

# 11 Advocacy Tips for Parents

By **Janice Schacter**

It seemed as if appropriate access at cultural institutions was unpredictable wherever our family went. Our daughter who wears binaural hearing aids never knew if the access she needed would be available. When we started going to the theatre and museums with her, we found that hearing aid compatible (HAC) assistive listening devices (ALDs) that would enable her to hear an exhibit or program were often not available or didn't work and videos were not captioned. It seemed to us that she should be able to participate and enjoy exhibits and performances since technology is available to provide it and the Americans with Disabilities Act (ADA) of 1990 required it.

So, four years ago, I started the Hearing Access Program as collaboration with the Alexander Graham Bell Association for the Deaf and Hard of Hearing, Hearing Loss Association of America and The League for the Hard of Hearing. The goal of The Program is to build on the advocacy efforts that had come before and to ensure that consistent access would be available for my daughter and others with hearing loss.

My goal was to implement access quickly so that my daughter and other children like her could benefit from important cultural and educational experiences while she was growing up. In this role, I developed some effective strategies.

## 1. Advocate for your child.

If you don't, who will? Advocating at cultural organizations on behalf of your child is part of your role as a parent and no different than advocating at your child's school. Your child will learn by your example that they can have an impact.

## 2. Use your network.



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Using and building my network of people with hearing loss as advisers was critical to the program's success. It is quite a bit easier to resolve issues when you know the background of the institution, what has already been accomplished and who the helpful players are.

## 3. Complain and don't be afraid to ask for what you need.

Don't let an organization deter you when they tell you that no one else has ever complained or advocated for access. Access is used when the organization implements it and asked for when the organization promotes it.

Many people know what they need but won't ask for it because they are too embarrassed. What is the worst thing that can happen? All they can say is, "no." Many people are happy to help and only a small percentage of people won't.

Some visitors with hearing loss feel why bother advocating if they don't plan on returning to the institution. My philosophy is what goes around comes around. If I fix this site then maybe someone else will fix another site so it will be accessible to my daughter when we arrive. The more

advocates, the more access will be implemented.

Sometimes it is not always convenient to fix the issue when you are there. So, contact the organization soon after your visit.

## 4. Tell the person what the issue is and how it can be solved.

Access typically isn't implemented because most organizations don't understand what people with hearing loss need. Every organization is under time and budgetary constraints so why expend limited resources if no one is asking for it?

Results tend to happen when I identify specific issues, why it is important and how it can be solved. A complaint without a solution can be perceived as a rant.

For example, my daughter needs both HAC ALDs and captioning when videos are shown. When it isn't available, I contact the Visitor Services Manager and nicely advise them what is needed, what the approximate costs are (\$750 to caption a 15-minute video and \$750 to install an induction loop for a video) and the companies' contact information that can provide the access. Problems are resolved when I use readily available solutions that are inexpensive and the process is as "turn-key" as possible.

## 5. Identify the "low hanging fruit".

Organizations are outcome driven and like starting with solutions that they can accomplish for little or no money. When visitors begin to use what is available, the success of the early work drives the organization to seek additional access services.

For example, there are two compa-

nies that offer audioguides in museums. One audioguide is HAC and the other offers free neckloops. Both companies also offer free transcripts. The museum only needs to provide signage. That is usually easy for them to accomplish.

The museums can quickly see the results of accessible audioguides. Visitors will then seek other access once they know access is available at the museum.

The videos produced by The History Channel are another example. There is no need to pay to caption these videos since they already include captioning that just needs to be activated. This company will replace any video for FREE if the captioning is missing.

## 6. Remind the organization of the ADA if they are resistant to access.

Raising the Americans with Disabilities Act of 1990 is my last resort because it can be perceived as confrontational. But, I do keep it in my “hip-pocket” if the organization does not seem to understand their obligation to provide “effective communication.”

## 7. Go to the top of the organization.

When I can see my efforts are going nowhere, I go right to the organization’s Director. When a solution is costly, it usually takes a decision from the top to make it happen. Once that hurdle is cleared, people are usually happy to implement the recommended solutions.

## 8. Keep a log.

A phone log is started as soon as I start working on an issue. I note the date, the person’s name, their contact information, a summary of the conversation and what the next step is. I jot down a person’s exact words if they say anything odd or interesting. The log allows me to track the process. Many times I am asked who

I have already spoken with and on what dates. It is impossible for me to keep track of this information without a log.

The Assistant’s name is also noted. Assistants are more likely to help you when you take the time to know their name.

The benefits of a log occurred recently with a television program’s captioning was consistently misspelled. 50+ phone calls later, the issue was still not resolved. So,

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*“Not only must we insist upon quality captioning, but the future is here with the growth of digital, wireless and Internet-based telecommunications. It is critical that we are not left behind in the shift toward these communication mediums.”*

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I e-mailed the phone log to the Chairman’s Assistant to demonstrate why the network needed someone in charge of captioning.

The network agreed. They had no idea how bad the situation was until they read my log, saw the number of phone calls and read what transpired with each call. The success of the project rested solely on the help of a fabulous Assistant, the log and my persistence.

## 9. Follow-up and be persistent.

Most people just like to complain and never follow-up. People are surprised when I do follow-up on an issue. I am

convinced that many organizations don’t follow through with an issue until they are contacted again. There are too many complaints so only those that are critical receive attention.

Organizations also sometimes hope that the complainant will go away. Not only do I follow through but I also am persistent. The old adage, the squeaky wheel gets the oil is definitely true. Some issues are definitely resolved because someone just wants the problem to go away.

## 10. Know your legal rights and the process.

It is critical to know what your legal rights are and what the legal complaint process is. Otherwise, you can end up spinning your wheels unnecessarily.

For example, with U.S. government agencies like the National Park Service it is important to file a “504” complaint when there is not “effective communication.” Otherwise, the complaint just sits in a pile until someone gets to it. A legislatively mandated timeline to address and resolve the complaint begins when the complaint is filed as a “504” complaint.

Appropriate access was not always available when our family visited various National Parks. Someone, thankfully, advised me that I needed to include the words, “this is a 504 complaint,” in my letter to start the timeline process. My complaints would have languished if I had not included these key words. The National Park Service is now actively working to rectify access systemically.

## 11. Send a Thank-You Note.

Most letters organizations receive are sent via e-mail and are complaints. Therefore, a handwritten thank you note really stands out in the pile. Always say thank you when your request is implemented even if it was a tough battle. Let the person know how the access has helped. The

person will remember the letter and will be more likely to help you in the future.

All these strategies are useless unless you begin the process by asking for the access your child needs when it isn't available. Remember, Alexander Graham Bell once said, "Great discoveries and improvements invariably involve the cooperation of many minds."

*Janice Schacter is the executive director of the Deafness Research Foundation and a former attorney whose 11-year old daughter is hard of hearing. She is also the Chair of the Hearing Access Program. The Hearing Access Program is a collaborative effort between the Alexander Graham Bell Association for the Deaf and Hard of Hearing, The League for the Hard of Hearing/abc communication and Hearing Loss Association of America (f/k/a Self Help for the Hard of Hearing.) Our goal is to assist entertainment venues, museums, theaters, amusement parks, cruise ships etc. achieve their goal of accessibility for the entire hard of hearing and deaf community. Our service is*

*free unless technical assistance is needed. Some of our over 60 successes across the country include working with The American Museum of Natural History, Lincoln Center, National Park Service, The Museum of the City of New York, The New York Historical Society, Madison Square Garden, The Frick Collection, The Asia Society and Museum, The Jewish Museum, The Museum of Jewish Heritage, NYCity Center, American Girl Theater, The Biltmore Estate, Hillwood House and Garden, Ben and Jerry's, American Folk Art Museum, Bay Street Theater, Dahesh Museum of Art, The NYC Guggenheim, 92nd Street Y, Sylvia Kaye Playhouse, Town Hall, Lower East Side Tenement Museum, Guild Hall, Clear Channel Entertainment, The Schubert Organization, Sound Associates, Ampertronics, The Morgan Library, The Metropolitan Museum of Art, MOMA, The Smithsonian, Antenna Audio, Accoustiguide, The New York Times, The Wall Street Journal, Dan's Paper, Playbill and Cunard.*

*Schacter has testified before the Sub-Committee on National Parks*

*in Congress, the New York City Council's budget hearings and presented to organizations such as The NYC Department of Education, Department of Interior/National Park Service and Sound Associates. In addition, we worked with Build-A-Bear Workshop to develop a hearing aid for their fuzzy friends that is now part of their product line. I was also a member of the FCC's Consumer Advisory Committee.*

*Schacter's work has been profiled on the front page of the Arts section of The New York Times ([www.nytimes.com/2005/04/05/arts/05hear.html?ex=1138770000&en=febd72071149c750&ei=5070](http://www.nytimes.com/2005/04/05/arts/05hear.html?ex=1138770000&en=febd72071149c750&ei=5070)); AG Bell's Magazine, Volta Voices on several occasions; The Children's Hearing Institute's Newsletter, Echoes ([www.childrenshearing.org/custom/news.html](http://www.childrenshearing.org/custom/news.html)); Temple Emanu-El's Bulletin ([www.emanuelnyc.org/bulletin77\\_35.pdf](http://www.emanuelnyc.org/bulletin77_35.pdf)) and AG Bell's New York newsletter, Soundwaves. In addition, she has been quoted in The League for The Hard of Hearing's League Letter and interviewed on NBC's Today Show-Weekend Edition.*



# HEARING ACCESS PROGRAM

## MISSION STATEMENT

To promote appropriate access to public entertainment venues for individuals who are deaf or hard of hearing because such programs are basic to every person's intellectual, cultural and educational development.

We will accomplish our mission by reaching and educating the following core groups:

1. Audiologists and Speech Pathologists- To advise and educate them how they can assist their clients in gaining better access at public entertainment programs.
2. Individuals/Parents of People with Hearing Loss- To educate and teach people with hearing loss how they can self-advocate to obtain appropriate equipment and access for themselves or their children at public entertainment venues.
3. Venues- To become a resource center for venues by providing centralized information, technical support and assistance through training employees and periodic monitoring so that they can provide consistent appropriate accommodations to their consumers who are deaf or hard of hearing.