

WI Families for Hands & Voices

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“What works for your child is what makes the choice right”

Understanding Deaf-Blindness — by Jodi Anderson



**HANDS &
VOICES**

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PART TWO:

“Once I knew only darkness and stillness...my life was without past or future...but a little word from the fingers of another fell into my hand that clutched at emptiness and my heart leaped to the rapture of living (Keller, n.d.)” Those fingers that helped connect Helen Keller to the world around her belonged to Ann Sullivan. Ann Sullivan was an intervener. Interveners provide deafblind individuals access to the world around him or her.

Helen Keller was fortunate to have the dedication and help of a person that connected her to her world. The darkness and emptiness she describes is often a related experience of many deafblind individuals. A skilled and knowledgeable person is needed to help these individuals. An intervener is the bridge between this darkness and the world. The intervener gives access to the environment and assists in the development of communication as well as social and emotional well-being with others. With the support of an intervener, the deafblind person can become part of the world and leap into the living.

The intervener presents information to the deafblind student in ways the student is able to detect, interpret, and understand. Without the assistance of a knowledgeable intervener, making connections to his or her environment would be challenging for a deafblind child. The intervener works with the child to create a positive relationship so learning can occur. To be a bridge, the intervener must learn the student's unique learning needs and communication style. Once this is known, the intervener can encourage the student to try new things, problem solve, and make choices so the student can understand he or she is in control of what happens instead of playing a passive role in any interaction. Other ways the intervener can act as a bridge to the student and the world around him or her is to give the student plenty of time to process and respond to information, give feedback and positive reinforcement, encourage use of residual vision and hearing as able, and give plenty of support in a variety of settings throughout the school. All of these strategies allow the intervener to create connections for the student instead of being in the way of communication and development. An intervener removes barriers in order to reduce the isolation often felt by a deafblind individual.

What is the difference between big “D” Deaf and little “d” deaf?

A capital “D” refers to Deaf people as a distinct cultural group of individuals who use American Sign Language (ASL). In the same way, a Spanish person who speaks fluent Spanish comes from the Spanish culture; cultures have language associated with them. Language is tied to culture; this is why Deaf people do not identify their deafness as a “loss” or disability; instead, Deaf individuals view themselves as part of a distinct (minority) culture. On the other hand, lower case “d” deaf is used when describing hearing loss from a medical perspective; deaf indicates a person’s audiological status and ability to hear. Lower case “d” deaf people are those who grew up mainstreamed in a hearing classroom and do not associate with culturally Deaf people. Big “D” Deaf people identify themselves as culturally Deaf, use ASL and are part of the Deaf community. Even a hearing person can be considered Deaf with a capital D. If a hearing person was raised in both the Deaf culture at home, has fluent use of American Sign Language and finds that her/his heart is truly in the Deaf world, this person, although not audiotically deaf, is considered Deaf. This can happen when the person is a CODA (Child of Deaf Adults) and is culturally Deaf. This is a fairly recent terminology and many are still unfamiliar with its use. Any person who is deaf, Deaf, hard of hearing, deafblind, or hearing can, if they want to, be a part of the Deaf community. The Deaf community and culture is strong, proud and inclusive.

Continued from Page 1: Understanding Deaf-Blindness

Finding the right person to be an intervener for a child who is deafblind is essential. It is important for the interviewers to have a clear understanding of the skills and abilities required of interveners before beginning the interview process. An intervener must have a strong interest in working with children who are deafblind. An intervener should sincerely like the child with whom he or she works. The bond between an intervener and a student is critical for success because it is the foundation for a student’s learning, development, and socialization. A good match between a student and an intervener in terms of personality and energy level is important. Interveners are required to have specific training in deafblindness. Many state deafblind projects offer intervener training and support to educational teams. There is also an Intervener training program available online with national credentialing through Utah State University (see intervener.org for more information).

Next - Part Three: Intervener, Interpreter, SSP, What’s the Difference?

Our Mission:

Wisconsin Families for Hands & Voices is a non-profit organization dedicated to supporting families statewide who have children who are Deaf, Hard of Hearing and Deafblind without bias around communication modes or methodology. We are a parent-driven organization providing families with the resources, networking and information they need to improve communication access and educational outcomes for their children. Our outreach activities, parent/professional collaboration and advocacy efforts are focused on enabling Deaf, Hard of Hearing and Deafblind children to reach their highest potential.

Board Member Spotlight: Michelle Pandian

I am honored to begin serving on the Board of Wisconsin Families for Hands & Voices. As a DHH teacher for nine years, I have worked with students whose needs were as individual as they are. I have experience teaching students who use cued speech, ASL, signed English or total communication, a Bi-lingual/ Bi-cultural method, and students who only used their amplification technology and spoken English to achieve equal access to communication. It is my understanding that equal access may not look the same for any two DHH students. Thus, I am an advocate of providing all necessary means of communication support for the child to not only have equal access at school, but also at home and in the community.



My background includes a master's degree in Deaf Education from the National Technical Institute for the Deaf, in Rochester, NY. I am a member of the Convention of American Instructors of the Deaf (C.A.I.D.), the AG Bell Association for the Deaf, and hold C.E.D. certification (Council on the Education of the Deaf). Additionally, I am a current member of the Wisconsin State Superintendent's Advisory Council for DHH students, filling the itinerant teacher position.

The philosophy of Wisconsin Families for Hands & Voices is a refreshing solution to the multiple challenges and realities DHH individuals experience in today's world. As such, this organization is a strong advocate for optimal communication access for DHH children and their families. I agree with and highly support the philosophy of Hands & Voices, and am excited to be able to further its influence in the fields of education, legislation, advocacy, and parent support. I will share my experience and expertise as a DHH teacher, as well as learn from the other talented and skilled members of the board, as we join together to support families/DHH children in Wisconsin.

Newborn hearing loss diagnosis statistics from 2012 Hands & Voices Annual Report:

- Average number of days from birth to final hearing loss diagnosis: 115.9
- Median number of days from birth to final hearing loss diagnosis: 89
- Minimum number of days: 4
- Maximum number of days: 528

This is far reduced from the national average of 24 to 36 months prior to universal newborn hearing screening.

HELP OTHERS BY DONATING USED HEARING AIDS!

WI Families for Hands & Voices is now accepting hearing aids donations as part of a partnership with Starkey. If you have old hearing aids that are not being used and would like to make a charitable donation to help WI Families for Hands & Voices....



Recycle now!

Call Michelle Kihntopf at 920-609-7815 for a self-addressed, stamped envelope to send to Starkey.



Recycle Old Hearing Aids Now!

Renew Your Membership or become a member today!

2013

Hands & Voices WI Membership

Please circle one of the following

Parent of a deaf/HH child	\$25.00
Deaf /HH Adult	\$25.00
Student	\$25.00
Professional	\$40.00
Organization/agency	\$75.00
Additional Donation	\$_____

Name _____

Address _____

Phone _____

E-mail _____

Method of Payment

Check _____ Scholarship _____

Become a Member/Renew Online!

Credit Card Payment NOW Accepted!

Please Visit:

<http://www.handsandvoiceswi.org/>

Or clip and mail to:

WI Families for Hands & Voices

PO Box 9644

Green Bay, WI 54308



ANNUAL STATEWIDE FAMILY CONFERENCE

REGISTER NOW!

Family Conference, March 7-9, 2014
"Renew, Re-energize, Relax"

Olympia Resort, Oconomowoc, WI

The 12th Annual Statewide Family Conference will be held March 7-9, 2014 at the Olympia Resort and Conference Center in Oconomowoc. We are proud of this event as it is offered specifically FOR families of children with hearing loss and is planned BY family members. All families with children who are hard of hearing, deaf, deafblind, or deaf with additional disabilities are encouraged to attend!



Our theme this year is **"Renew, Re-energize, Relax."** *FEATURING Family Conference Keynote Speaker...*

Tina Childress, MA, CCC-A
"Come. See. Hear. - Life As A Deaf Audiologist"

Saturday, March 8, 2014

Tina is an educational audiologist who works in the mainstream school setting and is also a consultant and cochlear implant specialist in the residential school setting. She is a sought out presenter, trainer and adjunct lecturer by families and professionals on a variety of topics relating to hearing loss but especially cochlear implants, assistive technology, aural rehabilitation and the social/emotional impact of hearing loss. Tina's perspective is unique in that she is a late-deafened adult (she was an audiologist first!) and received her first cochlear implant in 2000 and became a bilateral recipient in 2005. She has a PASSION for mentoring, teaching and helping others navigate through the world of hearing loss and believes in paying it forward with her dual perspective as an audiologist and bilateral cochlear implant recipient. Tina is active on many local and national Boards and Committees where she is a strong advocate for accessibility and sharing resources. She currently lives in Illinois with her husband and two daughters.

FEATURING Our Keynote Speaker for Deafblind/Deaf+ Families,

Dr. Kasee Stratton

" 'BUT THE DOCTOR DOESN'T BELIEVE IT IS PAIN' - RELATIONSHIP OF PAIN TO BEHAVIOR"

Dr. Kasee Stratton has worked and completed research in the field of CHARGE syndrome, developmental delays, and challenging behavior for nearly ten years. Dr. Stratton completed her doctoral training at Central Michigan University's School Psychology program. She went on to complete pre-doctoral and post-doctoral training in pervasive developmental disorders and disruptive behavior at the Johns Hopkins School of Medicine/Kennedy Krieger Institute in Baltimore, Maryland. Dr. Stratton specializes in children and adolescents with low-incidence disabilities who exhibit challenging behaviors, e.g., limited functional communication, tantrums, non-compliance, self-injury, aggression, and academic decline. She has a particular interest in individuals who present with deaf-blindness, multiple disabilities and CHARGE Syndrome. Dr. Stratton currently is conducting a continued line of research on identifying pain non-vocally among children who present with CHARGE and deafblindness.

For a detailed tentative Family Conference schedule, as well as the Childcare Activities Schedule, please go to: <http://www.wesp-dhh.wi.gov/wesp/>.

Costs

Family Conference Registration Fee: \$175 per family until 01/24/14
 \$275 per family from 01/25 – 02/07/14
 Extended Family / Childcare Provider: \$ 75 each additional individual

Family Conference registration fee can be paid in full OR in monthly installments in November, December, and January. **ALL registration fees are due by February 14, 2014.**

Payments can be made to: WESP-DHH Family Conference
 Business Office
 1700 W. State Street
 Janesville, WI 53546

Hotel Costs

Participants are responsible for making their own hotel reservations:

Olympia Resort and Conference Center in Oconomowoc, <http://www.olympiaresort.com>

- \$ 80 per night one adult; kids stay free
- \$ 90 per night two adults; kids stay free
- \$ 10 each additional adult in the room
- \$ 10 per rollaway
- \$190 for a suite – 2 queens, living room pull out couch, kitchenette

Scholarships

Partial Scholarships for families are available through *Wisconsin Families for Hands & Voices* and you must be a member of Hands & Voices for your application to be considered.

To join/renew as a Wisconsin Families for Hands & Voices member, click here: <http://www.handsandvoiceswi.org/joinus.html>

For scholarship information and application, please visit: <http://www.handsandvoiceswi.org/activities.html>

NO SCHOLARSHIP APPLICATIONS WILL BE ACCEPTED AFTER JANUARY 24, 2013! Families MUST complete the online registration system before JANUARY 24, 2014 regardless of when they submit their scholarship application.

WHAT ARE YOU WAITING FOR?

Register Now! (<http://www.regonline.com/1325312>)

TELL YOUR FRIENDS AND OTHERS WHO MIGHT BE INTERESTED!

QUESTIONS?

If you have any questions about the Statewide Family Conference, please contact Laurie Nelson at 608-822-3756, leave a message at 1-888-656-8556 or email laurie.nelson@wesp-dhh.wi.gov.