whole family: a trip to Omaha's world-class Henry Doorly Zoo and a pioneer-style Family Cookout with campfires, music, and stories of the Wild West

THE 2007 CONFERENCE WILL BE HELD AT:

Hilton Omaha ★ 1001 Cass Street ★ Omaha, Nebraska 68102

SPONSORS

National Association for Parents of Children with Visual Impairments
American Foundation for the Blind
The Seeing Eye



The Seeing Eye



Keep an eye on the following web sites for more information:
www.napvi.org ★ www.afb.org ★ www.seeingeye.org

See Back Page for Additional Information

Funds Available for Families to Attend FCF Conference

The 2007 Families Connecting with Families Conference is fast approaching. It will be held in Omaha, NE on July 13-15 at the Omaha Hilton. This conference will cover all aspects of raising and educating a child with a visual impairment and will include:

- *Interactive sessions and panel discussions to address parents' most pressing interests such as Braille, social skills, college preparation, getting a first job, children with low vision or additional disabilities, and much more*
- *Networking with other families and professionals*
- *Child care for children*
- *Activities designed specifically for teens*
- *Fun for the whole family; a trip to Omaha's world-class Henry Doorly Zoo and a pioneer-style Family Cook-out with campfires, music, and stories of the Wild West.*

Sponsors for this conference are the National Association for Parents of Children with Visual Impairments (NAPVI), American Foundation for the Blind and Seeing Eye.

Stipends to cover registration and two nights lodging for Kentucky families of children with visual impairments are available from the Kentucky School for the Blind Charitable Foundation. For information concerning the stipends, contact the Foundation at 502-897-3990. Ask to speak with April Wright or Allan Steinberg. You will need to let them know that you are inquiring about stipends for the National Families Connecting with Families Conference. You should also know that you need to get registered as soon as possible because the conference is quickly filling up and so are the motels.

For additional information concerning the conference contact the following web-sites: www.napvi.org, www.afb.org, www.seeingeye.org

For more information about hotel reservations, registration, and sight-seeing in the Omaha area, please contact Mitch Dahmke, Family Support Specialist, Kentucky School for the Blind, 502-897-1583, x205 or mitch.dahmke@ksb.kyschools.us



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