

## LEARNING ABOUT ADVOCACY EXPERIENCES OF FAMILIES OF COLOR:

# Multiple Perspectives Guiding the Research Process

By Susan J. Schatz and Lori Lutz

Parents and caregivers have hopes and dreams for their deaf and hard of hearing children and have aspirations for their success whether it is at school, home, and/or in the community. Advocating for their deaf or hard of hearing children's needs, education, and/or access is one of the different ways families are involved. Research provides examples of key parent advocacy strategies and activities (e.g., Henderson, Mapp, Johnson, & Davies, 2007); however, some of these suggestions may reflect Anglo American cultural values (Scheetz, 2004; Trainor, 2010), which raises the following question: *“What are some of the advocacy strategies and/or resources parents/caregivers of color have used to advocate for their children’s educational needs?”*

This question is important because factors impacting families' abilities to advocate include financial or time limitations, imbalance of knowledge between schools and families, and issues with school-family communications (Lake & Billingsley, 2000), differing perspectives regarding school and family responsibilities (Scheetz, 2004; Trainor, 2010), and experiences of barriers related to ethnicity, race, and socioeconomic class (Ramsey, 2000; Lo, 2008; Stanley, 2015) as well as language barriers for families using a language other than English (Hughes, Valle-Riestra, & Arguelles, 2002; Lo, 2008).

### **Understanding the Meaning of Parent Advocacy**

A review of parent advocacy literature (Kinsella-Meier, 2019) suggests that successful parent-advocates: 1) know how the education system works; 2) build

*Illustrations courtesy of the Laurent Clerc National Deaf Education Center*

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## Are you a parent or caregiver of color who has a deaf or hard of hearing child?

The Clerc Center is conducting a nationwide study to understand the experiences of families of color in supporting their deaf or hard of hearing child's educational needs.

### We want to know:

- What resources (e.g., community or church members, videos, apps, organizations) and strategies (e.g., communication, school involvement, technology, parent-school meetings) have you used to ensure your child's educational needs are being met?
- What experiences and challenges have you faced while advocating for your child's education?

Join us for a small 60- to 90-minute focus group discussion on this topic. Your contribution will be valuable in determining the next steps for supporting deaf and hard of hearing children's education.



**Dr. Sandra Jowers-Barber** researches and writes about the history of the African American Deaf community in Washington, D.C. She is the stepmother of an adult deaf daughter who is the mother of three hearing children.

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positive relationships and work with teachers and school personnel; 3) support their child's education throughout the years; 4) know how to get support; 5) know how to speak out for their child's needs; 6) know and understand the special education laws and their (as well as their child's) legal rights; 7) know their child's strengths, weaknesses, and academic performance; and 8) plan for the long term (Henderson et al., 2007; Jackson & Lutz, 2016). An educational advocacy guidebook is also available for parents seeking resources to advocate for their deaf or hard of hearing children (DesGeorges, Johnson, & Seaver, 2013).

However, Kinsella-Meier (2019) points out

that the general understanding of parent advocacy may reflect the Anglo American cultural values more than we realize and suggests that we should learn more about perspectives and meanings of parent advocacy held by other ethnic, racial, and/or culturally diverse communities (Lo, 2008; Stanley, 2015; Trainor, 2010). Understanding meanings of parent advocacy from other communities' views may help schools and parents with different perspectives regarding parent advocacy to work together for a common goal—to ensure their deaf or hard of hearing children have the supports they need to achieve their potential in school.

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## Families of Color Advocacy Research Team



**Dr. Valerie Borum** *Research Team Consultant*

Dr. Valerie Borum's research agenda includes a focus on the role of ethnic culture in health, mental health, and disability and hearing families with deaf or hard of hearing children, with special attention to African Americans. She is a graduate of Gallaudet University (MSW) and Howard University (PhD).



**Dr. Sandra Jowers-Barber** *Focus Group Facilitator*

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**Darrius Doe** *Research Assistant*

Darrius is a research assistant. He also works in Gallaudet University's Communications office as the social media copywriter. Doe has a small deaf family, and is from Maryland. He is a graduate of Gallaudet University with a sociology degree.



**Dr. Lori Lutz** *Co-Researcher*

Dr. Lori Lutz has more than 20 years of experience with evaluation, focusing on training and programs, and research about hearing families' experiences with their deaf and hard of hearing children. Currently in Washington, D.C., Lutz, who is deaf, is the child of hearing parents from a rural midwestern state.



**Zoe Rodriguez** *Research Assistant*

Zoe Rodriguez is a research assistant. She previously worked as an assistant director for Youth Leadership Camp under the National Association of the Deaf. Rodriguez is from Puerto Rico, and she is fluent in Puerto Rican Sign Language and Spanish as well as American Sign Language and English. She is a graduate of Gallaudet University with a psychology degree.



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result, the research study is based on three principles: 1) openness to multiple meanings of parent advocacy, 2) inclusion of multiple perspectives, and 3) involvement of community members throughout the research process.

**1. Openness to multiple meanings of parent advocacy**—Special education advocacy strategies often require a specialized knowledge and understanding of special education laws, legal rights, and navigation of educational systems (Lo, 2008; Stanley, 2015; Trainor, 2010)—knowledge that may not be available to many parents. Trainor (2010) has suggested that there are different ways parents advocate for their children's special education needs. Also, parent advocacy may be understood differently based on cultural beliefs and values (Trainor, 2010). Kinsella-Meier broadly defines a parent advocate as one "who represents the needs of the child and is a constant presence in the child's life, who knows the child intimately and thereby knows the child's needs" (2017). Using this definition for the research study allows us to be open to different approaches, strategies, and resources families of color use to advocate for their deaf or hard of hearing children.

**2. Inclusion of multiple perspectives**—To learn about parent advocacy experiences from

### Families of Color Advocacy Research Study

The Laurent Clerc National Deaf Education Center has begun a research project, Families of Color Advocacy, to learn about parents/caregivers of color's advocacy efforts and experiences to ensure their deaf or hard of hearing children's educational needs are met. The undertaking of this research project is based on key principles so that individuals involved with the project learn about perspectives, knowledge, and experiences that are not a part of their culture, language, and/or identity.

#### PRINCIPLES GUIDING THE FAMILIES OF COLOR RESEARCH STUDY

Knowledge about experiences of parents/caregivers of color advocating for their deaf or hard of hearing children (Borum, 2007; Ramsey, 2000; Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997; Struxness, 2000) is still developing. As a

parents/caregivers of color, the research study was designed and implemented based on the belief that the process should be as inclusive as possible to ensure cultural relevance and transparency. Focus groups, rather than one-on-one interviews, were selected for the study because this format allowed people to share their own perspectives and stories with others (Hennick, 2014). This opportunity for parents/caregivers of color to respond to others makes it possible for them to think about, explain, or clarify their comments with each other, leading to a clearer and possibly a deeper understanding of their advocacy efforts (Carey & Asbury, 2012; Hennick, 2014). Parents, educators, and school professionals of color reviewed focus group questions and some participated in a mock focus group. Their feedback was used to revise materials and procedures so that the study process, from learning about the

study to the study's completion, would be clear, relevant, and supportive for Black/African American or Hispanic/Latino parents who want to participate in focus groups to share their parent advocacy experiences.

**3. Involvement of community members throughout the research process**—Learning about advocacy experiences shared by parents/caregivers of color is best accomplished when Black/African American and Hispanic/Latino individuals are involved with the study processes to the development and dissemination of parent advocacy resources for educators working with families of color. Their involvement helps us to glimpse understandings through their perspective and to provide insights into the experiences of parents/caregivers of color that may be missed otherwise. The process to include community members for all parts of the research project involves developing and building trust among community members and research team members.

### Lessons Learned So Far

We have learned many important lessons from people of color who have provided assistance with and feedback for the research study before we began setting up focus groups with parents/caregivers of color. Their feedback regarding language included:

- **Language needs to be clear and to the point.** Even though we worked hard to ensure language in parent letters and consent forms was easy to read, culturally relevant, and jargon-free, some words may be intimidating to or misinterpreted by parents. For example, some parents may view research as an experiment. Also, focus group reviewers suggested avoiding the use of vague terms such as *greatest* and *helpful*.
- **Use language with which parents are familiar.** Black/African American professionals who reviewed the focus group processes suggested changes to a focus group question about educational planning meetings by first checking with parents to learn whether they have participated in an educational planning meeting before specifically asking about Individualized Education Program (IEP), Individualized Family Service Plan, and 504 meetings.
- **Clarify meaning of terms by providing examples.** Some terms, such as *resources* and *types of support*, were not clear to focus group reviewers. They suggested adding examples

for these terms so that parents would have a better idea of their meaning.

- **Keep questions brief and to the point.** Feedback suggested that some of the focus group questions were too long, and that questions needed to be short, specific, and straightforward.
- **Include community members in all aspects of the research design and process.** The involvement of Black/African American professionals in a pilot focus group, role playing as Black/African American hearing parents of deaf and hard of hearing children, provided

critical feedback regarding the flow and setup of the focus group discussion. As a result of their feedback, we changed the process of introductions, the order of focus group questions (starting with general questions and ending with more specific ones), and revised some questions to improve clarity. We are especially grateful to this group of professionals for their honesty, straightforward commentary, interest, and investment in this process because their involvement led to improved focus group processes for Black/African American parents participating in the research study. We plan on continuing to seek feedback from committee members throughout the entire study. Along with lessons learned, the three principles guiding our research project will continue to its completion.

### Focus Groups for Families of Color: Sharing Stories About Their Advocacy

The Clerc Center is hosting five focus groups with Black/African American parents/caregivers and Hispanic/Latino parents/caregivers in different parts of the United States. The groups include:

#### Residential or Day Schools for the Deaf

Site 1 – Black/African American parents

Site 2 – Hispanic/Latino parents

#### Public Schools

Site 3 – Black/African American parents

Site 4 – Hispanic/Latino parents

A fifth site will be identified within the next year.

As a result of these families' sharing their experiences with us, information about successful strategies used by

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parents/caregivers and schools to support their advocacy efforts, barriers these parents/caregivers encountered, and resources they used to advocate for their deaf or hard of hearing children's education will be used by the Clerc Center to develop resources to meet this need.

### **Our Work: Looking Within and Outward**

Learning from parents/caregivers of color about their experiences advocating for their deaf or hard of hearing children means first looking within ourselves and through other people's eyes to discover what parent advocacy means to

us. It also means understanding that each one of us as individuals and as members of specific groups have experiences and identities that influence how we see, learn from, and open up to each other as we work together to learn about the meanings of parent advocacy, advocacy strategies, and resources used by these parents/caregivers, successes and/or barriers to their advocacy efforts, and other insights critical to understanding these families' experiences. It is a rich, complex journey that will involve many lessons about what it means to be a parent or caregiver of color advocating for their deaf or hard of hearing children's education in our society.

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