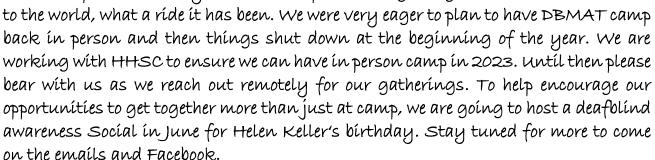


## In Touch

### The Newsletter of the Deaf-Blind Multihandicapped Association of Texas Spring 2022

### From the President's Pen

I hope this finds you all doing well! Another year has gone by and we're part Covid stay at home and part Covid getting back



I want to share a story with you because this morning I participated in a blog survey about supporting families with special needs. There was a variety of questions about what I would advise families to do and with many of the responses I had always came back to stay connected with other families, find a support group that fits your family's needs and stay connected. That is how we help each other throughout the years as things change for our loved ones and for our families to have support and resources. DBMAT works hard to stay connected with resources and professionals throughout Texas and across the nation to help our deafblind community stay connected. We have also been here to help advocate for you and with you over the years. Please stay connected with us as we want to be here to help you when the opportunity arises and those who are yet to come.

I know it's not easy and it's been hard throughout Covid. Each day is a new opportunity to find moments of joy and hopefully we can string multiple moments of joy throughout our days, weeks, and months. You're not alone! Our Board and members would be honored to touch base with you if you ever want to reach out to us.

The things we have been working on over the past year have been much legislative training, preparation, and exploration of topics that we can advocate for at state and federal levels. We have had a group that has participated in federal level training with NFADB. This led to calls with legislators to help support our deafolind community at the federal level. We also have a group that has been participating with Health and Human Services (HHSC) to help bring providers together with the waiver administrators to establish efficiencies that can be gained and improve the DBMD Medicaid waiver delivery services throughout Texas. Thank you to those who have provided feedback and participated when we've reached out for your input. We are hopeful for continuous improvements in our deafolind community and if ever you have something you can help us with, please do let us know! It takes a community to make change happen. We need YOU to help us help you, especially when it comes to Legislative advocacy. On the agenda for the season coming up is DBMD Waiver Budget Caps. So please be in tune and ready to act when we reach out with requests for legislative advocacy action, as it will be a new Legislative season SOON.

We will share updates with you at camp and we have a new keynote speaker this year that will share a deafolind education model in the regional day schools. We look forward to seeing you at DBMAT camp (virtually for one more year) in the fall, September 24th and 25th.

See us, Hear us ~ We are DBMAT!! Forward we go!

Best regards, Vívecca

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# 2020 DBMAT Awards



Chris Montgomery Professional

Tish Smith, Chris Montgomery

Becky Harmon Olivia Cruz Award



Danny Gregory, Becky Harmon



Christine Givens, Sky Givens
SKY GIVENS

Christian Knapp "Great Motivator"

# 2021 DBMAT Awards

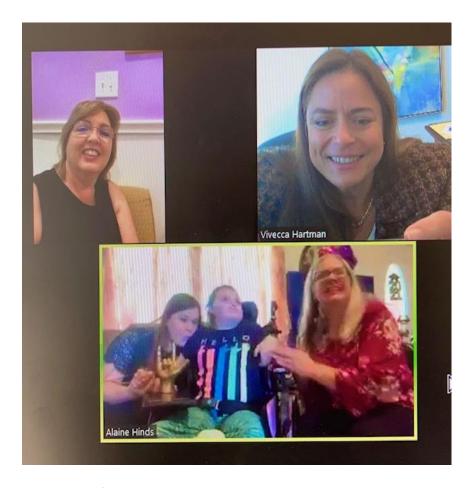


Fran Ware Professional

Tish Smith &
&
Cari Anderson
Olivia Cruz Award



Cari Anderson, Tish Smith



Christine Givens, Vivecca Hartman, Sarah Hinds, Rebecca Hinds, Alaine Hinds

### Rebecca Hinds

Christian Knapp "Great Motivator"



### DBMAT SPECIAL AWARDS



Jackie Gannt Special Advocate

Ginger Mayeaux Special Advocate





### DBMD Campers at Camp Summit

By Abbey Cumnock, Camp Summit

We had such a remarkable week at camp with our Deaf Blind Multiple Disability (DBMD) campers this July. But first, let's look back at 2020. Last year presented us all with many firsts and unknowns. But Camp Summit handled the pandemic the best way we know how — we adapted! Our remarkable campers stayed connected with us through a full line-up of virtual programs, Zoom events, and even a few camp-to-your-door programs. We also incorporated new software for subtitles on pre-recorded videos and auto-captioning for our Zoom events.

After a year without in-person camp, the new COVID-19 policies and procedures were well worth it to welcome everyone's smiling faces back to camp. With reduced capacity, our DBMD week served 36 campers from July 4-9. Our COVID-19 precautions also meant not offering flights to camp, but instead we were able to provide millage reimbursements for those that requested it. We look forward to offering transportation again in the future. Our staff received special training and prepared specialized sensory activities for this unique week. We are so thankful for the intervenors and consultants that provided extra support as well. "Although our numbers were lower due to COVID-19, the campers still had a great time and thoroughly enjoyed the activities," said Lisa Braziel, Director of Camp Operations and Strategy.

Specially designed activities for sensory impaired participants included cotton ball snow people, salt dough leaves, rain sticks, air-dry clay making & painting, slime making, cloud dough, braille painting, nature hikes, senses of sound, and many more. We also enjoyed archery, swimming & splash pads, and we rolled out our new and improved fishing program, a fan favorite from our days in Argyle. We continued to use our music garden. These six outdoor instruments and turfed areas continue to be a big hit. We also designed two special sensory areas for each cabin group, one inside the cabin and one in an area for more messy activities that everyone enjoyed greatly. Evening activities included a water night, spa night (complete with foot soaks, essential oils, and more), chaos night, food night (no bake cookies, fruit pizza, and pasta necklaces) and of course the end-of-week dance.

To learn more about Camp Summit's free DBMD week, click <a href="here">here</a>. For any additional questions, please call us at 972-484-8900 or email us at <a href="mailto:camp@campsummittx.org">camp@campsummittx.org</a>



## 10 Issues to Always Consider When Intervening for Students with Deafblindness

By David Wiley, Texas Deafblind Outreach

Abstract: This article provides a framework for analyzing ten common issues a teacher, intervener, or caregiver must address when effectively supporting a student who is deafblind. Questions are provided to help guide a team in planning the best sensory access for the student in all environments.

Key Words: Effective Practices, deafblind, access, vision, hearing, tactile

A primary role for those intervening with a student who is deafblind is to make accommodations to provide the best possible access to information, spaces, and materials. These accommodations should be planned in advance for the best visual, auditory, and tactile access. This planning is most effectively done as group including teachers, interveners, related service professionals, the student, family, and other caregivers.

During advanced planning, write strategies that will help the student be more successful when each of the following basic issues are considered, taking into account vision, hearing, and touch:

physical space – qualities of the room and activity area;

positioning – where the student, instructor, and materials should be;

materials – how teaching materials look, sound and feel;

devices and equipment – adaptive aids used for sensory impairments;

orientation & mobility – knowing where you are, and getting around;

communication – getting information from, and giving information to others;

trust and security – feeling supported, connected, and safe;

literacy – recording information for future reference, and retrieving recorded information;

pacing - how quickly the lesson should move forward; and

content of the activity or coursework – adding to, reducing, or changing what is taught.

It might be easiest to divide a planning sheet into three columns for vision, hearing, and touch, so each is considered for each issue. The strategies developed should help the student access as much information as possible, as easily as possible. This will help the student use his or her energy for learning, rather than trying to figure out what is happening, or what is expected.

Despite the best planning, however, the student and staff will encounter some settings and situations that are new or unexpected, before there is a chance for advance planning. For this reason, those intervening for a student with deafblindness should always have these ten issues in mind in every situation. At the point when making accommodations for these ten issues becomes second nature for the person doing the intervention, the student has the best opportunity to have the fullest access to instruction.

For each of the ten issues, the following are examples of questions that the planning team should consider, and that the person doing the intervention should always keep in mind. Please remember that these are examples, and there are many other things to consider, based on the individual student's settings, situations, abilities, and challenges.

### Physical Space – Qualities of the room and activity area.

*Primary question.* How should the room and activity area look, sound, and be arranged so the student can move freely, easily gather materials, easily access information, and not be distracted by visual, auditory, and tactual clutter?

Examples of other questions to consider:

Is the lighting bright enough, or is there too much glare?

Does the room decoration create a good visual background?

How are the acoustics in the room?

Is there a lot of distracting background noise?

What kind of furniture is best to help the student be in the best position, and have clear convenient access to learning materials, communication partners, and activity areas? Is the workspace clear enough to easily explore tactually, or visually scan?

### Positioning – Where the student, instructor, and materials should be.

*Primary question.* What positions for the student, instructor, and materials would maximize the student's access to and understanding of information?

Examples of other questions to consider:

Where should the student sit or stand to see and hear most easily?

Are there specific parts of the room to be avoided because of shadows, glare, or background noise?

Does the time of day affect what position is best in this setting?

Does the student need permission to move when necessary to improve his or her ability to see or hear, or to tactually explore what the other students are exploring visually?

Are materials placed so the student can easily observe or get to them?

### Materials – How teaching materials look, sound and feel.

*Primary question.* Are all teaching materials easy for the student to recognize and use? Consider color, contrast, sound quality, texture, etc. These materials could include anything from a toothbrush to a washer, or a picture symbol to a computer.

Examples of other questions to consider:

Do learning materials have good color and light/dark contrast when compared to the background, and between the different parts of the materials?

Are the materials large enough to easily see?

Do materials have distinctive sound qualities, that make them easy to recognize, or interesting to explore?

Are tactual elements, such as raised lines and textures, added to reinforce visual materials?

Whatever possible, are tactile models and symbols made from real objects that are tactually distinctive, rather than plastic replicas?

### Devices and Equipment – Adaptive aids used for sensory impairments.

*Primary question.* During the activity, how should the student use any adaptive devices or equipment such as magnifiers, assistive listening devices, electronic Braille notetakers, or switch activated appliances?

#### Examples of other questions to consider:

- In what situations would magnification be helpful, and which devices would be most effective, efficient, and easy to use?
- Do the student and others in the environment know how to use any amplification, or other sensory devices?
- Are computers, telecommunications equipment, or other tech tools equipped with accessibility features?
- Does the student need help setting up and using devices quickly enough to keep up without missing instruction or other essential information?

### Orientation & Mobility – Knowing where you are and getting around.

*Primary question.* What would help the student know where he or she is, be able to find people and things, and go to familiar and unfamiliar destinations?

### Examples of other questions to consider:

Are rooms and hallways free of clutter to promote ease of movement?

Are materials stored in consistent locations that are easy to access?

Are landmarks for orientation identified or created?

Has the student learned clear consistent routes to independently move through familiar settings?

### Communication – Getting information from and giving information to others.

*Primary question.* What strategies would help the student express him or herself to staff or classmates, and what strategies would help staff or classmates be more clearly understood by the student?

#### Examples of other questions to consider:

- Does the person intervening need to learn new vocabulary or create new communication symbols in order to be prepared for a new lesson or activity?
- Which communication partners in any setting can communicate directly with the student, and in which cases is there a need for someone to interpret or facilitate interactions?
- In any situation, does the student have an effective way to communicate both expressively and receptively, and all the materials and equipment necessary to do so?
- Are symbols, devices, and other materials available if necessary for the student to communicate about unexpected concerns or topics?
- Does the student need to switch to different communication strategies based on the situation, such as during group discussions, when the room becomes noisy, or when the lights are dimmed?

### Trust and security – feeling supported, connected, and safe.

*Primary question.* What would reduce anxiety for the student, so he or she can feel secure and focus on learning?

Examples of other questions to consider:

During the activity, how does the student remain connected to someone he or she knows, and with whom he or she has a trusting relationship?

How does the student know what is about to happen, and what other people's expectations for the student are?

Does the student know who else is involved in the activity, and what they are doing?

Does anything in the situation or activity create confusion or uncertainty for the student, and what can be done to reduce it?

Does the student need instruction in how to advocate for appropriate modifications, such as asking a teacher or classmate to repeat something, slow down, or change position?

### Literacy – Recording information for future reference and retrieving recorded information.

*Primary question.* What would help the student be able to read or otherwise retrieve recorded information, such as tape recordings, pictures, tactile symbols, object symbols, etc.?

Examples of other questions to consider:

What medium would be most effective in this setting: print, Braille, voice output, pictures, tactile graphics, tactile symbols, object symbols, etc.?

Is all print easy to read, considering size, color, and type style?

If the student uses voice output, is there a good listening environment?

Would the student benefit from headphones or an alternative listening device?

If the student reads Braille, are Braille materials available in advance?

When pictures cannot be visually accessed, are tactile graphics or tactile symbols available?

### Pacing – How quickly should the lesson move forward.

*Primary question.* How do the student's needs related to vision, hearing, and touch affect the pace at which information is given to the student, how long the student needs to explore materials, and how much time he or she needs to respond?

Examples of other questions to consider:

Before beginning a lesson or activity, is time set aside to allow the student to explore the area, become acquainted with materials, get into proper position, prepare and test equipment, or otherwise assure accessibility?

Does the student need extra time to orient to a communication partners, especially in a group?

Is the student given extra time when needed to pause for gathering and/or processing information?

Are breaks needed to prevent fatigue for the student, or for the person providing intervention?

### Content of the activity or coursework – Adding to, reducing, or changing what is taught.

Primary question. How should the content of the lesson be modified to account for the student's needs related to vision, hearing, and touch? For example, do demands need to be reduced? In addition to the regular content of the lesson, do other skills (e.g. visual scanning) or information (e.g. background concepts) need to be added?

Examples of other questions to consider:

Because of the student's pace, does the amount of work need to be reduced?

If some of the lesson must be omitted due to time, which elements take priority, and which can be removed?

Are there concepts in the lesson or activity that are unfamiliar to the student, so that additional explanation or background information must be provided?

Does the student need pre-teaching before a lesson, or does extra instructional time need to be set aside later to fill in gaps in the students understanding, or to reinforce concepts?

Do the goals of the activity or instructional methods need to be modified to take into account the student's sensory needs and capabilities?

Are activity routines and materials used consistently, so the student can more easily recognize them?

In addition to subject area content, does the lesson need to include instruction on sensory issues, like how to effectively use vision, hearing, or touch to actively participate in the activity?

By answering such questions in each area, accounting for vision, hearing, and touch, educational teams will provide better intervention for students with deafblindness. Students will have better access to information about the environment, what is happening to around them, and what others are communicating. They will be able to concentrate on learning, rather than struggling to gather information. Access to information and environments is a right.

It is important to keep in mind, the purpose for these accommodations is not to provide a crutch or make to students dependent on the people providing the intervention. When done well, this intervention will increase students' independence by providing better access. For that reason, staff people doing the intervention should always be trying to help others in the environment, and the students themselves, be aware of these issues so better access can occur more naturally, even without assistance. This access makes things easier and fairer for everyone involved.

Originally published in *TX SenseAbilities* 4 (1), Winter 2010. (Outreach Program, Texas School for the Blind and Visually Impaired.) <a href="https://www.tsbvi.edu/Outreach/newsletter/index.htm">www.tsbvi.edu/Outreach/newsletter/index.htm</a>



### **Embrace The Blessings Podcast**

April 27, 2022

Deafblindness, DBMAT, & Touch Base Center for the DeafBlind with Vivecca Hartman

http://www.embracetheblessing.com/etb-27-deafblindness-dbmat-touch-base-center-for-the-deafblind-with-vivecca-hartman/



### Genetic Counseling

by Denise Sewell

### Hello everyone!

We recently (well it was a year ago) had some genetic testing done on Blu. His neurologist and psychiatrist wanted a little more information on the epidemiology of Blu's medical diagnoses. In our case, they were requesting the genetics test to better understand Blu and give them an idea of what the future might hold.

For you younger families, I am writing this because it might give some of you a different avenue to look in to. The results of Blu's genetic testing showed that he was born with a very rare syndrome. The Chudley-McCullough syndrome. What is Chudley-McCullough syndrome (CMS)? "CMS is an autosomal recessive condition characterized by sensorineural hearing loss, near normal development, a distinctive combination of brain malformations: partial agenesis of the corpus collosum, cerebellar dysplasia, frontal heterotopia, frontal polymicrogyria, and arachnoid cysts. Some patents develop hydrocephalus. It is important to diagnosis CMS, since typically, patients with these types of brain malformations have very substantial developmental problems."

In Blu's case the gene GPSM2 mutation is how it all began. Since it is so rare the doctors do not know what or the extent of his medical condition will develop, if any. Our doctor told us he was only able to find 24 cases.

How does this relate to deafblindness? We really do not know and have not been able to find much in the research "google" world. But if it helps any of you young parents out who are trying to figure all the "why's and how's of our DB world" then I would suggest looking into genetics testing. Hope everyone is well and making each and every day the best!





### **Attention Former TSBVI Students and Families!**

Completing the organization's first full school year, **TSBVI Family Lynx** encourages community among TSBVI families, alumni and staff.

Parents, other family members and guardians of all students (day, residential, EXIT, short-term, summer) are encouraged to join, as well as adult students and staff. Former students, family members and staff are also welcome. Working together we are stronger and better able to support each other.

Although parents of students are scattered across the state of Texas, Family Lynx is committed to fostering opportunities for parents to engage with staff and feel a part of the TSBVI community and learn from each other.

Family Lynx holds virtual monthly meetings featuring a special guest to share experiences and expertise and periodic Alumni Mixers for former students to connect. Members have access to members-only resources via our website and emails.

Continuing the TSBVI community into adulthood, Family Lynx is dedicated to strengthening alumni ties with their fellow classmates and the school. Current TSBVI families are eager to meet former TSBVI families to learn more about life after TSBVI. The Alumni Lynx effort is in its infancy. If you are a former TSBVI student, parent or staff member and interested in helping, please contact Family Lynx Leader Amy Potts (mom of DB Rees Potts) at <a href="mailto:familylynx@tsbvi.edu">familylynx@tsbvi.edu</a>.

More information and Membership Registration Form are available at <a href="www.familylynx.org">www.familylynx.org</a>. (Please note that many of the links on the website are restricted and accessible to Family Lynx members only.)



### **DBMAT Committees**

### WE NEED YOUR HELP!!!

DBMAT Committees: DBMAT loves to have new ideas and other people's involvement! We are most effective when we divide and conquer our time and talents! To assist us in being able to do this, we have focus group committees that you can select one (or more ©) to join. The purposes of these committees are briefly defined as follows:

### **Legislative:**

To obtain and share legislative (both state and federal) information that affects people who are deaf blind and multi-handicapped with the whole group. When there is action to be taken, where DBMAT may have an impact, this committee can organize and plan an approach for all to be able to participate. This link gives great ideas to learn how to be more informed in legislating for our deafblind. <a href="https://tahch.org/tahchorg/advocacy/getinvolved/advocatetoolkit">https://tahch.org/tahchorg/advocacy/getinvolved/advocatetoolkit</a>

### **Fundraising:**

To organize and communicate fund raising tips for all to participate in.

### **Conference Planning:**

To organize and plan the annual conference. Much of the work for this committee is via conference calls starting 6 months prior to each annual conference.

#### **Education:**

To organize ideas that are good for sharing amongst our families. Based on each family's experiences and tips and tricks learned, one of the goals of this committee is to have a webbased place for knowledge sharing.

### **Regional Coordinators:**

To have a DBMAT member in each region of Texas as a contact person for any new locals that want to reach out and talk to someone close by.



### 2022 Legislative updates

By Becky Harmon

We've been very busy trying to do the research involved in getting the DBMD Waiver cap raised. Making comments in meetings with HHSC and the Governor's Committee on Public Disabilities (GCPD) has led us to believe DBMAT will be leading efforts to change the DBMD Waiver with legislation regarding the total cap amount of \$114,736.37. Since HHSC has increased monies for the services in 2019 and again this year, many individuals like adults have been adjusting for a loss in services. We knew this would be happening when it was changed back in 2019. However, we found that just asking HHSC to update the cap would not work. It will take an act of Congress!

We also will be asking to update the DBMD Waiver wait list by adding 25 slots every year with 50 each biennium. This will help many people that have been waiting for years on the waiver.

On another note, we are also leading efforts to improve our waiver by increasing the number of provider agencies that serve across the state. Last year, an agency dropped their contract across the state leaving everyone scrabbling to find another provider to take on the DBMD Waiver. In Region 1 (Amarillo and Lubbock area), 10 DBMD Waiver individuals lost their slot and were forced to the HCS Waiver which does not have two very important services... Interveners and Orientation and Mobility. Provider agencies have many obstacles to hurdle with the rules and regulations made by HHSC to provide good services for the DBMD individuals. We are hoping to all work together to make it the best waiver in Texas!

We will need your help to get a bill(s) passed so please start now by introducing yourself to your state legislators and explain your situation to them even if you're not on the waiver. Tell them your families' story! Share a one pager with pictures of your deafblind loved one and describe the daily challenges as well as your hopes and dreams. Make it personal! Legislatures count your contact in everyway (in person, calls, and emails) and you being their constitute influences where they concentrate their time and effort.

### So, please HELP US HELP YOU!!!

Who Represents Me?

https://wrm.capitol.texas.gov/home



### More Resources

#### **WEBSITE**

The Deaf-Blind Multihandicapped Association of Texas - Home (dbmat-tx.org)

#### **MEMBERSHIP**

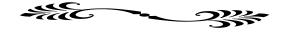
The Deaf-Blind Multihandicapped Association of Texas - Join Us (dbmat-tx.org)

### **HISTORY**

https://tsbvi.edu/575-tx-senseabilities/summer-2018/5889-dbmat-early-days-to-the-present

#### CONTACT

DBMAT President at vivecca.hartman@dbmat-tx.org



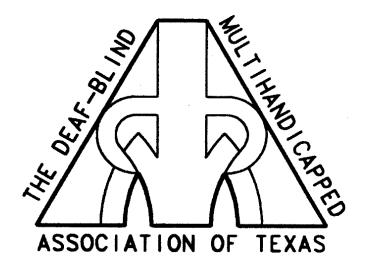
### **UPCOMING EVENTS**

## CELEBRATING HELEN KELLER'S BIRTHDAY "MOMENTS OF JOY"

June 27<sup>th</sup>, 2022

Information to be shared soon!

DBMAT CONFERENCE Virtual September 24-25<sup>th</sup>, 2022



**IN TOUCH** is a Publication of the Deaf-Blind Multihandicapped Association of Texas (DBMAT). If you would like to contribute anything to this newsletter, please contact <a href="mailto:becky.harmon@dbmat-tx.org">becky.harmon@dbmat-tx.org</a>