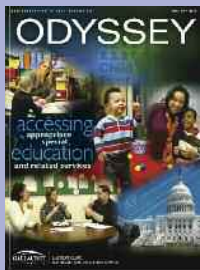


ODYSSEY



ODYSSEY



T. Alan Hurwitz, President, Gallaudet University

Edward Bosso, Vice President, Clerc Center

Susan Jacoby, Executive Director, Planning, Development, and Dissemination

Elizabeth Meynardie, Director, Training, Products, and Dissemination

Catherine Valcourt-Pearce, Managing Editor, Catherine.Valcourt-Pearce@gallaudet.edu

Glenn Lockhart, Director, Public Relations and Communications, Glenn.Lockhart@gallaudet.edu

Susan Flanigan, Coordinator, Marketing and Public Relations,

Susan.Flanigan@gallaudet.edu

Cathryn Carroll, Editor

Patricia Dabney, Circulation, Patricia.Dabney@gallaudet.edu

John T. Consoli, Image Impact Design & Photography, Inc.

ODYSSEY • CLERC CENTER MISSION STATEMENT

The Clerc Center, a federally funded national deaf education center, ensures that the diverse population of deaf and hard of hearing students (birth through age 21) in the nation are educated and empowered and have the linguistic competence to maximize their potential as productive and contributing members of society. This is accomplished through early access to and acquisition of language, excellence in teaching, family involvement, research, identification and implementation of best practices, collaboration, and information sharing among schools and programs across the nation.

Published articles are the personal expressions of their authors and do not necessarily represent the views of Gallaudet University or the Clerc Center.

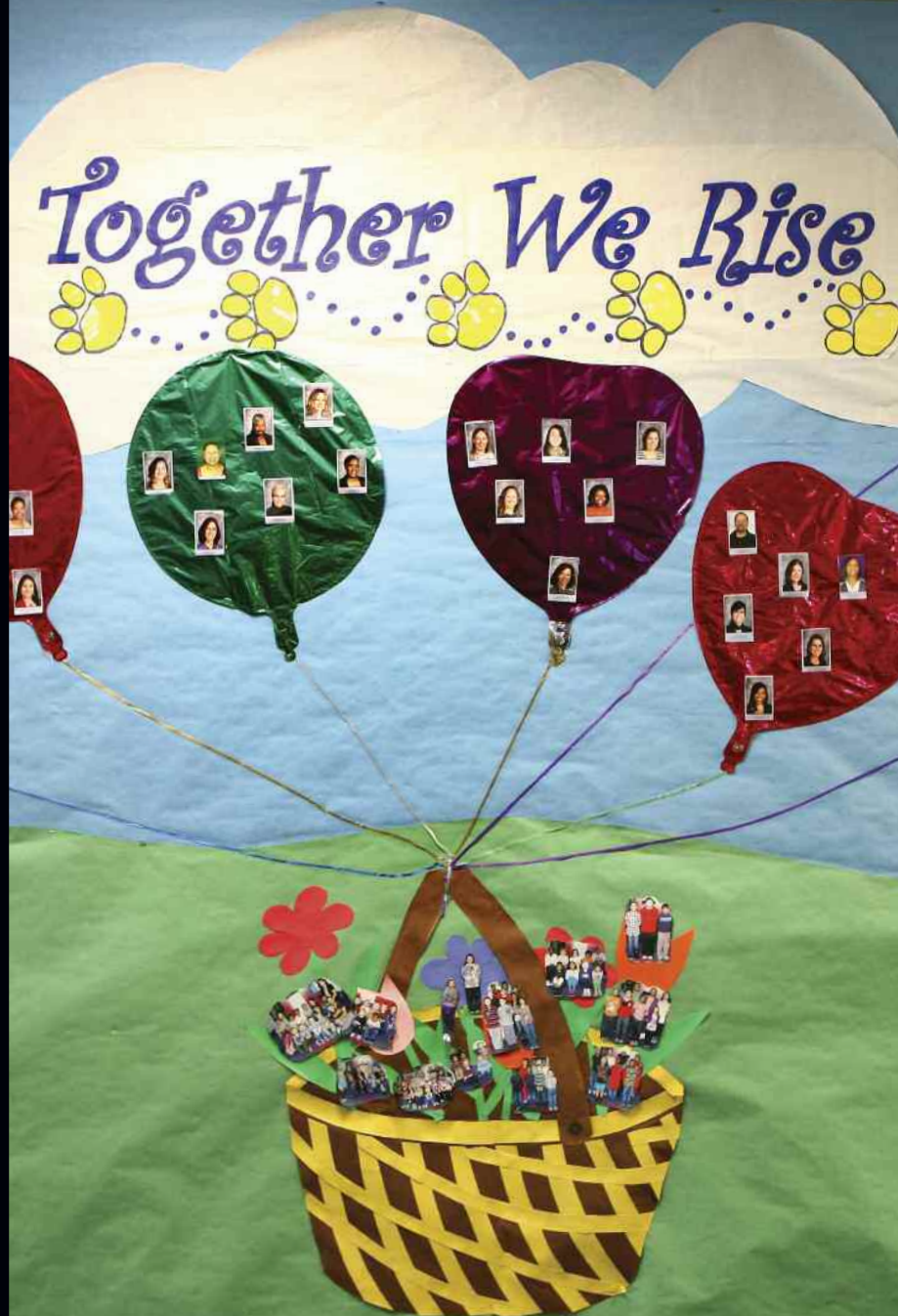
Copyright © 2013 by Gallaudet University Laurent Clerc National Deaf Education Center. The Clerc Center includes Kendall Demonstration Elementary School, the Model Secondary School for the Deaf, and units that work with schools and programs throughout the country. All rights reserved.

Subscription information: Please e-mail Odyssey@gallaudet.edu with your mailing address if you would like to receive your copy of *Odyssey* in the mail, or give us your e-mail address if you would like us to notify you when *Odyssey* is available online.
Website: <http://clerccenter.gallaudet.edu>.

The activities reported in this publication were supported by federal funding. Publication of these activities shall not imply approval or acceptance by the U.S. Department of Education of the findings, conclusions, or recommendations herein. Gallaudet University is an equal opportunity employer/educational institution and does not discriminate on the basis of race, color, sex, national origin, religion, age, hearing status, disability, covered veteran status, marital status, personal appearance, sexual orientation, family responsibilities, matriculation, political affiliation, source of income, place of business or residence, pregnancy, childbirth, or any other unlawful basis.

On the cover: *Collaborations among parents, schools, and agencies ensure that deaf and hard of hearing children have access to the services and supports needed to meet their individual needs. Cover collage design by John T. Consoli*

We would like to thank all of our student, parent, and teacher models from the Clerc Center for their assistance in illustrating this issue.



3 LETTER FROM THE VICE PRESIDENT

By Edward Bosso

4 IT'S THE LAW! A REVIEW OF THE LAWS THAT PROVIDE AMERICANS WITH ACCESS FOR ALL

By Barbara Raimondo

10 GENERATION TO GENERATION: THE FIGHT FOR LANGUAGE ACCESS CONTINUES

By Travis Zellner

14 A RURAL SCHOOL EDUCATOR BUILDS STUDENT LEARNERS THROUGH ACCESS TO CURRICULUM, SELF-ADVOCACY, AND CONNECTIONS TO THE DEAF COMMUNITY

By Megan Mathisen

18 WHEN THE LEAST RESTRICTIVE ENVIRONMENT IS RESIDENTIAL: MEETING THE NEEDS OF OUR SON

By Djenne-Amal Morris

22 CONNECTING SCHOOLWORK TO LIFE WORK: STUDENTS PRACTICE SETTING THEIR OWN EDUCATIONAL GOALS

By Theresa Johnson, John A. Serrano, and Daniel Veit

26 STANDING UP FOR OUR CHILDREN

By Christine Griffin

30 INDIVIDUALIZING DEAF EDUCATION SERVICES: MORE IMPORTANT THAN EVER BEFORE

By Janet DesGeorges

34 FOSTERING SKILLS IN SELF-ADVOCACY: A KEY TO ACCESS IN SCHOOL AND BEYOND

By John L. Luckner and Sharon J. Becker

40 THE GREAT SELF-ADVOCACY WAVE! MOM TEACHES MOST IMPORTANT LESSON: "EXPLAIN!"

By Joey Lynn Resciniti

44 ADVOCATING FOR CHILDREN AND THEIR FAMILIES WITHIN THE SCHOOL SYSTEM: REFLECTIONS OF A LONG-TIME SPECIAL EDUCATION ADVOCATE

By Ruth C. Heitin

48 ESSENTIAL IN ENSURING ACCESS TO SERVICES: A TEACHER OF THE DEAF

By Heather Stinson



10



14



18



22



26



40



70

52 BEYOND THE CLINIC: PROVIDING SERVICES, SUPPORTS AND CONNECTIONS TO HELP CHILDREN AND THEIR FAMILIES THRIVE

By Kevin J. Nolan, Jr.

56 CREATING COMMUNITY: BALANCING THE PERSONAL AND PROFESSIONAL

By Connie Stevens

60 EDUCATIONAL INTERPRETERS: MEETING THE COMMUNICATION NEEDS OF CHILDREN WITH COCHLEAR IMPLANTS

By Julie Melton and Renée Higbee

63 SECTION 504—THE 1973 LAW STILL MAKES A DIFFERENCE

By Beth Ann Dobson

66 FOR PARENTS AND CHILDREN ACCESS IS KEY—TO CURRICULUM, TO SERVICES, AND TO EACH OTHER

By Jodee S. Crace, Jennifer Ronco, and Tami Hossler

70 TRANSITION SPECIALISTS PARTNER WITH STUDENTS TO TURN DREAMS INTO REALITY

By Ann Flannery

74 MINNESOTA BRINGS TOGETHER STAKEHOLDERS TO DEVELOP A PLAN FOR CHILDREN WHO ARE DEAF, DEAFBLIND, AND HARD OF HEARING

By Mary Hartnett

78 TO SAVE A SON

By Sherri Zummo

82 CHILD FIRST: A BELIEF, AN ATTITUDE, AND A PATH TO CHANGE

By Jane Mulbolland

88 THE BACK PAGE: THE PARENT AND THE ADVOCATE WITHIN

By T. Alan Hurwitz

CLERC CENTER NEWS

- 55** Seeking Submissions for the 2014 Odyssey
- 85** Clerc Center Sets Priority Areas for 2013-2018
- 86** Clerc Center Implements Bullying Prevention Program
- 86** Commemorating 25th Anniversary of DPN
- 87** Coming Soon from the Clerc Center

Clerc Center



Creating Connections and Sharing Resources for Deaf Education

Coming soon:

- Deaf Students with Disabilities Network
- Classroom Interpreting: A Series of Tip Sheets
- Educating Deaf and Hard of Hearing Students: A Guide for Professionals in the Mainstream

...and more!



LETTER FROM THE VICE PRESIDENT

“I would not give a whit for the simplicity this side of complexity, but I would give my life for the simplicity on the far side of complexity.”

~ O.W. Holmes



It seems simple at first glance: all students should have equitable access to educational opportunities that maximize potential and lead to successful postsecondary and career outcomes. However, all too often this is not the case for deaf and hard of hearing students across our nation. There is a complexity to access for deaf and hard of hearing students that defies common sense and logic. Access to language and communication-driven programs and services based on individual needs is critical for each and every deaf and hard of hearing student and should be a basic right. We know that deaf and hard of hearing children thrive in environments where their language, communication, and educational needs are met.

The educational landscape is changing rapidly, even more so for deaf and hard of hearing students. It seems that change is the only constant when it comes to educating deaf and hard of hearing students. The tsunami-like wave of advances in early identification, medicine, and technology and in educational practice, policy, and accountability create both opportunity and risk for the students we serve. It is imperative that we do not lose sight of the “whole child” and his or her individual needs. Indeed the needs of deaf and hard of hearing students can seem quite complex to those who lack training and experience. However, this lack of knowledge should not lead to overly simplistic solutions that often leave deaf and hard of hearing students alone in programs that do not meet their educational or linguistic needs.

The stories of parents and professionals contained in this issue of *Odyssey* illustrate the complexities and challenges faced in obtaining and providing appropriate services for deaf and hard of hearing students. These articles also demonstrate the power of determination as well as the perseverance and advocacy often necessary for parents and professionals to achieve access. Perhaps they represent “...the simplicity on the far side of complexity.”

It is my hope that these articles are a catalyst for dialogue and necessary change. It is my hope that we reach “the simplicity on the far side of complexity” with regard to the basic right of deaf and hard of hearing students to have access to the services and programs they need to flourish and grow beyond expectations.

As always, I extend my sincere appreciation to those who contributed to this issue of *Odyssey*. I am confident that it will serve as a valuable resource as we advocate for the students and families we serve. They deserve nothing less than the very best.

Thanks for joining the readership of this issue. Be sure to share your thoughts and comments with us at Odyssey@gallaudet.edu.

—Edward Bosso
Vice President
Laurent Clerc National Deaf Education Center
Gallaudet University

it's the law!

a review of the laws that provide americans with access for all

By Barbara Raimondo



Barbara Raimondo,

Esq., is a long-time advocate for the rights of deaf and hard of hearing individuals and their families. She and her husband are the parents of two deaf young adults, and this year are host parents of a deaf student from Ghana. She welcomes questions and comments about this article at baraimondo@me.com.

Marta, 19, a freshman in her state's best public university, is excited and concerned. She has achieved her dream of getting into her first-choice college, but is the school required to provide Communication Access Realtime Translation (CART) in the lecture hall and the classroom?

Mendez, 18, wants to work part time in a large store near his home. When the manager sees his hearing aids, he says, "You have to be able to hear to do this job." Does Mendez have a right to accommodations?

Sam, 9, loves soccer and wants to join his city's soccer team. The coach and the boys on the team are hearing; Sam is deaf and uses American Sign Language. Is the city required to provide an interpreter?

The United States is more accessible to deaf and hard of hearing individuals and people with disabilities today than it was 50, 20, or even 10 years ago. A variety of laws ensures equality in the treatment of deaf and hard of hearing people. Communication barriers have been addressed, and wider opportunities are available in education, employment, and community. Here is a look at this legislation.

NEWBORNS

Early Hearing Detection and Intervention (EHDI)

All states are required to screen babies at birth to determine if they are hearing or suspected of being hard of hearing or deaf. The screening indicates whether it is necessary to provide additional audiological assessment to determine the baby's hearing levels. States have established systems of follow-up audiological assessment and links with early intervention programs. Approximately two to three of every 1,000 newborns are hard of hearing or deaf.

Photos by John T. Consoli

Right and below: Under the IDEA, children receive services as mandated by their IFSPs or IEPs.



In most cases, these babies are eligible for early intervention services until they are 3 years old.

For more information:

- National Center for Hearing Assessment and Management, www.infanthearing.org
- Boys Town National Research Hospital, www.babyhearing.org

BABIES AND TODDLERS **Individuals with Disabilities Education Act (IDEA), Part C** **Early Intervention**

Early intervention systems are required to evaluate eligible children's physical, cognitive, communication, social-emotional, and adaptive development. Then goals are developed and services provided to meet the needs of each child and his or her family. This information is documented in an Individualized Family Service Plan (IFSP) developed by an IFSP team that includes parents and professionals.

For more information:

- U.S. Department of Education, <http://idea.ed.gov/part-c/search/new>
- The Children's Hospital of Philadelphia, www.raisingdeafkids.org

CHILDREN **IDEA, Part B** **Preschool Through Age 21**

Many—but not all—children who receive early intervention services under Part C of the IDEA will continue to be served by Part B of the IDEA, which serves children ages 3 through 21 years or graduation from high school. However, there is a separate eligibility process. To receive services after the age of 3, deaf and hard of hearing children must be able to show that their “hearing impairment...adversely affects [their] educational performance” and because of that, they need special education and related services (20 U.S.C. § 602(3)(a)). Like Part C, Part B requires that the child be evaluated and his or her needs, goals, and services identified. This information is documented in an Individualized Education Program (IEP) developed by an IEP team that includes parents and professionals. Among other things, Part B requires the IEP team to ensure that:

- The child's language and communication needs are addressed.
- The child is placed in the “least restrictive environment,” that is, an educational setting that meets the child's language, communication, and academic needs. The least restrictive environment may be a regular education class, a special education class, a special school, or another environment.

- The child has access to the regular education curriculum, with support where needed.
- The child takes the same state and local assessments as all other children.
- The child has access to extracurricular and nonacademic activities.
- The child's special education and related services are based on peer-reviewed research to the extent practicable.
- The child's goals and services for transition into postsecondary education or the workplace are included once the child is 16 years old.

Procedural safeguards are in place to protect students' rights. Due process complaints or state complaints may be filed. Each state is responsible for providing information to parents on their rights and how to file complaints.

PRIVATE EDUCATION

When a parent places a child in private school, the child is not eligible for all the IDEA services he or she would be eligible for if he or she attended public school. In a private school the child becomes eligible for a "services plan," which generally is not as individualized or as strong as an IEP. The private school, however, is also covered by the Americans with Disabilities Act (ADA), Title II.

For more information:

- U.S. Department of Education, <http://idea.ed.gov>
- National Dissemination Center for Children with Disabilities, www.nichcy.org

ON THE JOB

ADA

Title I, Employment

This section addresses discrimination and accommodation in applying for a job and in the workplace. It applies to employers with 15 or more employees and deaf and hard of hearing individuals who are able to perform the "essential functions" of a job, with or without "reasonable accommodation" (42 U.S.C. § 12111). Reasonable accommodation may occur during the job application process, in the work environment, or in ancillary areas of the workplace; reasonable accommodation enables the individual with disabilities to enjoy work benefits and privileges on a level equal to those enjoyed by nondisabled employees. These accommodations may include job restructuring, access to telephone relay services or captioned telephones, and the provision of interpreters.



"Mitigating measures," such as the use of assistive technology, do not convert a person with disabilities into a nondisabled person in the eyes of the law. For example, a deaf person who hears well with a hearing aid or a cochlear implant is still considered deaf—and remains entitled to Title I protections.

There is a limit to the scope of the ADA;

for example, an employer is not required to provide accommodations that will impose an "undue hardship," i.e., a significant difficulty or expense (42 U.S.C. § 12111). If a deaf or hard of hearing individual believes an employer or a potential employer has violated the ADA Title I, he or she may file a complaint with the Equal Employment Opportunity Commission.

For more information:

- The Equal Employment Opportunity Commission, www.eeoc.gov/youthb//disability.html
- United States Department of Labor, www.dol.gov/odep/pubs/fact/ada.htm

COMMUNITY EVENTS

ADA

Title II, State and Local Governments

The ADA requires state and local governments to make their programs, activities, and services accessible to individuals with disabilities. State and local governments must ensure their services—including schools, after-school programs, summer camps, sports teams, and community events—are as accessible to deaf and hard of hearing individuals as they are to non-deaf individuals. They must provide "auxiliary aids and services" to make this happen, including:

- Qualified interpreters on site or through video remote interpreting
- Real-time computer-aided transcription services
- Written materials
- Exchange of written notes
- Telephone handset amplifiers
- Assistive listening devices
- Assistive listening systems
- Telephones compatible with hearing aids
- Closed caption decoders
- Open and closed captioning, including real-time captioning
- Voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), videophones, and captioned telephones, or equally effective

telecommunications devices

- Videotext displays
- Accessible electronic and information technology
- Other methods to make aurally delivered information available to individuals who are deaf or hard of hearing

In addition, public entities cannot refuse calls that arrive through the Telecommunications Relay Service (TRS).

However, there are limits. The ADA does not require a public entity to take any action that would result in a fundamental alteration in the nature of a service, program, or activity, or undue financial and/or administrative burdens. The burden is on the public organization to prove that providing access would result in an undue burden. Further, the entity is still under obligation to provide access in a manner that would not constitute a fundamental alteration or financial burden.

If an individual believes a public entity is violating the state and local government provisions of the ADA, he or she may file a complaint with the U.S. Department of Justice or a lawsuit in a local court.

For more information:

- U.S. Department of Justice, www.ada.gov
- ADA National Network, <http://adacourse.org/solutions.php?idarea=Government>

IN THE MARKETPLACE ADA

Title III, Public Accommodations

While Title II covers state and local governments, Title III covers private entities that have goods, services, or areas that everyone (the public!) uses. Title III also requires these organizations to provide auxiliary aids and services to ensure effective communication, except when a fundamental alteration or undue burden would result. These private entities are required to accommodate the public:

- Hotels, motels, and places of lodging
- Restaurants, bars, and places serving food and/or drinks
- Movie theaters, concert halls, stadiums, museums, and places of entertainment
- Auditoriums, convention centers, halls, and places of public gathering
- Bakeries, groceries, clothing stores, hardware stores, shopping centers, and sales and rental locations
- Laundromats, dry cleaners, banks, barber shops, beauty shops, travel services, shoe repair services, funeral parlors, gas stations, offices of accountants or lawyers, pharmacies, insurance offices, professional offices of healthcare providers, hospitals, or other service establishments

- Terminals, depots, or other stations used for public transportation
- Museums, libraries, galleries, or other places of public exhibitions
- Parks, zoos, amusement parks, or other places of recreation
- Private schools, including nurseries, elementary, secondary, undergraduate, and postgraduate, and other places of education
- Day care centers, senior citizen centers, homeless shelters, food banks, adoption agencies, and other social service center establishments
- Gymnasiums, health spas, bowling alleys, golf courses, or other places of sporting events or exercise

If an individual believes that an organization open to the public has discriminated against him or her, he or she may file a complaint with the U.S. Department of Justice or file a lawsuit.

For more information:

- U.S. Department of Justice, www.ada.gov
- ADA National Network, <http://adata.org/tags/title-iii>

ASSISTANCE WITH PHONE CALLS ADA

Title IV, Telecommunications

This section of the ADA establishes the TRS, which use communication assistants to facilitate communication between hearing and deaf callers. For example, a deaf caller using a videophone may call a hearing individual using a voice phone, with a sign language interpreter serving as an intermediary. The Federal Communications Commission (FCC) sets out rules that TRS companies must follow.

For more information:

- FCC, <http://transition.fcc.gov/cgb/dro/trs.html>

TELEVISION CAPTIONING

All television receivers with screens 13 inches or larger are required to include closed captioning capability. The FCC rules require that nearly all video programming display captions, with only a few types of exemptions. Consumers may file a complaint with the FCC when video programming does not show captions.

For more information:

- FCC, www.fcc.gov/guides/closed-captioning
- National Association of the Deaf, www.nad.org/issues/television-and-closed-captioning/improving-closed-captioning

ACCESSIBILITY AND THE INTERNET

The 21st Century Communications and Video Accessibility Act (CVAA) Update for the Internet

The CVAA, passed in 2010, updated the telecommunications law to ensure accessibility in the range of telecommunications products and services available today. For example, when laws requiring television captioning were passed, the Internet was not yet in people's homes. The CVAA extends closed captioning to Internet-based video programming, requires telephones used with the Internet to be hearing aid compatible, and requires user controls for TVs and other video programming devices to have a button, key, or icon designated for easily activating closed captioning. The FCC has been writing rules to implement this new law. Complaints for violations of the CVAA can be filed with the FCC.

For more information:

- FCC, <http://transition.fcc.gov/cgb/drol/>
- Coalition of Organizations for Accessible Technology, www.coataccess.org

ADDITIONAL PROTECTION

Section 504 of the Rehabilitation Act Prohibiting Discrimination

Passed in 1973, the Rehabilitation Act (29 U.S.C. § 701 et seq.) was in some ways the first legislation protecting individuals with disabilities and served as a model for the ADA. Section 504 prohibits discrimination on the basis of disability in any program or activity that receives federal financial assistance or is conducted by a federal agency. Public schools, colleges, and universities receive federal funds, as do most private colleges and universities. Each federal agency has developed rules as to how recipients of its funds must comply with the law.

For more information:

- U.S. Department of Education, www2.ed.gov/about/offices/list/ocr/504faq.html
- Wrightslaw, www.wrightslaw.com/advoc/articles/504_IDEA_Rosenfeld.html

A Look at Marta, Mendez, and Sam

Marta: The university is a function of state government, so Title II of the ADA applies. Further, because public universities receive federal funds, Section 504 of the Rehabilitation Act applies as well. Marta will have CART in her lecture hall and classrooms.

Mendez: Title I of the ADA applies. If Mendez is otherwise qualified to perform the essential functions of the job, the store he seeks to work in has more than 15 employees, and providing reasonable accommodation will not impose an undue hardship, he has a right to accommodation.

Sam: Since the soccer team is under the auspices of local government, Title II of the ADA applies. The team must provide an interpreter unless doing so would constitute a fundamental alteration in the nature of the activity or would result in undue financial and administrative burdens.



References

21st Century Communications and Video Accessibility Act. (2010). Pub. L. No. 111-260.

Americans with Disabilities Act of 1990. (1991). Pub. L. No. 101-336, § 2, 104 Stat. 328.

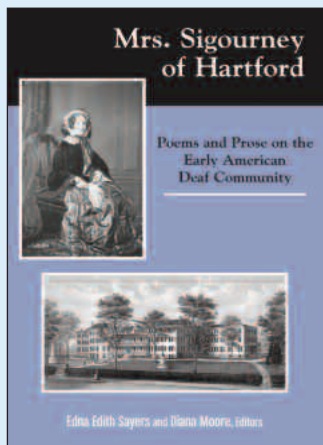
Early Detection, Diagnosis, and Treatment Regarding Hearing Loss in Newborns and Infants. (2012). Pub. L. 112-123, 42 U.S.C. § 280g-1 (20).

Individuals with Disabilities Education Act. (1990). Pub. L. 101-476, 20 U.S.C. § 1401 et seq.

Rehabilitation Act, Section 504. (1973). Pub. L. 93-412, 29 U.S.C. § 701 et seq.

Telecommunications Act of 1996. (1996). Pub. L. 104-104, 47 U.S.C. § 613 et seq.

DISCOVER DIVERSE DEAF WORLDS IN 19TH-CENTURY LITERATURE, BLACK DEAF LIVES, AND KANGAROOS



Mrs. Sigourney of Hartford

Poems and Prose on the Early American Deaf Community

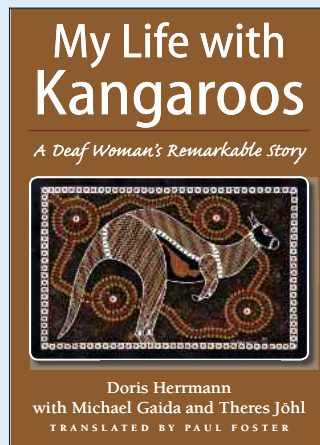
Edna Edith Sayers and Diana Moore, Editors

Lydia Howard Huntley Sigourney, a renowned 19th-century poet and the first person to teach deaf American student Alice Cogswell, has her legacy restored in this collec-

tion of her poems and prose centered on the nascent American Deaf community.

Print Edition: ISBN 978-1-56368-557-6, 6 x 9 paperback, 128 pages, \$45.00

E-Book: ISBN 978-1-56368-558-3, \$24.95, **March 2013**



My Life with Kangaroos

A Deaf Woman's Remarkable Story

Doris Herrmann with Michael Gaida and Theres Jöhl

Translated by Paul Foster

Born deaf in 1933 near Basel, Switzerland, Doris Herrmann turned her childhood fascination with kangaroos into a lifetime in Australia as a

respected researcher on their behavior, all told here in her fascinating autobiography.

Print Edition: ISBN 978-1-56368-559-0, 6 x 9 paperback, 248 pages, photographs, \$24.95

E-Book: ISBN 978-1-56368-560-6, \$19.95, **May 2013**

On the Beat of Truth

A Hearing Daughter's Stories of Her Black Deaf Parents

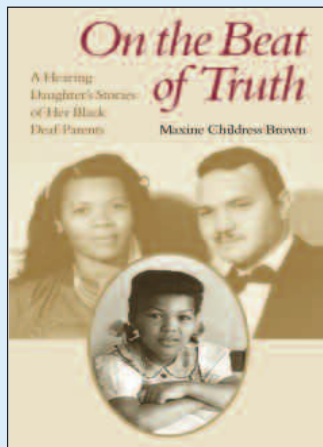
Maxine Childress Brown

The oldest daughter of deaf, working-class African American parents in the 1960s, Brown tells stories of her parents' youth, their tenacious work ethic, their interactions with the deaf African

American and white hearing communities, and the suffering they endured living in a hearing world.

Print Edition: ISBN 978-1-56368-552-1, 5½ x 8½ paperback, 184 pages, photographs, \$29.95

E-Book: ISBN 978-1-56368-553-8, \$29.95, **May 2013**



Service Learning in Interpreter Education

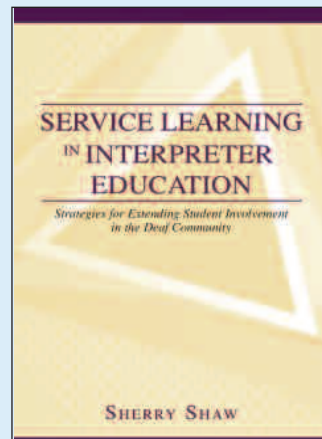
Strategies for Extending Student Involvement in the Deaf Community

Sherry Shaw

This book introduces and develops the concept of service-learning in interpreter education as a tool for re-centering the Deaf community to extend student involvement beyond field experiences such as internships and practicums.

Print Edition: ISBN 978-1-56368-555-2, 6 x 9 casebound, 172 pages, tables, figures, references, index, \$65.00

E-Book: ISBN 978-1-56368-556-9, \$65.00, **April 2013**



Call Toll-Free 1-888-630-9347 TTY; Fax: 1-800-621-8476

Visit us on the Internet: <http://gupress.gallaudet.edu>



Gallaudet University Press

Chicago Distribution Center
11030 S. Langley Avenue, Chicago, IL 60628

generation to generation:

the fight for language access continues

By Travis Zellner



Travis Zellner

resides in Uxbridge, Massachusetts, with his wife, Pam, and their two beautiful children, Miia and James. He welcomes questions and comments about this article at tpzell@yahoo.com.

Obtaining appropriate special education and related services to establish the best educational environment—academically and socially—for our children is not only challenging but also downright daunting. Our decisions supporting our children, 6-year-old James who is deaf and 12-year-old Miia who is hard of hearing, are, in part, derived from our experiences growing up.

Both Pam and I are deaf. We were born into hearing families, both of us the first deaf individuals our parents had encountered. It astounds us that our parents fought for us 30 plus years ago, much like we are fighting now for James and Miia. They say they spent countless hours in their local libraries doing research. They begged for help from medical and educational professionals who had either poor answers or no answers at all.

I started my education in a small preschool program with other deaf children at a public school in Connecticut using both spoken English and American Sign Language (ASL) under a philosophy known as Total Communication. I moved on to a local public elementary school in my hometown where I was mainstreamed to fifth grade. I struggled socially and academically, often feeling frustrated and sometimes depressed. I actually told my parents, “I want to go to school with other deaf children.”

Wanting me to have both a peer group and role models, my parents worked to transfer me to the American School for the Deaf (ASD) in Hartford, an hour north of home. They hoped I would be happier among a larger group of deaf and hard of hearing schoolmates and learn directly from teachers who used ASL. They realized I needed ASL to establish friendships.

After some resistance from our town, my parents were successful and off to ASD I went, where I was indeed much happier. However, after extensive testing it was determined that not only was I intellectually ahead of my peers but also that ASD didn’t have the means, curriculum, or program to support the style of learning I had acquired from mainstreamed classrooms and living with my hearing family. Finally, a compassionate professional directed my parents to Clarke School for the Deaf in Massachusetts, an academically challenging oral

Photos courtesy of Travis Zellner



program a bit further from my home. My parents found themselves with a much greater fight on their hands, but they were again successful. At Clarke, I found peers, academic challenge, and success, and I was very happy.

After eighth grade graduation, I was enrolled in a private hearing high school. I was the only deaf student. I started to struggle again. After a few months, I transferred to a very large public high school closer to my home with a small program for deaf students. This was not a good fit. The next year my parents and I were able to work out a new plan. I attended a public school for half of each school day and then went to ASD for the rest of the day. This worked well. I successfully finished the remaining three years of high school.

After graduation, I entered the Rochester Institute of

Technology (RIT), where I had support from the National Technical Institute for the Deaf. I graduated from RIT with a bachelor's degree in furniture design/woodworking. I continued my education at the Rhode Island School of Design, completing my master's degree in interior architecture.

Pam, my wife, didn't endure the same nomadic education. She started in a small deaf preschool program with other deaf children. She was then mainstreamed into her local public school system in Fairfield County, Connecticut, where she remained from kindergarten to graduation from high school. Pam and her family learned how to sign through an Easter Seals program when she was 3 years old. A "teacher of the hearing impaired" assisted her throughout high school. She, too, struggled socially and academically. Her parents also



fought to obtain support. Like me, Pam attended and graduated from RIT, earning her bachelor's degree in illustration.

We both remember struggles with communication, loneliness, and ignorance. Today we consider our first language to be English. However, we prefer to converse primarily in ASL. Pam, program manager at the Rhode Island Commission on the Deaf and Hard of Hearing, seldom uses spoken English. I, purchasing agent and materials coordinator at an architectural millwork company, utilize both ASL and spoken English. I volunteer as commissioner for the Rhode Island Commission on the Deaf and Hard of Hearing, where previously I was chairperson. I am also chairperson of the Board of Trustees for the Rhode Island School for the Deaf.

Services for Our Children

Miia, our first child, passed her newborn hearing screening but at 6 years old was diagnosed with mild to high frequency hearing loss and classified as hard of hearing. She was immediately outfitted with hearing aids. We established a 504 plan under the Rehabilitation Act to ensure equal access in education. The 504 plan fosters communication and awareness among teachers, school professionals, and parents to make sure

Miia does not miss out or fall behind. The plan allows for specific accommodations, such as ensuring media are closed captioned and audiologists are available.

When Miia was 6 years old, James was born. He did not pass his newborn hearing screening test and was diagnosed as profoundly deaf. When the audiologists broke the news to us, we were quite surprised. No one had been aware that our deafness could be a genetic trait.

As deaf professionals, Pam and I did not have any concern that deafness would impede James's development to his full potential. Unfortunately, this was not true of the other professionals who surrounded us. If we had 25 cents for every forlorn professional expression reacting to the infant they were discussing being deaf, we could be rich. We knew that James was born into the best family he could be born into—a loving family with experienced grandparents and understanding relatives. We are not only deaf but also experienced and knowledgeable about deaf and hard of hearing education and culture. We knew what to do.

Still Pam and I were shocked by the gloom that marked our first contacts in the medical industry. We had heard about this often, and now we were experiencing it. We looked at each other and thought of the inexperienced hearing and deaf parents who would not know what to do, where to go, or whom to trust. How would they handle being surrounded by these forlorn faces? These faces told us—two deaf professional parents—that deafness is a tragedy. We learned long ago not to be bothered by ignorance and to move on. Pam and I reached beyond the limited services initially offered, insisting that the first priority for our son must be exposure to ASL. Although spoken English is important, it is not the foundation for James's academic, social, and emotional development.

At 6 months old, James received his first hearing aids. We also reached out to Early Intervention (EI). We stressed that the most important service James required was access to language via ASL. Our EI person did not know anything about deaf culture or

We looked at each other and thought of the inexperienced hearing and deaf parents who would not know what to do, where to go, or whom to trust.

education, nor had she worked with deaf people. Ironically we were the teachers, not vice versa. We shared everything we knew, including information about implantable and biologically assistive technology. Soon EI hired another support person experienced in early childhood deaf education. This helped tremendously. We were told that we were one of the few families in the country to secure a certified sign language interpreter for daycare when James was 6 months old. We continued with the interpreter through the expiration of EI services.



When James was 2, we contacted the special education director. We wanted to be proactive. We knew it was impossible to establish James's needs within the normal two- to three-month time frame for transition of EI students to public education. Deep down, we feared we would have to relocate. Still, we were hopeful; perhaps our town would work out James's needs for education. By the time James was 3, we'd already had several tense discussions. Our town's definitions of *least restrictive environment* and *appropriate education* were about as similar to ours as apples to oranges—or apples to orangutans! We insisted that they contact The Learning Center for the Deaf (TLC), a well-respected school in Framingham, Massachusetts, to evaluate our son. We refused to rely exclusively on evaluations from the public school speech pathologist and psychologists—none of whom knew anything about deaf education or the idea that access to language for some students may best be promoted through ASL. Our town remained adamant: The foundation of their beliefs was that the only way for deaf students to succeed in academics was through spoken English.

We insisted that the town hire a full-time deaf teacher, retain consultation from a speech pathologist experienced in working with deaf children who knew sign language, and hire an interpreter certified in educational interpretation. We wanted James in preschool full time to prevent him from falling behind his hearing peers. We didn't get everything we wanted; James's preschool was only half day. We did secure a speech pathologist trained in working with deaf children and a good interpreter with a degree in early childhood education. After the school year ended, we requested that the special education director continue services for James throughout the summer. Unfortunately, James's first day of summer school found him in a class with children with severe developmental disabilities. This was not acceptable. We pulled him out the next day.

We decided to relocate. We put our home up for sale and secured a new home in Massachusetts. There, we talked with

everyone—from individuals at the Massachusetts Commission for the Deaf and Hard of Hearing to pathologists, psychologists, special education teachers, and other educational professionals in our new town. We felt reassured that, once there, we could enroll James in the program where we knew he would get a good education—TLC. We felt things were falling into place, and we thought the worst was behind us. A short time later, the town notified us that the “team” had determined that the local school—without one deaf child, one deaf teacher, or even one deaf adult on its premises—would provide an appropriate education and least restrictive environment for James.

This was a slap in our faces. As deaf individuals, deaf parents, and deaf professionals, our words, emotions, knowledge, experience, and professional testimony had been totally discounted. We were furious. We reached out to professionals in deaf education, speech pathology, and psychology. We contacted the Deaf and Hard of Hearing Program at Boston Children's Hospital, one of the largest and most experienced programs in the nation. We retained a highly regarded



attorney, formerly a hearing officer of the Massachusetts Bureau of Special Education Appeals. We were prepared to fight all the way. Still, we'd never felt so alone and frightened for our son. There was a lot of correspondence, many meetings, and a mediator from the Bureau of Special Education Appeals was assigned. A hearing was scheduled. Suddenly the town reversed its position and agreed that James should enroll full time at TLC. We collapsed and cried.

A Dream Becomes Reality

Now we are moving on. James loves his school. He and Miia are doing awesome. Both are well on their separate ways to successful futures.

Still, it infuriates us that so many officials have resisted my wife and me, experienced deaf professionals. We are even more infuriated for all those hearing parents who receive the news that their babies are deaf. We worry about the inappropriate, often inaccurate, and sometimes counterproductive counsel regarding their children's future and options.

Communication—not speech—is the primary factor in children's development. Sometimes we ask why there are so many overcrowded prisons with speaking prisoners. We ask why there are so many speaking American families struggling in poverty. Clearly if speech alone were the mark of success, this would not be the case. However, speech is meaningless without communication, education, and loving, active parents. Like so many others, that's what we intend to be for our amazing children.

Megan Mathisen

received her bachelor's degree in deaf education from MacMurray College in Jacksonville, Illinois. She teaches deaf and hard of hearing children at St. Anne Grade School, in St. Anne, Illinois, as part of the Kankakee Area of Special Education. Having taught at Phoenix Day School for the Deaf in Arizona for two years, Mathisen moved back to Illinois to be closer to her family. She welcomes questions and comments about this article at mathisenm@sags.k12.il.us.



Right: The students learn about responsibility and respect during character counts from social worker Heather Oosterhoff in their deaf and hard of hearing class via interpreter Jenna Saathoff.

A RURAL SCHOOL EDUCATOR BUILDS

student learners

THROUGH ACCESS TO CURRICULUM, SELF-ADVOCACY, AND CONNECTIONS TO THE DEAF COMMUNITY

By Megan Mathisen

In a small town 65 miles south of Chicago, where there are no Walmart stores, no McDonald's restaurants, no chain stores at all, a deaf teacher and an educational interpreter work together to maximize educational access for three deaf and hard of hearing students. The school is St. Anne Grade School; I am the deaf teacher, and my students are two boys in second grade and one boy in fifth grade. I teach them in a split class of reading and language. For nearly two-thirds of each school day, the boys, accompanied by their sign language interpreter, are in mainstream classes where each works with his respective peers and the general educational curriculum. For my students—as for all St. Anne students—this curriculum is geared towards the state's ever-present Common Core Standards.

When the boys come to my class, I work with them to discover and ameliorate areas where they need help. At the beginning of the school year, it was clear that they had reading and language delays. Now, however, my second grade boys are on grade level; my fifth grader is using the third grade curriculum, but we also focus on the fifth grade Common Core Standards.

For all three boys, the goal is the same—to catch them up, or keep them on par, with their peers. We've used reading strategies to help them not only in literature but in all subjects. For example, I use the strategy of predict/infer, whereby students are asked to infer information from the story they are reading as well as to predict what might happen next. I select a story that their hearing classmates are reading

Photos courtesy of Megan Mathisen



from the Houghton Mifflin second and third grade curriculum, and I work with my students in American Sign Language (ASL), breaking down the story into its simplest components for ease of understanding. For example, to illustrate one of the reading strategies, I modified a story from http://resource.deyogroup.com/330/sdr_predictinglessonplan.pdf and asked my students to “Picture Walk.” Here is the story:

Bobby and Kimmy put on their snowsuits. They got their hats, boots, and scarves. They went outside and began to roll the snow into three large balls. They put the largest ball on the bottom and stacked the snowballs on top of each other. They went to look for two sticks.

Then I found questions that require students to apply predictive and inferential thinking. Here are some of them:

- What season is it in this story? How do you know?
- Why do you think they need two sticks?
- What are the children doing?

Clearly, answering each of these questions requires that students understand the story and exercise their ability to think reflectively, creatively, and inferentially. Teaching my fifth grader, with his lagging performance scores in reading, is a little more complex as I strive to bring him up to grade level. Sometimes a warm-up activity is necessary. For example, I once used a SMART Board and asked students to sort pictures into their respective categories, such as *musical instruments*, *animals that fly*, *mammals*, and *reptiles*. Then they did a worksheet that required their comprehension skills as they read a short story in their workbook, “Around the Swamp,” classifying and categorizing common and specialized words, such as *trees*, *snakes*, *birds*, *nocturnal animals*, and *fish*.

My students are also learning the most daunting, most important skill of all—to advocate for themselves. Instead of imploring the teacher with their eyes and facial expressions, they are guided to think, grasp, and understand the material presented, and to ask questions if they do not. For example, my students stumbled while trying to identify sentences as “fact” or



“opinion.” They looked at me with their faces blank and their eyes wide—the deer-in-headlights stare—so we made up our own sentences, making statements that applied to our own class, sharing experiences, and identifying each sentence as fact or opinion. When the students used the interpreter, the teacher, and each other to craft sentences, they not only became delighted but, after a little daily practice, they noted correctly which sentences were fact and which were opinion. One of our students even walked to the principal’s office and explained which sentences out of several “Nature Walk” stories were fact and which were opinion.

I sometimes teach by modeling. I model the importance of self-advocacy by showing how to proactively work with the interpreter, both in the classroom and in school-wide assemblies. I model the importance of informing the interpreter if I do not understand, and I model asking the general education teacher for clarification.

It is important to teach beyond academics, and we try to expose our students to the rewards that can only be reaped in a vibrant Deaf community. Technology makes this at least partly possible. My students now have access to video relay services (VRS) to place calls. Recently our classroom was equipped with an iPad, and the first thing we did was download the reading and

educational apps. We then installed, with the help of Purple VRS, an app that allows us to interact with other deaf individuals and an interpreter when necessary to relay our calls. The first call we made was to a Purple representative, who let us know when students would be able to place their first VRS call to Santa Claus. (It was December and our goal was to tell Santa what they wanted for Christmas, of course.) We have also tried to attract deaf performers to St. Anne to interact with my students and broaden their educational experience.

Thanks to the Internet, my students have seen other deaf role models. They have seen deaf storytellers and poets on YouTube. Hopefully in the future they will gain more meaningful experiences as they meet more deaf adults in the wider community.

Before I arrived, my students had limited access to the academic curriculum. Isolated in a rural area with limited access to communication, using primarily gestures and oral language to communicate with their families or hearing friends, their English skills were weak. Even when they wanted to share a personal experience or an idea, they struggled for words.

“Mom, dad, me, store,” one might say. “Me scare. Saw rain,” another might volunteer. In class, I found my three young boys remained dependent on modeled academic and social language as well as guided writing and other developmental strategies.

They are improving now, both socially and academically. This is perhaps partly because my students and I have overcome some of the obstacles that many deaf students encounter in rural areas. Academically, two of them strive to remain on grade level while one tries to improve his ranking, and all three experience greater access to the curriculum of their hearing peers. Socially, all have been exposed to other deaf individuals and to ASL literature through VRS and the Internet, and, of course, through direct interaction with each other. Lastly, they have an adult deaf role model—me—their teacher, who is able to model, explain, and understand in a way that is unique to those who are deaf like we are.

While learning these new concepts and strategies, my students learn to question what they read, apply their own thoughts, evaluate, and summarize. Through differentiated instruction that allows a hands-on approach, they are taught the value of taking responsibility for their learning. This is the skill that I hope will be instilled in them for the rest of their individual educational journeys and the knowledge that will last each of them a lifetime.



Deaf and Hard of Hearing Infants, Toddlers and Families: Collaboration and Leadership Interdisciplinary Graduate Certificate



The Infants, Toddlers and Families certificate program is an 18-credit program with courses both online and on campus. This program provides professionals from a wide range of disciplines with current evidence-based knowledge and skills for working with families and their very young children who are deaf or hard of hearing.

Applications are now being accepted for the 2013-2014 cohort beginning May 20-22 with three days on campus.

Apply for graduate or professional studies training credits online:

<http://gradschool.gallaudet.edu/programs/c-itf>

or

http://www.gallaudet.edu/CCS/Certificate_Programs



Questions? Contact us:

ITF@gallaudet.edu

The co-directors of this program are Beth Benedict (Beth.Benedict@gallaudet.edu) and Marilyn Sass-Lehrer (Marilyn.Sass-Lehrer@gallaudet.edu).

Gallaudet University
800 Florida Avenue, NE
Washington, DC 20002-3695

Check us out on Facebook!

<https://www.facebook.com/GallaudetITFProgram>

American Society for Deaf Children

The American Society for Deaf Children (ASDC) is a national, independent, nonprofit parent organization that supports and educates families of deaf and hard of hearing children and advocates for high quality programs and services.



23rd Biennial ASDC Conference

June 26-30, 2013

The ASDC Biennial Conference provides families with information and fun! Daytime workshops captivate parents while children participate in educational and recreational activities. Evening events bring families together, providing the opportunity to form new friendships and peer support.

Mark your calendars now for the 2013 conference hosted by the Arizona School for the Deaf and Blind in Tucson.

For more information, contact conference chair Kelly Birmingham at (520) 770-3725 (voice) or e-mail Kelly.Birmingham@asdb.az.gov.



#2047 - 800 Florida Avenue, NE
Washington, DC 20002-3695

www.deafchildren.org asdc@deafchildren.org
Telephone: (800) 942-2732 Fax: (410) 795-0965

when the least restrictive environment is residential: meeting the needs of our son

Djenne-Amal Morris

is a parent educator/family specialist serving families of children who are deaf, hard of hearing, and deaf-blind and the professionals who work with them.

She provides support, training, workshops, and advocacy, and as the mother of a special needs child offers the unique perspective of a parent and professional. A North Carolina resident, Morris is most proud of being a wife and the mother of three amazing children. She welcomes questions and comments about this article at djennemorris@gmail.com and www.todaywithdjenne.com.



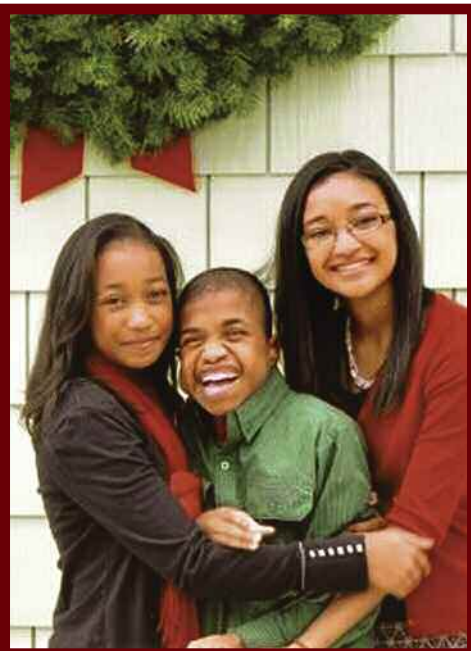
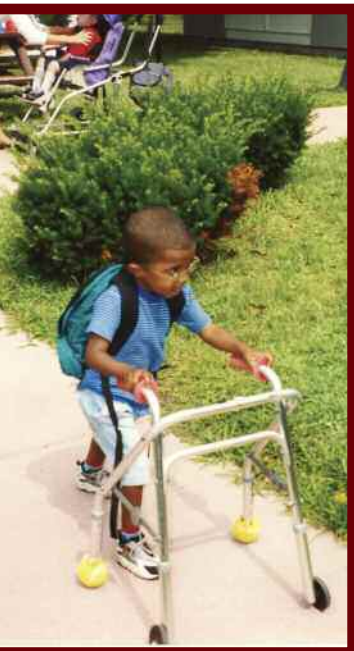
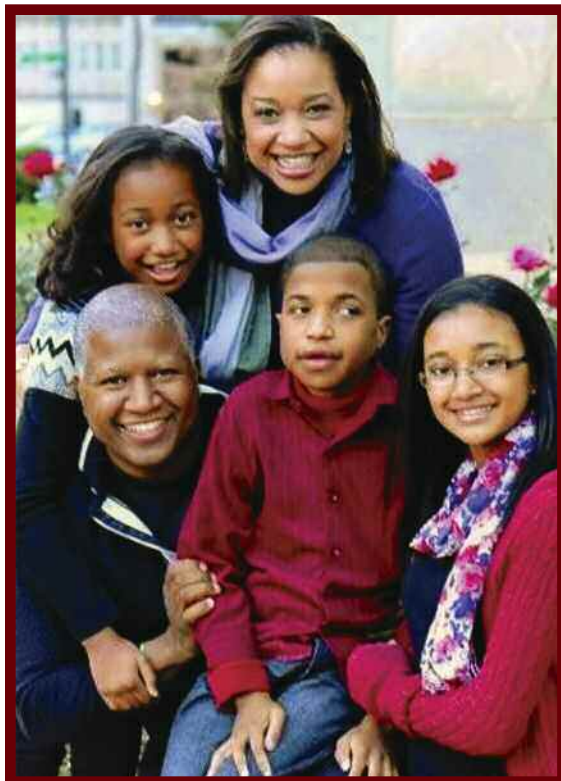
By Djenne-Amal Morris

Malik-Asante Lamar, whose name means “the King that we are thankful for who is destined to do great things,” was born in 1996, just 13 months after his big sister, Imani. The excitement of having our first son soon turned into a medical and emotional nightmare when he was diagnosed with tracheal esophageal fistula, a hole between the four chambers of his heart, and coloboma, a cleft in the iris of the eye that causes vision loss. It did not stop there. Within 48 hours, we’d been told that Malik was profoundly deaf, legally blind, and developmentally delayed. Our beautiful baby boy was also fighting for his life, but he had a strong will and spirit. He wanted to live! My husband, Michael, and I embraced him, and we braced ourselves for the unknown roads that lay ahead.

During his first three years, Malik received intensive therapies from amazing practitioners at state agencies and the Perkins School for the Blind in Watertown, Massachusetts. At age 3, he was diagnosed with CHARGE Syndrome, a genetic anomaly that underlay his medical condition. This knowledge didn’t change our situation. We assumed that he would transition into the pre-school program at Perkins and remain there for his education. We did not anticipate an educational battle with our local school system. However, when Malik turned 3 and was no longer eligible for early intervention services, this is exactly what ensued. Over the next five years, we tried to convince our local school system that his current placement was, indeed, the least restrictive for Malik.

Photos courtesy of Djenne-Amal Morris





At Perkins, they were familiar with CHARGE syndrome, and Malik was having his educational and medical needs attended. Our local educational agency (LEA) contested his placement, however, claiming that Malik could be successfully educated at the public school for deaf children. Unfortunately, this school did not have a teacher experienced in educating deaf-blind children, or the medical staff to handle Malik's tube feedings and nutritional maintenance, or the knowledge to handle what was then a fragile child through the variety of complex situations he would encounter throughout the day. If Malik attended what was the nearest public school, his day would be constantly interrupted as inexperienced personnel attempted to care give, and little learning would take place. Still the LEA was determined that Malik be removed from Perkins. We were equally determined that Malik not be a part of a program that did not yet

exist or that would be created for just him and did not include peer interactions or qualified staff, and we realized that we needed legal representation. This came in the form of a terrific lawyer, who happened to have coached my husband in high school soccer. We worked together to prove—not once but multiple times—that Malik needed to remain where he was. We found many allies, including a newspaper reporter who kept our story in the public eye, and doctors who wrote countless recommendations for Malik's placement at Perkins. After years of three- to four-hour meetings where we argued, the LEA finally seemed to accept our decision, though perhaps she was just worn down.

Meanwhile, Malik had become a handsome charmer. He was making friends, gaining weight, learning to sign, and had his amazing teachers wrapped around his finger. He zoomed around with his walker until he

took his first steps independently at age 6. By the time Malik was 8 years old, our family had grown yet again, and Malik now had two sisters. The northern winters seemed to be wreaking havoc on his young body, and we decided it would be best for our family to move south. I found that Eastern North Carolina School for the Deaf (ENCSD) had a program in which Malik would fit nicely. The placement was residential. This, of course, was the hardest decision I'd ever had to make. Still, I realized that it was the best place for Malik to grow and learn. He would benefit from the sign language immersion, peer interaction, and on-site medical facility. It would be best for the rest of us, too; we would be able to focus on the needs of the girls without the constant requirement of meeting Malik's needs around the clock. We would have a bit of normalcy.

Perhaps we should have expected it, but once we moved the educational nightmare blindsided us again. Our new LEA thought that the local school district—which had never enrolled a child like Malik with his specific and intense needs—should be where he was educated. I thought I had awakened from that dream! Here we go again, I told my husband. However, we had practice now. We immediately found an advocate, a person from the Exceptional Children's Advocacy Center. I was put in touch with the center by my parent educator at Beginnings for Parents of Children Who are Deaf or Hard of Hearing, the organization with which I now work as a parent educator. We called the newspaper and rallied to present our case to the LEA. Another round of endless meetings followed. We dug in our heels; we wanted our young King to receive the education he deserved. Fortunately, this process didn't take quite as long as last time, and Malik was placed in ENCSD, where he still is today. At ENCSD, he is taken care of by a great staff. This includes two deaf-blind interveners—individuals who

are deaf-blind. Both of these individuals are deaf adults, and they help Malik navigate his world, gather information, gain independence, and improve his self-help and communication skills. Malik is in heaven. He goes to school Sunday through Friday and hangs out with his family on the weekends, so he has the best of both worlds. He has made friends, his ability to communicate has improved, and his health, while still up and down with viruses and respiratory issues, is as stable as it has ever been. Our biggest challenge today is that we now have a teen on our hands!

A new, scary yet exciting, world opened up on the day Malik was born, and I would not be who I am or know the wonderful families that I know without him. What a journey this has



been! Has it always been smooth? Surely not. It's been a journey paved with fear, uncertainty, hospital stays, and sleepless nights. I've faced recurring crises—over the mortality of my child, the sanity of my family, and the challenge of keeping a marriage together and strong, all while trying to hold on myself. Still, because of Malik I have found my life's work: supporting families of children with special needs and the professionals who serve them. For this work, for my son, for our two daughters, and for my husband, I am grateful.

WHEN FIGHTING THE GOOD FIGHT

Tips for Parents

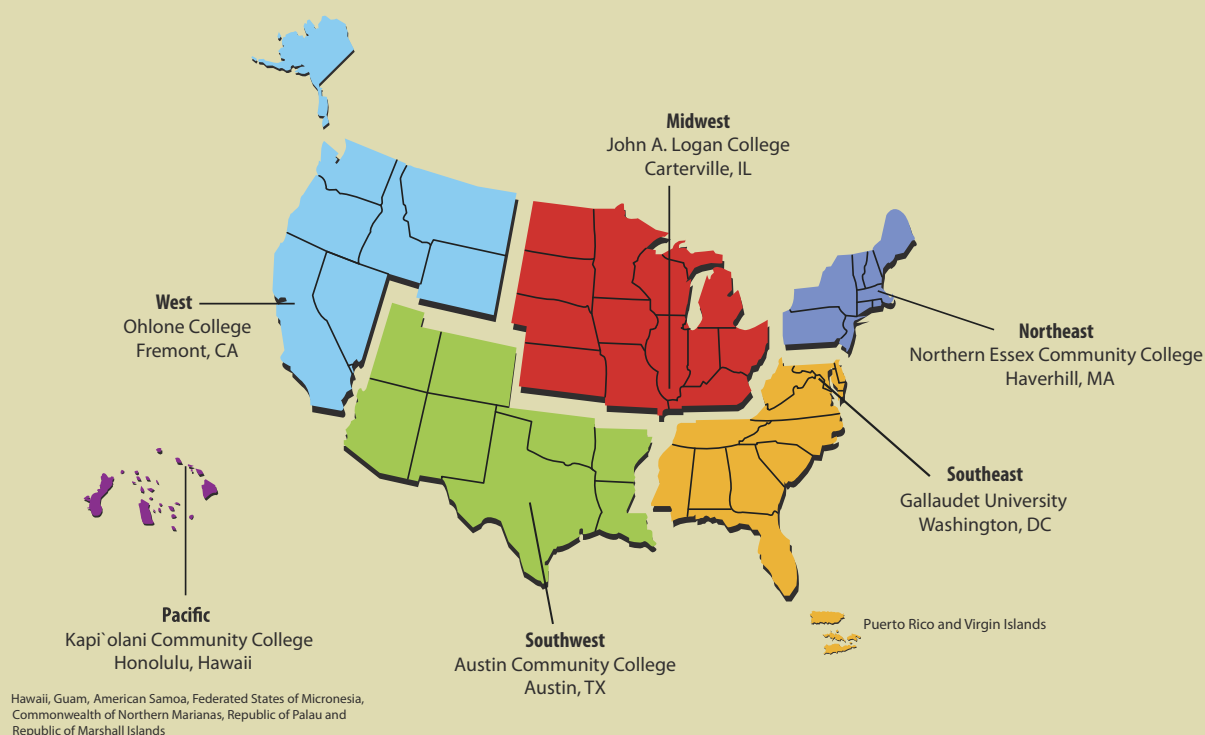
By Djenne-Amal Morris

- **Don't doubt yourself as a parent.** You are the true expert on your child. Remain confident that you know your child's needs the best. Trust your gut—sometimes instinct is the best guide.
- **Activate your support network.** Identify those—friends, family, coworkers, parent groups—that can give you honest advice, help you advocate for your family, and provide a shoulder to lean on when you need it.
- **Persuade with perfume!** Assume the best and think creatively and collaboratively to find solutions. Show gratitude.
- **Don't wait...escalate!** When you realize that you can't handle it alone, get help from the experts—educational, legal, social, and psychological.



REGIONAL CENTERS

Sharing resources across the regions!



The Gallaudet University Regional Centers (GURCs) share the resources of the world's only liberal arts university for deaf and hard of hearing people with regions across the country through partnerships with Austin Community College in Austin, Texas (Southwest), Kapi`olani Community College in Honolulu, Hawaii (Pacific), John A. Logan College in Carterville, Illinois (Midwest), Northern Essex Community College in Haverhill, Massachusetts (Northeast), and Ohlone College in Fremont, California (West) as well as directly from Gallaudet University (Southeast) itself.

Through the host institutions, Gallaudet University and the Laurent Clerc National Deaf Education Center, the GURCs offer extension courses, training workshops, and technical assistance to address the educational, transition, and professional development needs of deaf and hard of hearing people throughout the United States.

Contact us at gurc@gallaudet.edu or visit gurc.gallaudet.edu for more information.

Theresa Johnson,

MEd, obtained her graduate degree in education from the University of Georgia in Athens. She works at the Educational Resources Center on Deafness as an outreach specialist and serves as the director of Summer Programs at the Texas School for the Deaf (TSD) in Austin.

**John A. Serrano,**

MA, has worked at TSD as a teacher, assistant high school principal, and high school principal. He is currently TSD's director of Academic Affairs.

**Daniel Veit, MS,**

transition specialist for TSD, provides a variety of support to students and teachers. Veit was previously a career consultant at Gallaudet University in Washington, D.C., and a work study program coordinator at the New Mexico School for the Deaf in Santa Fe.



The authors welcome questions and comments about this article at theresa.johnson@tsd.state.tx.us, john.serrano@tsd.state.tx.us, and daniel.veit@tsd.state.tx.us.

CONNECTING SCHOOLWORK TO LIFE WORK:

students practice setting their own educational goals

By Theresa Johnson, John A. Serrano, and Daniel Veit

As educators working with high school students, we face questions such as:

- *How can students become better self-advocates?*
- *Are students sufficiently prepared for life after graduation?*
- *How can we help students become more motivated in planning their future?*
- *What can we do to encourage students to actively participate in their Individualized Education Program (IEP) meetings?*

At the Texas School for the Deaf (TSD), a committee faced the task of exploring these questions. Our goal was to increase student participation in transition planning and foster student involvement during meetings in which their IEPs were discussed, updated, and written. Hawbaker (2007), who studied what happened when high school students led their IEP meetings, showed that these students demonstrated more involvement in their academic work and transition planning than those who participated in staff-led IEP meetings. Through leading IEP meetings, students develop a firmer understanding of their need for services and supports and grasp more clearly how accommodations help them to access the curriculum. This understanding might prepare them not only for their coming years in high school but for their years in university or postsecondary school—and for the world of work beyond.

With evidence—and hopes—we decided to give this a try, and intensive planning began.

Photos courtesy of Theresa Johnson, John A. Serrano, and Daniel Veit



Advisory Time

One of our first actions was to reframe the homeroom period. Instead of having students show up for attendance and study time alone, we renamed this time “advisory time,” and devoted it to academic and personal uses. Advisory time can be described as an organizational structure that allows a small group of students to identify with one educator who nurtures, advocates for, and looks out for the individuals in that group (Cole, 1992). Research indicates that advisory groups improve the relationships between student and teacher and lead to improvement in academic achievement (McClure, Yonezawa, & Jones, 2010). Through the use of advisory time, students gain feelings of support, increased self-knowledge, and additional access to the curriculum. We revised the

schedule for all of the students in high school, incorporating 20-minute advisory periods Monday through Thursday and a 60-minute advisory period on Friday.

We planned a series of mini-workshops and presentations that broke the complex concept of transition into teachable ideas and skills. Presentations and materials were developed in advance for teachers. Topics included:

- What is Transition?
- Self-Determination and Advocacy Skills
- Knowing Yourself (Self-Assessment)
- Identifying Postsecondary Goals
- Developing a Coordinated Set of Activities
- Preparing for Your IEP Meeting

STUDENT CONTRIBUTORS



Margaret Kopp, a senior at TSD, is co-enrolled for courses at Austin Community College. An aspiring writer, she plans to attend Gallaudet University after high school graduation.



Amy Johnson, a senior at TSD, is a member of the Junior National Association of the Deaf, president of her class, and active in sports and other extracurricular activities. She spends her summers working in the science labs at the University of Texas.

Above left: The concept of *transition* is taught through a series of mini-workshops and presentations.

IEP Meetings

Advisory group teachers engaged in a dialogue to come to common understandings and to give us an opportunity to gather feedback and refine our materials. At the beginning of the year, students took various assessments and surveys to identify their interests, strengths, and needs. This led to students developing transition goals that were more relevant and meaningful. Once their goals were established, students were able to identify priorities. From there, they worked on developing presentations to include their goals, interests, skills, areas of need, and other concepts related to transition. Seniors were our priority, but over time we worked with all high school students.

The advisory group teacher worked closely with each student to prepare his or her presentation. The student would practice his or her presentation and make revisions as needed. The IEP meetings began with the student's presentation; this reinforced the idea that IEP meetings are about the student and his or her future. After the presentation, the IEP committee members asked questions and made comments about the student's presentation and his or her transition plans. They also asked the student questions to sharpen his or her focus. These questions might include:

- How does your course selection connect to your postsecondary goals?
- How do your present levels of performance and goals align with your transition plan?

Once the students see the connection between their schoolwork and the jobs they will hold after graduation, transition planning becomes more meaningful and streamlined, which prompts the students to be more engaged in their IEP discussions.



A Student Perspective

By Maggie Kopp

First thing in the morning, while students are still feeling the effects of staying up far too late the previous night, we go to our advisory groups. Our discussions there include topics such as bullying, college applications, and preparing our resumes. Our advisory teachers are people we can talk to about our grades or any other problem.

Our advisory teachers also help us assemble our PowerPoint presentations for our IEP meetings. By empowering us to lead our own educational proceedings, our teachers have taught us several important life lessons. We have learned how to discover the path we want to follow—and how to take steps accordingly. We have learned how to communicate our needs and goals to our teachers, our counselors, and our parents, and we have learned how to make commitments towards results we will not realize until sometime in the future. Taking small steps, such as having an opportunity to lead our own IEP meetings, prepares us to take the world head-on.

Even though I was quite involved with meetings in the past, until last year I never had the chance to be the one standing up at the head of the table giving a presentation. Instead of staff discussing my future while I watched, I could be more in charge of the meeting—and my own academic future. Instead of discussing “what to do with Maggie,” the principal, my teachers, and my parents asked me questions. It was refreshing to feel like my voice was actually taken into consideration.



Left: Amy Johnson practices a PowerPoint presentation in preparation for her IEP meeting.

A Student Perspective

By Amy Johnson

When I was in eighth grade, I became the first student in our school to make a presentation for my IEP meeting. The IEP committee liked this idea, and they suggested that other students make presentations for their IEP meetings, too.

Students use their presentations to educate everyone in the meeting about their point of view. My presentation has changed a lot since eighth grade, and it has been helpful for me to compare the old and new presentations to see how my goals have changed over time. My hypothesis is that if students are motivated to create presentations and show everyone their future goals and ways to improve, they will get more support from their teachers, the principal, and others. They will be more prepared for college and know what to do in college with the knowledge they gained from high school.

A Mother's Perspective

By Theresa Johnson

As a parent, I had the normal concerns about my daughter Amy and her academic progress, career goals, and life plan in general. Like most teenagers, she changed her mind frequently and often talked of selecting a college based on the single criteria of where her friends were going. However, I am blessed with a child who is bright, motivated, and competitive—and she realizes the value of a good education and making good choices regarding transition planning.

Although I was only marginally aware of some of the changes TSD principal John Serrano was initiating, as a teacher who has worked both in higher education and rehabilitation, I am familiar with the requirements driven by the Individuals with Disabilities Education Act and I understood what needed to be done to achieve a good transition plan. As a result, Amy began attending her IEP meetings in the first grade. Of course, at best she was too young to understand everything, but the experience served to plant the seed that this meeting is about her school and her life plans. By middle school, Amy did not like the meetings, but she was able to hold her own and participate in the IEP discussions, expressing preferences, needs, and dislikes.

It was in her eighth grade year that I suggested she prepare a PowerPoint presentation and assume some leadership during the meeting. Student-led IEP meetings had yet to be implemented at TSD, but we were fortunate to have Mr. Serrano's support. He requested the AV equipment and allocated plenty of time for the meeting. He recognized the potential in Amy and encouraged her to speak her mind and have an equal voice in the meeting. Without her even realizing what was happening, he empowered her to be assertive about her preferences. He honored her choices even when they might be questionable and gently guided her towards considering alternatives. By the ninth and tenth grades, the transition

meetings really became Amy's meetings. Mr. Serrano explained each document, and if Amy did not know the vocabulary, he would take as much time as needed to make sure she fully understood what was happening. By this time, I had a very small role during these meetings. I signed papers, gave nods of approval, and occasionally reminded the group about something I knew Amy felt was important.

Amy is in the throes of her senior year now. She will likely only have one last IEP/transition meeting in the spring before graduation. As she is very motivated to make this year her best, I have no doubt it will be a successful year full of plans for college, career goals, and excitement about the impending independence.

In spite of the success we've had, more work remains. We continue to refine the materials and resources for advisory group teachers, adding topics for specific student groups, and using student presentations that were developed last year as a starting point for their electronic portfolios related to transition planning. Still, we are proud of what we have accomplished so far. At TSD, our students are learning to take the lead.

References

- Cole, C. (1992). *Nurturing a teacher advisory program*. Columbus, OH: National Middle School Association. (ERIC Document Reproduction Service No. 360078)
- Hawbaker, B. W. (2007). Student-led IEP meetings: Planning and implementation strategies. *TEACHING Exceptional Children Plus*, 3(5). Retrieved September 4, 2012, from <http://journals.cec.sped.org/cgi/viewcontent.cgi?article=1305&context=tecplus>
- McClure, L., Yonezawa, S., & Jones, M. (2010). Can school structures improve teacher-student relationships? The relationship between advisory programs, personalization and students' academic achievement. *Education Policy Analysis Archives*, 18(17). Retrieved September 4, 2012, from <http://epaa.asu.edu/ojs/article/view/719>

Resource

- Uphold, N. M., Walker, A. R., & Test, D. W. (2007). Resources for involving students in their IEP process. *TEACHING Exceptional Children Plus*, 3(4). Retrieved September 4, 2012, from <http://journals.cec.sped.org/cgi/viewcontent.cgi?article=1145&context=tecplus>



Christine Griffin

lives in Bellingham, Washington, with her husband, Steve, and two amazing children who were identified with hearing loss 11 years ago. She is the program coordinator for Parent to Parent of Whatcom County and for the Hands & Voices and Guide By Your Side programs in Washington State. She welcomes questions and comments about this article at gbys@wahandsandvoices.org. Readers can also visit www.wahandsandvoices.org for more information about Washington State Hands & Voices.

standing up for our children

By Christine Griffin

I stepped into the sound booth with our 2-year-old daughter, Tess, on a warm fall day, battling my own fears. Only six months earlier, I was here in the same sound booth with the same audiologist with our 5-year-old son, Sawyer. Here, we had learned that Sawyer had a bilateral hearing loss. He received his first hearing aids only one month before entering kindergarten.

Our son's diagnosis had not come easily. We had voiced concerns about our quirky, fun-loving, seemingly shy boy to our family doctor, called a local speech clinic whose representative educated me on the spectrum of language development in toddlers, and even failed an evaluation with our district's developmental preschool when Sawyer "shut down," eventually burying his head in my lap during the testing process. Still, it wasn't until we changed doctors that we began to make progress. At the end of Sawyer's 5-year-old "well check," our new physician asked, "Do you have any concerns?" Of course we did, and this simple question started us on an incredible journey.

As we began discovering what our son's hearing loss meant, I began to wonder about Tess, his younger sister who was then a toddler. I put my suspicions temporarily to rest, remembering that Tess had passed her newborn hearing screening during a re-screen after discharge from the hospital. She also nearly always responded when we called her name and by using simple gestures made her demands very clear. Still, our beautiful and brilliant girl wasn't talking. I had to find out why.

After the testing, we were escorted to an examining room where we sat while the ear, nose, and throat doctor and the audiologist stood and gazed down at us. No one said anything, but the audiologist slid an audiogram into my lap. I was confused, and after a moment I asked, "Why are you showing me *Sawyer's* audiogram?" "This isn't Sawyer's," she said. "This is Tess's." For the second time in my life, I felt like I was hit over the head with a brick. The audiologist gave me the contact number for the lead family resources coordinator in our county, explaining that this person could put me in touch with others who could help. This was an improvement from the moment when Sawyer had been

Photos courtesy of Christine Griffin



diagnosed. It was a great relief knowing I only had one phone number to call.

During our initial meeting, the lead family resources coordinator described options for the services from which we could choose. From that moment on, we all benefited. Our family began using signs to communicate with our daughter and unbeknownst to us, Sawyer, who had no services at all in his neighborhood kindergarten, was learning signs alongside his sister. I have a degree in theater, and I began to use signs along with gestures to tell our children elaborate stories before bed. *Good Night Gorilla*, *The Lady with the Alligator Purse*, *Jamberry*, *Dream Snow*, *Paper Bag Princess*, and so many others were part of our library in those early years. For Tess, progress came quickly. The gestures she was already using grew to a collection of over 300 signs by the time she was 3 years old.

Yet during the time while Tess was involved so successfully with Birth to Three services, we continued to search for services for Sawyer. We had continued concerns about how he was accessing information and the lack of progress he was

making as he struggled in a mainstreamed classroom without any supports. I thought the professional educators would know what to do. They didn't, and our frustration increased as did that of our son, who began developing coping strategies for himself.

Meanwhile extended family support was fragile. Both sides were consumed with the question of why this could happen. When the science finally arrived—a genetic testing process that identified Connexin 26 as the cause—I was in need of support, someone who could listen rather than try to fix our situation. I craved just talking about the weather. This is when I reached out to Parent to Parent, a little known statewide program in Washington State that supports families of children with delays, developmental disabilities, and ongoing health care needs. The other parents I met there understood our situation; I felt as if I could breathe again. Many of these parents of children with similar diagnoses and experiences were a few steps ahead of me. I recognized right away their strength, persistence, and incredible knowledge. They had learned everything about their children and about their

**For me—and for
parents like me—the
relationships that I’ve
developed with
others have kept me
strong when I have
felt most vulnerable.**

community resources—and they empowered me to learn the same.

Initially I began doing parent-to-parent volunteer work for the same reason most of us do—I didn’t want another person to go through what we had gone through. However, now it’s more than just that. As coordinator of Parent to Parent in our local county and the Guide By Your Side program for Washington State, I am thankful for others whom I have bumped into and rubbed shoulders with, discovering ways in which to empower our children. Connecting one to one, I enjoy offering support and guidance to other parents as they move through diagnosis to acceptance and empowerment. It is a moving and individual journey that not only shapes their child’s future but that of Washington State—and our nation—as well.

With Tess’s diagnosis, I was lucky to meet professionals and other parents who helped me. The challenges with our son’s education grew, however, and eventually we had to look at an environment where Sawyer’s academic, social, emotional, and self-advocacy skills would be supported.

By the end of kindergarten when we finally got Sawyer’s Individualized Education Program, we knew that an itinerant teacher for deaf and hard of hearing students would not be enough for him; he was too far behind. We also understood that Sawyer was a visual and kinesthetic learner. He could describe the color and the style of people’s clothing. He knew what kind of shoes they wore. Still, he did not know how to ask people their names or he would immediately forget their names if he caught them. In addition to the appropriately offered academics, I wanted Sawyer to have peer interaction and be with other children with whom he could communicate freely. This meant Sawyer would be least restricted by attending a program that supported his learning in a signing environment. It also meant that my husband, Steve, and I would need to learn sign language.

For Parents You are Not Alone

As parents, we have a lot to consider in a very short period of time following identification of a hearing loss. It’s not enough that we want to love our child. Questions arise: How will we communicate with our child, and how will our child communicate with us? How will he or she form friendships with others? How will our child learn?

What makes it more difficult is that many families are caught in the ongoing argument over which communication is best for deaf and hard of hearing children. Experts and community members disagree—sometimes adamantly—about cochlear implants, the auditory/verbal system, Signing Exact English, American Sign Language, Cued Speech, Pidgin Signed English, and a variety of other communication beliefs that have turned the field of deaf education into a battleground.

Hands & Voices helps parents face this dilemma by offering information without bias towards any single communication mode. At Hands &

Below: Sawyer and Tess at about the time of their diagnosis with hearing loss.



Voices, we believe: “What works for your child is what makes the choice right.” Washington State formed a Hands & Voices chapter six years ago, adding the Guide By Your Side program two years ago. Our goal is to use trained parent guides to work with families individually, guiding and empowering parents to find and use the local, state, and national resources available for their children. We also offer an empathetic ear and help families make informed decisions for their children.

Through experience, I have learned about understanding perspectives that others bring. It’s essential to remember that as a parent, I am part of the system that serves my children and the children of others. I used to trust professionals completely. However, slowly through my own trial and error investigations and working with other parents, I have learned that often the most informed, enlightened, and dedicated advocate for a child is his or her family. If I do not raise my voice with other team members when decisions are made about my children, the wholeness is lost.

It is nice that educators acknowledge and often tell us that as parents we know our children best, and that we are our children’s best advocates. Still, knowing the skills to carry out such a role is another thing all together. What questions do we ask? How do we respond to comments made by others less knowledgeable about our children? And where do we find our courage and stamina to carry through? For me—and for parents like me—the relationships that I’ve developed with others have kept me strong when I have felt most vulnerable.

Today Tess is 13 and Sawyer is 16, and, despite attacks of typical teenage foibles from time to time, they are doing well. There is no doubt that early intervention was absolutely crucial. However, it’s not enough that we ask ourselves to merely survive, but rather we must actively explore in order to live productive and meaningful lives—both for ourselves and for our children.

Parents...Be Prepared! Check Out the On-line IEP

By Christine Griffin

The National Center on Severe and Sensory Disabilities (NCSSD) at the University of Northern Colorado posts a graph (www.unco.edu/ncssd/dhhIEP) to help parents of deaf and hard of hearing children prepare for working with school professionals on the Individualized Education Program (IEP). In the squares appear some of the possible explanations—called “conversation stoppers” by the NCSSD—that school officials use to deny a child services.

By clicking on the sentence in each square, parents can see possible responses to these often-used explanations. Using these responses, the NCSSD promises to help parents get the IEP team meetings moving again—in a more positive direction.

For each number, the NCSSD lays out the problem that the response represents. A possible parental response to this problem and the law supporting it are available with additional clicks.

For example:

14. Official explanation:

“Your child is two years delayed in language...we can’t really expect more than that.”

The problem:

Is this communication delay due to cognitive potential or lack of access to communication?

Possible responses:

- *Let’s make sure that my child is getting the communication he/she needs to learn.*
- *Let’s look at my child’s IQ scores again. What do we need to do to get his/her work in congruence with the IQ score?*
- *Lets look at tutoring...summer school...extra help.*

The law:

The Individuals with Disabilities Education Act of 2004 specifies that higher expectations for children should be assured, as should their access to the general curriculum to the maximum extent possible. Further, the law notes that in developing the IEP, the team shall consider the strengths of the child, the concerns of the parent...and establish short-term objectives related to the child’s needs.

1. “Sorry... we don’t have the money.”	2. “We’re not convinced your child needs that.”	3. “I have 400 other children in this building.”	4. “We assess your child using only teacher observation.”
5. “The general education teacher couldn’t be here today.”	6. “We’re the professionals, we know what’s best for your child.”	7. “Let us get back to you on how that might work.”	8. “I don’t have the authority to make that decision.”
9. “Your child is doing great... compared to other deaf/hh kids.”	10. “If you don’t teach your child sign, he’ll use it anyway when he grows up. You better do it now.”	11. “If you teach your child to sign, she will never learn to talk.”	12. “We took the liberty of filling out a ‘draft’ IEP ... please sign here.”
13. “Your child will have to use signed exact English. We don’t do ASL here.”	14. “Your child is two years delayed in language... we can’t really expect more than that.”	15. “You must be in denial, your expectations are too high for your child.”	16. “We don’t need to write that suggestion down in the IEP, we’ll do the best we can to get that done.”

Developed by Families for Hands & Voices

Copyright © 2008 National Center on Severe and Sensory Disabilities

Copyright © 2002, 2006 National Center on Low-Incidence Disabilities

Permission to use for educational purposes granted.



Janet DesGeorges, the executive director and co-founder of Hands & Voices headquarters, lives in Boulder, Colorado, with her husband, Joe, and three daughters, Leah, Danielle, and Sara (who is hard of hearing).

DesGeorges is an author of the National Center on Hearing Assessment and Management (NCHAM) e-Book, co-author of a chapter in *Special Education Law: A New IDEA for Students Who Are Deaf or Hard of Hearing; Auditory Disorders in Children*, and has written for many other publications. She serves on the faculty of the National Institute for Children's Health Quality Early Hearing Detection and Intervention Learning Collaborative and the Marion Downs Center Advisory. In addition, she co-chairs the Centers for Disease Control Parent-to-Parent Committee and chairs the NCHAM Parent Advisory Committee. DesGeorges welcomes comments on her article at janet@handsandvoices.org.

individualizing deaf education services: more important than ever before

By Janet DesGeorges

Every parent of a deaf or hard of hearing child has been there—sitting in an Individualized Education Program (IEP) meeting where services for their child are being determined by assumptions based on labels. Here are some of those labels:

- *Your child is deaf.*
- *Your child is hard of hearing.*
- *Your child uses spoken language.*
- *Your child uses sign language.*
- *Your child has no need for academic accessibility; therefore your child has no need for social accessibility.*
- *Your child has...unilateral/bilateral/mild/moderate/profound hearing loss.*

The list goes on, as educators fill in the blanks: “*Your child is X, so he or she needs Y.*”

As a parent just starting out with three children, one of whom was hard of hearing, navigating my way through communication and educational decisions was difficult. As a hearing person, I needed time to acclimate to what my hard of hearing daughter's life journey would look like. Also, I was inundated with people's opinions

Photos courtesy of Janet DesGeorges



about what I should or shouldn't do. As time went on and as I began to understand Sara, my daughter, more clearly, I became a stronger and more confident advocate. I was able to think about what she needed beyond the labels we often place on our own children and the children of others.

My thinking shifted as a result of my opportunities within the organization of Hands & Voices (www.handsandvoices.org), and the parents, deaf and hard of hearing adults, and professionals I met there. The organization supported the emerging culture of doing what works for an individual child rather than doing what others believed to be true for all deaf and hard of hearing children. I began to think that the primary goal for Sara was acquiring language, communication, and self-sufficiency—and not let modality drive our decision making. When each family does this, the steps may look different but the goal is the same. Our story is not, nor should it be, the story of every family, but the outcome should be the same: communication access and the success of the child.

An Interpreter for Our Daughter

Born with a moderate hearing loss, Sara had excellent speech, her primary communication was through voice, and her native language was obviously English. By the time she started school, people would make comments such as, “We would

never even guess....” However, when Sara was 7 years old, we began to question her communication access in the classroom. I had read *Our Forgotten Children: Hard of Hearing Pupils in the Schools* (Davis, 2001), an enlightening text that focused on education for kids who were not deaf and not hearing (i.e., hard of hearing); it cautioned about the potential for these children to “fall through the cracks,” not only in education but socially. We also had evidence that Sara’s hearing loss was progressing, and we wanted to think about her future, not just her current level of functioning.

A turning point came as I saw her results on *The Functional Listening Evaluation* (Deconde Johnson, 2010) that was administered in her classroom (available online at www.adevantage.com). This test showed that when Sara was in a quiet environment and close to the speaker, she could access 96 percent of spoken language. However, if she sat eight feet from the speaker in an environment with minimum background noise, and she had no access to the speaker’s lips, her speech reception dropped to 28 percent.

This was the data that convinced the IEP team that Sara needed more than listening to receive an appropriate education. At first there was some hesitancy: “After all,” some of her IEP team members said, “...Sara is hard of hearing” and “...Sara is oral.” It was my connection with other parents who



communication was through spoken language, signing would be a secondary support in the classroom. Therefore it made sense to provide signs in English word order—a type of signing that used to be called Pidgin Signed English and is now often referred to as Sign Supported Speech. Still, we also wanted Sara to become fluent in ASL so we incorporated acquisition of ASL grammar and structure into her day; at specified times, she would work with her interpreter to learn this language. As a family, we also gave her opportunities to be immersed in ASL through attending summer camps with other deaf and hard of hearing children.

had hard of hearing children that helped me begin to look beyond Sara's label—of *moderate hearing loss*, of *hard of hearing*—and seek fuller communication accessibility for her. Finally, the IEP team decided to pilot educational sign language interpreting services for Sara.

It proved to be a success, bringing Sara more fully into her classroom. I will always remember the day when she skipped through the door from school and said, “Today, the teacher said ‘mumble, mumble, mumble.’ I looked at the interpreter and understood to put my book in my desk.” I knew then that we had made the right decision.

As the years went by, Sara used both her visual and auditory skills as she stayed abreast of her work; she maintained her high level of spoken communication, and she maintained her good grades. When she started school as a high school freshman and walked through the door to her geography class, she was met with a teacher who had a full beard and a speaking style that resulted in her understanding nothing he said. Luckily, the interpreter was there for communication access.

Of course, interpreting services were just part of the accessibility toolbox we delved into with Sara. Like many parents, not only did we have to identify the need for an interpreter, but we also had to discuss the signs that would be used. At first I advocated for American Sign Language (ASL), understanding that it was the form of signing that most deaf adults use and wanting Sara to be competent in that language. However, as we began to discuss Sara's individualized needs, it became apparent that because her primary access to

Over the years, we faced many issues that resulted from Sara being an atypical interpreter user. She has good speech, so people think that she must be hearing well, even hearing everything. We have had to negotiate with the interpreters themselves to create a new level of awareness that the interpreting services would be her back up, not be her primary mode of communication. We have also had to deal with other issues such as boundaries, an important part of the personal relationship that develops in this unique and extended relationship between an interpreter and a student. We managed to navigate these issues, but if the IEP team, including myself, had been stuck on labels—*excellent speech*, *moderate loss*, *good grades*—we may not have gotten to the best solution for Sara's access.

Some of the benefits of utilizing interpreting services have been an increased competency in sign language skills, enhancement of social life through access to other deaf kids and adults, and possession of a tool that will be at her disposal whenever she so desires. Although everything has positives and negatives, neither Sara nor I have ever regretted the decision.

When Sara went to college, she chose other methods to access communication, such as using an FM system and increasing communication between herself and her teachers. To me, this was coming full circle; I'm glad Sara has felt the freedom in her own life to explore communication accessibility and make her own decisions.

Putz (2012) notes in *The Parenting Journey: Raising Deaf and Hard of Hearing Children* that, “Sometimes on the course of the

journey...the path changes in ways we can't imagine. As our kids get older, they begin to weigh in on our decisions and make decisions of their own. Sometimes their decisions go against everything we've known" (p. 55).

A New Generation of Children—Different and Yet the Same

The Individuals with Disabilities Education Act (IDEA) has always had *individual* as part of its spirit and its letter. However, as a parent and an advocate who has attended many IEP meetings, I've found that getting to *individual* can sometimes be a challenge, particularly with the low incidence of deaf and hard of hearing students in the special education system.

This generation of children who are deaf and hard of hearing are emerging with different needs than in the past. Due to advances in technology, early identification of hearing loss, and societal shifts, the old labels have blurred. Yet the differences of today's generation have not negated the truisms of old. It remains true that children today share the same heritage of those who have come before them—that high expectations and access to a solid education for individuals who are deaf and hard of hearing should be pursued relentlessly, developed individually, and enhanced through partnerships.

We, as parents, must partner with educators and support personnel to approach our children as individuals. A child's label—whatever it is—should not determine eligibility, school placement considerations, access to a critical mass of peers, or related services. IEP decisions should not be guided by a child's labels. Of course, there are shared and unifying rights for all

children who are deaf and hard of hearing, including rights to language, but there are individualized approaches to getting there. The paths to success are unique to each child.

Portions of this material were derived with permission from an article by the author on www.classroominterpreting.org.

References

- Davis, J. (2001). *Our forgotten children: Hard of hearing pupils in the schools*. SHHH publications.
- Deconde Johnson, C. (2010, revised). *The functional listening evaluation*. Available at <http://www.adevantage.com>
- Putz, K. (2012). *The parenting journey: Raising deaf and hard of hearing children*. Barefoot Publications.
- U. S. Department of Education. (2004). *Individuals with Disabilities Education Act*, Section 1400 Part A(d) Finding and Purposes.

Resource

- DesGeorges, J., & DesGeorges S. (2008). A "Why me?" *The story of an oral, hard of hearing atypical educational interpreter user*. Available at <http://www.classroominterpreting.org/parents/CaseStudies/DesGeorges.asp>

Strategies for Convincing the IEP Team

By Janet DesGeorges

The strategies that we used to convince the IEP team that our daughter needed additional support (i.e., a sign language interpreter) to access classroom communication included:

- **Objective testing/data**, i.e., *The Functional Listening Evaluation* indicated need
- **Subjective beliefs**, i.e., I, as a parent, was able to articulate to the team in a practical manner with support from research and articles what my daughter needed
- **Mastering details about who, what, when, why, and how** interpreting services would be used in Sara's particular case, including the need to build Sara's sign language skills in order to access interpreting effectively
- **Considering future needs**, as the IDEA specifies that the purpose of special education services is "to prepare students for further education, employment, and independent living" (U.S. Department of Education, 2004).
- **Agreeing to a time-limited pilot** to see if indeed this support service would be beneficial



John L. Luckner, EdD, is professor and coordinator of the deaf education teacher preparation program in the School of Special Education at the University of Northern Colorado in Greeley.

fostering skills in self-advocacy:

a key to access in school and beyond

By John L. Luckner and Sharon J. Becker

Self-advocacy occurs when deaf or hard of hearing individuals explain to hearing teachers, classmates, bosses, and officemates the nature of their hearing loss, their language skills, and the accommodations they require in order to effectively do their work, participate in conversations, and get involved in other activities.

Self-advocacy may be especially important for students who are deaf or hard of hearing and attend schools with predominately hearing peers and teachers. Similarly, it may be critical for deaf and hard of hearing adults who work with hearing coworkers. Self-advocacy may be like learning arithmetic; the skills for it may not come easily to some people. Therefore, self-advocacy should be taught while students are in school, giving them multiple opportunities to understand and practice their skills prior to entering postsecondary education and the world of work.

What is Self-Advocacy?

Self-advocacy has been defined as “the extent to which a student can identify the supports that he or she needs to succeed and communicate that information to others, including teachers and employers” (Friend & Bursuck, 2012). Educators and researchers have indicated that self-advocacy skills are vital for deaf and hard of hearing students to succeed in school, postsecondary education, and work environments (Bullard, 2003; English, 1997; Fiedler & Danneker, 2007; Garay, 2003; Hammer, 2004; Luckner & Stewart, 2003; Schreiner, 2007; Spencer & Marschark, 2010; Test, Fowler, Wood, Brewer, & Eddy, 2005; Wehmeyer, 2007).

Despite this widespread agreement, self-advocacy skills and opportunities to self-advocate are frequently not included in the instruction of students who are deaf or hard of hearing (Garay, 2003; Ingraham & Anderson, 2001; Velaski-Sebald, 2005). The consequence can be severe—students who are unable to advocate for themselves may end up unemployed, underemployed, and unable to live independently (Bowe, 2003; Wheeler-Scruggs, 2002).

Photo by John T. Consoli

Right: One of the four components in the framework to develop students' self-advocacy is leadership. Students should be able to lead their own meetings and make presentations.



Sharon J. Becker, MA, is a doctoral student in the School of Special Education at the University of Northern Colorado and has been a teacher of students who are deaf and hard of hearing for over 20 years.

The authors welcome questions and comments about this article at john.luckner@unco.edu and sjoybeck@gmail.com.

To Teach Self-Advocacy A Conceptual Model for Planning and Assessment

Test, Fowler, Wood, Brewer, and Eddy (2005) conducted an extensive literature review of self-advocacy and solicited input from more than 30 professionals to develop a conceptual framework. Based on four components, the framework has been modified by us for use with deaf and hard of hearing students. Using this framework, educators can develop a guide for planning and assessment. The components of the framework are:

- **Knowledge of self**—Students should develop an understanding of their interests, preferences, strengths, and needs. Simultaneously, they should be able to explain their hearing loss, be aware of the potential impact of their hearing loss on their academic and social lives, and be able to identify strategies that enhance their performance.
- **Knowledge of rights**—Students should know their rights as citizens, as individuals with a hearing loss, and as students receiving education under state and federal laws.

- **Communication**—Students should be able to interact effectively with individuals and small groups using appropriate body language, negotiation, persuasion, compromise, and, when necessary, assertion.

- **Leadership**—Students should be able to function in groups, lead their own Individualized Education Program (IEP) or transition meetings, make presentations about hearing loss, and mentor younger students.

Promoting Self-Advocacy Teaching Knowledge and Skills

Knowledge and skills in self-advocacy may be gained when professionals provide explicit instruction, set up role playing opportunities, and structure occasions to practice. Each of these educational activities is described below.

Explicit instruction. When providing explicit instruction, Archer and Hughes (2011) suggest using three processes to show students what they are expected to learn, to give them opportunities to practice the skill under conditions that promote high levels of success, and to provide an opportunity to demonstrate that they can perform the skill independently. The processes are:

1. Modeling or demonstrating the skills (the *I do* stage, in which the teacher models skills)
2. Providing guided practice (the *we do* stage, in which the teacher and the students practice skills together)
3. Providing unprompted practice (the *you do* stage, in which the students demonstrate skills unaccompanied)

Role play. Prior to situations that require students to use self-advocacy skills, educators and students talk through scenarios and use role play to practice the appropriate skills. Examples of role play include acting through situations that involve school and situations that involve transition. School

role play might prompt students to cope with such emergencies as the battery of his or her cochlear implant dying or a general education teacher who consistently chooses not to wear the frequency modulation (FM) system. Transition role play, on the other hand, might include a student choosing a plan of study to become a car mechanic, scheduling an interpreter for a medical appointment, or making plans to move out of the family home.

Structuring practice opportunities.

Students can practice using self-advocacy knowledge and skills during their IEP meetings. A four-level incremental approach for student involvement in IEP meetings, adapted from Mason, McGahee-Kovac, and Johnson (2004), allows students to address levels of opportunity as well as progress through levels in accordance with their age, capability, and opportunities for practice:

- **Level 1**—Students introduce everyone at the meeting to each other.
- **Level 2**—Students present their goals for the future.
- **Level 3**—Students explain their disability, share their individual strengths and challenges, and explain beneficial accommodations.
- **Level 4**—Students lead and close the meeting.

Putting It Together Teaching the Critical Skill of Self-Advocacy

Teaching self-advocacy should begin during elementary school, and specific self-advocacy goals should be embedded in IEPs to ensure that instructional opportunities for practice take place. Successful self-advocates overcome barriers, educate others, and make positive transitions to adult life. What more can we want for our students?

An Educator's Guide: Self-Advocacy Resources

Hands & Voices,
www.handsandvoices.org/needs/pdf_imgs/selfadvocacy.pdf

Hearing Loss Association of America, *www.hearingloss.org/content/advocacy-people-hearing-loss*

PepNet, *www.pepnet.org/resources/faq19*

National Association of the Deaf, *www.nad.org/issues/about-law-and-advocacy-center/advocacy-tips*

Informal Inventory of Independence and Self-Advocacy Skills for Deaf/Hard of Hearing Students,
www.handsandvoices.org/pdf/SAILInventory.pdf

Phonak's Guide to Access Planning, *www.phonakonline.com/MyGap/GapMain.html*

Self-Determination Synthesis Project, UNC Charlotte, NC,
http://sdsp.uncc.edu/sd_lesson_plans.asp

Me! Lessons for Teaching Self-Awareness and Self-Advocacy,
www.ou.edu/content/education/centers-and-partnerships/zarrow/transition-education-materials/me-lessons-for-teaching-self-awareness-and-self-advocacy.html

Self-Advocacy Competencies for Students Who are Deaf or Hard of Hearing

Developed by examining the work of Clark and Scheele (2005), the Douglas County School District (2009), the Iowa Department of Education Bureau of Student Family Support Services (2010), and the Laurent Clerc National Deaf Education Center's (2006) K-12 program, the chart below allows students to be evaluated on knowledge and skill competencies for each component necessary for successful self-advocacy.

	1	2	3	4	5
KNOWLEDGE OF SELF					
<i>Individual</i>					
Understands strengths and weaknesses					
Identifies interests and goals					
Understands his/her hearing loss					
• Type/degree of his/her hearing loss					
• Potential impact of his/her hearing loss on communication and learning					
• Technology, amplification, and assistive listening devices					
• Responsible for care of technology, amplification, and assistive listening devices					
Evaluates postsecondary options with respect to skill level and personal goals					
<i>Environmental</i>					
Understands impact of the environment on learning (e.g., noise, distance, attention, fatigue)					
Understands classroom factors that may help or hinder learning					
Understands accommodations					
Understands modifications					
Cultural awareness and preferences					
KNOWLEDGE OF RIGHTS					
Indicates basic wants and needs					
Understands the concept/definition of self-advocacy					
Understands the concepts of laws and rights					
Understands how laws and rights apply to self					
Understands the basics and implications of the IDEA					
Understands the basics and implications of the ADA					
Understands the roles and responsibilities of the interpreter/transliterators					
Understands the services, accommodations, and modifications listed on his/her IEP					
Understands the roles and responsibilities of the members of the educational team					
Understands public accommodations and how to access them					
Understands where complaints and suggestions can be directed to school personnel, various government agencies, or consumer groups					
Knowledge of local and national resources available to support the rights of persons who are deaf or hard of hearing					
COMMUNICATION					
Responds to meaningful information					
Attends to/participates in classroom discussions and respects other students' input (i.e., proper eye contact, turn-taking, social greetings)					
Follows directions and class rules to share information/communicate during instruction					
Monitors understanding and uses strategies to aid in comprehension					
Explains his/her hearing loss, potential impact, use of equipment, accommodations, and modifications					
Awareness of and identification of barriers to communication					
Effectively works with interpreters/transliterators					
Demonstrates communication repair strategies					
Effectively uses other access options (e.g., CAN, CART, peer notes)					
Expresses communication, academic and social rights, needs, and wants appropriately					
Accesses communication in the community					
LEADERSHIP					
Participates in goal-setting conferences					
Participates in IEP meetings					
Participates in transition planning					
Makes presentations to groups (e.g., students, parents, preservice teachers, teachers, community members)					
Mentors younger students					
1 = <i>Date selected</i> 2 = <i>Not observed or not applicable</i> 3 = <i>Inconsistent</i> 4 = <i>Consistent</i> 5 = <i>Generalized</i>					

Professionals on the Importance of Self-Advocacy

“If students do not learn to make choices based on their own interests and to experience and learn from the consequences of these choices in the structured environment of school, it is unlikely that they will be able to do so in response to the ever-changing demands of home, community, and work.”

~ Michael L. Wehmeyer
(2007, p. 18)

“Clearly, the embedding of specific self-advocacy goals into an IEP is one of the strongest assurances that such instruction will take place and be monitored for accountability, just as teachers instruct and monitor other important student goals.”

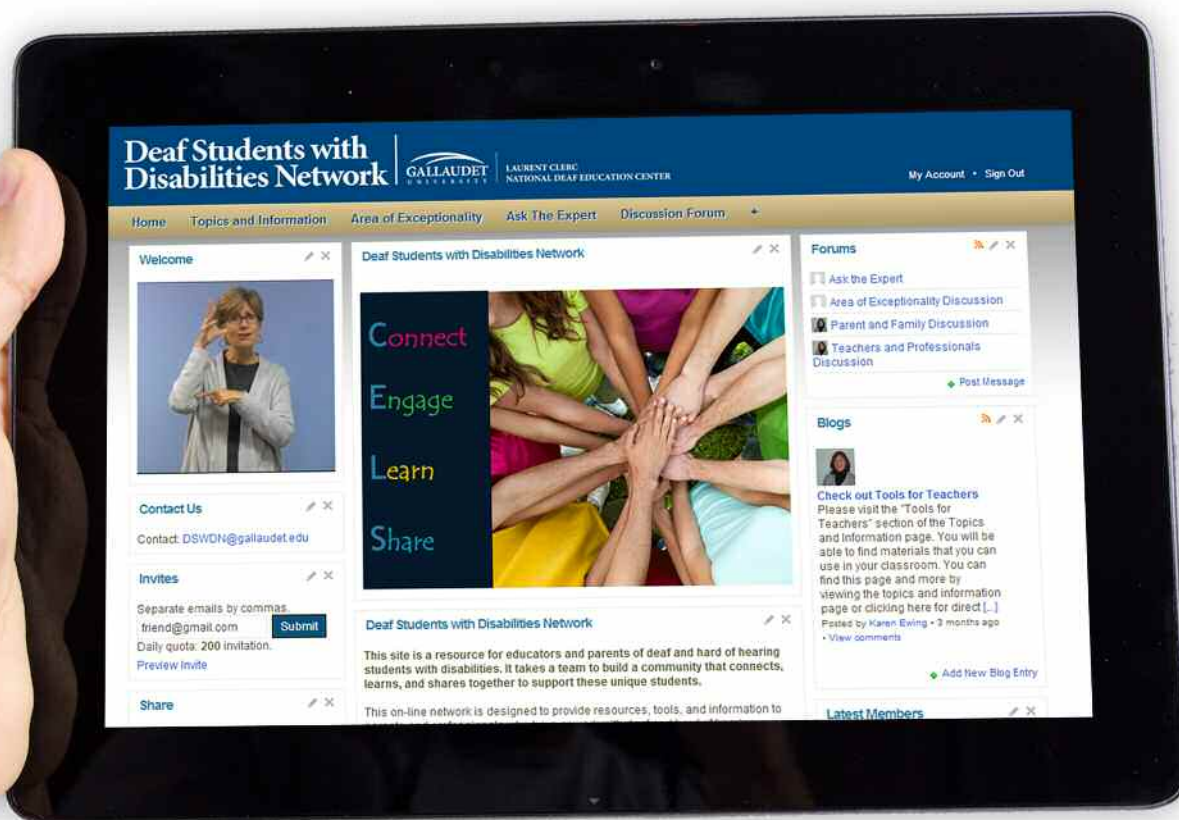
~ Mary B. Schreiner
(2007, p. 303)

References

- Archer, A. L., & Hughes, C. A. (2011). *Explicit instruction: Effective and efficient teaching*. New York: The Guilford Press.
- Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education*, 8(4), 486-493. doi.org/10.1093/deafed/eng024
- Bullard, C. (2003). *The itinerant teacher's handbook*. Hillsboro, OR: Butte Publications, Inc.
- Clark, G., & Scheele, L. (2005). *Informal inventory of independence and self-advocacy skills for deaf/hard of hearing students*. Retrieved from <http://www.handsandvoices.org/comcon/articles/selfAdvocacy.htm>
- Douglas County School District. (2009). *Self-advocacy skills for students who are deaf or hard of hearing*. Unpublished manuscript.
- English, K. M. (1997). *Self-advocacy for students who are deaf or hard of hearing*. Austin, TX: Pro-Ed.
- Fiedler, C. R., & Danneker, J. E. (2007). Self-advocacy instruction: Bridging the research-to-practice gap. Focus on *Exceptional Children*, 39(8), 1-20.
- Friend, M., & Bursuck, W. D. (2012). *Including students with special needs: A practical guide for classroom teachers* (6th ed.). Upper Saddle River, NJ: Pearson Education, Inc.
- Garay, S. V. (2003). Listening to the voices of deaf students: Essential transition issues. *Teaching Exceptional Children*, 35(4), 44-48.
- Hammer, M. R. (2004). Using the self-advocacy strategy to increase student participation in IEP conferences. *Intervention in School and Clinic*, 39(5), 295-300. doi:10.1177/10534512040390050601
- Ingraham, C., & Anderson, H. (2001). Self-determination, transition, and deaf-blind students. *Odyssey*, 2(3), 24-25.
- Iowa Department of Education Bureau of Student Family Support Services. (2010). *The expanded core curriculum for students who are deaf or hard of hearing*. Retrieved November 6, 2012, from http://educateiowa.gov/index.php?option=com_content&view=article&id=584:audiologydeaf-and-hard-of-hearing-education&catid=539:programs-a-services&Itemid=3099
- Laurent Clerc National Deaf Education Center. (2006). *Transition skills guidelines*. Retrieved November 18, 2012, from <http://www.gallaudet.edu/documents/clerc/tsg.pdf>
- Luckner, J. L., & Stewart, J. (2003). Self-assessments and other perceptions of successful adults who are deaf: An initial investigation. *American Annals of the Deaf*, 148(3), 243-250. doi.org/10.1353/aad.2003.0020
- Mason, C. Y., McGahee-Kovac, M., & Johnson, L. (2004). How to help students lead their IEP meetings. *Teaching Exceptional Children*, 36(3), 18-24.
- Schreiner, M. B. (2007). Effective self-advocacy: What students and special educators need to know. *Interventions in School and Clinic*, 42(5), 300-304. doi.org/10.1177/10534512070420050701
- Spencer, P. E., & Marschark, M. (2010). *Evidence-based practice in educating deaf and hard-of-hearing students*. New York: Oxford University Press.
- Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*, 26(1), 43-54. doi.org/10.1177/07419325050260010601
- Velaski-Sebald, A. M. (2005). *Teacher perceptions of self-determination for students who are deaf or hard of hearing*. Unpublished doctoral dissertation, University of Northern Colorado.
- Wehmeyer, M. L. (2007). *Promoting self-determination in students with developmental disabilities*. New York: Guilford Press.
- Wheeler-Scruggs, K. (2002). Assessing the employment and independence of people who are deaf and low functioning. *American Annals of the Deaf*, 147(4), 11-17.

Deaf Students with Disabilities Network

Announcing a new on-line resource from the Clerc Center that provides support to families and professionals of deaf and hard of hearing students with any of the 13 disabilities identified in the Individuals with Disabilities Education Act



Resources, recommendations, and promising practices

- “Ask the Expert” Forums
- Parent-to-Parent Networking (coming in summer of 2013)
- Discussion Forums





Joey Lynn

Resciniti lives in the greater Pittsburgh area with her husband, Tim; 7-year-old daughter, Julia; and two Shih Tzus, Luke and Leia. Resciniti is the president of Hands & Voices of Pennsylvania, an organization dedicated to helping families with deaf or hard of hearing children whatever their chosen mode of communication. She welcomes questions and comments about this article at contact@handsandvoicespa.org.

Right: Julia and her surfing instructor communicate face to face while out on the water.

THE GREAT SELF-ADVOCACY WAVE!

mom teaches most important lesson: “explain!”

By Joey Lynn Resciniti

My first lesson on childhood hearing loss was a speech banana printed on glossy paper with bright red X's and O's. My daughter Julia was almost 3 years old. The speech banana showed that she had not been hearing most of the conversation in our house. She had not heard the birds singing outside or the whoosh of traffic along the busy road. The clinical term that described this was *moderate sensorineural hearing loss*.

Soon after she got hearing aids, Julia stood transfixed as a neighbor scraped garbage cans across asphalt. Soon, however, she turned her attention to speech and by her fourth birthday had caught up with her hearing peers.

Ever a proud parent, I was there for almost every moment of her earliest years. I followed wherever she went, carrying fresh batteries and a safe dry case in which to stow the hearing aids in case of rain or trips to the swimming pool. Julia patiently tolerated me, and I remember our first triumph of understanding and self-advocacy came with her pronouncement, “My magic ears can’t get wet.”

Lots of other self-advocacy pieces came together quite easily. Julia is a front row character by nature. She automatically seeks the first pew in church, dragging us along with her, even in the face of our discomfort at being so close to the preacher—only to abandon us 10 minutes later for the children’s program.

Kindergarten found her proud to explain hearing loss to her classmates. She had a trained teacher of the deaf and embraced the information and strategies she learned from her. She mastered drawing a remarkably clear picture of a cochlea and informed adults and children that “those little hair cells that transmit sound to my brain are not

Photos courtesy of Joey Lynn Resciniti



working or missing.”

For all Julia knew about her hearing loss and assistive technology, there was much she was content to let Mommy handle. She lost more hearing in late 2010 and started having a tougher time communicating when the hearing aids couldn't be worn. As she was an avid swimmer, the no-hearing-aid-possible occasions occurred frequently during the summer.

I took on the role of interpreter, repeating loudly in her ear what anyone might be trying to say to her. The next summer, she became reliant on me to announce, “Julia can't hear very well. Can you try to talk louder? Don't be afraid to get right in her ear.” We learned a few signs together as a family and got on fairly well when it was just the three of us in the pool. It was those other people in the world that caused the problems. A group swim lesson became a near complete waste of time when even I couldn't get the instructor to make himself heard. I ended up sitting in the hot sun at the side of the pool taking direct splashes to the face so I could repeat instructions into Julia's ear. It was then that I realized I

could not protect my daughter forever. Yes, she was still a child, but already she was going places I could not be, dealing with adults and other children as the individual she would become. I knew I had to step back, and I adopted a new mantra: Tell people what they need to do for you to hear them.

From then on, I would help her, but not without reminding her that she could do it herself. Instead of explaining to others, I told Julia to explain herself.

“Tell your cousin you need her to talk louder if you can't hear her.”

“It might help if you teach her some signs.”

“They probably don't realize your hearing aids are out. You might have to remind them.”

Julia learned—and she learned quickly and well. This past summer swim class went much better. Now a mature first grade graduate, Julia would at least give a hearty, “What?!” if she didn't catch what was said. “Don't go with the instructor unless you know what you're supposed to do,” I advised. Julia would nod and stay on the steps until she understood, often forcing the



instructors to repeat the directions or demonstrate the required stroke. She passed her swim test with flying colors, possibly empowered by the knowledge that it's always okay to ask for clarification. It was a little win, but instead of telling the story myself I just constantly reminded Julia to tell her own story. Still there was that part of me, always charged, ready to take up my daughter's cause.

The last week of August presented an extraordinary opportunity for my family. My husband, Tim, had to travel to Honolulu. Julia and I were fortunate to have the chance to accompany him for the week before the start of second grade. Influenced by a certain Barbie movie, Julia had developed what she called a lifelong dream. She wanted to learn how to surf. Living as we do in Pittsburgh, I spent the better part of two years trying to talk her out of this. "Surfing is hard," I counseled. "We don't live near an ocean... You might not even be able to do it!"

Once in Hawaii, Julia talked about surfing so much that her dad and I rather brusquely informed her that if she so much as mentioned the 'S' word again, we would most certainly not be surfing. She settled down and we set up a time for Julia and her dad to have a semi-private lesson with the North Shore Surf Girls. The two of them sat on gigantic surf boards talking to the instructor, Carol. I was hanging back from the group, waiting for a break in conversation and wondering if I should give my spiel about Julia's hearing loss. Midway through Carol's long talk, Julia's hand went up. I expected she might have some Barbie-related question that would possibly make

me laugh or just shake my head. "I can't wear my hearing aids in the water," said Julia. "So I'm going to have a hard time hearing you when we're out in the ocean." That began the conversation, and Carol and Julia proceeded to discuss communication needs. Tim and Julia taught Carol the signs for "yes" and "no." Carol indicated she'd give Julia a big thumbs-up when she was doing it right.

That moment froze in my memory. I could have laughed, cried, and done a happy dance. That was it! It took years and happened 3,000 miles from home, but Julia, at 7-and-a-half years old, had finally told someone exactly what she needed. Unprompted.

The plan worked flawlessly. Julia stood up on the first wave and rode it all the way in before politely crouching back down on her board. Time and time again she surfed, talking to Carol in between. At one point she told Carol, "My mom told me I wouldn't be able to do this."

"I was wrong!" I told her when she finally came in from the water two hours later. "You did it!" Later Tim and I told Julia how special it was for us to see her explaining her hearing loss to her teacher—self-advocating during her surf lesson. Julia shrugged. Suddenly it was no big deal.

But it *is* a big deal. It is a tremendous accomplishment. Now I know Julia has the tools. She can do anything.





The Conference of Educational Administrators of Schools & Programs for the Deaf (CEASD) Announces the Child First Campaign

Child First is a national campaign to ensure that the Individuals with Disabilities Education Act (IDEA) appropriately addresses the language, communication, and educational needs of deaf and hard of hearing children. Child First was developed and is being driven by national organizations that advocate for the educational rights of deaf and hard of hearing children.

Child First seeks to:

- shift the focus of the IDEA back to the individual needs of the child; and
- ensure that deaf and hard of hearing children's IEPs and educational placement facilitate full language and communication development, which will lead to greater educational success.

To find out how you can support improved outcomes for deaf and hard of hearing students visit www.ceasd.org.

Take Advantage of the Best Resource for Educating Deaf Students



American Annals of the Deaf

The standard for teaching deaf students for more than 160 years, the *American Annals of the Deaf* quarterly is complemented by the annual reference issue, which lists educational programs for deaf students in the United States and Canada.

Read issue abstracts online!
<http://gupress.gallaudet.edu/annals/>

Annual Subscription Rates

Individuals: \$55/yr. Institutions: \$95/yr.

Subscribe online for discount rates:

<http://gupress.gallaudet.edu/annals/subscrib.htm>



Gallaudet University Press
800 Florida Ave., NE, Washington, DC 20002-3695

VL2 PRESENTS...

THE BAOBAB

INTERACTIVE ASL/ENGLISH
STORYBOOK APP



- First of the VL2 Storybook Apps for the iPad!
- Original story told in ASL and English
- 170-word American Sign Language glossary
- Vivid Retina-supported watercolor illustrations
- Design principles are based on research



NSF supported
Science of Learning
Center on Visual
Language and
Visual Learning
Grant No.: SBE-1041725



www.vl2storybookapps.com

ADVOCATING FOR CHILDREN AND THEIR FAMILIES WITHIN THE SCHOOL SYSTEM:

REFLECTIONS OF A LONG-TIME

special education advocate



Ruth C. Heitin, PhD, is a special education consultant in private practice serving students with special needs in Northern Virginia. Heitin previously taught special education and has certification both as a teacher and as an elementary school principal. She received her doctorate in special education administration from Gallaudet University in Washington, D.C. She welcomes questions and comments about this article at info@educationalconsultingva.com.

By Ruth C. Heitin

As I often tell people, my parents, who died in the late 1980s, would not understand what I do for a living. In their day, the idea of questioning the schools in any way was heresy. Educators always knew best, and teachers always had the last say in all matters of education. However, with enactment of a federal special education law in 1975, local schools had to abide by federal laws and regulations in order to guarantee the rights of students with disabilities. Educational decisions for students with special needs became the joint responsibility of parents and school professionals. Parents not only needed to become advocates for their children, but the field of special education advocacy opened to assist parents in doing so.

Early in 1992, I embarked upon my career as a private special education consultant. I do not usually call myself an advocate because, by definition, advocate means to speak or plead the cause of another, and I am always hopeful that the schools, the parents, and I will work in collaboration and all work for the same cause. Still, it may be necessary to specify what a special education advocate does. Advocates can serve as independent specialists, or, like those in the medical profession, offer second opinions on educational issues. Advocates work for parents, either directly or through a nonprofit group, but their real clients are always the children.

In order to support the child, advocates should be able to support parents through every step of the special education process, from initial evaluation through graduation and beyond, from the initial identification of the child to, if necessary, due process. Advocates are not lawyers, nor can they serve in lieu of attorneys. Their role is one of support for parents in understanding and addressing the issues related to their children's educational needs. Advocates go to meetings with parents, assist in writing Individualized Education Programs (IEPs), help parents understand their child's educational records, clarify the child's educational needs, and help identify and locate appropriate educational services and programs.

Photos by John T. Consoli



Above and right:

Special education advocates can provide parents with support as needed to navigate the complex educational process.

Below, I share with you my reflections or “confessions.” Some of these I say with pride, while others I admit with due humility.

Confession #1

The school’s reception is not always warm. While the result of the advocate’s work is that parents feel empowered, unfortunately sometimes school administrators feel inconvenienced at best and, at worst, they may feel the need to “circle their wagons” against the parents’ and advocates’ attempts to secure appropriate education and accommodations for children with special needs. Remember, parents always have the right to bring anyone to meetings that they feel has some specialized knowledge related to their children’s needs.

Confession #2

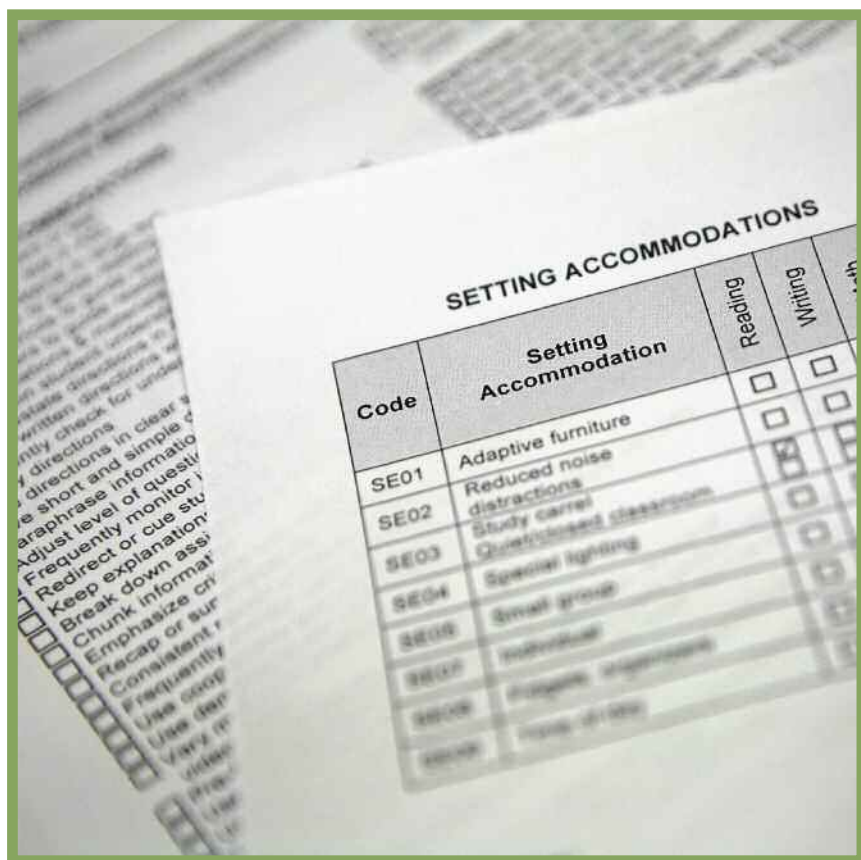
All advocates are different. Advocates have no licensing board, and there is not yet an independent professional licensing body for advocates. This means that there is no agreed-upon standardized set of skills that would qualify one as an advocate. Advocates can get training and sometimes certificates from professional groups or private professionals. Unfortunately, though, anyone can call him- or herself an

advocate. This means buyer beware.

Generally, there are two types of advocates—those who enter the field following a career in special education, usually as teachers, and those who fall naturally into the role of advocacy after they have secured success for their own children’s special needs following a long fight with the schools. I fall into the former category, although it was only a few years into my practice when I found myself advocating for my own son’s special needs. Advocates often have different ways of practicing. While there are those who prefer to show up to meetings unannounced, I always call ahead and let an administrator know that I am coming. I also meet and interview the child—after I first read all the background material available about his or her situation. Different advocates have different styles and practices. Parents and school administrators must feel free to ask about an advocate’s style, background, and experience.

Confession #3

Not all advocates love to fight. However, no advocate should be afraid to disagree over issues, and it is an advocate’s job to be sure that all the tough issues are addressed. Standing up for what we believe in the face of dissension and disagreement is often a necessary part of our job. We have to



Confession #5

Yes, sometimes advocates do know more than school professionals. A good advocate has studied special education law and regulations extensively. School professionals do not always have the luxury to take the time to do this. They rely on school system policies and training to keep them informed about what they need to know. As a result, too often school professionals confuse policy with law. An example of this is that school professionals too often do not address teaching methodology—such as that of a specific reading program—in IEP discussions. However, there is nothing in the law that prevents them from talking about reading methodology and including it in the IEP. A school system’s policy or preference should not take precedence over or limit the legal rights granted in special education law and regulations.

Confession #6

Some school professionals find advocates helpful. In helping parents to advocate effectively, I have sometimes had to advise parents to send fewer e-mails or educate them

keep the child’s needs separate from the school’s needs as we know they aren’t always in sync. Like it or not, we often have to deal with hard issues. Whether or not we “like to fight,” often fight is what we have to do.

Confession #4

Advocates nitpick over details because details matter.

Too often, it is the details of the IEP that make a difference. When advocates scour the details, it is for a very good reason. For example, too often schools write accommodations that include the words *if necessary*. Those two words can negate the accommodation by failing to assure that it is offered.

Details can also make a difference in giving parents the information they need to make informed decisions about their children’s proposed IEP. For example, recently I had an IEP meeting in which a professional wanted to include several different service models in a single time period. She did this to give herself flexibility: she could observe the child, consult with teachers, or meet directly with the child. The problem with an IEP structured this way is that the parents cannot know the setting or duration of the services offered. Without these details, the parents cannot make an informed decision; they cannot know if their child is getting an appropriate education. After discussion, the individual finally agreed to specify how much time would be spent in each of the services.

on what is reasonable and what is not in terms of accommodations. Additionally, an outsider can sometimes make a case for a child more effectively than a school professional, who may hesitate to voice his or her opinion for fear it may be seen as “making waves.”

Recently, in writing an IEP for a child with a physical disability, the parents and I gathered information to make a case for more special education help in the general education environment to ensure the child’s safety. It was clear to me that the general education teacher welcomed this child in her class, but it was also clear that the general education teacher was relieved both to have additional support for this child and not to have to ask for it. In this case, the parents, school professionals, and advocates all wanted what was appropriate. It is my experience that if school administrators are doing their professional best, they should never be afraid of working with an outside professional.

Confession #7

Advocates are not simply representing parents. I often tell my clients that if they have chosen me to say what they want, they have the wrong person. It is my job to give my best professional opinion based on a great deal of information gathering about what is appropriate for a child—and to do what is best for the child. Of course, the parents and I should

be in agreement over the issues and, before attending any meeting, we work together to reach a mutual understanding and consensus.

I have lost clients over this. Most recently I consulted with the parents of a young girl with autism. My observations and the child's records indicated that this child's behaviors and language skills were so problematic that she needed the support of a small class with very specialized instruction. The parents wanted her to be integrated full time in general education. I could not support their decision. I maintained my professional ethics, and we parted ways.

Confession #8

Parents need the support of advocates now more than ever before. The economic downturn and its resulting tighter budgets and fewer resources in education have increased the natural tension between parents and school professionals. Even though the law mandates that children qualifying for special education receive appropriate services regardless of cost, administrators are always aware of budget constraints and this has naturally shifted their perspective. What was once deemed a necessary service is, in today's economy, sometimes viewed as a luxury that schools feel they cannot afford.

I have seen a tightening of services offered across the board, whether it is in the hours devoted to special education and related services, the provision of technological aids, the support of nursing or paraprofessionals for health and safety issues, or generally the undertaking of any task, such as data gathering, that could consume professional time. Given the school's budget constraints, parents are in the position of having to build clearer and better cases to show what their children need. School officials often believe that parents work from emotion rather than from reason or reality, and the support of an advocate can help ensure that parents' concerns are

appropriately addressed. Further, in this economy, teachers are often reluctant to recommend that a child receive more support, whereas the identification of this need from an advocate can take that pressure off the teachers.

And Finally...

Perhaps my biggest confession is so important that it does not have a number.

Here it is: During my practice, I have been able to help parents obtain special education eligibility and services for their children when they could not do so on their own. When parents face a room full of school professionals whose perspectives may differ from theirs, it sometimes helps to have an experienced professional on their side.

Advice for Parents

WITH CONCERNS ABOUT THE EDUCATION OF THEIR DEAF OR HARD OF HEARING CHILD

By Ruth C. Heitin

- **Consider an advocate.** Advocates may be skilled evaluators of a child's educational program, and they are sometimes more successful in obtaining services than the parent or other educators.
- **Don't be upset if the school tries to discourage your decision to have an advocate involved in your child's education.** You have the right to seek counsel from whatever expert you choose—and to bring that expert to meetings.
- **Select an advocate based on references from an organization or individuals you respect.** There is no licensing board for advocates.
- **Provide the advocate with all the paperwork concerning your child.** If the advocate does not ask for this, consider looking for someone else.
- **Expect the advocate to show interest in the details of your child's IEP.** As the saying goes, the details are where one finds both angel and devil—effective strategies and useless speculations.
- **Consider the advocate's opinion.** A good advocate will not mimic your point of view or embrace it without thinking about your position. A good advocate will place your child first.



PHOTO COURTESY OF RUTH C. HEITIN



Heather Stinson,
CAGS, MED, S/LP-A,
received her master's
degree in education of
the deaf from Smith
College in 2006, and her
CAGS in education:
children, families, and
schools, with a
concentration in research
methodology, from the
University of
Massachusetts in 2012.
Stinson, an itinerant
teacher for the Clarke
Schools for Hearing and
Speech, works with
families and students
with hearing loss of all
ages in a variety of
settings, providing
services to students in
western Massachusetts
and southern New
Hampshire. She
welcomes questions and
comments about this
article at [hstinson@clarke
schools.org](mailto:hstinson@clarke
schools.org).

ESSENTIAL IN ENSURING ACCESS TO SERVICES:

a teacher of the deaf

By Heather Stinson

From down the hall in the local preschool, laughter can be heard as 4-year-old Jacob works in the physical therapy room. Among the colorful balls, heavy mats, climbing stairs, and therapy tools, Jacob's soft red curls bounce and his eyes sparkle behind the frames of his blue glasses. "Go!" His therapist models the word by saying it and gesturing across the line of colorful rubber squares. Jacob, his hearing aids tucked behind his ears, attempts to imitate her as he awaits the opportunity to hop across the colored mats.

Due to a complicated birth, Jacob has multiple developmental delays and receives services from the occupational therapist, physical therapist, and speech-language pathologist who are employed by his school district. Jacob also works with a vision specialist and a teacher of the deaf and hard of hearing, both contracted through local agencies outside of the school.

In addition to working with Jacob individually, the teacher of the deaf and hard of hearing works with Jacob's family and other service providers to develop communication goals and coordinate the activities of the other professionals. In this way, Jacob's language goals are incorporated into his occupational, physical, and vision therapies, and into the instructional practices in Jacob's general education classroom. Research on inclusion for students with hearing loss (Eriks-Brophy et al., 2006) and special education and general education collaboration (Chidindi, 2012) support this practice.

It was not always this way. Jacob began his first year in his local public preschool program attending five full days each week with support from an individual aide. His classroom included typical three year olds as well as children with a variety of special needs. In addition to time spent in the classroom participating in the traditional centers, circle time, projects, and activities, Jacob was pulled out to work individually with his specialists. Included in his pull-out times were twice-monthly, hour-long services from a teacher of the deaf and hard of hearing.

Photos courtesy of Heather Stinson



weekly, a schedule that has continued into the current school year. Jacob's classroom aide frequently sits in on Jacob's sessions and then shares information on that teacher's activities and suggestions with the teacher in Jacob's classroom for use throughout the week.

The teacher of the deaf and hard of hearing also shares objectives with Jacob's other service providers, communicates with the adults in the school to facilitate achievement of Jacob's communication goals, and implements strategies for increasing the involvement of Jacob's family at home. Increased time in the school means that the teacher of the deaf and hard of hearing has more opportunities to confer with individual service providers while sharing and modeling strategies for communication and management of amplification.

Effective Inclusion for Children with Hearing Loss

With the onset of universal newborn hearing screenings and early identification and amplification, children with hearing loss are able to receive education in mainstream classrooms as early as preschool. According to a 2011 report from the U. S. Government Accountability Office (GAO), 52.6 percent of preschool-age children with hearing loss in the United States are educated at least part of the school day in their local preschool classrooms; this increases to 86.3 percent for school-age children (GAO, 2011).

The teacher of the deaf and hard of hearing is critical to effective inclusion. Only this teacher

During his time in the early intervention program, Jacob and his mother had received support from a teacher of the deaf and hard of hearing at the Clarke Schools for Hearing and Speech in addition to support from his local early intervention agency. As Jacob transitioned into preschool, the early intervention caseworkers argued for continued support from a teacher of the deaf and hard of hearing to support development of his auditory skills and educational goals. The Individualized Education Program (IEP) team—which included Jacob's mother, his classroom teacher, an individual aide, an occupational therapist, a physical therapist, and a vision specialist—was initially unsure of the benefit of contracting with a teacher of the deaf and hard of hearing. However, at the request of Jacob's parents, the rest of the team agreed. After only a few short months, Jacob's parents and the professionals, noting how much Jacob had benefited from the involvement of the teacher of the deaf and hard of hearing, increased her visits to twice

is in a position to build relationships with classroom teachers and service providers and to provide ongoing support for parents and their children. Successful inclusion, of course, also includes the willingness of the IEP team members to actively promote inclusion through a team approach and a willingness to understand, monitor, and use assistive technology (Eriks-Brophy et al., 2006).

Today Jacob spends the majority of his day in a regular education classroom with children his own age. With the support of his aide, Jacob participates in large and small group instructional periods, art and music activities, and free play alongside his classmates. The acceptance and support of Jacob's classroom teacher allows him to participate at his own level in all aspects of classroom life—with modifications provided by the teacher of the deaf and hard of hearing. For example, during circle time, the classroom teacher led a discussion regarding the characteristics of apples. Jacob was handed a picture of an



deaf and hard of hearing helps ensure Jacob's access to the words of his teacher and classmates in a variety of settings throughout the school day.

Due to the number of service providers working with Jacob, communication among them and with the parents must be organized to ensure comprehensive services (DeVore, Miolo, & Hader, 2011). As Jacob began services with a teacher of the deaf and hard of hearing, she observed each service provider

therapist to give Jacob time to process the auditory information, connect it to the present task, and respond. Through modeling and encouraging "wait time," Jacob's understanding of verbs continues to develop not only in the classroom but also during the time with his physical therapist. His success motivates everyone—Jacob, the professionals, and Jacob's family—to continue practicing.

In order for children with multiple disabilities to develop a range of skills, activities based on objectives from individual service providers must be practiced several times each day in a variety of settings (Hollingsworth, Boone, & Crais, 2009). To help Jacob develop broad communication skills, each service provider develops three monthly objectives in accordance with Jacob's IEP goals; specific activities are developed that support these objectives, practiced twice daily with his aide, and carried over into his therapies. The

apple to hold as a way of helping him understand the topic of conversation. When children were asked to share their ideas about apples, Jacob raised his hand and said, "apple," then pretended to eat the picture he held. His teacher repeated, "Yes, Jacob! We *eat* apples," modeling the word "eat" which Jacob attempted to repeat.

Jacob's classmates have gained a level of understanding regarding his needs and are enlisted to help him navigate familiar routines, sometimes by modeling spoken language. "Wash your hands, Jacob," one classmate might say, while walking with him to the sink. Jacob demonstrates comfort in his classroom as he offers a friendly wave to familiar adults and classmates and manages daily routines with decreasing reliance on adults.

Collaboration Among Service Providers

The National Association for Education of Young Children (NAEYC) position statement emphasizes collaboration with families across service providers when children with disabilities are educated in mainstream settings (2009). Jacob's hearing aids provide access to spoken language but cannot improve clarity of the speech signal, and adults who work with him must understand the limitations as well as the benefits of assistive technology. The teacher of the

interacting with him, and each, in turn, was encouraged to observe Jacob's sessions with her. During this initial period, informal observations and meetings were conducted weekly. Service providers frequently dropped in on Jacob's sessions to observe, ask questions regarding Jacob's progress, glean information about his language goals, and develop strategies for incorporating communication into new activities. These observations continue and serve as a way to build relationships and trust.

Verbs and commands that Jacob practices with the teacher of the deaf and hard of hearing are carried over into his physical and occupational therapy sessions. For example, Jacob's physical therapist was struggling with how to prompt him for the verbal responses "stop" and "go." The teacher of the deaf and hard of hearing showed the therapist how to do this by modeling the visual and spoken cues for these words in a manner that was familiar to Jacob. She also encouraged the physical

Strategies for Coordinating Services

By Heather Stinson

Teachers of deaf and hard of hearing students may want to use some of the following strategies in maximizing services for their students:

- **Videotape sessions** to share with families and other therapists when direct observation is not possible. With parental permission, sessions can be recorded and shared electronically or burned to a DVD and sent home with the child.
- **Develop and use a communication book** to record communication progress. This may include current communication goals, the child's strengths, and vocabulary that the child understands.
- **Set regular times for meetings** to develop shared therapies and strategies, and discuss incorporation of communication goals into therapies.
- **Create and post monthly activities** that can be carried over for use among all service providers.

While educators and service providers are responsible for high quality services during school hours, children with disabilities cannot benefit from comprehensive services without the involvement of their parents.

activities are described in detail, as are the materials needed and the language prompts or target word(s) and phrases, which, all together, comprise Jacob's "Monthly 3." They are e-mailed to his classroom teacher who then posts the goals in the classroom. The teacher of the deaf and hard of hearing makes an effort to follow up regularly.

Parent Participation

While educators and service providers are responsible for high quality services during school hours, children with disabilities cannot benefit from comprehensive services without the involvement of their parents (GAO, 2011; Hanline & Correa-Torres, 2012; NAEYC, 2009). The teacher of the deaf and hard of hearing helps parents maintain the same level of involvement that is often experienced during early intervention, ensuring, for example, that parents are active members of the IEP team. To facilitate communication with Jacob's family, each therapist records pertinent details from his or her work with Jacob in a communication notebook that travels between home and school. In the back of the book, therapists note new vocabulary that Jacob has used. This proves a means not only of tracking his communication but

also of alerting everyone for vocabulary that should be reinforced in a new context. As Jacob progressed, sometimes he said what needed to be said himself—and sometimes he said it better!

In addition, a 45-minute session with the teacher of the deaf and hard of hearing is videotaped weekly and sent home for Jacob to watch with his family. When first presented with the idea of recording sessions, Jill, Jacob's mother, was doubtful that her son would perform before the camera. After viewing the first video last February, Jill responded with an 8:30 a.m. e-mail. "Ohhhh, MY GOD!" she typed. "Thank you so much! I've watched [the video] 3x already this morning! Once by myself, once with my mom, and then Jacob had to watch it!" In a second e-mail later that morning, Jill included a vignette about playing the video for her boss and the whole office running in to watch. Jill now reports that Jacob loves watching the videos as much as she does, and she went as far as filling his Easter basket with materials similar to those in the therapy videos so that Jacob could get more practice at home.

Regular contact with Jacob's family—through telephone conversations, e-mail, and written notes in his communication book—ensures that no concern is left unattended. The communication is two-way: When the teacher of the deaf and hard of hearing learns of Jacob's interactions at home with family members, she is able to provide professionals with a more in-depth understanding of expectations at school.

Meeting Jacob's complex needs may be a daunting task but because of the facilitation of the teacher of the deaf and hard of hearing, the dedication of his school team, the involvement of his family, and the flexibility and willingness of all the members to learn from each other, these needs are met on a daily basis. For Jacob, having a teacher of the deaf and hard of hearing communicating and organizing the communication among his family and the professionals who work with him is

not only a part of his program, it is the key component. It is essential to Jacob's continued success.

References

- Chidindi, J. (2012). *Creating enabling environment for inclusion for students with developmental disabilities*. (ERIC Document Reproduction Service No. ED 531 888). Retrieved November 30, 2012, from <http://www.eric.ed.gov/PDFS/ED531888.pdf>
- DeVore S., Miolo, G., & Hader, J. (2011). Individualizing inclusion for preschool children using collaborative consultation. *Young Exceptional Children*, 14(4), 31-43.
- Eriks-Brophy, A., Durieux-Smith, A., Olds, J., Fitzpatrick, E., Duquette, C., & Whittingham, J. (2006). Facilitators and barriers to the inclusion of orally educated children and youth with hearing loss in schools: Promoting partnerships to support inclusion. *Volta Review*, 106(1), 53-88.
- Hanline, M. F., & Correa-Torres, S. (2012). Experiences of preschoolers with severe disabilities in an inclusive early education setting: A qualitative study. *Education and Training in Autism and Developmental Disabilities*, 47(1), 109-121.
- Hollingsworth, H. L., Boone, H. A., & Crais, E. R. (2009). Individualized inclusion plans at work in early childhood classrooms. *Young Exceptional Children*, 13(1), 19-35.
- National Association for the Education of Young Children. (2009). *NAEYC position statement*. Washington, DC: Author. Retrieved November 30, 2012, from <http://www.naeyc.org/positionstatements>
- U.S. Government Accountability Office. (2011). *Deaf and hard of hearing children: Federal support for developing language and literacy*. (No. GOA-11-357). Washington, DC: Author. Retrieved November 30, 2012, from <http://www.gao.gov/products/GAO-11-357>



beyond the clinic:

PROVIDING SERVICES, SUPPORTS, AND CONNECTIONS TO HELP CHILDREN AND THEIR FAMILIES THRIVE

By Kevin J. Nolan, Jr.

As one of the premier pediatric hospitals in the United States, Boston Children's Hospital serves a wide range of children and provides top quality medical care, including a program for deaf and hard of hearing children that extends services beyond the medical scope. Within this program is a unique and particularly critical position—that of outreach and support services coordinator for the Deaf and Hard of Hearing Program.

While doctors and clinical personnel on the team focus on specialty care appointments, the outreach and support services coordinator provides essential information and connections to services that reach beyond what otolaryngologists and audiologists traditionally provide. The essence of the work done by the individual in this position is to offer reassurance and understanding to deaf and hard of hearing children and their families.

For over 30 years, Boston Children's Hospital has had an interdisciplinary team serving deaf and hard of hearing children. The team includes psychologists, speech-language pathologists, American Sign Language (ASL) specialists, a psychiatrist, audiologists, doctors, and surgeons. Working together, these specialists provide a truly multi-disciplinary unit that offers a wide range of information about technological interventions, habilitative regimes, and programmatic services. The outreach and support services coordinator, a relatively new addition to the team, ensures that patients have access to a full range of support and information.

When a child is diagnosed with a hearing loss, the first contacts that parents often

Photos courtesy of Kevin J. Nolan, Jr.

Kevin J. Nolan, Jr., MA, is the outreach and support services coordinator for the Deaf and Hard of Hearing Program of Boston Children's Hospital. Having served as an advocate and leader at the state, national, and international levels, he is also an instructor for the G. "Bummy" Burstein Leadership Institute at Gallaudet University and chairperson for the Massachusetts Commission for the Deaf and Hard of Hearing's Statewide Advisory Committee. He welcomes questions and comments about this article at kevin.nolan@childrens.harvard.edu.

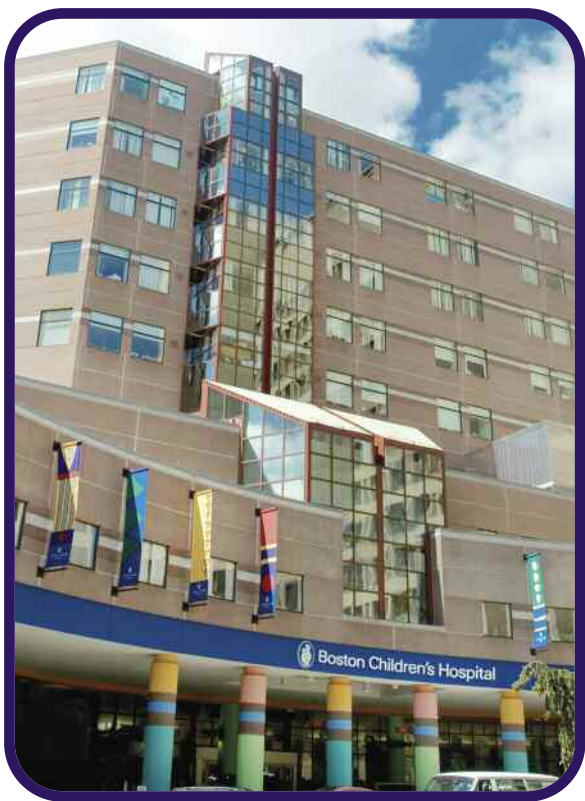


have are with audiologists and medical personnel. Doctors and audiologists are specialists in the clinical aspects of hearing loss, but they may not be familiar with all of the services, supports, and connections that help children and their families thrive. As a professional with a wider knowledge of services and community connections, I, as the outreach and support services coordinator, frequently participate in clinical meetings with families who have recently been informed that their child has a hearing loss. My presence contributes to a broader and deeper approach to the deaf or hard of hearing child; the clinicians focus on the medical aspect of the diagnoses while I provide information about programs and resources for stimulating language acquisition, options regarding day care providers,

parent support groups, a full array of early intervention options, and agency professionals.

Every situation is different so flexibility is paramount. In the morning I may assist a family for whom the oral/aural approach is used and spoken English is the primary language, and in the afternoon I may meet and relate comfortably with a family who is fostering ASL as their child's primary language. The goal remains the same: to support the families—parents and children—while appreciating the uniqueness of each one.

One of my most important roles is helping parents navigate the myriad of agencies and resources available. Many parents beginning the journey of raising a child who is deaf or hard of hearing feel overwhelmed by the amount of



information that they receive. I can sit down with each in turn, helping parents understand the information in an objective way. Before parents can make informed decisions regarding their child, it is important for them to have access to as much information as possible and to fully understand the resources at hand. Only then can they truly make informed decisions that are best for their child and family. In a field that has experienced conflicts of opinion almost since its inception, I remain neutral and present factual information without biases. This is crucial.

Here in Massachusetts, we are fortunate to have a number of resources we can offer to our patients and their families. Families of infants and toddlers can learn ASL through the Family Sign Language Program, which is now run through the Gallaudet University Regional Center at Northern Essex Community College. Massachusetts has numerous regional Parent-Infant/Toddler Programs. Parents can choose from a variety of language intervention options, ranging from emphasis on acquisition of ASL as a first language to

the acquisition of spoken language as a priority.

My involvement does not end after the initial meetings. My role helps ensure coordinated care among providers, specialty programs, early intervention providers, school districts, mentors, and a variety of community resources. A crucial, and often overlooked, aspect of the outreach and support services coordinator's role is aiding parents in their introduction to and learning about the deaf and hard of hearing community, providing the parents with information, and modeling cultural awareness and sensitivity. Parent support groups and information sessions, sponsored by the

hospital and facilitated by the outreach and support services coordinator, deepen levels of knowledge and awareness.

Working in our urban medical center, with its constant influx of new patients and their concerned families, the interdisciplinary team works together on a daily basis to provide the best possible care. Through my position, the child and family members are also offered a reassuring and understanding "bridge" that serves to connect them with clinicians and support services. As most clinicians are not free to travel to meetings, participate on advisory committees, conduct observations outside the clinic, or offer in-service training off site, the outreach and support services coordinator represents the clinical team at such venues. Thus the duties vary from day to day. One day I consult in a public school setting; another day I serve as a resource specialist for a family; still another day I represent our team on a statewide committee that advocates on behalf of the interests of deaf and hard of hearing children. I also arrange inspiring and

informative speakers for family forums and workshops. Ultimately, my position ensures that the families in our program have access to all the information and support services available—both through our hospital-based program and through our community-based, educational, therapeutic, and social organizations.

Perhaps for parents who do not have an outreach and support services coordinator for deaf and hard of hearing children within a medical center in their community, the breadth of services we offer may be a challenge to find. Yet there are professionals and parent organizations that provide information and guidance for families in a variety of other settings. Many states have specialists who focus on children's services within state agencies that serve deaf and hard of hearing people. Many educational programs and schools for the deaf offer outreach and support for parents and family members. Many early childhood specialty programs have strong parent support components. By developing cooperative relationships among or between state agencies, school programs, and/or specialty programs and medical centers or clinics where deaf and hard of hearing children are followed, bridges that support families and professionals can be constructively forged. Such bridges benefit clinicians and physicians as well as families who are raising children who are deaf or hard of hearing.

Author's note: *I feel very fortunate to be able to work in a caring medical environment with team members who provide world-class medical care and who maintain a deep appreciation and understanding of the importance of culture and robust language acquisition. The outreach and support services coordinator position ensures that the focus is never on just a child's ears and mouth but on the developing and complex individual who is the child. In that role, I am able to create bridges that these children and families may never have known existed but absolutely deserve.*

Seeking Submissions for the 2014 Issue of Odyssey

THEME: High Expectations for All: Their Importance and Influence

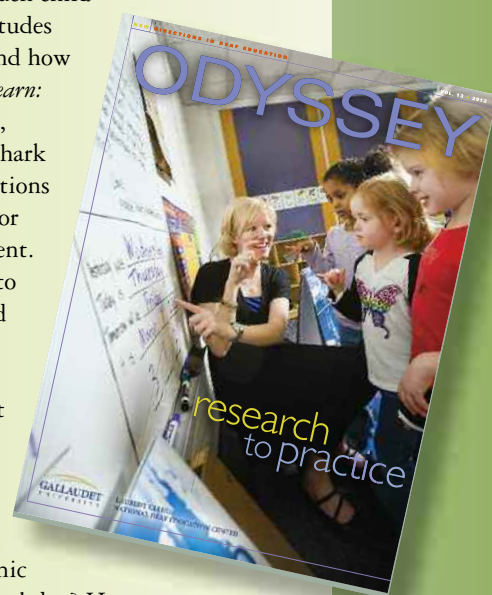
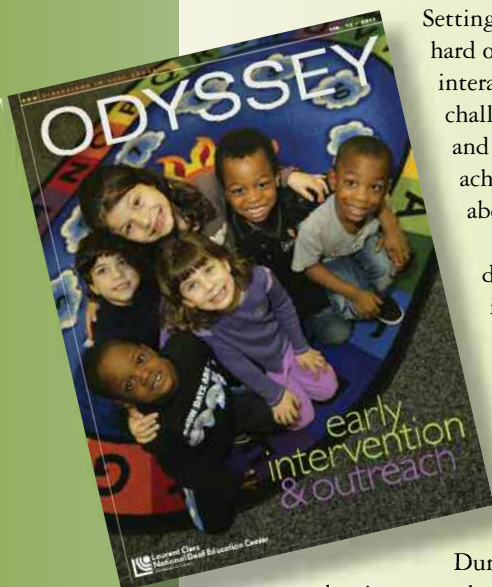
Setting high expectations is an essential factor in the achievement of deaf and hard of hearing students. Depending on their expectations, teachers may interact differently with students. If they have high expectations, they may challenge students to think more deeply, tackle increasingly difficult work, and establish an environment that reflects their beliefs that students can achieve. Teacher expectations can also influence how a student thinks about him- or herself: "If the teacher thinks I can, I think I can, too."

It is also important that professionals demonstrate high expectations of deaf or hard of hearing children from the time each child is identified as their language, actions, and attitudes can influence the expectations of the parents and how they view their child. In *How Deaf Children Learn: What Parents and Teachers Need to Know* (2012, Oxford University Press, New York), Marschark and Hauser state that parental high expectations may be one of the best predictors of a deaf or hard of hearing child's academic achievement.

During the Clerc Center's recent two-year process to gather input on the barriers impacting the achievement of deaf and hard of hearing children, parents and professionals alike repeatedly shared the lasting consequences that low expectations and misguided beliefs have had within deaf education. They noted the need to impart higher and more rigorous expectations for all students.

For the 2014 issue of *Odyssey*, the Clerc Center is seeking articles on how schools, professionals, and families are establishing and maintaining high expectations for deaf and hard of hearing students. How are teachers infusing high expectations into the academic curriculum? What do high expectations look like throughout the school day? How are schools measuring and monitoring the use and impact of establishing high expectations? How are families creating high expectations at home and in the community? In what ways are professionals and parents instilling a sense of "I can do it!" in deaf and hard of hearing students? Articles can focus on all aspects of a child's development and the role of expectations from early intervention programming through postsecondary transition planning. The Clerc Center is particularly interested in articles about experiences involving setting or raising expectations for deaf and hard of hearing students from traditionally underserved groups, including those students who are lower achieving academically, who come from families that speak a language other than English in the home, who are members of diverse racial or cultural groups, who are from rural areas, and/or who have secondary disabilities.

Please e-mail your ideas to Odyssey@gallaudet.edu by September 3, 2013; fully developed articles are due by October 3, 2013. Contact us via e-mail at any time with questions or to discuss your ideas.





Connie Stevens, MA, mother, sociologist, and former family educator/program coordinator, is the Guide By Your Side follow-through parent guide coordinator for Wisconsin's Early Hearing Detection and Intervention Program supported through the University of Wisconsin-Madison Waisman Center. She is also a Guide By Your Side parent guide with the Wisconsin Department of Public Instruction. She has co-authored Wisconsin's *Babies and Hearing Loss Parent Notebook* and helped found its Families for Hands & Voices chapter. She welcomes questions and comments about this article at conniedangracetess@yahoo.com.

creating community: balancing the personal and professional

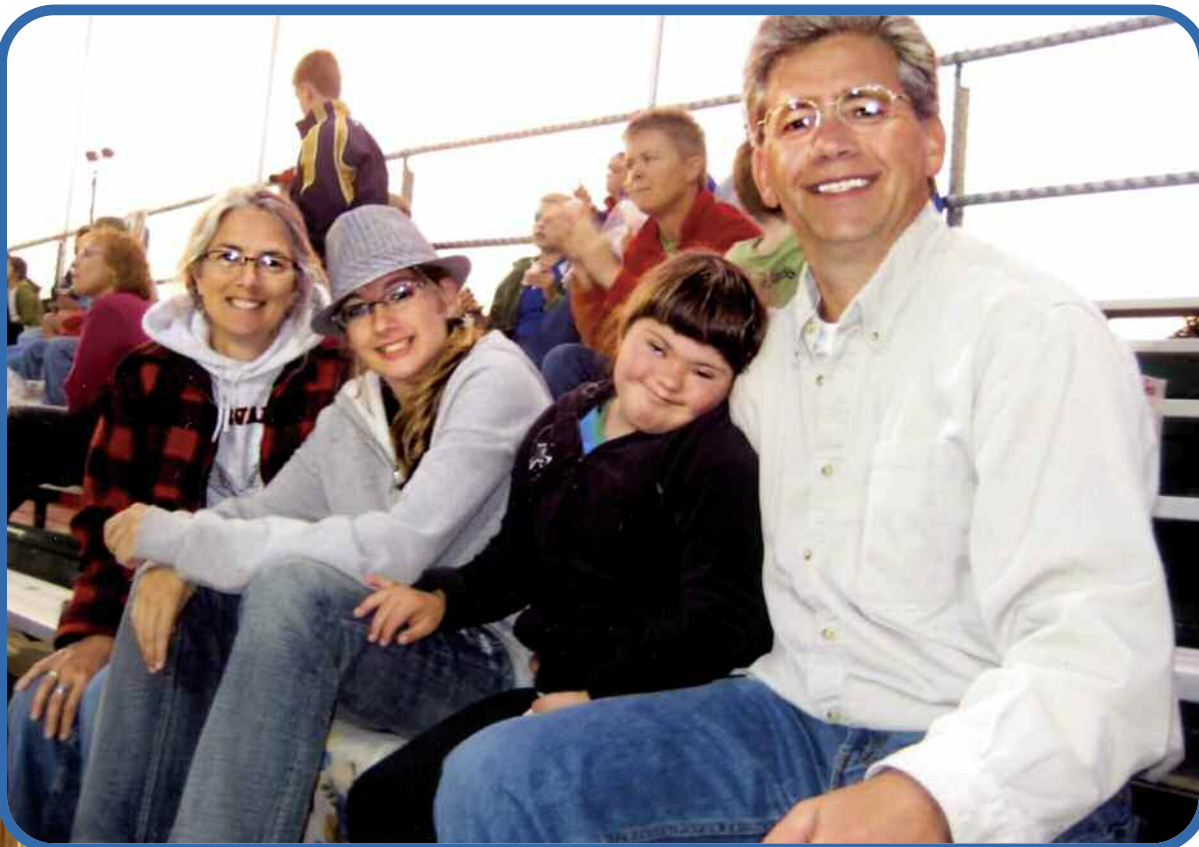
By Connie Stevens

Since I was a young girl, I dreamed of having a family and feeling part of a community...but I never dreamed I'd be a mother to a child with Down syndrome who at seven months of age was diagnosed with profound hearing loss. Being a sociologist and researcher, I looked for direction, including reading about deaf history and memoirs of deaf adults and parents. There wasn't much support for families like ours; however, a movement was developing. With the help of dedicated professionals and Wisconsin mothers and fathers, a wide and diverse support system blossomed. I hope my story makes the road others travel less scary and that they reach out to the community that is there to help, attain the courage they need to advocate for their child, learn to manage the bumps and unplanned curves, and remember that they are parents first—and enjoy the ride.



Newborn hearing screening was just springing up across the country; our rural hospital did not offer it. Due to Tess's Down syndrome (which we found out about when she was placed on my belly just after birth) and the fact that one of my dearest friends had a son with Down syndrome, our family was enrolled in Wisconsin's Birth to Three program by the time Tess was a month old. Tess's speech therapist suggested we test her hearing early,

Photos courtesy of Connie Stevens



Left: Connie Stevens, daughters Grace and Tess, and husband Dan enjoy some family time.

and when we learned she had a profound hearing loss, down that new road we went, gaining new information and ridding ourselves of extra baggage we found wasn't true or didn't matter. In addition to appointments with multiple audiologists and ear, nose, and throat doctors, we sought emotional and social support.

We were welcomed into Shore to Shore, a language-focused family support group started by two mothers with children who were deaf. They knew it would be necessary for their kids to be around others who could communicate with them and help them develop as well-rounded children, with access to visual language to avoid typical developmental delays that can occur when there is not timely access to screening, diagnosis, and intervention services.

We also participated in and received much help from the University of Wisconsin as well as the Deaf Mentor Program. Supported through the Wisconsin Department of Public Instruction, the Deaf Mentor Program pairs employees who are deaf or hard of

hearing with children of families who want to learn about the culture and language of deaf and hard of hearing people. I attended conferences on Down syndrome and childhood deafness and hearing loss. I was becoming the expert on my child and her strongest advocate.

It wasn't easy. In fact, it was hard. Tess was one of the first deaf children to participate in our county's Birth to Three program and our school's early childhood program. I struggled with the professionals in both of these programs because they didn't seem to understand issues surrounding hearing loss and the importance of early and equal access to language. Although no one said to me, "You are just the parent; we're the professionals. We know better," I felt awkward stepping up, saying, "This is the way it needs to be for Tess. We know her best and we've studied our options."

Tess was not benefitting from her hearing aids, and with her frequent ear infections we knew she needed as much access to visual language as possible. My husband or I soon ended up on the highway for two

hours a day transporting Tess to a program in a different school district. We were doing this so that she could have a teacher who used her natural language—sign language—because we'd seen how it benefitted her. She attended that program for five years.

At the same time, we were learning that experts were reconsidering the option of cochlear implants (CI) for prelingually deaf children—and that in some cases CIs were now recommended for children like Tess. She was five years old when, after much reflection, we had the operation—I say *we* because preparing for and experiencing the hospital, sedation, operation, and readmittance to the operating room was a group effort. We found ourselves on a new roller coaster.

We didn't know what to expect. There were various appointments, surgeries, and therapy plus the ever-present lack of knowing how it really feels inside to be Tess. Her language skills were very basic. She gave very subtle indications of hearing and did not understand the tests. This made programing difficult. In addition, she has a habit of rubbing, sometimes roughly, the side of her head that is not implanted—and we do not know why she does this.

Thankfully, the roller coaster ride seems to be ending because Tess currently enjoys hearing. She doesn't ask for her CI, but she cooperates when it is time to pin it to a ponytail holder and have the wire clipped to her hair. I hope that soon she will be able to use the behind-the-ear piece so she can become more independent with the use and care of the CI.

For five years we had focused on signing because Tess couldn't hear, and then with the CI we switched tactics and start using our voices again. We had to again advocate for Tess and ask that others use their voice with her. We learned more about her auditory needs and discovered that, indeed, her delays



Above: Tess at age 4 with her sister, Grace.

were more related to Down syndrome. We learned to continue giving her access to visual language while we spoke with her. It was important to do both. When we spoke, we signed, and when we signed, we spoke.

Late access to auditory stimulation combined with Down syndrome and the speech problems that many kids with Down syndrome experience means that Tess has not learned to talk. However, she expresses herself through sign language and uses her voice to get our attention, to alert us to her feelings of pain, surprise, fear, and laughter. She is quite the actor and a continual puzzle. My husband and I typically team-interpret her stories, which are invariably based on the latest thing she's seen on TV or experienced in her life. We maintain a daily home/school communication notebook so we can try to be on top of what's going on in her wonderfully imaginative head.

When the Road Takes a Professional Turn

Soon into my journey with Tess, Wisconsin's Early Hearing Detection and Intervention program (EHDI), Wisconsin Sound Beginnings, contacted me and asked me to share my family's experiences with early intervention. This was another new road—a professional highway—and I was excited to explore it. I helped co-author an extensive resource guide for newly diagnosed families and was secretary and founding board member

of Wisconsin's Families for Hands & Voices chapter. I also became parent educator/program coordinator of Shore to Shore, the program that we found so essential in Tess's early years. I helped other families learn how to bond and communicate with their children through story hours, education, presentations, home visits, and sign language classes taught by deaf adults. In my role, I was also helping these families become their own strongest advocates and, for some of them, supporters of other families.

Now I work for the state, dividing my time between two agencies that have collaboratively created a Hands & Voices Guide By Your Side Program for Wisconsin. The program offers parent-to-parent support from screening through intervention. With the Department of Health and Wisconsin Sound Beginnings, my team and I help ensure that all babies born in Wisconsin have their hearing checked and, if necessary, receive timely services. I contact medical providers, birthing hospitals, primary care physicians, audiologists, and individual families to discuss case-by-case issues and ways to improve practice. What every family wants is: to know their options, to be understood and respected for their choices, and to have their children attain equal access.

With the Wisconsin Department of



Public Instruction's Educational Services Program for the Deaf and Hard of Hearing Outreach Program, I am one of 20 or so parent guides throughout the state. Parent guides meet with families in their homes—either shortly after diagnosis or when the family is ready to participate—to provide parents with the opportunity to establish a supportive relationship with another parent of a child who is deaf, hard of hearing, deaf-blind, or deaf with additional disabilities. Parent guides can share the unique needs of infants, children, and teenagers who have hearing loss. They are trained to offer unbiased information and support, as well as to connect families with resources (locally, regionally, statewide, and nationally), so families have the information and knowledge they need to make informed decisions on behalf of their child. In my role as a parent guide, I've helped plan our annual state family conference and participated in the national EHDI conferences.

We often say that we wear many hats in our lives. Lately, I've felt like I am collecting them. Balancing all these hats is tricky. Being a parent and professional, I feel the need to be positive all the time and show how well

Tess has grown. I hesitate to talk about our struggles because I don't want to discourage people, but I remember wanting people to be honest with me when we started this journey. In my Guide work, I usually say, "In my experience..." so parents know I am only one story among thousands. For instance,

sometimes I feel that I must explain both Tess's use of sign language and her CI. If she'd had the CI earlier, would her ability to use it be different? We don't know—and to assume that early use would have meant that she could hear and speak better than she does negates the reality of the problems we've experienced as well as the realities experienced by other families. If we had chosen only the auditory method, how could we communicate when we were sledding outside and her CI wouldn't stay on? Or during the summer when she is almost always in the water? Or when she's sick and the CI coil won't stay on her head because she is lying down and throwing up? As a result of these experiences, I've always strongly supported full opportunities for visual and auditory access to communication. I



also keep in mind the mantra of Hands & Voices when making decisions: "What works for your child is what makes the choice right."

Being a parent guide involves connecting to others on their schedule. This works fine when I'm away from home. It's much easier to be the professional. However, once I get home my family needs me, too. For this reason, I am very protective of the families I work with when there is a need for more parent input or parent guides. I know how much guilt there can be when you try to do too much and be there for everyone. A Brazilian doctor, who became an expert on brain trauma after his own son suffered an injury, said, "It's okay to focus on your own child. You are not being selfish." In addition, my mother-in-law's words, echoed recently during a conversation with members of Hands & Voices—"You are doing the best with what you have at the moment you have it."—help me to be comfortable with what I achieve.

I've felt very blessed to have a daughter who wants to look in my eyes and pretend that we're giraffes and elephants and communicate on a different level. I'm blessed to have another daughter who understands these highs and lows, loves her sister unconditionally, and encourages me to keep going. I'm blessed to be married to a man who supports my choices, and I feel honored to share my story and to meet other families, gain their insight, and help build a community.



EDUCATIONAL INTERPRETERS:

meeting the communication needs of children with cochlear implants

By Julie Melton and Renée Higbee



Julie Melton, MS, began her teaching career as adjunct faculty in 1999 and since 2005 has served as a clinical assistant professor at Idaho State University in the Sign Language Studies/Interpreting program, which is one of the only programs in the United States to offer a bachelor's degree with a focus on educational interpreting. Certified by the Registry of Interpreters for the Deaf, Melton, interpreting since 1982, is passionate about teaching and presenting workshops related to interpreting.

Right: American Sign Language interpreters provide students with access to information through visual means.

Since the early 1990s, when the U.S. Food and Drug Administration approved cochlear implants for deaf and hard of hearing children, the number of children who have cochlear implants has increased in mainstream settings. Recent research (ASHA, 2012; Yoshinago-Itano, Baca, & Sedey, 2010) suggests that these students, like their deaf and hard of hearing peers without implants who use sign language, may benefit from the use of a sign language interpreter. As of December 2010, approximately 26,000 children in the educational system had received implants (NIDCD, 2011), and today the number continues to increase. This makes it important for parents, teachers, and audiologists to understand that some of these children have more success in understanding their teachers, classmates, and curriculum by combining their auditory and speechreading skills with sign language than in approaching their education through auditory/speechreading skills alone.

Deaf children with cochlear implants may be able to access spoken language to varying degrees which is why parents—hearing and deaf—and teachers may overlook the benefit visual communication and the support of an educational interpreter may offer these children. Children with implants are still deaf children. When these children take off their cochlear implants, they have varied degrees of speech recognition, and they may function as severely to profoundly deaf children. Further, the understanding of speech that implanted children demonstrate in the audiologist's office

Photos courtesy of Renée Higbee



Renée Higbee, BA, BS, is an educational interpreter in the Boise School District and a visiting clinical professor at Idaho State University in the Sign Language Studies/ Interpreting program. She is a wife and mother of two school-age children, one of whom is deaf. As an advocate for individuals who are deaf or hard of hearing, Higbee has served on various boards and committees nationally and throughout the state of Idaho.

The authors welcome questions and comments about this article at meltjuli@isu.edu and higbren2@isu.edu.

or in one-on-one conversations is often degraded in the rapid discussions of the classroom, where ancillary noise may include everything from other children talking out of turn, to chairs scrapping, to pilings being driven into the asphalt of the street outside.

An interpreter can provide access to classroom information through visual means to support what a student with an implant receives auditorally. The decision to provide interpreter support should be made by the team that determines the student's Individualized Education Program (IEP). The team should consider the student's needs first and provide interpreters if the student has difficulty accessing information through watching and listening alone. Data about the student's performance in school and in the range of classroom environments should be considered, as should the student's access to incidental information and ability to participate in social communication. Phrases such as "the child...doesn't need an interpreter...doesn't watch the interpreter...doesn't sign expressively" may be too subjective without

supporting information to be considered in the IEP process. The team should remember that students whose education has been based on spoken English are eligible for interpreters, too. According to Yoshinago-Itano, Baca, and Sedey (2010), auditory input can be primary and visual support secondary to a child's understanding, and sign language interpreters can still provide a "fast map" in conjunction with spoken language to a fuller understanding of English and spoken language. In fact, Yoshinago-Itano, Baca, and Sedey found that students who use sign interpreting services may develop spoken language skills more quickly than their oral-only peers.

The team must consider the type of interpretation that is most beneficial for the student. Often for a child that relies heavily on his or her listening skills, an interpreter who transliterates—that is, an interpreter who signs with a form of manually coded English—may provide the best access to information. When an interpreter renders spoken English into signed English, the student uses listening, speechreading, and sign support to receive and understand



language. When transliterating, the interpreter may sign almost as quickly as individuals talk (that is, with little “lag time”). Sometimes the interpreter may use forms of chunking and waiting for the student to look for sign support or the interpreter may sign consistently so the student can look over at any time to receive the information visually. In

some mainstream classrooms, the teacher and hearing students talk, the interpreter transliterates into a form of manually coded English, and the deaf or hard of hearing student links the auditory and visual information and responds to it orally. The National Association of the Deaf and the Registry of Interpreters for the Deaf (NAD-RID,

2005) note that a transliterator is appropriate for students who are fluent in English and can quickly process information presented in oral English.

Parents’ input is essential in guiding the IEP and, as early as possible, the student’s input should be considered, too. As the student achieves successes and meets challenges, the method of signing and interpreter support can be re-evaluated and modified as necessary. For instance, if a student has good auditory skills and is successfully identifying and attending to the source of auditory input, the interpreter will not need to direct him or her. Interpreters, as members of the IEP team, may give input during the IEP meetings, but they follow the accommodations that the team agrees on. The use of interpreters may provide a student with much needed access to discussions in the classroom and also help them improve their fluency in English. A student’s needs, abilities, and performance should all be considered when evaluating the use of a sign language interpreter or transliterator as an accommodation in a student’s IEP.

References

- American Speech-Language-Hearing Association (ASHA). (2012). *Cochlear implants*. Retrieved October 28, 2012, from <http://www.asha.org/public/hearing/Cochlear-Implant/>
- National Association of the Deaf-Registry of Interpreters for the Deaf (NAD-RID). (2005). *Code of professional conduct*. Retrieved November 4, 2012, from <http://www.rid.org/ethics/code/index.cfm>
- National Institute on Deafness and Other Communication Disorders (NIDCD). (2011, March). *Cochlear implants*. NIH Publication No. 11-4798. Retrieved November 4, 2012, from <http://www.nidcd.nih.gov/health/hearing/pages/coch.asp>
- Yoshinago-Itano, C., Baca, R. L., & Sedey, A. L. (2010). Describing the trajectory of language development in the presence of severe-to-profound hearing loss. *Otology & Neurotology*, 31(8), 1268-1274.

Resources

- Boston Children’s Hospital. (2010). *Children with cochlear implants who sign: Guidelines for transitioning to oral education or a mainstream setting*. Retrieved October 27, 2012, from <http://www.childrenshospital.org/clinicalservices/Site2729/mainpageS2729P4.html>
- Idaho State Department of Education-MHS Special Services. (2012). *Special education manual 2007*. Retrieved November 4, 2012, from <http://mbsspecialservices.weebly.com/special-education-manual-from-idaho-state-department-of-education.html>
- U.S. Department of Education. (2004). *The new IDEA website*. Retrieved November 4, 2012, from <http://idea.ed.gov>
- U.S. Department of Justice. (1990). *Information and technical assistance program related to the Americans with Disabilities Act*. Retrieved November 4, 2012, from <http://www.ada.gov>
- Young, B. (2009, Summer). Interpreting for the student with a cochlear implant. *VIEWS*, 20-22.

section 504— the 1973 law still makes a difference

By Beth Ann Dobson

I have been a teacher of deaf and hard of hearing students under the Special Education Department in Prince William County Schools for 11 years. I'd never had a student referred to the team that handles evaluations under Section 504 of the Rehabilitation Act of 1973—until Mary. Mary had received special education services for her profound hearing loss under the Individuals with Disabilities Education Act (IDEA) until the end of her freshman year, when it was determined that she was no longer eligible.

The IDEA requires that a student's disability have an adverse impact on his or her educational performance that results in the need for specialized instruction. The Individualized Education Program (IEP) team felt that this was not the case with Mary. They noted that Mary communicated skillfully with teachers and hearing peers, read as well as the average hearing students in her class, and had intelligible speech; therefore, the team felt that her profound hearing loss did not adversely impact her educational performance.

Of course, most people recognize that when profoundly deaf children do well in classrooms of hearing students, they are often working hard to compensate in ways that are invisible to their teachers and peers—and sometimes to IEP teams. Still Mary was referred to a different team of evaluators, the 504 team, which handles evaluations for accommodations under Section 504 of rehabilitation legislation.

With its mandate to ensure students with disabilities are not



Beth Ann Dobson,

MS, was born profoundly deaf and learned Total Communication and American Sign Language when she entered the National Technical Institute for the Deaf in 1984. She taught English at Gallaudet University for seven years before taking her present position as a full-time teacher of deaf and hard of hearing students at Woodbridge Senior High School in Woodbridge, Virginia. Dobson welcomes questions and comments about her article at dobsonba@pwcs.edu.

Photos courtesy of Beth Ann Dobson



Left and below: Dobson discusses with her students the agenda and objectives for the day.



discriminated against, the 504 team found Mary was eligible to receive accommodations because of her profound hearing loss. At first I was skeptical. The Rehabilitation Act of 1973, Section 504, states:

No otherwise qualified individual with a disability in the United States...shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

However, the processes 504 puts in place are not those of special education; they are designed to ensure the student accommodations in the general education setting. These accommodations help to minimize the impact of disability. Further, under 504 Mary would have a case manager—an individual stationed within her school—to ensure that her

accommodations were communicated to the general education teachers and implemented in every class. My district has a policy that special educators, such as myself, cannot be case managers. If Mary had problems with her accommodations, I would not be able to help her. I was afraid that she would not receive the understanding and services she needed. However, I was wrong. I had not taken into consideration Mary's determination, her outstanding rapport with general education teachers, and her diligence in getting the work done. Thanks to 504, Mary received copies of notes from general education teachers and peers, watched closed-captioned movies, and utilized her skills in order to achieve academic success.

The process of developing and implementing a 504 plan is different from that of implementing an IEP. The school must send official notice and consent for a 504 evaluation to



parents and give them a packet filled with information about their rights. Once the parents grant consent, the 504 team must find evidence of the student's disability and determine if that disability is keeping the student from performing according to his or her potential. The 504 eligibility team is generally composed of an administrator, a general education teacher, a case manager, a school psychologist, an individual who can interpret the data related to the student's disability (i.e., the audiogram), and any other individuals with expertise regarding the student and his or her disability.

Steven, another profoundly deaf student, also found 504 was the vehicle through which he could maintain his sign language interpreter, sit near the interpreter, be afforded extended time on tests, and be provided with a notetaker. Like Mary, Steven's IEP team decided that his profound hearing loss did not adversely impact his classwork. Like her, he has a case manager assigned and that case manager is responsible for distributing his 504 plan to his general education teachers and monitoring his accommodations. The 504 plans for both Mary and Steven—and for all students who receive services under 504—must be updated prior to the start of each new school year.

When Mary or Steven transfers to a different school district, a different 504 team needs to initiate a new plan, complete with referral for evaluation, as 504 plans do not automatically transfer between school districts. Parents are encouraged to review their local school district's Section 504 and special education policies and procedures in order to know what can be offered to the child or the adult student.

While 504 plans do not always have the specificity of IEPs, the rationale for each 504 accommodation must be explicit. For example, if a deaf student requires preferential seating (i.e., nearness to a sign language interpreter), the rationale for this must be stated. If accommodations or modifications are not being met, the student's school may be in violation of the law. For example, if a deaf student requires an FM system and a sign language interpreter, the school is obligated to provide them because they are crucial to the student's learning. The 504 case

manager needs to ensure that general education teachers understand the student's accommodations, the rationale for the accommodations, and the terminology, i.e., preferential seating, extended time, or sign language interpreter (Black & Koziol, 2012).

The feedback from parents is critical because they know their child well. They need to be certain that their child's accommodations are explicit, and that they are implemented. Wiggins (2012), in *7 Keys to Effective Feedback*, notes: "Feedback is information about how [teachers and administrators] are doing in their efforts to help students with disabilities reach success through Section 504." Relaying effective information is crucial in order for a student with a disability to have the opportunity to receive the same kind of education as his or her non-disabled peers.

Teachers, administrators, parents, and students need to understand and support implementation of the 504 plan in order for the students with disabilities to have an equal opportunity to be successful in the classroom. When any student has success, he or she begins to find meaning in life. Tim Tebow, quarterback for the New York Jets, reflected on success, stating:

"[Success] comes from having meaning in your life, doing what you love, and being passionate about what you do. That's having a life of success. When you have the ability to do what you love, love what you do, and have the ability to impact people...that's what having a life of meaning is." (Winged Foot Award, 2011)

Section 504 can assure that students like Mary and Steven keep their special education services; it can provide these students with the access needed to stimulate their desire, fulfill their potential, and attain academic success.

References

- Black, K., & Koziol, K. (PowerPoint presenters). (2012, October 23). *Section 504 keys to implementation in Prince William County Public Schools*. Manassas, Va.
- U. S. Department of Labor. (1973). National Rehabilitation Act of 1973 § 504. Retrieved October 28, 2012, from http://www.dol.gov/oasam/regs/statutes/sec504.htm#.UPk_QrZ4m2w
- Wiggins, G. (2012, September). 7 keys to effective feedback. *Educational Leadership*, 70(1), 11-16.
- Winged Foot Award. (2011, May 26). Excerpts from Tim Tebow's speech. *Naples News* (online). Retrieved October 30, 2012, from <http://www.naplesnews.com>



Jodee S. Crace, MA, is president of the American Society for Deaf Children (ASDC), www.deafchildren.org. She is the mother of four sons, three of whom are deaf and one of whom is blind and hard of hearing. A resident of Westfield, Indiana, she is a deaf mentor and parent advisor, visiting homes of families with deaf and hard of hearing children as part of the Sensory [Kids] Impaired-Home Intervention (SKI-HI) throughout central Indiana. Crace also teaches a summer course on infants, toddlers, and their families for Gallaudet University.

Right: Organizations such as the American Society for Deaf Children offer parents critical support, allowing them to share experiences and information.

FOR PARENTS AND CHILDREN

access is key— to curriculum, to services, and to each other

By Jodee S. Crace, Jennifer Ronco, and Tami Hossler

Why do parents seek other parents? They want advice, tips, and/or wisdom; they want to share stories; they want to learn from the experiences of those who have traveled a similar road before them. Sometimes parents bond with each other, and sometimes they form close friendships. Parents want informational and emotional support. They may prefer support that focuses on a specific concern, question, or need. They may also simply want to be a part of a group—for socialization, activities, or workshops. They may prefer to get information directly from others rather than through reading literature or searching online.

Parent-to-parent support is vital for parents of all children, but, of course, it is especially vital for parents who have deaf or hard of hearing children. Without the support of other parents, those with deaf and hard of hearing children can easily feel isolated, confused, and alone. Once they meet each other, however, those same parents feel enriched, both by learning about the experiences of others and by sharing their own.

Access is key—to each other for comfort and meaningful support, to information for the knowledge they need to support their children academically and emotionally, and, above all, to their children's thoughts and feelings. At the American Society for Deaf Children, our goal is to support parents and their children in whatever way they need to gain access. Below are two parents' stories.

Embracing “Deaf” with a Capital D

By Jenny Ronco

Every family's initiation into the world of parenting a deaf child is a unique and defining moment. No matter how events evolve, there is always *that* day, *that* comment, *that* look, *that* doubt, or *that* doctor's appointment in which a rift forms, a divide between what we took for granted before and

Photos courtesy of the American Society for Deaf Children, Jennifer Ronco, and Tami Hossler





what we will take for granted for the rest of our lives. I'm grateful that my transition, a terrifying experience from one side to the other of this great divide, only took 24 hours. When the Deaf community—and the hearing families and professionals within it—offered their support and complete unconditional acceptance of my daughter, my family, and myself, I was ready to accept it. This acceptance granted access to a community I would never have known otherwise. In turn, the Deaf community provided my daughter with access to language, opening the door to clear communication within our family and access to spoken and written English. All these elements empower her to succeed academically and use her communicative flexibility to enrich her life with an array of friends.

Our journey started on a Tuesday in May. First was the telephone call. On the other end was a technician. The information he provided was heavy on strange vocabulary and light on usefulness. I heard that my baby daughter had a bilateral severe to profound sensorineural hearing loss without having any idea what that meant. "She's not deaf, she's bilingual!" was my

knee-jerk response as we blamed our long wait for expressive language on the German/English input we provided at home. It was quite a wave of denial, but I pushed through it enough to make contact that day with the local Deaf and Hard of Hearing (DHH) program in our school district. By lucky timing, I was invited to a district-wide potluck the following evening to celebrate the deaf and hard of hearing seniors who would graduate that June. I went with my family.

At this event, parents shared their stories and the soon-to-be graduates talked about their accomplishments, struggles, and plans. The evening was a mosaic of speech and signs. When we were announced, along with the fact that we had received news of the diagnosis only the day before, everyone in the auditorium stood up and gave us a spontaneous ovation. Every prospective graduate stopped and visited my daughter, who was in her stroller, to sign "hi" and "welcome." Every one of them voiced the same to me.

Following the event, staff from the DHH



Jennifer Ronco, MA, is a mother, wife, teacher, pet lover, and "wannabe farmer" in San Diego, California. She earned her bachelor's degree in mathematics from California Polytechnic State University and her master's degree in education of the deaf from San Diego State University.



Tami Hossler, MEd, an ASDC board member and editor of ASDC's *Endeavor*, lives in Fort Meyers, Florida. She has two adult daughters, one deaf and one hearing.

The authors welcome questions and comments about this article at jscrace@aol.com, jennyronco@gmail.com, and asdctami@aol.com.



Left: Jenny Ronco and family on the John Muir Trail.

program encouraged us to visit the preschool, which I did that Friday. At the preschool, my daughter was immediately invited to join in though the staff didn't even know our last name. That obstacle was waived aside, and I was informed that the "paperwork would follow." We stayed and played. Dakota, her big brother, and I were sent home with name signs for each child and a stack of books and videos to get us started on signing at home. Our journey into the world of American Sign Language (ASL), hearing aids, and language acquisition started in that colorful and safe classroom. The German I had used with my daughter for the previous 17 months was set aside; *bilingual* in our household took on a whole new meaning—English, ASL, and *access*.

I would easily learn as much on those mats and tiny blue chairs as I learned in my college-level ASL 1 class. I was suddenly teaching a language that I did not know to my children. There was no time to waste. Dakota needed to know that I was her *mom* and she could tell me anything. I needed to learn, too, quickly enough to teach and fluently enough to listen.

Pitfalls of awkwardness, self-doubt, and a feeling of ineptitude were inevitable, but all paled to the reward of communicating with our toddler. Dakota learned to sign "no" in a few

days, and could "talk back" in signs in just over a week. Within a month she figured out that she could get the last word in any argument simply by closing her eyes.

I remember when she tested her boundaries by stepping away from me towards the curb. She rapidly signed "no, no, no" and squeezed her eyes as tightly as she could. Then, hands on her hips, hair shining in the morning sun, and chin jutting out like a little bulldog, she moved away—punctuating her communication with a giggle. She was one satisfied toddler. She had been waiting a year and a half to let me know

**From the beginning,
ASL easily and
immediately granted
my daughter a voice.
Through ASL, she
gained access to the
wider community and
a rigorous academic
curriculum.**

what she thought about some of the rules we had around the house. Now she was doing it.

Today Dakota is 13 years old. She stills says what she thinks, and I feel lucky to watch and listen to her. When sign language classes and parent workshops proved inadequate, I made a big move and got a master's degree in deaf education. Yet I cannot keep up with my daughter. She navigates the hearing/deaf worlds with grace. She is on target with academics and approaches communication with an open-minded persistence that is a sight to behold.

Dakota learns new and abstract information most quickly with ASL, and she articulates her questions and understanding in written and spoken English. She asks for clarification when she needs it, and she tends to take difficult concepts on a "test drive" in ASL and English to see where the connections are strongest, and pursues her questioning from there. Watching these moments makes our family's bilingualism less of a journey and more of a gift.

The Deaf, with a capital D, community and culture had stood and applauded a diagnosis that makes most of the population shake their heads. From the beginning, ASL easily and immediately granted my daughter a voice. Through ASL, she gained access to the wider community and a rigorous academic curriculum. She is empowered with fluid communication skills, ensuring her continued success academically and socially.

When did I find and embrace the Deaf community? The minute I picked up the phone and they gave us access—and embraced us.

Finding the Missing Pieces— Other Parents, Deaf Adults

By Tami Hossler

When we learned our second daughter, Erica, was deaf, we were overwhelmed with questions of what to do. Like most hearing parents, our daughter was the first deaf person we had ever met. While

we went through all the motions of detection and early intervention, we still felt a huge part of the information that would form the equation we needed to help us raise her was missing. What was it that we needed to know?

We didn't know what was missing until it walked directly into our path. For us, the missing pieces were two forms of access: we needed another hearing parent who was going through the same thing, and we needed a deaf adult mentor to give us insight, advice, and support as well as the tools to communicate with our daughter.

Living in a rural area, we finally found access to a preschool designed for deaf and hard of hearing children—an hour and a half away. For the first five years of our daughter's life, we made the trip to that preschool four days a week. That is where we began to meet other hearing parents. It was a great relief to be able to talk to others who were going through the same things we were. Access to people like ourselves enabled us to make some amazing lifelong friends.

Yet, something was still missing. It wasn't until we moved to Indianapolis, so our daughter could attend the Indiana School for the Deaf, that we found the other missing piece. Here we realized that access to and mentorship from parents and professionals who were

themselves deaf was critical. They helped us acquire fluency in ASL. They helped us understand the cultural mores of the Deaf community. They helped us set up our home to be visually accommodating. But most of all, they helped us embrace our daughter; we could understand and appreciate her for the child she was and the person she has become.

Providing our daughter with fluency in language was always our number one priority. We couldn't fathom not being able to communicate with her. This meant that we, her parents, needed to learn the language that was most accessible to her. This language was sign language. From the moment we learned she was deaf, we started learning signs. Unfortunately we didn't have full access to ASL until she attended the Indiana School for the Deaf. Prior to that we tried a variety of signed systems—all of which proved inadequate and frustrated us often. ASL, the language of the Deaf community, enabled us to deepen both our awareness and skills, and therefore increase the access our daughter would need to the community she would call her own, her school curriculum, and to us, her parents.

We learned how important it is for individuals to have a connection to others who use the same language and



live similar experiences. For our daughter, this came through her school and the Deaf community. By attending a school with other children who were deaf, she became connected to deaf and hard of hearing students from across the nation. Later, when she entered Gallaudet University, she connected with deaf and hard of hearing individuals from around the world. Just as important, the access that ASL afforded her to understanding English and the school's curriculum, through reading, exploration, discussion, and discovery, assured her access on par with her hearing peers around the country to the world we live in today.

Erica, now a graduate of Gallaudet University, works at the California School for the Deaf in Riverside and takes courses towards her master's degree. We don't see her as often as we would like, but we know she is happy—in fact, she is loving her life. This, of course, is what most parents want for their children. We could not ask for more.

As we reflect on the path our lives have taken, my husband and I agree: It was us, not our daughter, who needed an intervention. We are thankful to everyone who made our journey together so special, and we continue to work alongside the American Society for Deaf Children, the Deaf community, and other parents, professionals, and deaf individuals to ensure educational equality for deaf and hard of hearing children.



Above: Tami Hossler and her husband with their daughter, Erica.



Ann Flannery, MA, CSC, is one of two transition specialists who serve youth and families statewide through the Post-Secondary Transition Program of the Idaho Educational Services for the Deaf and the Blind. She welcomes questions and comments about this article at ann.flannery@iesdb.org.

Right: Transition specialists provide students with supports they can utilize in their quest to find work after graduation.

transition specialists partner with students

TO TURN DREAMS INTO REALITY

By Ann Flannery

Too often we saw our graduates coming back to school. They had tried to find a path to success. They had been ready to work hard. They had been ready to achieve. Again and again they had failed. Perhaps they were working but frustrated and angry about their jobs—never knowing where change was coming from or how to cope with it when it came. Perhaps they had been hired but quickly laid off. Perhaps they had been interviewed for jobs but had not been hired. Perhaps they had not even been interviewed. They returned to campus—the Idaho School for the Deaf and the Blind (ISDB)—to touch base with a place and a people who knew them, to reassure themselves of their own abilities and their own worthiness, to express their frustration with a system that did not seem to need or want them. In 2000, the Idaho Educational Services for the Deaf and the Blind (IESDB) responded.

The position of “transition specialist” was established. There was no model, no plan, no strategy. We plucked a coordinator, Paula Mason—one of our most dedicated high school teachers—from her classroom. The need was urgent; Mason would cover a state of 85,000 square miles, crisscrossed by more than 60,000 miles of road, attempting to serve young deaf and hard of hearing people in over 140 school districts and in private and charter schools.

Unintimidated, Mason—using an office on a nearby community college campus as her home base—met with individual deaf and hard of hearing young people

Photos courtesy of Ann Flannery



PHOTO COURTESY OF DREW NASH/MAGICVALLEY.COM

throughout the state. Her first goal was helping the students find summer employment. Most of them wanted to work while still in high school, and Mason was determined to find them jobs. In most cases she did.

When the students returned to school that fall, Mason continued to provide them with reminders that their time at ISDB would not be forever and suggestions about what they would do when the ties and supports they had known for so long vanished as they ventured out to make their way in their respective communities. Today, as students look for and obtain jobs, we see their lives as a “journey.” This program offers “itinerary choices,” “road signs,” and “travel tips” for our student travelers. These activities do not guarantee success, of course, but they do begin to level the playing field between deaf and hard of hearing youth and their hearing peers.

Idaho is one of the states in which often our youth cannot find work and our companies cannot find the trained employees they need. Whether the job is one of production and sales or development and service, the training demand does not seem to meet the trained supply. Mason was determined to change that, too.

By 2007, Mason was ushering her young sojourners into Idaho Division of Vocational Rehabilitation (IDVR) offices across the state, cultivating relationships with the vocational rehabilitation

(VR) counselors and state administrators along with her students. Slowly the VR counselors recognized the benefits of knowing that the steps their clients—our students—needed to take would be supported by a knowledgeable professional. As transition specialist, Mason did not duplicate services already offered; she was not behind a desk outlining the parameters of the statewide services designed to secure sustainable, gainful employment. Mason was on the ground—and usually running—to keep up with a young deaf traveler in search of his or her job. As our students learned that their transition specialist was part of their circle of support and aware of the unique challenges they might face, they willingly sketched out their own itinerary, chose their routes, and hurdled the obstacles they found in the road. These young travelers, with a seasoned “travel agent” at their side, were creative, full of energy, and not afraid.

Eventually, the IDVR agreed to partner with our school. The IESDB and the IDVR entered an interagency agreement that brought an additional transition specialist on board and deepened our collaboration with VR counselors across the state.

What began as a single individual finding summer jobs for kids became the foundation for a 12-year journey of building guide-on-the-side supports for youth across the state of Idaho. Mason was able to connect directly with individual high school students on our residential school campus and in schools across

our state. Leveraging the long-term connections fostered by our outreach program, Mason was able to identify transition-age students, discover their needs, and share the resources best suited to support their transition choices. Whether students are headed to a university, a post-secondary training program, or directly into employment, the IESDB transition supports can provide the information to empower their decisions and facilitate their next steps in achieving their dreams.

Cesar

Cesar was born in Mexico and attended public school in Idaho Falls until he reached middle school, when he transferred to the ISDB campus in Gooding. When his family relocated to

Colorado, Cesar transferred and eventually graduated from the Colorado School for the Deaf. Right after graduation, he secured a job working in a processing plant and earning a very substantial wage.

However, for Cesar money was not enough. He wanted to go to college. He was concerned about his

English writing skills, but he felt that college was where he belonged. Cesar reconnected with Mason, and the two began making plans for him to return to Idaho with the goal of attending the College of Southern Idaho in 2003. Unfortunately this proved impossible when Cesar's placement test indicated that he must take his first classes at the pre-college level. This proved frustrating for our ambitious student. Two weeks into the second semester of his Adult Basic Education English class, Cesar announced he was "so bored!" It was clear that if he had to keep spinning his wheels in this class, Cesar might change his destination again. Both the student disability services director (me!) and Mason were unsure that Cesar really understood the length and challenge of the road before him.

Mason helped re-conceptualize his work: "A boring two-year college program" became "Are you willing to work toward your goal—a college degree?" Cesar and Mason were able to find an instructor of developmental English and a tutor. Cesar began to see progress and that fired up his motivation. He completed the development levels—English 025, English

090—and moved into English 101 and then English 102. With each essay, Cesar felt his self-esteem and confidence build.

As transition specialist, Mason remained vigilant from the sidelines, always there to invite the team, including Cesar himself, to stitch together the needed supports and investigate the options, and Cesar found himself supported without ever losing the sense that he held his future in his own hands. By 2007, he had earned both his American citizenship and a degree in woodworking and cabinetry. Although Cesar has imagined himself a teacher someday, he is delighted to be transporting and installing granite in homes and businesses across the country.

Tim

Tim grew up in a very small town even by Idaho measure, using the same interpreter for 13 years. His parents were educators, and continuing his education beyond high school graduation was certainly expected. Even though the distance from his home to the College of Southern Idaho (CSI) was less than 150 miles, Tim's transition away from the familiar small town surroundings and into the unfamiliar college system and the urban flavor of his new home was more than he thought he could manage. His mother accompanied him to his new town of less than 40,000 residents and stayed in a local hotel for the first week. Before the end of the month, however, Tim was ready to quit college and head home.

Although Mason was not caught off guard, one might wonder how a transition plan so well constructed could unravel so quickly. Tim had met Mason during his junior year at his first transition Individualized Education Program meeting. From the moment he entered kindergarten, Tim knew he was college-bound, so the plan for his transition was simple: complete high school with all of the needed requirements, schedule college testing, apply for VR services, and develop an individual plan for employment. Once he enrolled, Tim would be ready to begin the conversation with the college about the needed accommodations.



TIM LEDINGTON

As Tim began to pack and head back home to the familiar, we circled the wagons! The word went out to all of his campus “touchstones” to increase the supports, empathy, and validation available to Tim. With her office on this community college campus, Mason had well-developed relationships with dormitory and CSI student services staff, instructors, and Tim’s family. Our transition specialist and the director of student disability services met with Tim, acknowledged his discomfort on campus, and invited him to remain engaged in his coursework and college activities until the end of the spring semester.

We bargained for time, feeling that if Tim would commit to stay until spring then we could build in the needed supports. Tim was encouraged to apply for the Ambassadors, a student service organization in which paid positions were offered to students who wanted to be of service to the campus community. The Ambassadors is a tight-knit group, with retreats, training, and frequent collaborations that might allow Tim to develop a sense of belonging that Tim’s family could not provide at a distance. Feeling isolated with the English-based signing he brought from his public school K-12 years, Tim enrolled in an American Sign Language (ASL) class and slowly made friends with students who shared his language, both deaf and hearing.

We began to see that the process was working. It was Tim who was willing to brave the challenge of being the college’s first deaf ambassador, and it was Tim who was willing to shelve his trusty way of communicating with others and try the “foreign” language of ASL. It was Tim who took on dorm life and roommates, group living, and an apartment on his own, and it was Tim who earned a degree in graphic design.

On the sidelines was the transition specialist who was there to recognize the potential danger that arrived with the initial onset of his homesickness. It was the transition specialist who knew what validation and supports were needed and who was able to weave, with Tim, these supports into his life.

Tim and the transition specialist would both build on these lessons as Tim continued his education. In fact, Tim went on to earn his associate’s degree in education and his bachelor’s degree in education. Today he is in graduate school at Idaho State University with the goal of eventually becoming a teacher of math for deaf high school students. Throughout his education, Tim has maintained the precious partnership with our IESDB transition specialists who helped him embark on his journey, continue through its unexpected hurdles, and without whom he may never have left the station.



CHELSEA NEWBERRY

Chelsea

Chelsea began and ended all of her K-12 education at our Gooding, Idaho, residential campus although she commuted from her home 35 miles southeast in Twin Falls. Precocious and fiercely independent from the beginning, Chelsea was always very social and quick to give her opinion on most issues. She graduated and, as everyone expected, headed to college.

Her least expensive and most supported option was the local community college while living at home and completing her general education core coursework. Chelsea planned to be a doctor. This type of academic and personal goal came with a prescribed set of steps: enroll in the required classes, stay at the top of the class, develop an academic prowess to stand

the test of time, and save money.

At first glance, there wasn’t much for the guide-on-the-side to do—until Chelsea began her capricious crossing of the higher education and employment challenges that followed. Between her valedictorian address at high school graduation in 2005 and her associate’s degree in liberal arts in 2011, Chelsea gave six majors a try, collaborated with three VR counselors, lived in 17 residences, and secured and terminated 12 positions of employment. Even her major, liberal arts, said something about her internal struggle with where she was headed and how she might reach that destination. As Chelsea was insistently self-sufficient from childhood, Mason and the transition specialist who followed Mason realized that being there with choices, resources, cheerleading, and a hand to hold would be the most effective ways to meet Chelsea’s needs and style for engaging in transition support.

As she stepped into her Miss Deaf Idaho sash and crown the spring following her college graduation, she knew her platform would be, simply stated, “Successes and Failures: Redo!” Chelsea believed this focus to be a way to share her post-secondary experiences in all their glory, “splattered with failures that blossomed into successes,” because she chose to “redo.” Time and again throughout her reign, Chelsea offered youth in her own community and across our state her own personal mantras: the courage to try again, the patience to keep on chugging when things don’t go as planned, the wisdom to not make the same error again, and the ambition to finish what they start—and Chelsea has done just that. She is now a student at the University of Montana working on her bachelor’s degree in women’s and gender studies. Chelsea claims that a master’s degree is next on her list.



Mary Hartnett is the executive director of the Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans, and she was the first recipient of the Antonia Branca Maxon Award for Early Hearing Detection and Intervention Excellence. She welcomes questions and comments about this article at mary.hartnett@state.mn.us.

MINNESOTA BRINGS TOGETHER STAKEHOLDERS TO DEVELOP A PLAN FOR CHILDREN WHO ARE

deaf, deafblind, and hard of hearing

By Mary Hartnett

With increased emphasis on accountability and access promoted by the No Child Left Behind Act of 2001, as well as the reauthorization of P.L. 94-142 as the Individuals with Disabilities Education Act of 1997, the inability of our state to identify the achievements and needs of our deaf and hard of hearing students was disturbing. While the media displayed test scores regarding the academic performance of students with and without disabilities, data regarding the academic progress of deaf and hard of hearing students in Minnesota, like so many other states, was relegated to parent-teacher narratives.

However, Minnesotans have a history of advocacy for children who are deaf or hard of hearing, and they demanded better. Past legislation resulted in mandates and funds for newborn hearing screening, acoustic standards for schools, hearing aid insurance coverage for children, parent guides, deaf mentors, establishment of a Hearing Aid Loaner Bank, appointment of a hearing loss coordinator for ages birth through 3, an advisory board for Early Hearing Detection and Intervention (EHDI), reporting of statewide test results for students who are deaf and hard of hearing, and special funds for a transition program for deaf, deafblind, and hard of hearing students. A lot of work was happening, but could we work better and smarter?

Looking for answers, the Commission of Deaf, DeafBlind, and Hard of Hearing Minnesotans (MNCDHH) and the Minnesota Department of Education co-sponsored remote participation in two National Summits on Deaf Education in 2009 and 2010. The summits were focused on improved outcomes for deaf, deafblind, and hard of hearing students, partnerships, and collaboration. Summit participants asked the MNCDHH to convene a Minnesota summit in 2011 to develop a data-driven statewide, deaf, deafblind, and hard of hearing education improvement plan with specific, measurable, and timely outcomes.

Photo courtesy of the Commission of Deaf, DeafBlind, and Hard of Hearing Minnesotans



To ensure that all perspectives were reflected in the plan, an outside consultant was recruited by the Commission to facilitate the planning process. She painstakingly prepared for the 2011 meeting and developed a framework that allowed participants to jump in as soon as they arrived. Twenty-five representatives from five state agencies, nonprofits, advocacy organizations, the Deaf community, academia, parent organizations, public and private residential and day schools, and school districts across the state were invited to two-day meetings in both July and November.

These gatherings—replete with interpreters, Communication Access Realtime Translation, and assistive listening devices—represented a diverse and broad spectrum of state and community leaders focused on a single issue: the educational outcomes for students who are deaf, deafblind, and hard of hearing. Would those invited be willing to come together to think

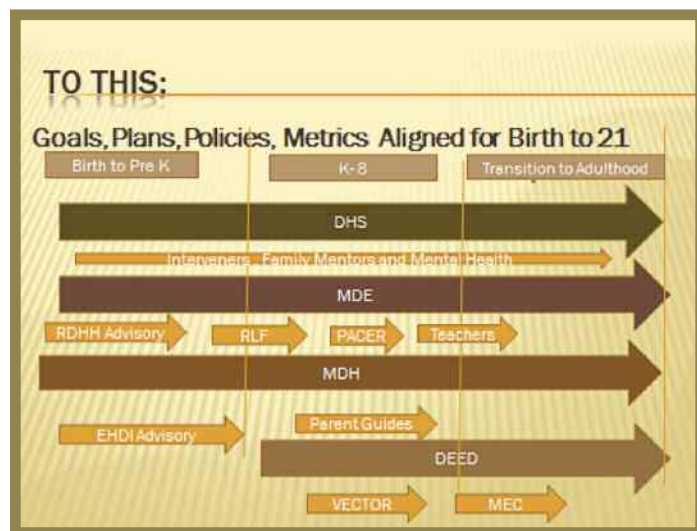
through such a tough and complicated issue? Could strong proponents of diverse programmatic and communicative approaches come together and forge a common vision? Could state agencies, each with its own federal and state mandates, funding streams, and data privacy laws, find creative ways to collaborate and maximize their resources for a common purpose?

Indeed. Every organization we invited was represented and fully participated. All were eager to build on past successes, identify barriers, and develop ways to collaborate. The attendees spoke from their hearts as well as from theory and practice. They agreed on a common purpose: to monitor and maximize learner progress for children who are deaf, deaf blind, and hard of hearing and to improve educational outcomes so that each student upon graduation is prepared to enter the adult workforce or continue his or her education as well as be a productive member of the

community.

Subsequently, the group developed the following tenets to guide all of the goals, objectives, and outcomes developed for this plan:

- Language and communication access is paramount.
- Literacy is the foundation of academic achievement.
- Communication competence is essential.
- Learners and their families have diverse and unique learning needs.
- Parents are critical to the success of children and youth.
- Children and youth have appropriate placements and programs that address their unique needs.
- A variety of technologies is available and used to support communication and student learning.



- Accountability for this plan is shared by all Minnesotan agencies that provide support to children and youth who are deaf or hard of hearing and their families.

The group plan resulted in 12 objectives that address critical components of development and education from birth to high school graduation. The goals and objectives are aligned with the goals of the National Agenda in Deaf Education (www.ndepnow.org/agenda/agenda.htm), Minnesota's State Performance Plan indicators for special education, and the goals of the state's EHDI that are reported to the Center for Disease Control (CDC). For each objective, outcomes, measureable indicators, benchmarks, and responsible agencies were identified. Continuous data collection has the potential to provide Minnesota agencies with information to monitor the progress of its deaf, deaf blind, and hard of hearing children and youth. The plan was approved in November of 2011 and implementation began.

A steering committee was created in January of 2012 that has one representative from each state agency/funding organization, the University of Minnesota, and Minnesota Hands & Voices. The commission contracted with collaborative coordinators to keep the project on track. During the first six months of 2012, we sought and obtained approval

from the advisory committees or boards of trustees of all organizations, including The Minnesota State Academy for the Deaf, Northern Voices, the Metro Deaf School, the Minnesota Association of Deaf Citizens, PACER, Minnesota Hands & Voices, MNCDHH, and the Newborn Hearing Screening Advisory Committee. Meanwhile, the steering committee contracted with the Minnesota Analysis Division to develop a reliable and valid survey for parents of deaf and hard of hearing newborns and children up to the age of 5 and a separate teacher survey for all age groups. Over 20 professionals participated in the survey development, including state epidemiologists, parents, and professionals in public health, vocational rehabilitation, and education. Two interpreter referral agency directors generously donated funds from their organizations for Target gift cards as an incentive to get a higher response rate from parents and teachers. The parent survey was distributed in November of 2012; we had a participation rate of 43 percent. Follow-up interviews with parents who did not respond have been conducted in Somali, Spanish, Hmong, and American Sign Language. The teacher survey was sent in February and March; we have a participation rate of 65 percent. The results of both surveys and an analysis of disaggregated data from the State Performance Plan, statewide high stakes testing, Part C and EHDI data reported to the CDC was analyzed

in time for the next summit in April of 2013.

The collaborative plan, now in its second year of implementation, focuses on identifying practices that are working and those that need to be implemented to ensure success for each deaf, deafblind, or hard of hearing student in our schools. In addition to the painstaking work of developing interagency agreements to share resources and information and the development of two statewide surveys, other progress has been made, including the development of:

- free software that can be used to monitor individual students' academic progress (developed by the University of Minnesota); and
- a "Transition Tool Kit" (development of this kit was led by the Minnesota Department of Education).

We have met others who are interested in data and who we hope will work with us, especially the Minnesota Office of Higher Education that oversees the State Longitudinal Education Data System. We believe that the work that they are doing may help us to track student progress in another powerful way.

Collaboration—across agencies and interest groups—is complicated, messy, and hard. It can also be exhilarating. We've learned that we can never

COLLABORATIVE PARTNERS

- MN Hands and Voices
- DeafBlind Technical Assistance Project
- MN Association of Deaf Citizens
- PACER
- Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans
- MN State Academy of the Deaf
- Northern Voices
- Metro Deaf School
- VECTOR-transition
- U of M
- DHS
- MN Dept of Ed
 - EHDI Coordinator
 - Part C Coordinator
 - Resource Center D/HH
- Vocational Rehab Services
- State Services for the Blind
- MN Dept of Health
- NE Metro D/HH
- St. Paul Public Schools



GOALS

1. A) All young children who have hearing loss will maximize their communication and learning potential, regardless of the degree of their hearing loss, and will be able to begin kindergarten with communication, social, and early literacy skills at a developmental level similar to that of their typically developing hearing peers, or to the maximum extent appropriate for the individual child.
B) All families will receive the supports they need to help their children develop and learn. *(Birth through 5)*
1. Children and youth who are deaf, deafblind, and hard of hearing will be prepared to live independently as adults. *(K-8)*
2. Students will maximize their potential and involvement in the areas of employment, education and training, and independent living in order to become productive citizens. *(9-Graduation)*

communicate enough. We've learned that the more people learn about our plan, the more they want to help us with it. We've also learned that something powerful happens when dedicated educators, parents, audiologists, deaf, deafblind, and hard of hearing advocates, administrators, and academics sit across the table from one another to have

learning conversations and to work toward a common purpose. We've learned that it's totally worth all the planning and the effort.

Our challenge now is to find data that are useful to parents and educators so they can help children be the best they can be and use the data to continuously improve our state system. We are

hopeful that will be the case with the continued implementation of Minnesota's plan for maximizing and monitoring the learning of our state's deaf, deafblind, and hard of hearing children. We have come together to continue making progress for each of these children—and for their families and to improve the statewide system.

Are you a Psychology Professional Interested in Working with Children Who Are Deaf or Hard of Hearing?

Kennedy Krieger Institute is now recruiting applicants for the nation's first psychology internship training program that prepares psychologists to meet the needs of children who are deaf or hard of hearing. The new program is fully accredited by the American Psychological Association.

The trainee will receive in-depth experience working with faculty in the Deafness Related Evaluations and More Clinic and the Pediatric Psychology Clinic and Consultation service.



Kennedy Krieger Institute

For more information or to apply, visit
kennedykrieger.org/PsychologyInternship-Deafness

Get Moving! Stay Moving! Change Your Life!



Child & Adolescent Counseling, Individual & Family Therapy, Behavioral Consultation, and Professional Training

The hardest thing about making an important change is getting started. Emotional inertia traps us in old thinking and unhealthy habits. Are you or is someone you know stuck in a pattern of poor decisions and negative thinking?

It's time for a change!

Matt Rider has over 20 years of experience working within the deaf and hard of hearing community on mental health-related issues.

Contact Matthew Rider, LCPC, a fully licensed and insured clinical professional counselor, today.

E-mail: Matthew.Rider@inertiacounseling.com

Phone: 240-232-6543

Skype: InertiaCounseling

Website: www.inertiacounseling.com

Internet-based counseling and consultation available in some areas. Some insurances accepted. Contact your health insurance provider to determine your eligibility. Inertia Counseling, LLC MD Lic # LC4564



Sherri Zummo,

mother to a daughter now in college and a son who is a student at the American School for the Deaf (ASD), is a member of ASD's parent advisory panel. She has testified before her state's legislature, advocated for passage of Connecticut's Deaf Child Bill of Rights, helped other families attain appropriate services for their children, and participated in parent leadership trainings for children with multiple disabilities. She welcomes questions and comments about this article at szummo6@comcast.net.

to save a son

By Sherri Zummo



After her son attacked a police officer, Sherri Zummo buddled with him in the Emergency Department of their local hospital and refused to leave until the state guaranteed her the services she knew he needed.

I was so impressed—I had finally found a program for Robby, my son. The Positive Attitude Concerning Education and Socialization (PACES) program—a very structured, sign language-rich learning environment at the American School for the Deaf (ASD)—was perfect. Robby was deaf, had cognitive and behavioral delays, autism, and a growing tendency to hurt both himself and those around him. At ASD, he would be in classes with kids similar to himself and everyone around him—students, staff, and teachers—would use sign language. Further, he would be monitored one-to-one by staff 24 hours a day. He would be able to participate in sports. He would be able to participate in group activities, and he would be able to communicate with someone besides me.

However, a two-year fight with my school district led nowhere. They said that PACES was too expensive; they weren't going to pay. When I pointed out that they knew they could no longer provide an appropriate education for Robby and that his behaviors were becoming too severe to handle, I was told that in Connecticut where we live, parents can relinquish guardianship to the state; then the cost of my son's care would be split—the state would fund the residential piece and the school district would fund the educational piece. I couldn't believe this. I could never give my child over to anyone else. He is my child.

At the Department of Developmental Services, where I had also asked for help, the

Photos courtesy of Sherri Zummo



information was just as surreal. I was told that the waiting list to fund his education and care was too long to include us. Further, even if we could have an “emergency meeting” and the case was decided in our favor, I would have to accept the placement they chose. ASD would not be an option. The closest approved program was in Florida. The information was devastating. I had not originally considered residential care. In fact, when an ASD teacher first suggested it, I was offended. Like so many parents, all I wanted for my son was the very best and who could best provide this but me? Yet every door was slammed in my face.

The Hopes of Birth

I remember the morning that I drove to the hospital to be induced for my son’s birth. He was my second child. At home waited my four-year-old daughter. Like me, she was excited about the arrival of a beautiful baby boy. Life would be perfect—one girl and one boy, a daughter and a son. I had planned all sorts of amazing things for them. My son would play sports; he would be the high school football captain, the college baseball star, the president of the United States. After a complicated delivery that almost took his life and an eight-day stay in the neonatal intensive care unit, I was finally able to bring him home. We saw that the thumbs on both of his hands weren’t developed, and he had failed a newborn hearing

screening. Still, everyone assured me that this was normal, just fluid in his ears. I thought the worst was over.

Re-tested at six weeks, Robby was confirmed to be profoundly deaf in both ears. I was devastated—he would never be able to hear me say, “I love you.” I cried for 24 hours straight, then I composed myself. I knew I needed to find a way for Robby to function in this world.

I didn’t feel sign language was a good option as he only had four fingers on each of his hands, so I decided to go the oral route. Robby had hearing aids by the time he was eight weeks old, and we began intensive auditory and speech therapy. However, the high-powered hearing aids were useless; he didn’t have enough usable hearing. I then investigated cochlear implants, watching 36 children with cochlear implants during therapy sessions. They did fantastically, and we were urged to get Robby implanted as soon as possible. We went through the evaluation process and learned that my son had a monodini malformation, a malformed cochlea. Still the surgeon felt that he would benefit from the implant, and we proceeded.

Robby was implanted at one year of age. Immediately after surgery, chaos broke loose. Robby had a spinal fluid leak, and we spent seven days in the Intensive Care Unit with a shunt in his spine. Everything healed, and we still expected good results. However, when we went for the device activation,



home, he bit, kicked, and hit others; he would also ram his head into walls, punch himself repeatedly, flip tables, chairs, and other furniture and equipment. Besides hurting himself, he hurt other children; teachers and staff were sent to the hospital and I had internal bleeding, broken bones, and hair ripped out of my head. My health declined. A doctor told me that if I continued to live like this, I would die. The thought of that scared me immensely. If I died, who would take care of Robby? I was his lifeline. How would he live in a world without me? What would happen to him? Who would fight for his services now and as an adult?

I finally agreed to accept some help. The Department of Developmental Services labeled my son “level one,” the highest level of need. Money now went towards people

there was no response. That attempt turned into many more. After years of failed attempts at auditory response, we started to learn sign language. Robby was three years old. By the age of five, he was diagnosed as profoundly deaf, legally blind, on the autistic spectrum, and intellectually delayed; there were other medical and physical issues as well. Worst of all, he was starting to display aggressive and self-injurious behaviors.

The therapies multiplied, too. During the Birth to Three program, he had speech, auditory and physical therapy, occupational therapy, vision therapy, and sensory integration therapy. At three years old, he had started in our local preschool where the staff had basic sign language skills. One success: his brain adjusted to very strong glasses, and he was able to use his vision well.

When Robby was five years old, we had tried to send him to ASD for half days. ASD was an hour and a half away, and due to the autism and the long rides he became over-stimulated. So back to our local public school he came. He entered our local elementary school and his autism was addressed intensively.

The next years were filled with struggles. My son’s needs increased, his aggressive behaviors became worse, the fight for services became harder—and the educational gap between Robby and his peers became wider. Still, by third grade his communication reception had grown tremendously and he had a full-time teacher of the deaf. His other needs were addressed as well. Unfortunately, the kids in his class became less interested in playing with him as they got older. Robby could only communicate with one person in school and with us at home.

Meanwhile the injurious behaviors increased. In school and at

coming into my home to allow my family some respite. For the first time in years, I could take a shower or cook or spend one-on-one time with my daughter and husband. Unfortunately, the help was extremely limited. We couldn’t find people that could communicate with Robby or deal with his behaviors. My son wouldn’t detach from me. One of the people that had come into my home to help was a teacher at ASD. This was the woman who, after spending time with my son, asked me if I had ever thought about the PACES residential program at ASD.

The Turning Point

My son’s injurious behaviors continued to escalate. When

Robby was 10, he went into a three-hour tantrum, hurting himself and attacking my husband and me. He would calm for a minute, then jump up and attack someone or something. After hours of this and my daughter watching and crying, we called the police for the first time.

When they arrived, Robby attacked one of the officers.

They subdued my son, and watching this ripped my heart apart.

They said they had to take him by ambulance to the hospital for a psychiatric evaluation, so off to the hospital we went.



Once we arrived, I was told we could not leave before Robby was evaluated. Our local hospital was not equipped to evaluate children, so they called every hospital in the tri-state area. One after another, the hospitals in three states told us that they were either full or weren't equipped to deal with a child so complex. There was nothing to be done. We were told to take Robby home.

I hunkered down in thought, and I knew this was my moment. I reached down and found the strength to do what I needed to do for my son. I would do it no matter what it took.

I refused to leave. We would not go home, I said, until we got the services that my son needed.

That refusal sparked a 10-day stay in the emergency department of our local hospital. I called my senators. I called the Office of the State's Attorney. I called the news stations, and I called the newspapers. The response was overwhelming. We were on the news and in the newspapers, and the senators and representatives offered their support and made phone calls. The hospital stood behind us in our fight.

At the same time, the state agencies threatened me with arrest. They said that once I was arrested, Robby would be placed in foster care—and they reminded me that they didn't have appropriate foster care but that's where he would end up anyway. I was terrified, but I knew I had to hold strong for the life and future of my son. Finally, after 10 days during which my son and I didn't see the light of day, I signed a contract. I would maintain guardianship with full parental rights over my son, who was approved for funding in the PACES program at ASD.

A Decision Affirmed

Six weeks later, when the school van came and drove away with my son, I felt as though my heart had been ripped from my chest, as though someone had taken my soul. However, after waiting a week for him to adjust, I visited Robby for the first time—and my fears were dispelled. My son put his arm around another little boy as soon as I arrived and signed, "Mom, this is Robby's friend." That's when I knew with 100 percent certainty that I had made the right choice.

It has been four years since Robby joined ASD. He transitions between home and school beautifully. He is receiving an appropriate education and is making great strides. He has the ability to function in a world without mom. He plays sports. He has friends, and he is in a communication-rich environment 100 percent of his life. He is happy. My health has improved. I have more time to be a parent to my daughter, who left for college a few months ago and is enrolled in an accelerated five-year master's program in special education.

Every child is different and has unique needs. As parents, we know what is best for our kids. Don't ever let anyone tell you differently, and, most importantly, don't ever give up the fight. Together we can move mountains. We are our children's voice in the wider world—and they need to be heard.



pepnet 2

deaf and hard of hearing

connecting people



Resources



Trainings



QuickClasses



Conferences



Working to improve postsecondary outcomes for individuals who are deaf or hard of hearing, including those with co-occurring disabilities.



eLearning Opportunities



Forum



Communities of Practice



Live Chat help

building capacity

Connect with us at www.pepnet.org





Jane Mulholland, MEd, MA, is the superintendent of the Washington School for the Deaf in Vancouver, part of the Washington State Center for Childhood Deafness and Hearing Loss. She has served as superintendent and in other educational leadership positions at the Oregon School for the Deaf in Salem, and as assistant superintendent at the Oregon Department of Education; she has also served as principal, dean of students, and teacher at the Arizona State Schools for the Deaf and the Blind in Tucson. In 2007, she founded Planning for Student Success, a private school improvement consulting business. Mulholland welcomes questions and comments about this article at jane.mulholland@wsd.wa.gov.

child first:

a belief, an attitude, and a path to change

By Jane Mulholland

Child First: Two small words that can change a life, a family, a school, a state, a country. Washington School for the Deaf (WSD), in Vancouver, and the Washington State Center for Childhood Deafness and Hearing Loss (CDHL), have committed to supporting Child First, a national campaign to ensure that deaf children have their right to language recognized and fulfilled regardless of which educational method specified in the Individualized Education Program (IEP). Initiated by the Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD) and endorsed by the National Association of the Deaf, the campaign (www.ceasd.org/idea/) attempts to relegate what some called the sign/speech “communication wars” to the dustbin of history.

Child First is modality neutral. Whether the child’s family embraces American Sign Language (ASL), listening, speechreading or speech, a system of signs that encode English, or a combination of approaches, Child First supports the child and his or her family. At Child First, the child’s human right to language is primary, but the chosen method of learning and exploring that language is based on the child’s needs and the decision of the parents and the IEP team.

Developed initially to help federal lawmakers understand the unique educational needs of deaf and hard of hearing children and to inform the reauthorization of the Individuals with Disabilities Education Act, Child First

Photos courtesy of Jane Mulholland



recognizes the following the principles:

- Language is a human right.
- There are multiple pathways to learning language.
- One size—or one system—does not fit all learners.
- The IEP should determine educational placement for each child.
- Monitoring each child's progress is critical to appropriate educational outcomes.
- Family involvement is critical to a child's success.

I initially learned about Child First from CEASD. As a longtime member, I have always found the technical assistance papers and other resources provided by this organization to be very helpful so when CEASD began talking about the Child First campaign, I watched the vlogs by CEASD president Dr. Ron Stern, superintendent of the New Mexico School for the Deaf, and read the information on the CEASD website. "I hope there is a ground swell of support for this campaign," I thought. "It is exactly what we need to ensure deaf and hard of hearing children in this country get the services they need and deserve." Then I went back to my everyday work and promptly forgot about it.

However, in April of 2012, Rick Hauan, director of CDHL, and I attended the CEASD conference in Connecticut and we were energized to find that much of the conference focused on Child First. Rick and I talked about how exciting

it would be to bring this campaign into our school, WSD, and what Child First could mean for the children of Washington State.

WSD is a state-funded residential school. From its inception in 1886, WSD has provided a comprehensive, high quality, 24-hour educational program for deaf and hard of hearing students from across Washington State. Until 2009, WSD was an independent facility; however in 2009, the Washington legislature, by a unanimous vote, created a new agency—CDHL—as a statewide resource to provide leadership and coordination for WSD and all school districts serving deaf and hard of hearing students in our state. CDHL developed a statewide outreach team of 36 representatives from WSD and school districts and private schools throughout the state, the state department of education, parent organizations, and the Gallaudet University Regional Center at Ohlone College (in Fremont, California). The goal was the provision of technical assistance, consultation, training, and in some cases direct services throughout Washington State.

While the environment of WSD is bilingual in ASL and English, CDHL works with programs and schools that follow other communication philosophies, including those that use the listening and spoken language approach. CDHL outreach team members provide support to all. Within the team, every modality and communication method is accepted, and team members learn from each other as they collaborate to support programs and school districts throughout the state.

As we worked to bring Child First to our state, we first



made a presentation to the CDHL Board of Trustees in November of 2012. The board enthusiastically supported the principles and goals of Child First and voted to formally endorse the campaign. Nine board members and eight staff became supporters that day. Next we began a series of presentations to the WSD leadership team and various departments within WSD. These are still underway, but by the end of that effort, more than 150 people will have heard the Child First message, bringing the total number of potential supporters to 170.

In January of 2013, the CDHL statewide outreach team held its quarterly meeting, and time was allotted on the agenda for a Child First presentation. At the conclusion, another 36 people had learned about the campaign, pushing the number of potential supporters to well over 200. More important, the network this group of people represents and the impact these 36 people can have in sharing the Child First principles throughout the state is enormous. The members of the outreach team interact with the state's nine educational service districts—potentially 295 school districts, private schools, and various agencies. We are beginning to explore how each of the team members can carry the message of Child First into their corners of the state. As of this time, presentations have been made with staff from the Department of Health, the Department of Early Learning, the Office of the Deaf and Hard of Hearing, and the Washington Sensory Disability Services. We are hoping that the number of people who receive the Child First message in Washington may reach the thousands within the next year.

As a Child First state, Washington would provide our deaf and

hard of hearing children with IEPs based on the needs identified in their evaluations, not on the services a particular program offers. We would see deaf and hard of hearing children's educational progress continually monitored and appropriate interventions, supports, and changes in placement provided so the children are not allowed to fail.

We would see deaf and hard of hearing children become emotionally and socially healthy young adults, capable of accomplishing their personal and professional goals. We would see parents of deaf and hard of hearing children receive unbiased information, training, and support throughout the lives of their children so they can make the decisions that are best for their families. We would also see deaf and hard of hearing children having the same opportunities, the same entitlements, the same basic human rights our society takes for granted for hearing children. Finally, we would see deaf and hard of hearing children become adults that take their rightful place in every field of

work, every level of government, every community organization, every opportunity afforded to citizens in our country.

The Child First campaign is about the power of keeping the concept of the *individual* in the IEP process. It is about having the individual child in the forefront of every decision we make and about every individual that reads this article having the power to impact 10; 20; 1,000 or more people by sharing the principles of Child First. Share them with your family, your colleagues, your school districts, and your legislators at the state and

national levels. Believe that you—one individual—have the power to make a difference in the lives of the children you serve.

When we left the CEASD conference last year, Rick and I had the goal of WSD becoming a Child First school. Once we started focusing on that, our goal changed to having CDHL become a Child First agency. Now we will not be satisfied until we are a Child First state. The beneficiaries will be every deaf and hard of hearing child and their families in Washington.

**The Child First
campaign is about
the power of
keeping the
concept of the
individual in the
IEP process.**



Clerc Center Sets Priority Areas for 2013-2018

From February 4-5, 2013, stakeholders from around the country participated in the Clerc Center's National Priority Setting Meeting to contribute to the development of its 2013-2018 strategic plan.



The two-day meeting was facilitated in American Sign Language by Dr. Susan Jacoby, executive director for Planning, Development, and Dissemination, and Dr. Richard Jeffries, a training specialist with the Clerc Center. Over these two days, the 23 stakeholders participated in a "Structured Dialogic Design Process" (SDD), which was developed by Dr. Alexander "Aleco" Christakis, who has more than 35 years of working in the field of complex change and has been consulting with the Clerc Center.

The stakeholders brought perspectives and values that represented a wide continuum of practices within deaf education. Christakis explained that this played to the strength of the design of the SDD. "A person's perspective is just that—an individual opinion. However, with many perspectives you have collective wisdom," he said. The co-laboratory process is democratic and engages all participants and, as a result, promotes consensus building and results in shared ownership of the priorities identified.

By the meeting's end, all of the participants had developed a shared understanding of challenges that, if addressed by the Clerc Center, would have a positive impact on the success of current and future generations of deaf and hard of hearing children. Based on that shared understanding, the group identified the following areas of focus for the 2013-2018 Clerc Center strategic plan:

- Creating productive collaborations among all stakeholders involved in the education of deaf and hard of hearing children
- Providing professional development for professionals serving deaf and hard of hearing children
- Developing and providing proactive collaborative training for parents and professionals

Participant Djenne-Amal Morris, a parent from North Carolina, felt like an equal stakeholder. "Just seeing and hearing the ideas, seeing the passion... but what made the difference for me is the process that we went through, that each person had an opportunity to say what his or her passion was or his or her belief was, give an explanation, and then move on. And you were heard. For me, I felt validated," she said.

"I sincerely appreciate the vision and passion of everyone who participated on behalf of deaf and hard of hearing students across the nation," said Ed Bosso, vice president of Gallaudet University's Clerc Center. "I believe this led to a successful outcome for the meeting and that all of the participants left with a powerful sense of contribution and accomplishment. I look forward to the work that lies ahead."

Thanks to All of You!

The Clerc Center anticipates releasing its strategic plan in the fall of 2013 and would like to thank all the participants of the National Priority Setting Meeting for their investment of time, energy, and wisdom:

Ed Bosso, vice president, Laurent Clerc National Deaf Education Center

Kimoy Campbell, parent, Laurent Clerc National Deaf Education Center

Ernest Garrett III, executive director, Missouri Commission for the Deaf and Hard of Hearing

Steve Gettel, superintendent, Montana School for the Deaf and Blind

Shira Grabelsky, teacher, California School for the Deaf, Fremont

Judy Harrison, director of programs, Alexander Graham Bell Association for the Deaf and Hard of Hearing

Lisa Herbert, psychologist, Laurent Clerc National Deaf Education Center

Hendi Kowal, parent, DC Public Schools

Cheryl Lee, interpreting services coordinator, Montgomery County Public Schools

Dr. Irene Leigh, professor emeritus of psychology, Gallaudet University

Mary Ann Mieczowski, director, Exceptional Children Resources, Teaching and Learning Branch, Delaware Department of Education

Djenne-Amal Morris, parent, Eastern North Carolina School for the Deaf

Susan Morrow, specialist, Christina (Delaware) School District

Taiyabah Naeem, teacher, Laurent Clerc National Deaf Education Center

Kevin Nolan, outreach coordinator, Boston Children's Hospital

Dr. Khadijat Rashid, professor of business, Gallaudet University

Charity Rogers, teacher, Saint Paul Public Schools

Dr. Ron Stern, president, Conference of Educational Administrators of Schools and Programs for the Deaf

Irvine Stewart, social worker, BJC Healthcare

Debbie Trapani, coordinator of inclusion and differentiation, Laurent Clerc National Deaf Education Center

Nanette Virnig, athletic specialist, Laurent Clerc National Deaf Education Center

Fred Weiner, interim assistant vice president, Administration and Finance, Gallaudet University

Dr. Christine Yoshinaga-Itano, professor, University of Colorado



Clerc Center Commemorates 25th Anniversary of DPN

In March 1988, Gallaudet University students, faculty, and alumni led a protest that resulted in the appointment of the university's first deaf president in its 124 years of existence. Since then, the Deaf President Now (DPN) movement has been hailed as a civil rights milestone. Celebrating this historic movement provided students at both of the Clerc Center's demonstration schools with learning opportunities across departments.

In art class at Kendall Demonstration Elementary School, students created and painted plaster casts of their hands set in ASL classifiers that symbolized events from the DPN week.

On March 8, social studies teachers at the Model Secondary School for the Deaf (MSSD) brought together the four DPN student leaders—Tim Rarus, Greg Hlibok, Bridgetta Bourne-Firl, and Jerry Covell—for a panel discussion with the students. The iconic student leaders shared that the impact of the week-long protest remains with them today.

On March 15, MSSD hosted a live webcast of alumni who reminisced on their DPN experiences at MSSD, which shares its campus with Gallaudet University. The alumni shared that their teachers used the occasion as a teachable moment on civil rights, the concept of peaceful protest, and how to advocate for themselves to members of Congress and the media. This panel discussion is archived at <http://webcast.gallaudet.edu/?id=138>.

Clerc Center Implements Bullying Prevention Program

Across the nation, schools are finding new ways to address bullying. The Clerc Center joined this nationwide effort by training personnel this past summer on the implementation of the Olweus Bullying Prevention Program (OBPP).

"The OBPP focuses on reducing bullying through improved social relations among students of all ages. The program reaches out to those who are bullied and to those who bully. It takes the power out of bullying and creates a safe school where all students can learn," said Cynthia Hunt, OBPP coordinator. "The OBPP is a true community-wide effort. It draws support from teachers, staff, administrators, parents, and students to help sustain its success."

The OBPP offers about 35 different class-based activities that are designed for different grade levels: from K-3, to grades 4-6, to middle and high school students. Clerc Center teachers, staff, and school administrators will be primarily responsible for implementing the program.

The four Olweus anti-bullying rules are:

- We will not bully others.
- We will try to help students who are bullied.
- We will try to include students who are left out.
- If we know that somebody is being bullied, we will tell an adult at school or an adult at home.

To prepare, the OBPP Coordinating Committee organized a two-day training session from August 9-10 and in-training sessions at both schools throughout the fall. OBPP presenters Mary Weiner, director of the Adult Degree Program at Gallaudet University, and Marsha Miceli, director of the Pennsylvania School for the Deaf Student Development and School-Wide Programs, emphasized that the success of the program will depend on the adults involved.

As part of the training, Weiner and Miceli reviewed national data statistics on bullying in elementary and high schools among hearing students and compared them to the results of a survey on bullying given to Kendall Demonstration Elementary School (KDES) and Model Secondary School for the Deaf (MSSD) students last year. The trainers praised the Clerc Center for being one of the frontrunners among schools for the deaf in implementing the OBPP.

The OBPP officially kicked off in January 2013 throughout the Clerc Center with professional development days for KDES and MSSD teachers and administrators, dedicated training sessions for Student Life and Transportation staff, artwork by MSSD students, and skits by KDES students. The OBPP implementation will continue throughout the 2013-2014 academic year.

Coming Soon from the Clerc Center



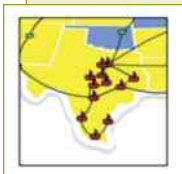
DEAF STUDENTS WITH DISABILITIES NETWORK

This on-line network will provide support to families and educators of deaf and hard of hearing students with any of the 13 disabilities identified in the Individuals with Disabilities Education Act. There will be a section on evidence-based resources, recommendations, links, and promising practices. The site will also highlight tools, have an "Ask the Expert" section, and allow for parent-to-parent networking, information sharing, and advocacy.



EARLY INTERVENTION NETWORK

This on-line resource will share the five areas that have been identified as beneficial for developing linguistic competence. The network will highlight practices of early intervention programs serving deaf and hard of hearing children and demonstrating how they are incorporating the five areas for developing linguistic competence.



EDUCATING DEAF AND HARD OF HEARING STUDENTS: A GUIDE FOR PROFESSIONALS IN THE MAINSTREAM

This series of on-line modules is being co-developed with the Texas Education Service Center, Region 20, and will provide guidance to educators who have limited or no previous experience working with deaf or hard of hearing students. Current modules under development are: An Introduction to Deafness, Considerations for Deaf or Hard of Hearing Students in the Classroom, and What a Mainstream Educator Needs to Know About IEPs/IFSPs/504 Plans.



CLASSROOM INTERPRETING: A SERIES OF TIP SHEETS

This series of publications for school administrators, educators, educational interpreters, and parents will be developed by Dr. Brenda Schick. It will be based on the content of Schick's Classroom Interpreting website which was developed in collaboration with Boys Town National Research Hospital. The publications will be designed to help ensure language access for deaf and hard of hearing children in mainstream schools and programs. Additional emphasis will be placed on the role of interpreters in schools and clarifying the skills and qualifications needed for educational interpreters.



NATIONAL K-12 ASL CONTENT STANDARDS

Work on developing national K-12 ASL content standards and benchmarks continues! The draft of the standards and benchmarks developed by the ASL Standards Contract Team is now being revised, and in the coming months a panel of ASL instructors and specialists will provide feedback on the draft. There will also be an opportunity for nationwide public comment and a final to be completed in 2013.



CLERC CENTER AND BOSTON CHILDREN'S HOSPITAL COLLABORATIONS

The Clerc Center is collaborating with Boston Children's Hospital on two projects. The first is a web-based seminar on early intervention that will have accompanying downloadable, printable, supplementary materials. The second is the revision of the 10-year-old *Children with Cochlear Implants Who Sign: Guidelines for Transitioning to Oral Education or a Mainstream Setting* (working title: *Children with Cochlear Implants: Guidelines for Transitioning Between Various Educational Settings*) which will include information on transitioning to a signing or visually supportive communication approach.



LIKE US ON FACEBOOK!

Chat with us, comment on our work, and get up-to-date news about where we are and what we're doing at the Clerc Center!
www.facebook.com/InsideClercCenter

the parent and the advocate within

By T. Alan Hurwitz



Dr. T. Alan Hurwitz is the tenth president of Gallaudet University, the world leader in liberal education and career development for deaf and hard of hearing students. Previously, Hurwitz was president of the National Technical Institute for the Deaf, a college within the Rochester Institute of Technology in Rochester, New York.

During the course of his career, Hurwitz has been involved in a variety of professional and community organizations. He has served on the boards of several of those organizations, including the Rochester School for the Deaf in New York, of which he was also president. He is a past member of the board of directors of the National Captioning Institute. He is also a past president of the National Association of the Deaf and of the World Organization of Jewish Deaf. Hurwitz lectures extensively and has been widely published.

Hurwitz earned his bachelor's degree in electrical engineering from Washington University in St. Louis, Missouri; his master's degree in electrical engineering from St. Louis University in Missouri; and his doctorate in education, curriculum, and teaching from the University of Rochester in New York.

My real introduction to education came when my wife Vicki and I welcomed our first child, Bernard, who was born hard of hearing. Later we adopted our 16-month-old profoundly deaf daughter, Stephanie. Vicki and I were fortunate to work with outstanding support services professionals, but parenthood was nonetheless a difficult journey as some of our decisions flew headwind into established policy or entrenched practice. We quickly discovered that as we grew into our parental roles, we also had to become advocates for our children. It was like being a 'tailor,' having to work with school professionals each year to 'tailor' an appropriate individualized educational plan for each of our children.

Fast forward several decades to April of 2012, when as president of Gallaudet University I sat through a panel of parents at the annual conference of the Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD), hosted that year at the American School for the Deaf in Hartford, Connecticut. Memories of my experiences as a parent-advocate resurfaced when the panelists recounted early intervention trials in their local districts when advocating for the learning needs of their children. Many of their stories mirror mine and those that are shared in this issue of *Odyssey*.

Gallaudet is an active member of CEASD, whose current Child First campaign is immeasurably important. As its name indicates, the child is paramount; as its name suggests, education and intervention decisions need to center around the interests of the child. CEASD spearheaded Child First as a national campaign to ensure that the Individuals with Disabilities Education Act (IDEA) appropriately addresses the language, communication, and educational needs of deaf and hard of hearing children. However, as stories provided in this issue illustrate, we are headed precipitously into a future where placement is prioritized over the student. This trend observed in the past decade threatens to

render irrelevant the 'I' in IDEA as well as in the Individualized Education Program (IEP), which was implemented by the IDEA to recommend placement but has increasingly become a result of placement in a mainstream setting without consideration for a student's unique language and communication needs.

Believing in individuality does not necessarily bear friction with believing in community. Anthropologist Margaret Mead said it best: "Always remember that you are absolutely unique. Just like everyone else." Indeed, studies conducted in Gallaudet's Brain and Language Laboratory, a unit of our Science of Learning Center on Visual Language and Visual Learning, and conducted elsewhere have shown that the brains of deaf learners exhibit differences from those who learn with aural input. This is not theory but fact. Students who are deaf or hard of hearing are unique, just like every other child.

We need teaching methods and classrooms that play to their inherent strengths. I often meet alumni from Gallaudet University who tell me that they struggled before arriving at Gallaudet, after which they went on to excel as professionals. Our alumni include a staff member in the recent Obama 2012 campaign, a seated member of the South African Parliament, a world-class hotelier in Rome, a standard-bred horse racer, San Francisco pizzeria owners with a Michelin rating, and many more whose diverse careers have redefined slivers of the local, national, and global communities.

From the signing of the University's charter by President Abraham Lincoln in 1864 to the present day, the University has seen and made a landmark impact on education, communication, policy, culture, access, and the arts. In the summer of 2014, Gallaudet University will celebrate its sesquicentennial. This is 150 years of an unparalleled legacy that extends to individuals and their families, both here and abroad.

Evidently then, Gallaudet University has been a driving force for positive change. The more

important consideration, however, is how should the University continue to lead in shaping the landscape of deaf education? I would like to take this opportunity to invite you to celebrate our sesquicentennial with us and help us envision the next 150 years in which the University maintains its vibrancy, impact, sustainability, and relevance. What needs to happen? The world is richer for Gallaudet University's influence, and this must continue.

Opportunities for deaf and hard of hearing children in academics and employment have evolved along with the world's industries, politics, technologies, and commerce, but what has not changed in these 150 years is the critical role that the family plays in the educational opportunities available to the individual deaf child. As my parents advocated for me, and in turn my wife and I advocated for our first and then second child, it is also worth noting that although those successful alumni I mentioned all received their higher education at Gallaudet University, their education began at home and they had parents who advocated for them early on.

This theme of the parent as advocate is present

across the stories in this issue of *Odyssey*, and so this issue is valuable in that we see that other parents and professionals encounter the same struggles that compromise the spirit of the IDEA. I encourage every one of you to share this resource with others at your school, in your organization, and at home. Individual experiences and stories are what we need to drive the IDEA and inform the IEP. This year CEASD will hold its conference in Tucson with, fittingly, "The Power of Collaboration" as its theme.

In closing, I would like to share another quote from Mead. She famously said: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." The challenge, however, is how we intend to share our collective expertise to the benefit of students. Together, we can show the power of the individual.

The CEASD website is www.ceasd.org/ and more information on the Child First campaign can be found at www.ceasd.org/ideal/.

Visit www.gallaudet.edu/150.html to learn more about Gallaudet University's sesquicentennial celebration.

**I would like to take
this opportunity to
invite you to
celebrate our
sesquicentennial
with us and help us
envision the next
150 years in which
the University
maintains its
vibrancy, impact,
sustainability, and
relevance.**



GALLAUDET
UNIVERSITY

150 YEARS
1864 - 2014

Celebrating 150 Years of Visionary Leadership

Gallaudet will reach its 150th anniversary in 2014! From the signing of our charter by President Abraham Lincoln in 1864 to the present day, the University has offered visionary leadership in education and cultural understanding. Follow the 150th anniversary events at:

www.gallaudet.edu/150.html



ODYSSEY

Laurent Clerc National Deaf Education Center
Gallaudet University, 800 Florida Avenue, NE
Washington, DC 20002-3695

Address Service Requested

Non-Profit
Organization
U.S. Postage
PAID
Permit No. 913
Washington, DC

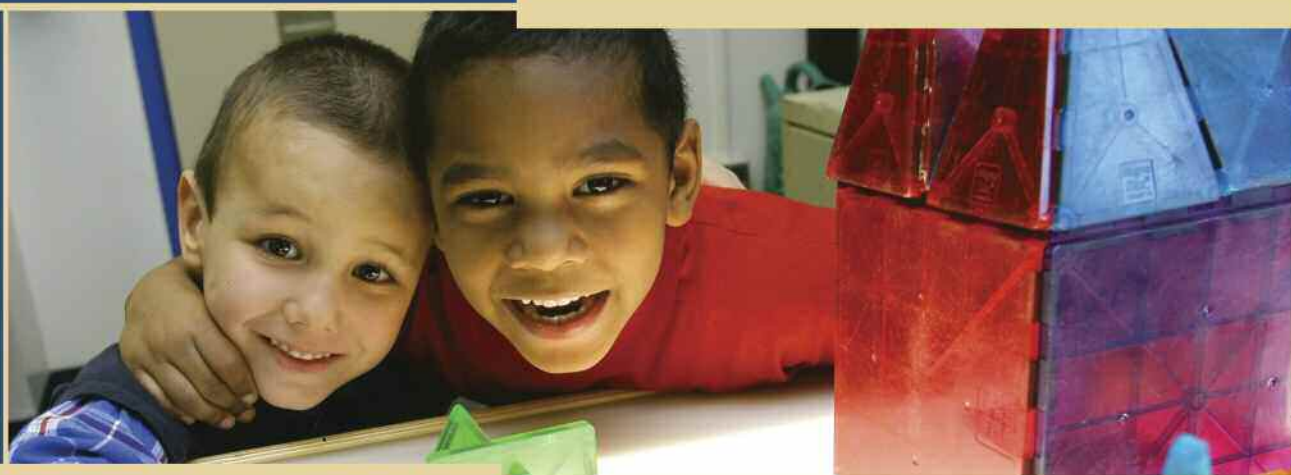
Eco awareness: Odyssey magazine is
printed on recycled paper using soy ink.



LAURENT CLERC
NATIONAL DEAF EDUCATION CENTER



Working for Deaf and Hard of Hearing Children Throughout the United States



How can we serve you?

- Educational Resources
- Training and Publications
- Demonstration Schools

clerccenter.gallaudet.edu

The Laurent Clerc National Deaf Education Center, a federally funded national deaf education center, ensures that the diverse population of deaf and hard of hearing students (birth through age 21) in the nation are educated and empowered and have the linguistic competence to maximize their potential as productive and contributing members of society. This is accomplished through early access to and acquisition of language, excellence in teaching, family involvement, research, identification and implementation of best practices, collaboration, and information sharing among schools and programs across the nation.