

# How to Best Support Families and Caregivers

## Who Are Disconnected, Alienated, and Underserved

### SO THEY CAN BECOME INVOLVED AND EFFECTIVE ADVOCATES

*By Mary Ann Kinsella-Meier*

In educational settings, where decisions must regularly be made related to what type and focus of services to provide, having a parent/caregiver advocate in their corner can be very important to children who are deaf or hard of hearing. In fact, when the Clerc Center reviewed public input from families, caregivers, and professionals in deaf education (2010–2012), strengthening the partnership between a family and their child’s school or agency became a priority area (Szymanski, Lutz, Shahan, & Gala, 2013).

As a result, a major focus of the Clerc Center Strategic Plan 2020, or CCSP 2020, is to support all groups to recognize the importance of parental advocacy and involvement, and to do that by strengthening both sides:

1. Increase parent/caregiver knowledge about special education law and their children’s specific needs so that they may advocate effectively for them, including at team meetings.
2. Increase awareness among school and agency educational professionals about the needs of deaf and hard of hearing children, and about the value of a parent or caregiver advocate (Gallaudet University, 2015).

As challenging as it may be for family members to advocate for what they believe is best for their child, the task can be far more difficult for families who may be disconnected,

**Mary Ann Kinsella-Meier**, AuD, CCC-A, was a project manager at the Laurent Clerc National Deaf Education Center at Gallaudet University until retiring in December 2018. She managed development of products focusing on innovative curricula and instructional technologies and strategies. Kinsella-Meier recently managed the collaborative partnership between the Deaf and Hard of Hearing Program of Boston Children’s Hospital and the Clerc Center. Previously, she coordinated the expansion of educational services to students with cochlear implants at the Maryland School for the Deaf. She also co-authored a book on sign language for audiologists and speech-language specialists and is a contributing author for a book on aural rehabilitation and communication therapy for culturally deaf consumers. Kinsella-Meier welcomes questions and comments about this article at [MaryAnn.Kinsella-Meier@gallaudet.edu](mailto:MaryAnn.Kinsella-Meier@gallaudet.edu).

*Photos courtesy of Ruth Reed*



PHOTO CREDIT: MATTHEW VITA

alienated, or underserved. Therefore, it has become a goal of the Clerc Center to figure out how to better support those families. Who exactly are these families?

The **disconnected** do not view themselves as included with others but as a burden to others (Bryan, Morrow, Anestis, & Joiner, 2010).

Families described as **alienated** experience uneasiness due to their “exclusion, or self-exclusion, from social and cultural participation” (Hajda, 1961), particularly when it involves the special education process (Jung, 2011). For example, culturally and linguistically diverse individuals experience strong feelings of isolation, powerlessness, and alienation during the Individualized Education Program (IEP) process, which can become too overwhelming for them to defend their opinions (Jung, 2011). This can become true for anybody; it is “not affected by an individual’s background, social stature, or age” (Dean 1961). Personal experience has shown some of us that anyone can become alienated sometimes. Some parents have two roles: as a parent of deaf or hard of hearing children or children with learning needs and as a professional who works with deaf or hard of hearing students. In this situation, we as parents can find ourselves joining a meeting with our



**Above and below:** The more families can be advocates for their children and support their progress, the better their children do and the longer they stay in school (Henderson et al., 2007).

coworkers about our deaf or hard of hearing child and still experience worry that we may not be able to express ourselves well enough to get what we feel our child needs. Although this may be an uncomfortable feeling, it gives us a special perspective of what other families experience.

The **underserved**, by definition, are “not getting enough help or services” (MacMillan Dictionary, n.d.). This group includes those who grew up in poverty and attended resource-poor schools (Rendon, 2006). Also included are families newly arrived from other countries, even if their children were born here or arrived at young ages. Included, too, are families on the other end who may have lived here for generations but have maintained cultural customs. Unlike newly arrived families, they may also have stayed in cultural communities that are different from the predominant Anglo European beliefs of the United States. Still others among the underserved are children or families who are significantly more mobile than families in general. The parents may be migrant workers, or the children may be in foster families or in the juvenile justice system.



**Left and below:** Parent-to-parent advice is invaluable in helping parents learn to advocate for their children.

### Defining “Parent Advocacy” or “Family Advocacy”

As we seek ways to encourage advocacy among those not of the predominant Anglo American culture, we should first ask whether the value given to advocacy is itself culturally based. Some cultures, and thus some immigrants and first generations, expect the school to control the planning of their child’s education (Trainor, 2010). The “culture” of teachers and educational administrators may sometimes agree with them.

Kalyanpur, Harry, & Skrtic (2000) noted that decisions made during IEP meetings are influenced more by assessments provided by the educators involved than by the anecdotal reports of parents. Lake and Billingsley (2000) listed further circumstances that can frustrate any family’s ability to advocate. Some of those situations seem especially relevant to the disconnected, alienated, or underserved. They include an imbalance of knowledge between school and the parent/family advocate, financial or time constraints, and communication breakdowns.

According to Scheetz (2004), the dominant Anglo American culture values “independence, freedom, assertiveness, equality, self-help skills, and self-directedness.” The key parts of advocacy—self-reliance, direct communication, and individualism—are encouraged, if not expected. These values may not be the same values shared by families from other cultures. Therefore, these families may reject, or have difficulty accepting, these Anglo American norms, values, and beliefs. Interestingly, the Individuals with Disabilities Education Act (IDEA) never mentions the term *advocacy*. Instead, it uses the word *participation*. As Trainor (2010) observes, that term can “invoke a range of involvement comportment, from passivity to adversarial, which may or may not include advocacy.” How can parents (or others who are temporarily or permanently taking on parental roles) be supported as they seek productive ways to participate in their child’s case?

### Possible Actions

It’s one thing to know that research shows parental involvement improves student achievement and school attendance while dropout rates also decrease. Research also shows that this is true for families of all socio-economic backgrounds, races, and ethnicities. However, it’s another thing to encourage that involvement from parents who feel and/or are disconnected, alienated, or underserved.

When we see family members hold back from speaking out about their children’s needs and strengths, we want to show them how valuable they are and stress the importance of sharing their insights with the educational team. An observation by Wright and Wright (2014) might be helpful here. They noticed that a child’s parent or guardian has the most detailed knowledge of a child’s interests, strengths, and challenges, and the greatest interest in what’s best for their child. As Henderson, Mapp, Johnson, & Davies (2007) stated, “The more families can be advocates for children and support their progress, the better their children do and the longer they stay in school.” In a PowerPoint presentation based on their book, Henderson et al. listed suggestions of what makes a family member a successful advocate for a child:

- An awareness of how the system works
- A willingness to work with school personnel to plan the child’s future
- A motivation to steer their child to higher-level classes or programs
- Knowing how to get help if needed, and to speak out for their own child and for other students and families, if problems develop







**Left:** Recruiting families as volunteers is one way to involve them in their child's school community.

- Provide language classes for families. These classes could include sign language classes.
- Publish reports about school board meetings and lists of coming events in multiple languages.

One of the most cited models of parental involvement was discussed by Epstein & Sanders (2006). It consists of six primary areas for schools to consider when attempting to keep families informed and to involve them and their communities in their children's educational activities:

1. **Parenting**—Assist families with parenting and childrearing skills, creating opportunities at home that support learning.
2. **Communication**—Through two-way communication, keep families informed about school programs and the student's progress.
3. **Volunteering**—Recruit families as volunteers.
4. **Learning at home**—Involve families with educational activities that support classroom learning.
5. **Decision making**—Include families in the discussion and decision-making process.

Henderson et al. also offered suggestions for advocating for a child with special needs in general, but these suggestions may also apply to families with deaf or hard of hearing children. These include:

- Building positive relationships with teachers
- Having a clear understanding of the IDEA and the educational process
- Planning for the long term, not just the current school year

### Parent Experiences and Priorities

Parent-to-parent advice can be some of the most trusted by the disconnected, alienated, or underserved. The Clerc Center recently completed a survey in which parents identified important strengths for successful advocacy. These included a knowledge of a child's strengths, weaknesses, academic performance, and legal rights. The parents offered the reassuring reminder that learning to advocate is an ongoing process, and that others can sometimes assist with advocacy efforts, including audiologists, friends, and parent support groups (Jackson & Lutz, 2016).

The variety of cultural norms among a school's families should not be viewed as a problem but a way in. Visiting new families in their homes can be one way of learning about, and committing to, those cultures, and recognizing and supporting differences in the forms of parental involvement:

- For instance, Hispanic/Latino families value the strength of family ties. Talk with families to learn how to integrate home activities with learning activities encouraged by schools to use at home.
- Work with human resources personnel at family members' work places to coordinate shifts and work schedules with school calendars to allow for parental involvement with the child's homework and attendance at meetings at school.



PHOTO CREDIT: CAT VALCOURT-PEARCE

6. **Collaboration**—Work with the families as well as with their communities to enhance student success.

The fifth category, decision making, brings us full circle. Supporting a family in its advocacy efforts can nurture their natural tendency to stand up for their child into an expertise in identifying what will work and an ability to express that to school personnel. In the words of DesGeorges, Johnson, and Seaver (2013), “A parent becomes an effective advocate when she blends her expertise in special education law with an ability

to skillfully turn theoretical knowledge into practical applications that work on an IEP for her child.”

Wright and Wright (2006) presented an equally positive conclusion for all groups. They pointed out that when informed parents present information on their child’s educational needs and legal rights, that can lead to “a healthy working relationship with the school”—and, in this case, to better educational outcomes for deaf and hard of hearing children.

## References

Bryan, C., Morrow, C., Anestis, M., & Joiner, T. (2010, February). A preliminary test of the interpersonal psychological theory of suicidal behavior in a military sample. *Personality and Individual Differences, 48*(3), 347-350. doi:10.1016/j.paid.2009.10.023

Dean, D. G. (1961). Alienation: Its meaning and measurement. *American Sociological Review, 26*(5), 753-758.

DesGeorges, J., Johnson, C., & Seaver, L. (2013). *Hands & Voices educational advocacy guidebook*. Boulder, CO: Hands & Voices Publishing.

Epstein, J. L., & Sanders, M. G. (2006). *Connecting home, school and community: New directions for social research*. Baltimore: Johns Hopkins University/CRESPAR.

Gallaudet University. (2015). *Annual report of achievements. October 1, 2013-September 30, 2014*. Washington, DC: Author.

Hajda, J. (1961). Alienation and integration of student intellectuals. *American Sociological Review, 26*(5), 758-777.

Henderson, A. T., Mapp, K. L., Johnson, V. R., & Davies, D. (2007). *Beyond the bake sale: The essential guide to family-school partnerships*. New York: The New Press.

Jackson, L., & Lutz, L. (2016). *Parent advocacy of children who are deaf or hard of hearing in the U.S.* Unpublished internal document. Washington, DC: Laurent Clerc National Deaf Education Center, Gallaudet University.

Jung, A. W. (2011). Individualized Education Programs (IEPs) and barriers for parents from culturally and linguistically diverse backgrounds. *Multicultural Education, 19*(3), 21-25.

Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families’ participation in special education. *International Journal of Disability, Development and Education, 47*(2), 119-136.

Lake, J. F., & Billingsley, B. S. (2000). An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education, 21*(4), 240-251.

MacMillan Dictionary. (n.d.). *Underserved*. Retrieved from <http://www.macmillandictionary.com>

Rendon, L. I. (2006, October). *Reconceptualizing success for underserved students in higher education* [PDF document]. Retrieved from [https://nces.ed.gov/npecl/pdf/resp\\_Rendon.pdf](https://nces.ed.gov/npecl/pdf/resp_Rendon.pdf)

Scheetz, N. A. (2004). *Psychosocial aspects of deafness*. Boston: Pearson Education, Inc.

Szymanski, C., Lutz, L., Shahan, C., & Gala, N. (2013). *Critical needs of students who are deaf or hard of hearing: A public input summary*. Washington, DC: Laurent Clerc National Deaf Education Center, Gallaudet University. Retrieved from <https://www.gallaudet.edu/clerc-center/ourresources/publications/pi-summary.html>

Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital. *Remedial and Special Education, 31*(1), 34-37.

Wright, P. W., & Wright, P. D. (2006). *Wrightslaw: From emotions to advocacy—The special education survival guide* (2nd edition). Hartfield, VA: Harbor House Law Press.

Wright, P. W., & Wright, P. D. (2014). *Juvenile justice*. Retrieved from <http://www.wrightslaw.com>