



MINNESOTA  
HANDS &  
VOICES™

# FOCUS

Supporting families with children who are deaf & hard of hearing

## The Role of Parent Advocacy and Parent's Impact on the Legislation Process

One definition for advocacy is to speak or write in favor of; support or urge by action; recommend publicly. In many ways when we became parents we automatically became advocates.

We learned as much as we could about our child and what each cry meant; hungry, tired, wet, or bored, and on our child's behalf we responded or communicated those needs to care providers. Through our modeling of advocacy our children learn how to self-advocate. They see our willingness to learn, clear communication, assertiveness, respectfully behavior, and most importantly, they see they are important and how much we care about their needs. Parenting and advocating often are one and the same.

Our role as parent advocate takes on added significance for parents of children who are deaf or hard of hearing (DHH). First things first, we begin educating ourselves on how to raise a child who is DHH. Then we begin the process of educating our immediate family, extended families, friends, neighbors, and many times the general public. Accommodations and accessibility issues for individuals who are DHH is not general knowledge and requires us to inform others. Our children should understand we advocate on their behalf, because we live in a society that values every person and they are worth every effort. Until our children are ready to take hold of the "advocacy helm" parents forge ahead gaining

knowledge and dispensing knowledge along the way.

"Over 12 years ago, we called our healthcare insurance company for preauthorization for our son to receive a cochlear implant. Our request was denied without a clear explanation. Unsatisfied we decided to read the policy. Imagine our surprise when we found the only mention of cochlear implants was listed in the VISION section," remembers a MNH&V mom. "Even our healthcare insurance needed to be educated!"

There are times when a higher level of parent advocating is required. Occasionally, overwhelming issues specifically affecting your child, as well as, other children who are DHH need to be addressed formally. Some issues call us into action, but where do we start?

"If you have concerns about specific laws that need to change, document what is happening and send the information to the Commission," suggests Anna Paulson, Coordinator of Educational Advancement & Partnerships for the Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans (MNCDHH). Anna also suggests checking out their website, "The Commission website is a great resource for information about current priorities, past successes, tools for parents and the rights of people who are DHH." In 2016 the MNCDHH is launching a new website with more resources, but Anna adds, "In the

meantime, check out our website which lists all state laws, statutes and rules related to people who are deaf, deafblind and hard of hearing."

At times parent advocating can feel like swimming against the current. Reaching out to legislators for support is a way to bring into the fold individuals who know how to effectively use the legislative system. Telling your family's story to legislators will help put a face on the policies we need their support. Raising a child who is DHH is a unique experience many policy makers do not have first-hand knowledge of. We can get involved in the legislative process by sharing our lives and discussing what is important to us.

"We knew we needed help expediting a change to our healthcare insurance policy for our son's cochlear implant," continues a MNH&V mom. "I am not a political person, but I called a program, which at the time was titled 'Senator Mark Dayton's Healthcare Help Line, and told them our story. One meeting between Governor Mark Dayton and the CEO of the company my husband worked for and the company changed how the policy was written. Not only did the company change our healthcare policy to include coverage for cochlear Implants, they changed all three of the healthcare plans offered so other employees and their families would have the benefit."

*The Role of Parent Advocacy continued on page 2*

*The Role of Parent Advocacy continued from page 1*

Not all issues require legislation. In the case of changing the healthcare policy to include cochlear implants the company was willing to change the policy once they were made aware. Legislators can facilitate access to the individuals or committees who make policy changes. When your family's situation is fully understood organizations want to be inclusive and accommodating.

"All parents of children who are DHH should sign up to get email alerts from the Commission to learn about the issues on which they are currently working and to find out when they need to take action," Anna Paulson encourages. "Also come to the Commission's lobby day which is held every other year—it's a powerful event with over 600 attendees who come together to learn about the issues, learn from each other and talk to their legislators."

MNCDHH website <http://www.mncdhh.org>

## 2016 Family Meet-Up

Family Meet-Up is a chance for families with children who are DHH and cochlear implant users to gather and network.

Thursday, February 4th, 10 to 11:00 am.  
Thursday, May 5th, 10 to 11:00 am.  
August TBD  
Thursday, November 3rd, 10 to 11:00 am.

RSVP call 612-365-8300 or email at [childrenshearing@fairview.org](mailto:childrenshearing@fairview.org)

Located at the U of M Masonic Children's Hospital, Family Resource Center and Children's Library, Main Lobby. Interpreter available upon request

Sponsored by Lions Children's Hearing & ENT Clinic and Fairview Audiology/Aural Rehabilitation.

## Thanks for your contribution!

**We rely on your generous support to build better lives for children who are deaf or hard of hearing.**

**Make a tax-deductible donation today.**

**DONATE**

## Highest Record of Government Employees with Disabilities

In the 34 years statistics have been recorded there has never been a higher number of individuals with disabilities who work for the federal government.

Between 2011 and 2014, federal agencies hired nearly 72,000 full-time permanent employees with disabilities. Between 2013 and 2014, the percentage of the total federal workforce with disabilities increased from 12.8 percent to 13.6 percent. In 2010, President Obama issued an executive order requiring agencies to hire a total of 100,000 disabled Americans within five years.

In 2014, close to 20 percent of the 104,000 new federal employees hired, including those who transferred, were individuals with disabilities. There has been a steady increase since 2004 when only 8 percent of new federal employees were disabled. The first 20 years statistics were kept the rate of federal employees with disabilities had vacillated between 7 to 8 percent.

<http://www.govexec.com/management/2015/10/disabled-employees-federal-government-again-reaches-all-time-high/122767/>

## Early Learning Scholarships Available to More Children who are Deaf or Hard of Hearing

Northern Voices is celebrating its 4 Star Rating from Parent Aware. This is the highest possible rating that an early childhood program can earn in Minnesota and increases program access to all families, regardless of income, through Early Learning Scholarships.

What does this mean for parents of young children who are deaf or hard of hearing? Children from low income households may qualify for new Early Learning Scholarships from the state of Minnesota. Early Learning Scholarships give families financial support to help pay for high-quality early care and education to prepare their young children for school.

How do you know if you qualify? Scholarships are available for children ages 3-5 years old from households with annual incomes at or below 185% of the Federal Poverty Guidelines. Call Think Small at 651-641-6604 or email [scholarships@thinksmall.org](mailto:scholarships@thinksmall.org) for more specific information.

Northern Voices works with every family interested in its listening and spoken language program to help make enrollment possible. In addition to the Early Learning Scholarships, Northern Voices also accepts county Child Care Assistance and raises funds throughout the year in order to award 81% of its families reduced tuition.

Please contact Erin Loavenbruck at 651-639-2535 or [erinl@northernvoices.com](mailto:erinl@northernvoices.com) to learn more about the Infant, Toddler, Preschool and Teletherapy Programs at Northern Voices.

☎ 651.265.2435 • 1.866.DHOHKID ✉ [mnhv@lifetrack-mn.org](mailto:mnhv@lifetrack-mn.org) 🌐 [mnhandsandvoices.org](http://mnhandsandvoices.org) 📺 MNHandsandVoices 📺 MNHandV

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 Lifetrack  
Putting Hope Within Reach



## IDEA 40th Anniversary, U.S. Education Department Released New Guidance

For the 40th anniversary of the Individuals with Disabilities Education Act (IDEA), the U.S. Education Department released guidance to ensure the 6 million children with disabilities receive the same quality education as peers without disabilities.

“In the 40 years since this law was enacted, we have moved beyond simply providing children with disabilities access to the school house,” said U.S. Secretary of Education Arne Duncan. “Today, we want to assure that these students have no less than the same equal shot at the American dream as their non-disabled peers.”

The guidance clarifies that students with disabilities should not only have access to a free appropriate public education,

but also they should have individualized education programs (IEPs) for all students receive high-quality instruction preparing them for success in college and careers.

### U.S. Education Department Guidance:

- Website featuring best practices from the field with resources on effective IEPs, instructional practices, assessments, student engagement, school climate, home and school partnerships, and post-school transition. <http://ccrs.osepideasthatwork.org>
- Classroom strategies for teachers with evidence-based, positive, proactive and responsive classroom behavior intervention and support strategies. <https://www.osepideasthatwork.org/evidencebasedclassroomstrategies/>

- Positive behavioral interventions and support implementation for educators is a new two-part blueprint on teaching behavioral expectations throughout schools. <https://www.pbis.org/blueprint/implementation-blueprint>

- Tip sheets for parents meant to help children with disabilities successfully reach adulthood includes information on financial management, healthcare and independent living. <http://www.parentcenterhub.org/repository/age-of-majority-parentguide/>

For more information about IDEA <http://www2.ed.gov/about/offices/list/osep/index.html>

## Celebrating 15 Years with Minnesota Hands & Voices Candace Lindow-Davies

Join us in congratulating Candace Lindow-Davies, Minnesota Hands & Voices (MNH&V) Program Director, on her 15 years of service to families with children who are deaf or hard of hearing (DHH).

“Parents and children who are DHH of Minnesota, as well as Lifetrack, are extremely fortunate to have Candace. She has made a real difference in so many people’s lives,” said a MNH&V team member when asked to describe Candace’s work at MNH&V.



Candace has been involved with MNH&V since its inception in November of 2000. Prior to her work at MNH&V, she worked for 8 years counseling families in crisis. Candace is a mother of two amazing children, the oldest of which is profoundly deaf. Her years with MNH&V providing parent-to-parent support is a shining example of the cornerstone the program was built on.

“Her dedication is such great inspiration to see as she focuses on what needs to happen to serve our families,” added an associate at Lifetrack.

In addition to being the director of MNH&V Candace is currently President of the Hands & Voices Headquarters Board, a member of MN Department of Health’s Newborn Hearing Screening Advisory Committee and Newborn Steering Advisor, and a Steering Committee Member of the MN Commission Serving Deaf and Hard of People (MCDHH) and the MN Deafblind Association (MDBA).

When asked for one word to describe Candace a team member said, “My word for her would be AMAZING. She has invested so much in this program and our families. She is just simply nothing short of amazing. I am so honored to work for her, and am very very appreciative of all that she’s done in her years here and all that she’s invested in us.”

Candace has been formally recognized by different organizations such as, MN Speech-Language-Hearing Association (MSHA) for “Distinguished Service” in 2002, MN Department of Health Betty Hubbard Leadership Award in 2006, Minneapolis Chief of Police Award of Merit in 2008 and 2010, and MCDHH Community Organizer Award in 2009. She has also developed parent materials for national use and presented at numerous national, state and local conferences.

“I could go on for days about Candace and what she has created at Lifetrack. She is a true team member and superb leader,” says a fellow team member.

## Accessible Health Care at Area MinuteClinics

MinuteClinic, the walk-in medical clinic of CVS Health, will improve accessibility for patients with visual, hearing and other disabilities. The plan is designed to remove barriers for people with disabilities who want to use the clinics' services.

"We are committed to providing the highest level of medical care and access to all, and are constantly looking at our delivery model to ensure that we're meeting the needs of the communities that we serve," said Andrew Sussman, M.D., President, MinuteClinic and Executive Vice President/Associate Chief Medical Officer, CVS Health.

As part of the plan MinuteClinic will arrange for sign language interpreters when requested by a patient, and treatment and other vital information will be provided in formats that are accessible for persons with vision loss.

## PAHrtners Deaf Services Residential Treatment Facility

PAHrtners Deaf Services is now accepting out of state applications for their residential treatment facility in Philadelphia. PAHrtners Deaf Services provides residential services to adolescents who are DHH with emotional, behavioral, developmental and/or psychiatric challenges that make living in their home environment impossible.

The residential treatment facility is staffed 24-hours a day, seven days a week. All-Deaf program offering life skills training and community integration as their core components. Psychiatric treatment, therapy, case management, and educational services are provided.

For more information contact PAHrtners Deaf Services, 215-884-9770, 215-392-2425 VP, email [info@PAHrtners.com](mailto:info@PAHrtners.com), or online [www.PAHrtners.com](http://www.PAHrtners.com)

## I am MNH&V



### John Wilson

John Wilson, who is a deaf adult, grew up with three younger brothers who are hearing. The boys and their parents, who are also hearing, lived in a small town in central Minnesota called Becker. The small town of Becker, MN, home of a large furniture store, Becker Furniture World.

John was born profoundly deaf due to congenital rubella. He received a cochlear implant at age 4 along with speech therapy. John is fluent in ASL and English, both parents learned to sign as well.

John was educated in a mainstream classroom with the use of an interpreter from kindergarten through his high school graduation. After graduation, he went to college at the U of M, Twin Cities, where he is a current student with only one semester left. He is majoring in Sociology with a minor in Social Justice. On campus he is involved in the Deaf Student Ambassador Program and he is the assistant coach for the deaf University of Minnesota College Bowl team.

Currently John has been interning at the Commission of Deaf DeafBlind and Hard of Hearing Minnesotans (MNCDHH).

A few fun facts about John Wilson, one, he is a huge fan of the Harry Potter book series and two, instead of having typical pets, such as a dog or cat, he has three pet rats.

## First Annual Health and Wellness Summit for Elementary Learners who are DHH

### SAVE THE DATE

**Thursday, May 19, 2016**

Topics for the Health and Wellness Summit are physical fitness, social/emotional health, positive self-image, and healthy habits. This Health and Wellness Summit is an opportunity for students who are DHH to collaborate with peers and practice compensatory skills in a real life situation.

The Health and Wellness Summit for Elementary Learners who are DHH will be held at the Conway Community Recreation Center in St. Paul, MN, on Thursday, May 19, 2016 from 10:00 am to 1:30 pm.

If you have any questions or concerns please email one of the D/HH Health and Wellness Summit Committee members.

[Taylor.Thomas@isd917.k12.mn.us](mailto:Taylor.Thomas@isd917.k12.mn.us)

[Emily.Manson@spps.org](mailto:Emily.Manson@spps.org)

[Amy.Erickson@district196.org](mailto:Amy.Erickson@district196.org)

[Kristine.Cinealis@district196.org](mailto:Kristine.Cinealis@district196.org)

## Gallaudet Online Course Cued English

A Beginners Cued American English course is offered online this spring through Gallaudet University, starting January 19 through May 6, 2016.

This course will cover the 8 handshapes and phonemes used in the system and developing expressive and receptive skills. Other topics will include the application of Cued English and evidence based use with children who are DHH, along with discussions on various ways Cued English and American Sign Language can be immersed in a variety of settings.

More online at <http://www.gallaudet.edu/ccs/spring-online-courses.html>

## Happy New Year to Our MNH&V Community!

### In Your Corner



A very Happy New Year to our MN Hands & Voices' Community! Wishing you and your family a happy, healthy, safe and fresh start to 2016. I hope you had time over the Holidays to draw your children in close and share special family traditions. As my kids get older, 20 and 16 years old now, time with them is precious and fleeting, and it sometimes takes some creativity to slow our busy schedules down so our calendars align. But oh, how very worth it!

The Holidays can also be challenging as we connect with our extended family, helping clear barriers to communication and realizing just how important technology is to providing access to everyone in our family. As our family came together this year, I had to periodically stop and just be grateful for the many tools my son has available to him and proficiency in as a young adult. I'm so thankful that he is so eager to learn about and keep up with all the new technologies to make his life easier. It's ME coming to HIM these days to ask for advice for a colleague or a family and his chance to show me how independent he has become.

## Fundraiser for a Barrier-Free Playground

Help raise the necessary funds for a state-of-the-art, barrier-free playground for students who are DHH with physical challenges. The Intermediate School District 917 D/HH Program has learners with physical challenges who attend Gideon Pond Elementary in Burnsville, MN.

A parent of a learner who is DHH with physical challenges and representatives of the ISD 917 D/HH Program, as well as the staff and community at Gideon Pond Elementary have embraced the vision of a barrier-free playground, a playground

Just the other day, my son texted my husband and me saying he had missed his bus home from work. Before either of us could even respond, he texted again and said that he had an Uber coming and would be home very soon. Amazed, my husband and I naively asked if he had cash, and how would he communicate his needs etc. to which he responded in a very matter of fact way, that he had downloaded the app, ordered the ride through that, prepaid his fare with his debit card (duh, you have to, I guess!) and was home already. Geez. Mom and dad were left stunned at his proactive and creative problem-solving. Now, we've had to talk about the affordability of taking an Uber on a regular basis, but I still have to give the kid credit for figuring this one out. So, I guess maybe this mom needs to stop worrying so much and permanently land that helicopter, once and for all.

May your days ahead be filled with endless examples of your kids successfully navigating the world ... completely without your help. May all your efforts and all the efforts of the many professionals surrounding your family be so apparent this coming year. Our best from all of us at MN Hands & Voices.

with no barriers to wheelchairs and walkers which provides fun options for all learners.

Consider making a donation for an accessible barrier-free playground for all learners. Make checks out to Gideon Pond Elementary PTO, and mail to Gideon Pond Elementary, 613 East 130th Street, Burnsville, MN 55337. For more information contact Kitri Larson Kylo by email [kitri.kylo@isd917.k12.mn.us](mailto:kitri.kylo@isd917.k12.mn.us) or call 952-707-3091.

## DHH Day at the U of M

### SAVE THE DATE

**Thursday, April 7, 2016**

Students in grades 9-12 are invited, along with their teachers and parents, for a day to explore opportunities at the U of M. Hosted by the Disability Resource Center and located at the Twin Cities Campus. Students can ask questions and consider continuing their education at the U of M.

Contact the Disability Resource Center at email: [dhhday@umn.edu](mailto:dhhday@umn.edu) or online at [diversity.umn.edu/diversity](http://diversity.umn.edu/diversity).

## MNH&V Welcomes Saida Sheikh-Mohamed

### Parent Guide for Northeast African Communities

I am a mother of four wonderful children, including a daughter who is hard of hearing and born with Cri Du Chat Syndrome. I love helping other families with children who have special needs in our community. I joined MNH&V, because I find the work profoundly important, and I want to share its resources and information with the African communities in Minnesota. At the same time, I think MNH&V will give me the tools to help my daughter to be successful in life.



*Saida Sheikh-Mohamed, MNH&V Parent Guide for Northeast African Communities*





## MNH&V Welcomes Mai Houa Lor

### Parent Guide for SE Asia Communities

I am a mother of two children. I have a son who is in college and a two year old daughter. My daughter was born very premature at 26 weeks and was diagnosed with hearing loss in the right ear and mixed hearing loss in the left along with other medical difficulties. She started wearing a Cochlear Baha and a BTE hearing aid at 6 months old. I became a stay home mom and attended to my daughter with her medical needs as soon as she was born. The journey has not been easy. I understand the struggles and emotions that one will have that's why I joined MNH&V as a Parent Guide. I want to help other families who are going through the same thing that I went through.

Being a parent with a child who is hard of hearing and also a member of the Hmong community, I understand the struggles and difficulty. The language barrier, views, culture, and the belief that hard of hearing and deafness can prevent or limit a family from receiving the support or resources for their child. I feel very happy and privileged to be an outreach person who will support and guide our Hmong families and South East Asian families through MNH&V as a Parent Guide.

## Minnesota Olmstead Plan Approved

On September 29, 2015, a federal judge approved the Minnesota Olmstead Plan, giving people with disabilities a clearer vision for how the state plans to integrate them in to the community workforce. The MN Olmstead Plan includes data, timelines to establish measurable goals and language for the plan to evolve.

The Court recognizes many individuals with disabilities value living and working alongside other individuals with disabilities. There are no plans to close facilities that serve individuals with disabilities, group homes, or sheltered workshops. The Court emphasized the MN Olmstead Plan decision will not force integration upon individuals who choose not work and live in a community setting.

In 1999 a U.S. Supreme Court decision made it unlawful to keep people with disabilities in institutions when they could live in the community. Every state is required to develop a plan to provide the means for people with disabilities to live as independently as possible.

State Ombudsman for Mental Health and Developmental Disabilities, Roberta Opheim, is concerned some of the goals to find an appropriate community alternative fall short. Others hope the plan will provide safety from abuse and neglect along with needed services for people with disabilities.

The approved Olmstead Plan has thirteen topics that broadly covers employment, housing, education, transportation, health care and transition services would be provided. Implementation of the MN Olmstead Plan will include public reports and monitoring of the progress of measurable goals in the plan.

[www.mprnews.org/story/2015/09/29/federal-judge-accepts-states-plan-to-integrate-people-with-disabilities](http://www.mprnews.org/story/2015/09/29/federal-judge-accepts-states-plan-to-integrate-people-with-disabilities)

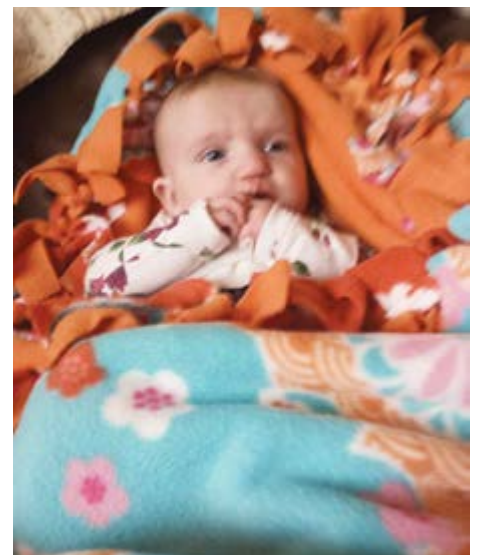


## Thrivent

Thrivent, in Central Minnesota, for volunteering their time to make welcome blankets for children newly identified as DHH of hearing in greater Minnesota.



Polly, from Thrivent, delivered 17 welcome blankets to MNH&V Parent Guide, Brenda Hommerding.



A welcome blanket delivered by Polly, from Thrivent, made it's way to Celina.

## The Importance of Hearing Aids for Children who are Hard of Hearing

A study published in the journal, *Ear and Hearing*, November/December 2015, looked at children who are hard of hearing over a longterm period. Researchers compared results of tests and exercises conducted on children who are hard of hearing with 117 children who have normal hearing.

From 2008 to 2012, researchers from the University of Iowa, Boys Town National Research Hospital in Omaha, NB, and the University of North Carolina at Chapel Hill, followed children who are hard of hearing, from six months to seven years old, to see how their language and speech development, social skills, and academic success were influenced.

### Key findings from the study include:

- Children who are hard of hearing, mild to severe, are at risk for depressed language development, which increases with unaided hearing levels.

- Well-fitting hearing aids reduce that risk and provide protection against delays.
- More than half of children's hearing aids were not fit optimally.
- Fitting children for a hearing aids early leads to better language outcomes. But later-fitted children also demonstrated accelerated language growth once they received hearing aids.

The study looked at children who are hard of hearing in both ears living in English-speaking homes. Researchers excluded children who had an additional disability.

The goal of the study was to recruit 450 children who are hard of hearing, but some children who are hard of hearing have not been identified or in special education. Instead the study tested 317 children who are hard of hearing in 17 states. Researchers conducted language tests, looked at speech development and reading outcomes, and asked the children

questions about social development, including friendships. Once a year the children filled out a survey, which asked questions about resources, if they saw an audiologist and what kind of services were offered at school.

Researchers found many children did not consistently use hearing aids and many did not have their hearing aids optimally fit. The dilemma for researchers was whether they should intervene and better fit the children's hearing aids. Ultimately they decided to send information home to parents on target settings for their child's hearing aids.

Researchers are seeking to secure another grant to continue the study, looking more closely at reading skills and how hearing aids affect social lives in high school.

Download of the *Ear and Hearing Journal*, November/December 2015, <http://journals.lww.com/ear-hearing/toc/2015/11001>



## The View from Greater Minnesota

## Latest Recipients of a MNH&V Welcome Blanket



Connor with his newly received MNH&V welcome blanket



Aubrey holding her new little sister, Julianna, both are hard of hearing.



Michael shows his appreciation for his welcome blanket.



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Minnesota Hands & Voices FOCUS Newsletter

January-February 2016

**MNH&V Roller Skating Event for Families with Children who are Deaf or Hard of Hearing.**

# Let's ROLL!

The Roller Garden will be closed to the general public so this is a great way to test your skating skills, socialize, and meet new friends!

**Sunday, January 31, 2016  
5:00 to 7:00 pm  
Roller Garden, St. Louis Park**

**Details & RSVP at [www.mnhandsandvoices.org](http://www.mnhandsandvoices.org)**