

Parent Advocacy App: Assisting Families of Deaf and Hard of Hearing Children in Grades K-12

By Mary Henry Lightfoot

How can I better participate in my child's Individualized Education Program (IEP) meeting? I really don't even understand what this "IEP meeting" means! What's the difference between a 504 meeting and an IEP meeting? Does my child need an IEP or a 504 plan? Why doesn't my child have any of these things?

Advocating for your deaf or hard of hearing child can be a daunting task ... and intimidating. So many professionals around a table ... and you as the parent. What can you do as a parent to advocate for your deaf or hard of hearing child? Why is advocating for your child at school meetings important?

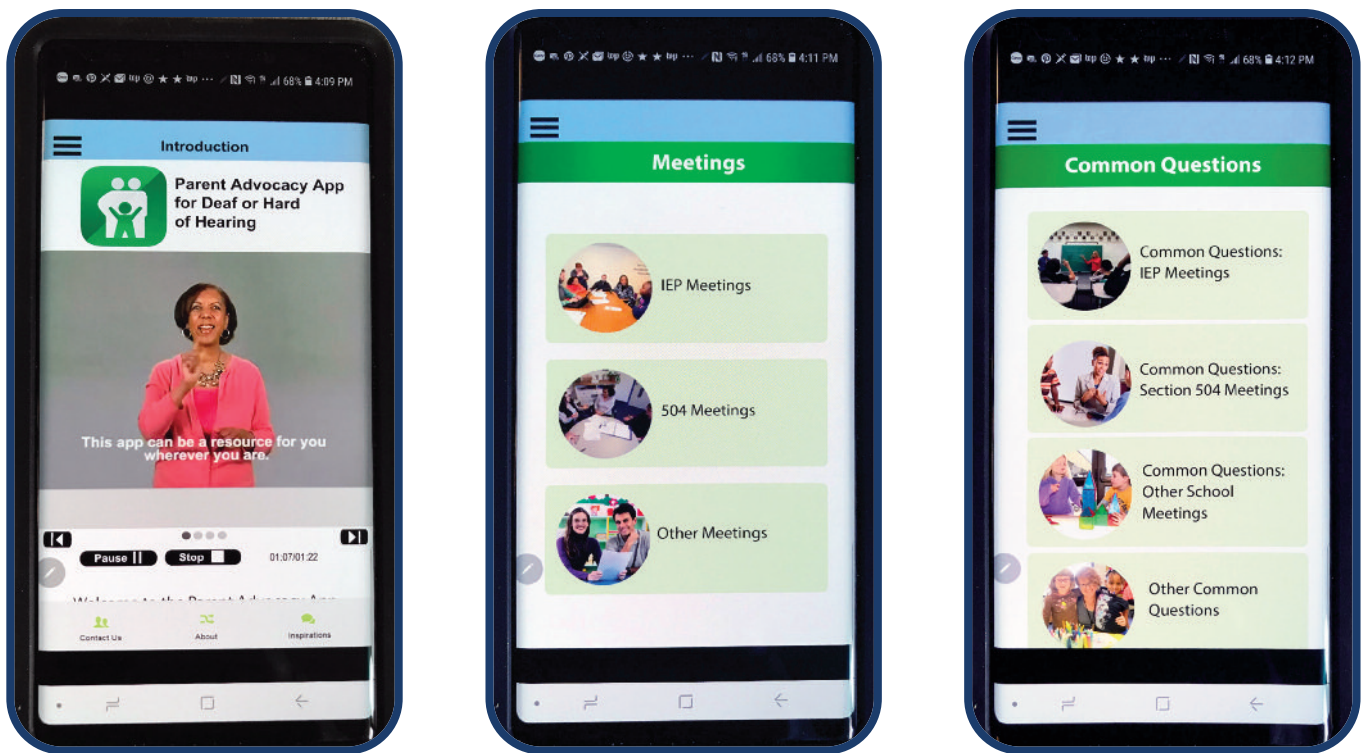
There is help at your fingertips. As Apple says (2009), "There's an app for that!" The Laurent Clerc National Deaf Education Center, in collaboration with the American Society for Deaf Children (ASDC), Hand & Voices, and the National Association of the Deaf (NAD), has created an app to assist you with understanding how to advocate for your child (kindergarten to twelfth grade) during educational planning meetings. The app details aspects of the IEP law and IEP meetings and the law regarding 504 plans and 504 plan meetings, and how to tell if your child may be eligible for one of these legal protections.

What Does Advocacy Mean?

What do we mean by "advocacy"? Trainor (2010) states, "Early disability rights literature described advocacy as the act of speaking and acting on behalf of another person or group of people to help address their preferences, strengths,

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Photos courtesy of Mary Henry Lightfoot



and needs (Wolfensberger, 1977).” This definition reflects the important role of families to speak up for their children and to advocate for their educational needs. Parent advocacy works toward your child receiving an appropriate education (Turnbull & Turnbull, 2001, as reported by Trainer, 2010).

Is MY Child Included Under the Topic of Advocacy for Deaf and Hard of Hearing Children?

Perhaps you are wondering if advocacy is needed if your child has a cochlear implant or if your child uses spoken English to communicate. Or perhaps you are wondering if advocacy is needed if your child is already working on grade level or, conversely, is behind cognitively. The answer is yes! Marschark and Hauser (2012) discuss the great diversity among deaf and hard of hearing children, stating, “Not only do we have to find the most effective way to support learning in deaf and hard of hearing children as a group, but each child may learn differently and at a different rate.” This underscores the importance of advocating for your child’s individual learning and social needs.

A foundational concept was stated by Hauser, clinical neuropsychologist and researcher: “... deaf children are not just hearing children who can’t hear” (Marschark & Hauser, 2012). Regardless of whether your child uses visual communication, uses auditory communication, or has a cochlear implant, how they learn may be different from their typical counterparts

Above and bottom right: The Parent Advocacy app assists you in understanding how to advocate for your deaf or hard of hearing child.

(Marschark & Hauser, 2012). Deaf and hard of hearing children can learn, grow, and progress on grade level and excel. However, simply removing communication barriers does not always equal satisfactory learning (Marschark & Hauser, 2012). As parents, part of our job is to advocate for accessible education that meets our child’s individual needs. While this can be a challenge, there are tools available. The Parent Advocacy app is one such tool.

Let’s Take a Closer Look at the App

The app provides information and explores common questions, strategies, and resources for three types of meetings: IEP meetings, 504 plan meetings, and other school meetings. It allows you to use a series of checklists to determine if you’ve adequately prepared for the meeting, determine what should be considered during the meeting, and determine how you might follow up after the meeting. It has a place for you to take notes as well.

The Common Questions section answers questions such as: *What special considerations should teachers be giving my deaf or hard of hearing child? How can I be the best advocate for my child at a meeting? What is a Section 504 meeting? Is my child eligible for 504 support? What happens at an IEP meeting? How can I*

participate in the IEP process? Perhaps you have had these same questions.

The Strategies section provides six strategies to help you advocate for your deaf or hard of hearing child, such as “soft skills for advocacy” and “get outside help.”

The Checklists section emphasizes the multipart role that you play in advocating for your child. Your role starts before you arrive at the school meeting and continues beyond attending the meeting. While this process may initially feel overwhelming, the checklists give you concrete ways to prepare for the meeting, participate in the meeting, and follow up after the meeting. This section is interactive and provides checkboxes that can be used to show completed items as you progress through the advocacy process.

The Resources section provides information to connect you with people, organizations, and information, helping you in your journey of advocating for your deaf or hard of hearing child. It takes you to the laws that are the foundation of the IEP and 504 meetings

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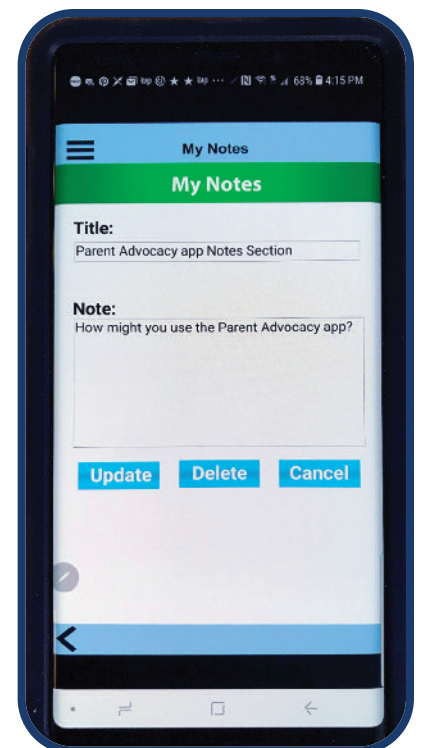
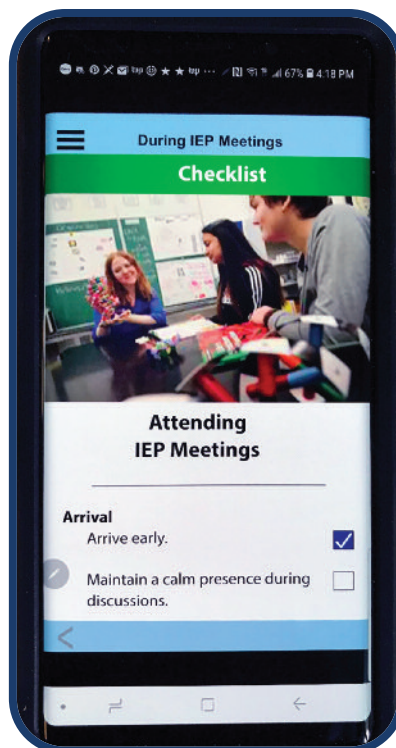
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and connects you with people and organizations in your state. There’s help with resources and assistance at the state level from ASDC, Hands & Voices, and NAD. The resource area has free information from the Clerc Center and the collaborating organizations.

Why an App?

Now that we have explored the Parent Advocacy app, you might wonder why we decided on creating an app instead of a website or other publication. The app is designed to provide flexibility for your individual needs and use. Pew Research Center states that as of 2017, “about three-quarters of U.S. adults (77 percent) say they own a smartphone, up from 35 percent in 2011, making the smartphone one of the most quickly adopted consumer technologies in recent history” (Perrin, 2017). The cellphone is closely held and used. It’s often the first thing people look at in the morning, it’s carried throughout the day, and it’s the last thing viewed in the evening. You can use your cellphone while on the go or sitting quietly at home. The smartphone is



accessible across income ranges. In fact, “One-in-five adults whose annual household income falls below \$30,000 are smartphone-only Internet users” (Perrin, 2017).

In terms of using the Parent Advocacy app, you can briefly look at one section or extensively explore the app and links. While the app has full usability with an Internet connection, you can use portions of the app even when not connected. The app is available to use while waiting in line at the grocery store, while in a school meeting, or while at home. You can view information to help while advocating and get what you need in real-time. The app format provides you with access to parent advocacy information in any place and at any time. This is quite a useful feature!

How the App Can Help You

Information provided from the organizations collaborating with the Clerc Center can help you on your journey to increased advocacy for your deaf or hard of hearing child. For example:

- ASDC offers a Knowledge Center of resources to parents/families and professionals. They (n.d.) state, “There is no one right way. Every child and family is different. Values, experiences, opinions, and resources vary from family to family. What works in one situation may not work in another. There are a number of ways to be successful raising a deaf or hard of hearing child. No one plan or formula will work for everyone.” The app shows how you can advocate for solutions that are tailored to your child’s individual needs instead of simply proceeding with one standard or popular approach.
- Hands & Voices’ *Educational Advocacy Guidebook* (DesGeorges, Johnson, & Seaver, 2013) discusses how advocacy for our children includes considering our child’s social and emotional health and development. They show that even when our child appears to be “fine” educationally, it may be appropriate to advocate for addressing social and emotional aspects. Within the app, an example of looking beyond a student doing “fine” educationally is the 504 meeting Common Questions section. The app specifies that children cannot be excluded from a 504 plan just because they are performing at grade level.
- In their publication *Legal Rights: The Guide for Deaf and Hard of Hearing People*, NAD (2015) discusses current laws supporting deaf and hard of hearing students and states that every child has “the right to qualified teachers, accessible classrooms, and appropriate materials and programs.” The app delineates the applicable laws and provides links for more detailed information.

Finally ...

Wright (n.d.) states, “In your advocacy journey, you need two things—accurate information and support. This journey is more difficult if undertaken alone.” We hope that the Parent Advocacy app will provide both information and support as you take the journey to becoming a knowledgeable, self-assured, and loving advocate for your deaf or hard of hearing child.

The app is available from the Google Play Store and Apple’s App Store; it is free for your use. You can do a search under “Parent Advocacy” or “Gallaudet University Mobile Apps” to find it. For questions about the app, contact onlinehelp.clerccenter@gallaudet.edu.

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