



# *In Touch*

*The Newsletter of the  
Deafblind Multihandicapped Association of Texas  
Spring 2014*

## ***Passing the Torch***

This is not goodbye, because we will still be around to continue to help from the sidelines. We would like to thank each of you for the opportunity to serve as DBMAT President for the past ten years. We started out not knowing very much about what we were to do, but had excellent mentors in parents, board members and professionals who helped us find our way and keep DBMAT out there. We couldn't have done it without your help!

One of the biggest things we learned is about the legislative process and how our voice (DBMAT) could make a difference. It made us realize that our legislators do listen to what we (parents) say. We are the voice and advocate for our children/adults who are Deafblind and we need to make sure our voices are heard loud and clear! We, as parents, can make a difference!

Thank you...each of you...for all your help. And, Thank You Melanie Knapp for taking over as President. I know you will do a wonderful job guiding DBMAT. Love, Paul, Susie and Jaceson

## ***From the (New!) President's Pen***

Hello all and Happy Spring! As many of you know, Paul Welch ended his 10 year position as President of DBMAT in October of 2013. I have served as Secretary, Vice-President, and now my current role as President. We have been so fortunate to have Paul, Susie, and our Ambassador Jaceson lead and represent us over these last years!

Gary and I have known the Welch's for quite a few years. Jaceson is a year older than Christian. It was Paul who brought us into DBMAT in 2004. Gary and I have been married for almost 38 years and have 2 boys, Landon and Christian. Landon is married to Christi and they have 2 children, Taylor, age 8 years, and Ethan Christian, age 3.

Christian was already an adult when we joined DBMAT. We had such busy lives...like most of you.....and we didn't know at the time that joining DBMAT would be one of the most important decisions we ever made.

We were still "new" to DBMAT when Christian passed away in 2005. Our whole world fell apart. There are no words to explain our pain. Suddenly, there was nothing that made any sense. For 25 years our family lived in Christian's world of deafblindness. In a matter of a few minutes, everything had stopped.

Christian had already been nicknamed "The Great Motivator." Meaning that he had motivated Gary and I to fight many battles for Christian in our school district, because at the time, there were NO intervener services. Ultimately, Christian won. I was passionate about the Intervener model; frustrated that Interveners were not even an option for deafblind kids; and I knew that Christian's story with his Intervener, Ann, could make a difference. I also knew that Christian would want me to help others. Gary and I are so very grateful for DBMAT's support over these past few years.

As President of DBMAT, I will continue my commitment to improve services for our deafblind children and adults. Hats off to a great 2014!

Melanie Knapp

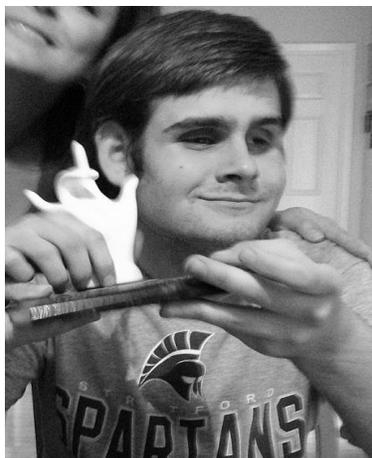
**Awards presented at the DBMAT Family Conference  
2013**



**Cyril Miller**  
received the  
**Everett Bryan Award**  
given to  
Professionals  
who go  
Above & Beyond  
In their work with  
people with  
Deafblindness.



Sherian Dayton  
accepts the  
**Olivia Cruz Award**  
on behalf of her  
sister  
**Mary Smith**  
for her dedication  
and efforts on  
behalf of persons  
with  
Deafblindness.



**Christopher Hartman**  
received the  
**Christian Knapp  
Award**  
for being a  
great motivator to  
Deafblind people.

# Tribute to Pat McCallum

By David Wiley

Past DBMAT President and Executive Director Pat McCallum passed away on August third, 2013. She was one of DBMAT's original founding members, and was involved in the leadership of the organization for almost 30 years.

During the early years of the 1970's Pat provided the energy and commitment to help keep DBMAT moving and growing. She was also an active member, leader, and officer during the early years of the National Family Association for Deaf-Blind (NFADB). For her years of dedication, Pat received the prestigious Ann Sullivan award from NFADB.

We remember Pat as a tireless and uncompromising advocate on behalf of her son Jon, and other children with Deafblindness all over Texas. Her efforts with policymakers helped bring about and expand programs such as the DBMD Medicaid Waiver. DBMAT will always be grateful for her many accomplishments.



## Thoughts from Norman McCallum and the McCallum Family

Our family is honored that DBMAT has chosen to acknowledge the decades of work and care that our mother, Patricia Joan McCallum, dedicated to persons deaf-blind multihandicapped and families. Her involvement in DBMAT began as a caring parent seeking answers and assistance for her child and evolved into a life of advocacy for others.

As one of the founders of DBMAT, she found friendship, love and joy as she fought the good fight. She remained steadfast in her determination to help create a higher quality of life for persons with disabilities and their family members and, with help from caring people like you, DBMAT was able to accomplish much. She celebrated and enjoyed remarkable people, including many of you.

In her last years, Mom remained happy that DBMAT continues to be a viable organization with purpose. DBMAT outlived her. That's what she wanted. With your help and dedication, DBMAT will continue to serve families and professionals and accomplish more than even my Momma could imagine.

You are not alone. That's a beautiful thing. Look around the room and you will see remarkable people, parents who make a difference, professionals who have dedicated their entire careers to serve you and your family, friends, friends for life, partners in a common cause. Now may be a time to take a deep breath and claim a moment of joy and gratitude. Smile at your neighbor. Hug somebody. Say thank you. You are not alone. You are family. Family matters.

Thank you so much for remembering Patricia McCallum with respect and fondness. She cared about all of you, even if she never knew you. You were, and are, family.

*Thank you.*

## A Transition Story

By Wayne Thompson

As many of you all know, our son Caleb was hospitalized with pneumonia at the end of October. During this time, the doctor decided that it would be best to do a tracheotomy. We thank you all for your prayers and concerns for Caleb and our family.

Over the years we have been to countless conferences and workshops. Transition is usually one of the topics discussed. We thought we were pretty well informed about the changes that would transpire when Caleb turned eighteen. The changes that took place in the hospital were surprising to us, even though they probably should not have been.

We were in the process of changing from pediatric doctors to doctors for adults. We had a pulmonologist that had only seen Caleb one time for a consult visit. Thankfully, Dr. Strong—who has been Caleb’s primary care physician since he was a baby, remains his doctor even though Caleb is no longer a pediatric patient.

Caleb was in the CCU (Critical Care Unit) for about two weeks after the tracheotomy. We had a very capable RN in CCU that told us she was “out of her comfort zone” with Caleb as her patient. It has been common over the years for doctors, nurses, therapists, and the general public to be intimidated by Caleb’s condition. We experienced this throughout Caleb’s entire stay in the hospital. The hospital was under-staffed, which is typical; most of the staff were under-trained and felt uncomfortable caring for Caleb.

Again, this was not surprising to us...but what was surprising and shocking to us, was the lack of follow up from the surgeon and the pulmonologist. When we left the hospital, we were pretty much on our own unless we took the initiative to make the call when we had questions or concerns about his continued care for his trach at home.

When Caleb was a pediatric patient, there was extensive training before we went home from the hospital. Follow up appointments were made prior to leaving the hospital. We would even receive calls from our doctor’s office staff or even the doctor once we were settled back in at home.

Another issue with transition that we have noticed is that we, the parents of Caleb, no longer receive mail from agencies of the state. Since Caleb turned 18, the mail is addressed to him. This is understandable, but when they call on the telephone and ask to speak to Caleb, that concerns us greatly. Caleb has been a client of Medicaid and TMHP for 16 plus years. You would think that they could glance at his records and see that he is deaf, blind, and non-verbal. What else do they not know about Caleb? In this high tech world the information should be available at the touch of their fingers!

Oh, well...I guess I really did not realize what all changes when our children “transition” into adulthood.

Just a short report on Caleb...He is doing well. He is adjusting to his trach. It is easier to suction him. We no longer have to put a mask on his face for breathing treatments or use a CPAP while he sleeps. He doesn’t seem to have as much GI distress as he used to, and surprisingly to us, his seizure activity has almost ceased since his procedure.

We thank God for Caleb’s recovery and for Dr. Strong who has been our rock throughout his illness.

# DBMD Guide

by Jillana Holt-Reuter

Hi there DBMAT Family and Friends,

I hope y'all are mightily into your new year full of energy, health and have many adventures planned. I know that the Reuter household has a few adventures planned for 2014 to keep our juices going and keep our thrill seeking gal happy! Maybe we will see you at one of the many events throughout our state!

September of 2013 was a very special month for DBMAT, as the first person under the age of 18 received services through the DBMD (Deaf Blind with Multiple Disabilities) waiver due to the addition of 100 slots to be added over the next 2 years. This makes a group of DBMD Waiver-specific services available to younger individuals who are Deafblind, whereby improving their quality of life throughout their lifespan and enabling them to lead more independent lives and accomplish their dreams and goals, whatever they may be. This doesn't mean that if these services are offered later in life, that they have little or no value, but the data tells us earlier is better for their life overall. We are well on our way to seeing lives change here in Texas because of improved service arrays, increased quality control and individuals seeking services in waiver programs having access to these services, much sooner than before.

I try to stay in "the know" as best I can about the issues and needs of our families, and also, what the State needs to hear from us, so we can give them better feedback. Since there is a growing list of people coming to the top of the interest list for the DBMD waiver, I have received calls from parents asking my insight about the waiver and our experiences being on the waiver for the past 6 years. I love talking with families and I never mind them calling, but I became inspired to get a prep list together of things you can be working on prior to your family members' name coming to the top of the DBMD interest list. This is also good information for you if you have a family member currently on the DBMD waiver!

This is by no means meant to be inclusive, just the thoughts of a mom who wants to try and smooth the road for families a bit.

1. **Gain knowledge of the different waiver programs so you can compare your current services to the DBMD waiver services.** Some services are unique to the DBMD waiver and adaptive aids are rather amazing! Knowing what is available is a great place to start to see if you think this is a good waiver for your family member. Who knows, you may find a waiver other than DBMD to be more appropriate. Having choices is such a great dynamic to have when making these difficult decisions.

Here is the web address: [http://www.dads.state.tx.us/providers/waiver\\_comparisons/LTSS-Waivers.pdf](http://www.dads.state.tx.us/providers/waiver_comparisons/LTSS-Waivers.pdf)

*Waiver programs comparison chart \*\* This was included in your folders from the DBMAT 2013 Conference along with DADS Waiver Update from Kathi Montalbano from DADS. \*\**

The program manual might help you also when you compare adaptive aids and other services. This information is in the waivers' handbook.

DBMD: <http://www.dads.state.tx.us/handbooks/dbmd/>

All other handbooks can be found at the main page here.

[http://www.dads.state.tx.us/news\\_info/publications/handbooks/index.html#handbooks](http://www.dads.state.tx.us/news_info/publications/handbooks/index.html#handbooks)

2. **See what agencies provide services in your area.**

Due to deafblindness being a low-incidence disability, not every region has providers set up in every county and there may not be one in your area at this time. DADS is actively recruiting providers for these areas and is working to make this less of an occurrence. If there is someone in your area, you might consider calling and seeing if one of the DBMD case managers would be willing to meet with you to discuss whether or not their agency would be a good fit for your family. I highly recommend this since your case manager will be your “go to” person for services and such and “interviewing” them isn’t a bad idea since they are going to be so involved with your family. Have a meaningful list of questions about the things that are most important to you or things you need to know more about compiled ahead of time so you feel more at ease and so you don’t forget to ask them. This one is a biggie for me! I forget that one question all the time!!

DBMD provider search Web address:

[http://facilityquality.dads.state.tx.us/qrs/public/qrs.do?page=qrsSelCounty\\_Zip1&lang=en&mode=P&dataSet=2&programType=4&dispatch=dbmdSelect](http://facilityquality.dads.state.tx.us/qrs/public/qrs.do?page=qrsSelCounty_Zip1&lang=en&mode=P&dataSet=2&programType=4&dispatch=dbmdSelect)

3. **Talk to others who have a family member on the DBMD waiver.**

Since the first minors are now being served through the DBMD waiver, only families with adult family members (over the age of 18) have hands on knowledge of services being delivered and we may not know all of the caveats of serving someone under the age of 18. These questions might be addressed by the person listed on your letter from DADS and there are people with TSBVI who can offer help, such as the wonderful Family Support Extraordinaire, Edgenie Bellah. Although we do have some pretty savvy family members out there, having more than one frame of reference is wise.

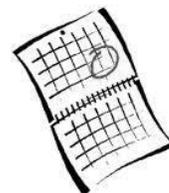
Edgenie Bellah - (512) 206-9423 - edgeniebellah@tsbvi.edu

I hope this very basic grouping of information helps you along the journey we all are on in providing the best care for our family members. It isn’t the easiest thing sorting all of this information out and I hope I gave you a good place to have a jump start from. Please feel free to share things you have learned too on our Facebook page about this process. We are in this together!!

Much love and success,

Jillana Holt-Reuter

“Life is either a daring adventure or nothing at all.” Helen Keller



**Save the Date!**

**Deafblind Week at Camp Summit is July 6th-11<sup>th</sup>, 2014**

Registration forms can be filled out online on their website. [www.campsummittx.org](http://www.campsummittx.org)

**Attention! The new date for DBMAT Family Camp is September 26-28, 2014**

Camp Applications will be mailed out in the summer with all the details. Hope to see you there!

**Christian Knapp Memorial Golf Tournament is Friday, November 7, 2014** at the Quail

Valley Golf Course in Missouri City, TX

Golfers are needed and welcome!!

Email Melanie Knapp ([rmkrn1@aol.com](mailto:rmkrn1@aol.com)) for more information.

## **“Open Hands, Open Access” (“OHOA”) Modules on Deaf-blindness By Vivecca Hartman**

In mid-December 2013, I went to the TASH Conference in Chicago, where I had the honor of presenting the “Open Hands, Open Access” (“OHOA”) Modules on Deaf-blindness. The OHOA Module is a National effort to assist in the development of content about intervention for students who are deaf-blind that can be adopted by Intervener training programs and others interested in learning about deaf-blindness! I am so honored to have been able to participate with Amy Parker, of the National Center on Deaf-Blindness (“NCDB”), and continue to help support the development and promotion of educational training for Interveners and anyone working with deaf-blind individuals. This is, of course, due to my personal experience as a mother of a 16 year old deaf-blind boy. We have spent many of our beginning years of having people with caring hearts in the role of Intervener, but not enough training. It was a major time loss for my son’s learning years. He was 10 when we experienced what it was like to have a trained Intervener. It was amazing and my son literally came to life!

I am dedicated to help spread and promote the need for quality education and training for Interveners; which the whole educational team would benefit from as well. When the whole education team understands the delivery methods needed for the deaf blind-child, the whole educational experience is enriched for the child!

It is every child’s right to an education, so deaf-blind children have that right as well. The point that took me so long to understand is that there is an established system in place for the majority of children that are “regular” education learners. However, due to the low incidence of deaf-blindness, with the dual sensory loss, here in the United States there has not been an established system in place where everyone knows what to do and how to educate deaf-blind individuals.

In addition, not every deaf-blind child is exactly the same, so you have to be savvy enough to know the various learning and communication techniques to work with each child to identify what works with them and then train their family so the efforts are not lost through time. It is the family that stays with the child life long, so they are a major aspect to the education of a deaf-blind child – not to mention the extreme importance of continuity between home and school when a deaf-blind child is first learning new skills.

These modules help establish a foundation to support wide spread access to information and training. Our families, children and communities will benefit from training!

It is important to be aware that these OHOA Modules do not currently lead to Credentialing for an Intervener. This is a work in process. When the modules are completed, they can be incorporated into Intervener Training Programs. In the United States, there are several training programs offered by state deaf-blind projects and online programs offered by universities. In my opinion, the modules would also be a particularly good fit for a 2-year college that also offered sign language classes.

Utah State University offers courses where students can become a Credentialed Intervener. These courses are wonderful and taught by Linda Alsop – who has been a major Leader in the development and promotion of the Intervener role in the United States! She also has great supportive material and information to share at [www.Intervener.org](http://www.Intervener.org) I recommend everyone review this site! There is also an online comprehensive certificate program at East Carolina University in North Carolina. It would be an ultimate system if the OHOA modules would be adopted by various community colleges across the nation, along with the other efforts in place (i.e. Utah and North Carolina). We could set a bar and allow the National credentialing to be accessible to many all over the Nation! This would lead to an established career and a recognized role for Interveners across the Nation!

Having a Nationally established “Intervener” role would be a wonderful foundation for a change that is needed in IDEA. IDEA currently states that “deaf blind interpretation” is allowed, but this needs to be formalized to include “Intervener” services as an available option of services to consider. With all the efforts to set the foundation of learning and the credentialing, there would be no reason not to allow for such wording in IDEA.

We just need to continue to promote and develop more wide spread training and credentialing opportunities nationwide to help the Intervener be a recognized and respected role!

## **Senate Bill 7: Landmark law to redesign health care and LTSS for people with I/DD**

(Reprinted with Permission from the Arc of Texas Website)

---

Governor Rick Perry signed SB 7, authored by Senator Jane Nelson, June 14. The new law means there will be sweeping changes to the system that provides health care and long-term services and supports (LTSS) to thousands of Texans with intellectual and developmental disabilities (I/DD). The first changes will come in September 2013. The full redesign will roll out gradually through 2020. In those seven years, there will be plenty of chances to evaluate and make adjustments along the way.

### **What does SB 7 do?**

The main goal of SB 7 is to give more people health care and LTSS suited to their personal needs in a cost-efficient way through managed care. It changes how the state manages and pays for services for people with I/DD who have Medicaid in these waiver programs: Texas Home Living (TxHmL), Home and Community-based Services (HCS), Community Living Assistance and Support Services (CLASS), and Deaf Blind and Multiple Disabilities (DBMD). It also affects medical services and LTSS in the Medically Dependent Children's Program (MDCP).

### **How can we be sure people with I/DD are protected in a managed care system?**

Throughout the legislative process, The Arc of Texas worked closely with Senator Nelson and other legislative and agency leaders to strengthen safeguards for people with I/DD in the redesigned system. Here are some of the results of our effort:

- New definitions for key terms for things that have a specific meaning to people with I/DD (such as “basic attendant services,” “habilitation services,” and “functional need”).
- A longer rollout period to give time to evaluate and improve each step of implementation.
- A new committee—the I/DD Redesign Advisory Committee—to make sure SB 7 is rolled out with extreme and thorough caution.
- Voluntary enrollment in STAR+PLUS (the state's Medicaid managed care program) for people in the DBMD, HCS, and CLASS waiver programs. People in a waiver program by 2020 can continue to get services through the waiver indefinitely, if they want. All others will get services through STAR+PLUS.
- HHSC can continue to operate Medicaid waiver programs or the Medicaid ICF-IID program to provide supplemental LTSS that STAR+PLUS doesn't provide.
- Initial functional needs assessments will be conducted by someone that is independent from the managed care organization (MCO) or service provider. The independent entity will also play a strong role in the Person-Centered Planning (PCP) process and provide independent case management (service coordination) services.
- MCOs will be required contract with traditional providers and other partners, such as local I/DD authorities, to leverage the strong LTSS networks that already exist.
- DADS can evaluate functional need using an evidence-based, nationally-recognized assessment tool that is specifically designed for people with I/DD.
- New and continuous reporting requirements to allow stakeholders and state leaders to monitor the progress of the redesign rollout and make adjustments when needed.
- Emphasis on person-centered planning, self-direction and self-determination, community inclusion, fair hearings and appeals, local safety net providers and services, and community-based services for all, including people with the most significant service needs.
- No premiums to get medical or LTSS.

### **TIMELINE: How SB 7 will unfold.**

#### **Phase One: Beginning September 2013**

- People with I/DD will get medical services through STAR+PLUS or a similar managed care model.
- Approximately 12,000 people with I/DD who are eligible for Medicaid and on a waiting list for waiver services will get basic attendant and habilitation services through STAR+PLUS.
- The I/DD Redesign Advisory Committee will be created.

- DADS will set up contracts with Local I/DD Authorities (LIDDAs) for service coordination, assessments, and individual plans of care. The local authorities may subcontract for those services. (Note: Local authorities can't provide service coordination if they provide basic attendant and habilitation services.)
- Written agreements will require MCOs to review and consider assessments for basic attendant or habilitation services conducted by LIDDAs.
- HHSC and DADS may pilot LTSS managed care models which start no later than September 2016, and end by September 2018. Participation in the pilots is voluntary.
- HHSC will develop a STAR Kids managed care program tailored for children with disabilities. Eventually, children in MDCP will be served in STAR Kids.
- DADS will develop or adopt a comprehensive, functional needs assessment for people with I/DD.
- DADS will also develop training and behavioral supports for people with I/DD.
- HHSC will work with other agencies to identify more housing options in rural and urban areas for people with disabilities.

### **Phase Two: Beginning September 2017**

- People with I/DD who have been in the TxHmL waiver program will begin to get their services from STAR+PLUS. HHSC can decide to continue TxHmL to provide services that are not available in STAR+PLUS.

### **Phase Three: Beginning September 2020**

- People with I/DD in HCS, CLASS, DBMD or an ICF-IID will get LTSS services through STAR+PLUS, unless they choose to stay in the waiver programs. HHSC can decide to continue the waiver programs to provide some services that are not available in STAR+PLUS.

### **What now?**

It is important for you to keep making your voice heard. Share your stories with us as Managed Care rolls out in Texas. You may contact Ginger Mayeaux at [gmayeaux@thearcoftexas.org](mailto:gmayeaux@thearcoftexas.org) or 1-800-252-9729 with experiences, concerns, and questions.

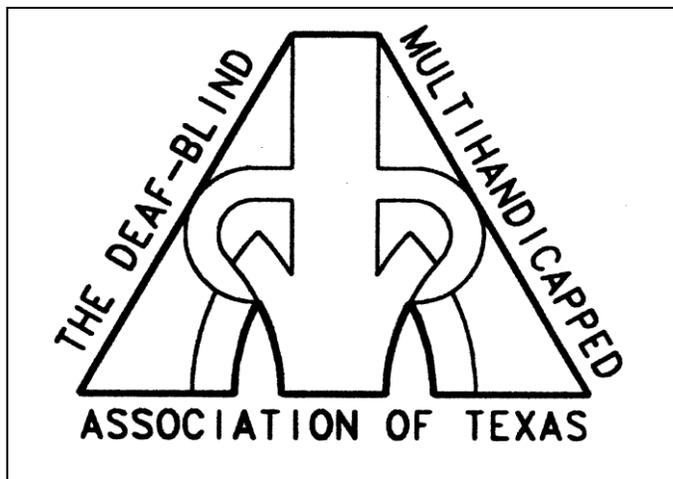
*For more information go to:*

[http://www.thearcoftexas.org/site/DocServer/SB\\_7\\_Brief\\_June\\_12\\_2013\\_2\\_.pdf?docID=2681](http://www.thearcoftexas.org/site/DocServer/SB_7_Brief_June_12_2013_2_.pdf?docID=2681)



The Deaf-Blind Multihandicapped  
Association of Texas (DBMAT)  
909 Mountain Park Drive  
Big Spring, TX. 79720

NON\_PROFIT.  
U.S. POSTAGE PAID  
MIDLAND, TX 79711  
Permit No. 10



In Touch is a Publication of the Deaf-Blind Multihandicapped Association of Texas (DBMAT)

If you would like to be dropped from DBMAT mailing list or have a change of address please contact: Paul Welch – Big Spring, TX.