

IPVI INSIGHTS

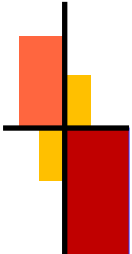
Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities

September
2016



PRESIDENT'S REPORT

Filiberto Almendarez III



The 2016 Olympics Games in Rio de Janeiro were exciting. Watching our athletes fighting for Gold and succeeding. Now, I wait patiently for the Paralympics to start on September 7, 2016. So, I send a good luck wish to our athletes of all abilities and a shout out to the U.S. Goalball team. I had the pleasure of meeting a member in Illinois who spoke on behalf of the U.S. Association of Blind Athletes (USABA). He is on the team representing the United States and gave my son his first Goalball. It is heavy, which explains why he is so fit. Good luck and let's go for the Gold. Either way, they all are champs. Keep on playing.

As for playing, parents and children activities. Find your child's ability and enroll them in that sport, activity and/or musical instrument. From swimming to Goalball to playing the piano. There are many physical activities to participate in. If your child is shy like mine, make it fun and then increase the challenge. Expire the energy, while learning your child's competitiveness. Also, parents, if you would like to have a Goalball Day, please relate and we can coordinate a date. We already have a Goalball to play with. Parent participation is encouraged. Staying active and healthy together.

Lastly, school has begun. Practice your Braille (I know I need too) and prepare for homework and IEP evaluation. Also, enroll your child in what interests them. Find the interest. Let your child learn what is possible. "You only fail when you fail to TRY". Happy Trying!





Inside This Issue:

President’s Report	1
A Parent’s Perspective on Braille	2
Memories of Heidi Musser	3
Akash Patel Applauds His Parents	3
Family Connect: Corporal Punishment in Schools	4
Making Sense	5
Chicago Talking Book Center Consolidation	5
Lay-Away Plan for Victor Reader Stream	5
FRCD Illinois Health Care Coverage Options...	8
WonderBaby.org	9
5 Resources for Back To School	9
Transitioning Your Blind Child to Preschool	9
How to Organize Your IEP Paperwork	9
IPVI Board of Directors	10
Autumn Poem	10
IPVI Membership Dues	15
IPVI Calendar of Events	16



Parent’s Perspective on Braille

By Mary Zabelski

When my daughter, Cara, was 3-1/2 years old, she had some remaining vision in one of her eyes. However, Her medical prognosis for continued vision was unstable due to her partial retinal detachment and various treatments for retinal cancer.

She attended a pre-school program in the neighborhood where I taught school half-days. This program provided social opportunities for her with non-disabled children of her own age. These social experiences were very important for her. However, her school tasks were causing increasing frustration due to her limited vision. She could no longer identify colors, numbers and letters with accuracy. It was obvious that she needed some classroom accommodations and modifications, which she could not get in the private neighborhood pre-school environment.

After some investigation, I enrolled my daughter in a district public pre-school program with a full-time vision resource teacher. The class had five pre-school students with one teacher and a classroom aide. Almost immediately, she began to learn tactile discrimination skills and the fine motor skills that would prove to be very helpful for future braille reading. Also, she began to learn about protective extension and other techniques, such as “trailing” the walls. The orientation and mobility teacher showed me these techniques and instructed me regarding this method. I was very excited to have these specialized teachers work with me and help me to understand how to teach her some very specific activities and techniques.

Her teacher explained that it would be a good idea to introduce braille even though we would still encourage her to use her remaining vision to identify letters and numbers. Like most parents who have

(Continued on page 6)

MEMORIES OF
HEIDI MUSSER

**I LOUDLY APPLAUD MY PARENTS
KAMLESH AND SMITA PATEL**

Prepared for: IPVI Insights - Issue September 2016

**MEMORIES OF
HEIDI MUSSER**

With enormous pride I would like to share with you three responses to the writing of my former student Akash Patel for the August IPVI Insights Newsletter:

We are so lucky to have had Heidi and now Akash as our students.

We have learned as much from them as they have learned from us.

Dr. Joanne L. Smith, President, Oakton Community College

"It warmed my heart to know that Seedlings had at least a tiny part in helping Akash. Please thank Heidi for all of us for reaching him and introducing him to the wonderful world of Braille."

Director Debra Bonde, Seedlings Braille Books for Children.

Beautiful articles that show Heidi and Akash's compassion, intelligence and perseverance. I love the idea in writing tandem!"

Community Engagement Librarian Holly Jin, Skokie Public Library

Please read on. We have fired Akash on to come forth with his feelings and opinion.

* * *

Please write me at:
hmusser@msn.com

If my life had remained in the hands of adults, who wanted to keep me in high school until age 22 and impose limitations on my potentials to have a career in what I am passionate about and pressure me to go into a career that they see as more appropriately fit for me based on being a blind individual, I would not be able to claim my success as a radio talk show host, U.S. Congressional intern, elected member of the Student Government Association (SGA) at Oakton Community College and lately, an author of news articles for IPVI Insights.

I feel very proud that throughout my entire young adult life, I have made decisions on my own. All along I have worried that adults outside my family are judgmental towards me on my life style. I am satisfied with my making the choice to be dependent on my family to provide me with assistance for independent living skills, transportation and financial needs. My parents support me in my choice to be unemployed and that I rather focus on my social needs and higher education goals, volunteer jobs and unpaid U.S. Congressional internships. I feel very lucky to have Supplemental Security Income benefits as my income source rather than be locked in with under-employed jobs that pay unsustainable wages.

I feel very thankful that I am involved in things that make me happy and offer me an opportunity to contribute to my community. With lots of free time available, I can focus on my studies and be all I can be. As a wise man once said: Do it right and do it light!

People have said to me over and over that as long as I am happy that's all that matters and that I should keep doing what I am doing and keep up the good work. It makes me feel really good, when I hear stuff like that.

I feel very proud of my parents and in turn, they feel very proud of me! They believe in my potentials and respect me! Both were born in India. They had only limited education growing up in India, but they fol-

lowed their heart and supported me to be what I am now.

* * *

Please contact me:

Akash Patel: 312-231-4444 (cell)

patelgames@gmail.com

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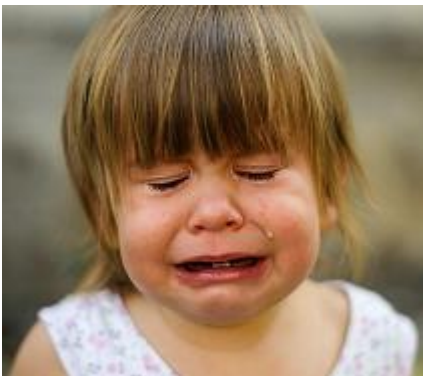
Corporal Punishment in U.S. Schools: Not Nearly As Uncommon As One Might Think

Posted 8/18/16 by *Scott Truax*

We are excited to share this blog that brings to us one of the hot topics generated at the Lighthouse Guild Telephone Support group. These groups are a great way to meet other parents by phone and is a free service. To get more information or to join a group, please contact Susan LaVenture at LaVentureS@lighthouseguild.org.

Corporal Punishment in Schools

by *Lilly Jackanin*



I recently received a call from a mom moving from the state of California to the southern state of Alabama. She had done a tremendous

amount of research in many areas, including the Alabama schools, before embarking on this decision. When she arrived, she went on the school district's website to read the procedures for registration and attendance. As she proceeded cautiously to read the district's handbook, she was outraged and alarmed to read – in much smaller print – that Corporal Punishment is legal in the state where she now resides. As she continued to further research this matter, she was appalled to see that this form of discipline is legal in 18 other states. As her explorations continued, she read about the disproportionate number of incidences that occur among disabled children, who are paddled mainly because their disabilities are poorly understood by so-called educators and school administrators. It should also be noted that there is an extreme disparity in the number of black male children targeted.

After hearing all this, I thought it prudent to explore further, because many of the families I work with at times find it necessary to move from one location to another in the hope of obtaining more adequate services for their children who have disabilities. After reading a number of articles regarding this practice, I came to the following conclusion: People are still haunted by memories of witnessing beatings and/or receiving them. Many report that the reasons for being paddled were arbitrary and inconsistent. There seems to be some decline in this method of discipline, primarily because the school districts want to avoid lawsuits. Abolition of this disciplinary measure has been met with mixed results. In some states, such as Texas and Alabama, parents have been given the choice of opting out of this practice. In other states, such as Maryland and Ohio, where Corporal Punishment has been banned, it is sometimes still put into effect. The detrimental effects of Corporal Punishment are so egregious that they are denounced by such groups as the American Psychological Association, the American Acade-

my of Pediatrics, and the American Medical Association. Human Rights Watch and the American Civil Liberties Union in 2009 collaborated on a report called "A Violent Education", in which they labeled corporal punishment a violation of students' "physical integrity and human dignity" and declared it "degrading, humiliating, and damaging."

The 19 states that continue to practice this method are as follows: Alabama, Arizona, Arkansas, Colorado, Florida, Georgia, Idaho, Indiana, Kansas, Kentucky, Louisiana, Mississippi, Missouri, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, and Wyoming.

The highest rate of incidents occurs in the state of Texas, followed by Mississippi and Alabama.

In conclusion, I feel that this technique causes so much emotional pain to all subjected to it, but particularly those who are weak, defenseless, and subordinate, such as our children. We as parents must nurture, love, and protect our children at any cost.

Editor's Note: Although Illinois is not listed as one of the States who practice Corporal Punishment, if you are planning to move to one of the above listed, do some research yourself on the school that you would be sending your child to.

MAKING SENSE

Chicago Talking Book Center Consolidation

Effective July 1, 2016, the services offered by the Chicago Talking Book Center at Harold

Washington Library have been transferred to the Illinois State Library in Springfield. The Springfield location now handles all talking book and braille materials via mail for qualifying residents of Illinois. To order materials by phone or to consult a reader advisor, call 800-665-5576. Harold Washington Library still offers a state-of-the-art adaptive technology center on the 5th floor open during library hours. The quarterly book club will continue to meet at Harold Washington Library until further notice. In addition, Harold Washington Library offers a wide variety of e-books that can be used with most screen readers. New descriptive videos can also be borrowed on a walk-in basis or by calling the library at 312-747-4700 and asking for your selections to be sent to your local library branch. Suburban patrons please note: at this time, the Illinois Talking Book Outreach Center in Burr Ridge is not affected by these changes.

Lay-Away Plan for Victor Reader Stream

Accessible Electronics is offering a new lay-away plan for the New Generation Victor Reader Stream. You can make a payment each month that fits your budget and when you reach the purchase price of \$349.99, your new Stream is sent to you. No other charges will be incurred. This purchase opportunity is only available via email, phone or Skype. To learn more, email, call 727-498-0121 or Skype lazmesa.



Reprinted from MAKING SENSE, August 2016, Second Sense, Beyond vision loss, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, www.second-sense.org.

(Continued from page 2) - A Parent's Perspective on Braille

no previous knowledge of braille and its usefulness, I was clueless. Several times, when we were waiting for an appointment in the eye clinic of the University of Illinois, I observed adults who were blind, reading braille from books or magazines. I was amazed at how rapidly their fingers could fly over the pages of dots.

Cara loved “reading time” and every night I would read a book to her before bedtime. I realized that her vision was failing and soon she would not be able to identify the pictures, words and letters in her favorite books. This realization made me very sad, knowing how much she valued books. I could see her frustration as her sight diminished to the point that she could not see the print or pictures very well anymore.

I listened to the vision teacher’s recommendations to work on pre-braille skills with her hands. I sought out a place to take courses in braille. Fortunately, I found a community college program that offered braille classes in an adult education program. (The university programs that offered braille instruction in my state were much too far from where we lived. There were no distance learning programs back then.)

I learned about the braille “cell” and was absolutely amazed. A teacher from the Hadley School for the Blind in Winnetka, IL, loaned me an old, used Hall Brailier and an old textbook that became my bible. Between assistance from the Hadley School for the Blind, Cara’s vision teacher and the community college classes that I took, I was able to read and use Grade 1 and beginning Grade 2 braille. Meanwhile, Cara was learning to identify and discriminate some braille alphabet letters tactually. Her classroom teacher was very helpful and gave me braille paper to use, explaining what alphabet letters she was working on. I would observe the teacher working with Cara in the classroom so that I knew what to work on at home. I have to commend this classroom vision teacher because she spent a considerable amount of time, explaining about braille, how she was going to introduce it and teaching me some basics at the same time. She told me that her “resource” classroom was

a resource for parents also. To this day I am thankful that the teacher, who was very young herself, had the awareness that the parent needs to learn about braille and teaching methods if the young child is to succeed.

I remember making sheets with lines of braille “a’s” and an occasional “b” which Cara had to locate. We did this with the other alphabet letters also. We would practice over and over. After we completed the worksheets, she would get to choose a favorite storybook that I would read to her.

At this time, Cara was not really interested in learning to read braille. She was now in the vision resource classroom for half of the day and a kindergarten classroom for the other half. She was the only student with a visual impairment in the class. She began to notice that she was different than other children. Even though she could identify the braille alphabet letters, she wanted to read “print” like the other children in her kindergarten classroom. She had memorized many of her storybooks and used to pretend to be reading them out loud when people were around. She convinced family members and friends that she could read large print (even though she was totally blind by this age).

Even at five years of age, she was becoming aware that she was somewhat different than the other students because she could not access print by reading and writing visually as they could. She was becoming angry in school, although I was not aware of this. She began to have temper tantrums in school, pushed the other children away if they wanted to be her partners and called the school bus driver “stupid” on several occasions. On her class picture she was the one sticking her tongue out instead of smiling. The school principal began to suggest that we should consider family counseling, which we did. Through our weekly sessions, I realized that Cara was angry inside because she perceived herself as different. As she was able to work through these issues through “play” situations and since I became aware of her hidden feelings, I learned how to discuss this issue with her, explaining that it was alright to be a person who is blind. I really felt that learning to read in

braille might be a key to her overcoming her anger and frustration due to her vision loss.

Fortunately, Cara's love of books and her intelligence won the battle with braille. Even though she didn't want people to notice her reading braille books, she couldn't keep her hands off the braille books she had. In the early elementary grades, she used to hide braille books in her desk and read with her hands inside the desk. By the time she was in third grade, however, her fellow classmates had already gotten used to the sound of her Braille, they had already explored her braille books, the novelty of her cane had worn off, and Cara' began to place her braille books on top of her desk as she read effortlessly and without embarrassment. Through the National Library Service for the Blind and Physically Handicapped (NLS), Cara was able to get books in braille and audiocassette delivered to our local library. She devoured the books, and her reading skills increased rapidly.

As Cara's braille skills increased, I also continued studying braille. In the early years, I had to help her with her homework by monitoring and proofreading her braille answers and tutoring her when she needed assistance spelling words. It was very fortunate that I found the classes, instructors, professionals, and mentors who helped me as I struggled to learn braille.

When Cara was in middle school, she had long since surpassed me as a braille reader and writer, and I didn't need to monitor her school work in braille anymore. As her braille literacy skills improved, mine slipped because I wasn't using them as I had in the past. One summer during this time, Cara had the opportunity to attend a two-week summer camp, Camp Lions, for children who were blind or deaf. She absolutely did not want to go because she had never been away from home for such a long period of time. I promised her that I would send her a brailled letter every day so she wouldn't feel lonely. After reading my letters that arrived at camp each day, Cara would pass them around the campfire for all to read, and her fellow campers would laugh hysterically over my misspelled or poorly written words.

Because she could read and write so rapidly in braille, Cara became an excellent student, getting top grades in all areas. In contrast, a friend of Cara's at school who was visually impaired and a dual-media reader had a more difficult time with reading. Debbie read print very slowly and sometimes suffered intense headaches after completing her homework. She learned to read braille for "recreational" reading, since her eyes bothered her too much to read print by the end of the school day. The same resource room teacher who helped Cara and me had the foresight to teach Debbie to read braille and print. Eventually, Debbie relied more and more on braille as her sole reading medium.

Because of Cara's excellent grades and her knowledge of braille, she graduated from high school with high honors, receiving several scholarships. She went on to college, graduated with high honors, and attended graduate school, acquiring a law degree. The opportunity to learn braille at an early age helped her to develop the academic skills she needed to be a successful student later in life. Braille was the key to literacy for her and helped to "level the playing field."

As Cara's experience illustrates, the decision regarding whether or when to introduce braille to children can have a great impact on their literacy and their future academic successes and employment opportunities. By talking to our children's ophthalmologists and low vision specialists, teachers of students who are visually impaired, and classroom teachers, we parents become a part of our children's educational team and are able to help make decisions about the relevance of braille as a reading medium for our children. Now more than ever, we, as parents, must be aware of the importance of braille to children who are blind or visually impaired.



In 1829 the first written book was published in braille



Illinois Health Care Coverage Options and Benefits Information for People with Disabilities



Illinois Health Care Coverage Options and Benefits Information for People with Disabilities

September 20, 2016

Doubletree Hotel | 5000 W. 127th St. | Alsip, IL 60803

AGENDA

8:00 - 8:30 a.m. Registration

8:30 - 8:45 a.m. - Welcome & Introductions:

- Tony Paulauski, Executive Director, The Arc of Illinois
- Faye Manaster, Project Director, Family-to-Family Health Information Center/Family Voices of Illinois

8:45 - 10:15 a.m. - “Update on Illinois Medicaid for Children and Adults”

Presented by Stephanie Altman, Assistant Director of Health Care Justice, Sargent Shriver National Center on Poverty Law and Erin Weir, Manager of Health Care Access at AgeOptions

10:15 - 10:45 a.m. - “Illinois Medicaid Redetermination Project”

Presented by John Spears, Bureau Chief, Bureau of Eligibility Integrity, IL Department of Healthcare & Family Services

11:00 a.m. - 12:00 p.m. - “Understanding SSI, SSDI and Medicare”

Presented by Sherri Schneider, Family Benefit Solutions, Inc.

1:00 - 1:45 p.m. - “Your Healthcare Rights”

Presented by Andrés Gallegos, Attorney, Robbins, Salomon and Patt, LTD

2:00 - 3:00 p.m. - “Making Health Coverage Decisions”

Presented by Kristin Hartsaw, Director of Training and Technical Assistance and Kathryn Nelson, Program Director for Public Benefits Access, DuPage Federation on Human Services Reform

3:00 - 3:30 p.m. - “Healthcare Advocacy and You”

Presented by Tony Paulauski, Executive Director, The Arc of Illinois
Questions, Discussion and Evaluation

There are 5 CEUs available for professionals
Financial Assistance if available for those who need it
If you have any questions, please call our office at (815) 464-1832



By Hillary Kleck

It's That Time of Year!

Going back to school after a fun-filled summer can be exciting for your child, but it can be a lot of stress and anxiety for you! For you, "back to school" means filling out endless forms, rewriting your child's complete medical history for the millionth time, preparing for the dreaded IEP meeting soon to come, and the knot in your stomach for the long list of *still* unanswered questions. Or, maybe you're one of the lucky ones who feels organized and confident this year and the unknowns simply lie in what will come... "What will the new teacher be like? Are the therapists going to work well with my child? How will his classmates behave around him?" *Read more at <http://www.wonderbaby.org/articles/back-to-school-resources-for-blind-kids>*



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. *Read more at <http://www.wonderbaby.org/articles/transitioning-to-preschool>*



Printable IEP Organizer

"Wait... Our IEP is when? And you need documents from me by this Friday?! How'd this sneak up on me again???"

Does this sound like you? I do pride myself on being an organized person, but when it comes to some of my son's medical and IEP paperwork, I must admit that my sorry excuse for "organized" is, "Oh, that goes in this big box here. Just throw it in. Done!" *Read more at <http://www.wonderbaby.org/articles/printable-iep-organizer>*

Reprinted with permission from *WonderBaby.org*, 175 N. Beacon St., Watertown, MA 02472

Please contact IPVI to see if you are up-to-date on your dues at
1-773-882-1331
Email: ipvi@ipvi.org
www.ipvi.org

IPVI

P.O. Box 316634, Chicago, IL 60631

1-773-882-1331 • Email: ipvi@ipvi.org • www.ipvi.org

PRESIDENT

Filiberto Almendarez III
5323 N Delphia Ave #124
Chicago, IL 60656
(773) 693-5713
falmendareziii@yahoo.com

OPERATIONS VP

Joan Bielawski
421 Applegate Court
Naperville, IL 60565
(630) 357-8576
wjbielawski@yahoo.com

SERVICES VP

Mary Zabelski
6153 N. Nettleton Avenue
Chicago, IL 60631
(773) 882-1331
maryzabelski@hotmail.com

TREASURER

Filiberto Almendarez III
(Temporary)

SECRETARY

Dawn Wojtowicz
9188 161st Place
Orland Hills, IL 60487
(708) 590-6447
deeder0477@aol.com

NAPVI REGION 3 REPRESENTATIVE

Pam Stern
1912 Mission Hills Lane
Northbrook, IL 60062
(847) 217-7590
pamstern3@gmail.com

SPANISH TRANSLATOR

Noelia Gamino





Join **IPVI** or renew your membership today!

The *Illinois Association for Parents of Children with Visual Impairments* is a state-wide, non-profit organization that enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities.

Your IPVI membership dues or generous contributions help to support all of our ongoing efforts:

- Regular communications which include: workshops, conferences, training seminars, legislative issues, organizational announcements, products, and advice about raising a child who is visually impaired.
- Offers several \$500 college scholarships each year.
- Publishes a resource catalog which includes anything and everything to do with visual impairment.
- Conducts training and support sessions where parents share experiences and ideas.
- Holds fun outings adapted for children with visual impairments at athletic, cultural, educational, and entertainment settings.
- Represents parents of children with visual impairments at conferences, public hearings, and on committees.

What does IPVI do?

- Promotes and provides information through meetings, correspondence, publications, etc., which will help parents meet the special needs of their children with visual impairments.
- Facilitates the sharing of experiences and concerns in order to provide emotional support and relief from feelings of isolation for parents and their families.
- Creates a climate of opportunity for children who are blind in the home, school, and society.
- Fosters communication and coordination of services among federal, state, and local agencies and organizations involved with providing services to people who are visually impaired.
- Advocates on a statewide level for services to children who are visually impaired and their families.
- Keeps members informed about current proposals and actions which impact on children with visual impairments and their families.

Check one:

Parent/Guardian Membership: \$15 per year.

Child(ren)'s Names: _____

Birthdate(s) of my visually impaired child(ren): _____

My child(ren)'s eye condition: _____

I give my permission to release my name to other parents.

Group/Agency Membership \$50 per year.

Extended Family/Friend Assoc. Membership \$15/year.

Medical Specialist \$50 per year.

Scholarship Fund \$10.00

Donation: \$ _____ (tax deductible)

New Membership

Renewal

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (_____) - _____

Email: _____

Please enclose this form along with your payment by check to:

IPVI • P.O.Box 316634 • Chicago, IL 60631

**Have questions or need
more information?**

**Call us at
1-773-882-1331**

**Illinois Association for Parents of
Children with Visual Impairments
P. O. Box 316634
Chicago, IL 60631**

IPVI CALENDAR

- ▶ **9/7 Paralympics**
- ▶ **9/20 FRCD Illinois Health Care Coverage Options and Benefits** **Alsip**
Information for People with Disabilities

Please call
1-773-882-1331
for any questions, concerns,
or comments that IPVI can
help you with.

**Newsletter Deadline for
October is September 15**



**Check Out
www.ipvi.org**

Calendar of Events!
News and Updates!
Useful Links to Web Sites!
And more...