



# In Touch

## From the President's Pen



I am reminded all the time through the good people who give their time to help others. Since joining DBMAT in 2004, I have witnessed this organization come together and make changes in our Government to benefit the lives of our children, siblings, grandchildren, and friends who are deafblind. DBMAT has proven to be a strong leader not only representing Texas, but known for our advocacy efforts around the United States. I truly am proud of all of you.

As we look toward the future, the reality is that we will always need to keep our advocacy work as a priority. This Legislative year, we have already had members testify in Austin. There will be times when the legislative committee will plea for members to make a call or even testify.

Remember that each one of us can make a difference.

I am looking forward to a great year. Yes, I know it is already April! And looking forward to seeing you at camp this year!

## Important Dates – Mark Your Calendars

Annual DBMAT Conference at CYJ, Wimberley TX. **September 18-20 2015.**

Annual DBMAT Christian Knapp Memorial Golf Tournament **October 23<sup>rd</sup>, Friday 1:00 p.m.**

Melanie

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## ***DBMAT Camp at Camp Young Judea in Wimberley Texas***

*By: The Hartman Family*

This was our first year at camp Young Judea. We were very impressed with the beautiful grounds and the nice facilities. The food was good and we loved the salad bar. They also had a great playground that was very accessible!

There seemed to be more options for activities for the kids and we loved the swimming pool area. All the kids that swam and rode the cool water slides looked like they had a GREAT time!

Our family really appreciated having the parents meeting hall right next to the cafeteria. This made it very easy to join our children for mealtimes.

The meeting sessions were very good and always full of great camaraderie.

The DBMAT Board positions that were up for election were elected as follows:

Secretary: Denise Sewell

Member-at-Large: Gina Sotiropoulos

Member-at-Large: Robbie Caldwell

Member-At-Large: Christine Givens

We are looking forward to camp next year!  
And looking forward to seeing you there :-)

*Jaceson Welch & Gloria at Camp CYJ-2014*



*Chris and "Sis" Kaylina Hartman at Camp CYJ- 2014*



## ***That "Vision" Thing***

*By: Stephen Schoen*

It has been said (by the Bible and the New York Times) that "without vision the people perish." The same statement about the need for vision can be said for organizations. DBMAT realized it needed a vision at a Board meeting in 2006. I happened to be there and it was an inspiring moment. The vision which can be seen on our website says in part, "When [intervener](#) services are provided from the age of diagnosis, the person who is deafblind multihandicapped is most likely to develop to their full potential with an abundance of "Moments of Joy."

After making this broad vision statement the Board of DBMAT acted to ensure that this vision would become reality by setting some goals. The first goal was to make a career ladder within the Deafblind Medicaid Waiver for the interveners who work

directly with deafblind children. This goal was achieved when Texas Senate Bill 63 was signed into law by the Governor in 2009. The second goal was to modify the Deafblind Waiver so that children who were deafblind could receive services (instead of having to wait to age 18.) This goal was also achieved when the Governor signed Senate Bill 37 into law in 2009.

Since the time of these bills, vision remains, but I sometimes think people don't know they can have an active role in achieving it. Most people who are reading this newsletter can help achieve the vision in some way. Here are some hints as to what you might do:

***If you are a parent of a person who is receiving services through the DB-MD Waiver.***

- 1) Be sure you have intervener services picked for your child when you write or amend the annual plan of care. The more hours of skilled intervener services your child receives, the more likely they will achieve maximum independence and satisfaction in life.
- 2) Be sure your intervener gets training so they can move up the career ladder. Unless your intervener knows best practices, the services they provide won't help your child all that much.
- 3) Insist that your intervener gets training using the DBMAT scholarship which will pay full costs if need be.
- 4) Even if your child is in a DBMD 24 hour assisted living home or apartment, you need to be sure they receive the maximum hours of skilled one on one intervention which is available to them. This is the way their individual needs can be addressed.

***If you are a parent of a child in school:***

- 1) Be sure you advocate in your child's ARD meetings for intervener services. This can make the difference between a meaningful school experience and sitting in a corner with no stimulation.

- 2) Your child is eligible for DBMD Waiver services as well as school services. This way an intervener can help with home and community skills. Make sure your child is on the interest list or enrolled.

***If you are a provider of deafblind services:***

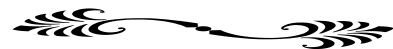
- 1) Be sure you add the service of intervener for all your deafblind clients, even those in assisted living.
- 2) Be sure your interveners are trained properly so they can move up the career ladder. Their salary will increase as will your rate.

***If you are an interested party or advocate you can do the following:***

- 1) Help us raise money to keep the DBMAT intervener scholarship fund available for all who request it. Convince your friends to play golf at the Annual Christian Knapp Golf Tournament. Or, just send money by clicking here: <http://www.dbmat-tx.org/donate/donate.php> Or send this link to your generous friends.
- 2) If you have connections with higher education, help us set up a Texas based intervener training program.

***If you are a deafblind person who is reading this newsletter:***

**CONGRATULATIONS:** The fact that you are reading this newsletter means that somewhere in your life you used your initiative to gain independence and communication skills. We'd love to hear from you. You are the reason DBMAT exists.





## *A letter From an Intervener*

*By: Morgan Stasny- Lauren Daley's Intervener*

*As our time with Lauren's intervener, Morgan, is coming to an end so she can pursue her college education, we asked her to share her thoughts about her journey in our deafblind community. We believe what appears to be "luck" is preparation meeting opportunity. We were confident that if we seeded our town with information about intervention and deafblindness, we would prepare the right person to be ready to join our journey when the opportunity presented itself. Morgan is one of those people! We are sending her out into the real world with the love and confidence of her biological parents. Thank you, Morgan! XO PCLEJ (the Daley Family)*

Six years ago, when I was just in seventh grade, I was lucky enough to enter the deafblind community. I began working with Lauren Daley as a babysitter after Caroline saw me in a nail shop, signing to my friend. I was already aware of Lauren's story because the Daleys had come to our school to talk about interveners and deafblind individuals. Since then, I have seen and learned so much that I have gradually worked my way up from a babysitter into the position of Lauren's intervener. I feel like I have gotten to experience more things and been given far more opportunities than anyone my age.

Probably my favorite experience has been taking Lauren to Camp Summit and DBMAT camp, both of which were life changing experiences for Lauren and me. Being given the opportunity to watch a child who can neither see nor hear thrive, make friends and have a normal summer camp experience is without a doubt the most joyful experience you can imagine.

The Daleys consider me a "homegrown" intervener. That idea may be confusing, so let me explain. Over the years, Caroline and Paul Daley have put their time and money into my education as an intervener. They have brought highly trained interveners from Canada to observe Lauren and me working together. Those interveners have given me ideas and taught me how to be a better teacher for Lauren. The Daleys also enabled me to learn braille so that I may teach it to Lauren. Most of all, they have helped me realize my passion and purpose in life. I will forever feel blessed to have been a part of

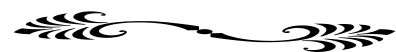
the "Lauren Team" and have made a difference in Lauren's life and education.

When I say "Lauren Team", I truly do mean "team". It takes parents, educators, interveners, extended family and helpful people in the community to truly do everything it takes to give your child the education and life that they deserve. In less than three years, I have watched Lauren go from understanding and signing very little to understanding most of what we sign to her and signing hundreds of words while learning to read and write braille. None of this would have been remotely possible without a "Lauren Team" that was willing to do everything it takes.

Parents, if there was one piece of advice I could give to every other family with a deafblind child out there it would be if you have not already, learn to sign! Communicate with your child! Hire an at home intervener, trained or homegrown, because they will give your child the opportunities, communication and education your child needs to be able to thrive and become part of society. It is possible. Lauren Daley is living proof.

Although I feel that Lauren has taught me more than any four year university ever could, I will be starting Texas Tech University next year. I will not forget the Daleys or the deafblind community who have helped me on my journey to become a successful intervener. I want to come back after getting an education with more ideas and a better skill set to help serve Lauren and the deafblind community. Thank you! Morgan Stasny

*Lauren and Morgan*



## *Finding an Intervener*

*By: Suzie Welch*

One of the most frustrating things I have experienced is trying to find an intervener to work with my deafblind son, Jaceson. In Texas there are not very many trained interveners. The providers offer to help but as a parent you know the needs of your child best. You know you will need that someone special who is ready for a challenge and has lots of patience! You have to be able to trust this person because they are going to be taking your child /adult out into the community. There are a lot of places to look in our communities for people to work with your son or daughter such as colleges, churches, word of mouth, and asking friends. The list goes on and on but it is still difficult to find that person. Then when you find someone, there is the challenge of teaching them how to work with your child/adult. You have to think up ideas of what they can do during the day. We live in a small town so there aren't a lot of places to go or things to do as there is in a big city. You have to really be creative. You do not want your son or daughter sitting all day being bored and adding behaviors.

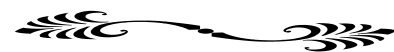
We as parents are going to have to give the providers a small push to get the individuals who work with our deafblind children/adults to take advantage of the on-line intervener training courses.

DBMAT has scholarships for interveners to take these courses and learn better ways to work with our children. This can also aid them in achieving a higher pay rate on the intervener career ladder on the DBMD Waiver.

We looked for someone to work with our son for several years. Finally, this year we found a young woman, Amanda, who was working with special needs individuals at Special Olympics who was interested in our son. She could sign too! It took us several months to get her hired and the special training she needed but she is now working part-time with our son and he is so happy. She is taking the on-line course for the intervener so she can improve her skills and make more money on the intervener career ladder. The intervener has worked with Jaceson to improve his self-help skills, paint, exercise, swim and go out in the community. One day she even took him to the pet store and he got to hold a lizard! He goes to the mall to the guitar store and gets to play the guitar.

He gets to experience things that normal sighted and hearing individuals take for granted. We were so lucky to find someone for him, but we know that it will be an ongoing challenge to find and keep interveners to work with our sons and daughters in the programs. We are going to need to get more people trained in Texas. But don't give up hope. There is a "Special Person" out there to work with your son or daughter. Just keep looking!

*Jaceson and his new intervener, Amanda*



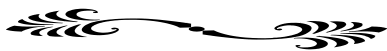
## *AVIT Working on Legislative Issues*

*By: Nancy Toelle, AVIT*

*(Editors Note: We asked Nancy to provide some information regarding key Legislative issues this year.)*

Representatives of AVIT, the Alliance of and for Visually Impaired Texans, have made several visits to the Capitol regarding the Sunset Commission recommendations regarding services for blind and visually impaired children and adults. They have visited the offices of the state senators and representatives who have sponsored bills, or who will be sitting on the committees that conduct hearings, to provide information about the unique needs of this low incidence population. Our message to all

legislators is to “**keep blindness services together**” as we fear that separating them into two or more agencies will result in a loss of service and/or less effective services. **At the current time, it looks like blindness VR services may be moved to the Texas Workforce Commission.** If that is the case, then we propose that the Blind Children’s Program, Criss Cole, and Independent Living Services go too. We have testified at one hearing and provided written testimony at another. Two young DBMAT members testified before the House Committee on Health and Human Services. They did an outstanding job and engaged the committee members in a back and forth question and answer session. Their moms were equally well spoken. We are waiting for the bills that specifically address those services to return to the Capitol. We appreciate the support of DBMAT and the many other membership organizations who are stepping up to address these bills. Nancy Toelle, AVIT Chair.



## *Testifying at the Capital*

*By: Kim Huston*

*(Editor Note: Kim and her daughter Amanda stepped up to the plate to testify at the Legislature regarding moving Division of Blind Services Programs. The following 2 articles tell their story)*

I went to the capital with my daughter. It was my first time there. My family and I moved to Austin a little over a year ago. We wanted to become more involved with the deafblind community here since my daughter graduated from the school for the blind in 2013.

I have been waiting for the chance to go and testify. I was on a phone conference the night before with people who do this all the time so I felt somewhat confident. I read the sunset bill and I am against it. I believe that DARS/DBS would suffer greatly if this bill passes. We all know who would really suffer, our loved ones. So I decided this would be a good time to jump in and try to do my part.

When we got there we had to park a block away. You would think with our governor being in a wheelchair himself he would be more considerate of that fact. We finally got in the building and my daughter’s wheelchair through security. We met up with our group in the cafe and decided to split up into two groups to cover more ground. We went to different congressmen’s offices and plead our case. My daughter thought this part was boring. I enjoyed meeting some of them; others seemed indifferent to our being there.

Finally after lunch it was time for the hearing. We all signed in on a computer noting: your name, if you were for or against the bill and if you would be testifying. My daughter wanted to testify. I was not so sure. I thought I would watch the others who have done it before and maybe wait and testify next time. To be quite honest I felt a little intimidated by the whole process.

When we got in there and were seated we waited for a while. My daughter, being deafblind, had an interpreter with her. This woman is an awesome interpreter and she volunteered her time to do this. I felt even more nervous the longer we waited. The committee came in and the hearing came to order. We sat and listened to the first people to go, they were part of our group. They gave their testimony and then the questions started. Some of the things that were being said made me realize that half the people on the committee did not know or have a special needs person in their life. That is when I knew I could not let these people make a decision that would affect my daughter and others like her without giving my testimony. The longer I listened I learned most of the committee did not understand the effects this would make to DARS/DBS consumers. That is when I felt empowered.

We were next. My daughter went first and did very well. They ask her some questions and she gave good answers. Then it was my turn. I was a little nervous but not intimidated anymore. I knew that I probably understood what this bill would do better than some of them and I was going to enlighten them.

I think I did a good job, considering it was my first time to give testimony. I know I will do better next time. Now I have confidence. Do not let them intimidate you. You know what your loved one needs far better than anyone. It is up to you and her, if she is able; to fight for what is right.





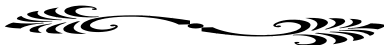
*Here's Amanda Huston chilling at home after testifying*



### *I Testified at the Capital*

*By: Amanda Huston*

Hi, I testified because I do not want DARS to be separated. That would be hard on people like me because they have specialized people to help me there. I do not think the workforce could help deafblind people as well.  
The capital is big and loud but I was not scared at all. I have been there before but not to testify. I knew I needed to testify to advocate for myself and other deafblind people who can't. I liked speaking and will do it again when I can, I am at ACC fulltime and very busy.  
Those of you who can, please go to the capital and testify. Deafblind power!



### *We Walked The Halls*

*By: Jacqueline Izaguirre*

My daughter and I walked the halls of the Capitol  
We were armed with just our story, that's all.  
We had others guide us through the day  
As we traveled to any office willing to hear what  
we had to say  
We just wanted to ask them all to think about our  
need  
They could see our faces and hear our plea.  
Patsy stood brave and told her story  
I was very proud and saw that I need not worry.  
We hope that our words fell on listening ears  
And that it was worth overcoming our fears.  
As stakeholders we should speak out  
We can give them a face to think about.

*Patsy Izaguirre Walking the Halls in the Capitol*



## *Patsy's Story*

*By: Patsy Izaguirre*

Hello, my name is Patsy Izaguirre. I am deafblind and 27 years old.

We went to the Capitol in Austin to ask legislators to keep blind services together so that blind children like me could get the same services that I got as a child.

I had the DARS people to help me to do everything.

I had DARS people come to my ARD meetings when I was still in school.

After school, Tanya helped me get training at the Helen Keller National Center in New York.

Rick helped me to go to independent living training in Waco and Kathy help me to get equipment to start a Braille business to do tasks like Braille the menus for the restaurants.

DARS has helped me a lot.

It is important that other blind and deafblind children get the same services as me so we tried to talk to many people working in the Capitol.



## *Editor's final Note*

*By: Stephen Schoen*

This was our first "online edition. DBMAT is saving a considerable amount of money by avoiding print and mailing costs. (We are also saving trees.) That money will be better spent providing intervener training for as many people as possible. If you are having any problems with this online edition, please send an email to:

[webmaster@dbmat-tx.org](mailto:webmaster@dbmat-tx.org)

Our conference edition of the newsletter should appear in a matter of months.