

Working with Challenging and Under-Involved Families

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Author's Note

"I'll always remember the day I stood in front of a room full of people at a conference. I was sharing the story of my involvement and advocacy strategies as a parent in navigating the medical and educational systems that were serving our family's journey in raising our daughter who is hard of hearing. One of the professionals raised her hand and commented, "I wish we had parents like you in our area." – I was flattered, of course. But later as I began to reflect on that comment, I began to think of the thousands of families I have had the honor to meet from literally all over the world, and realized – of course there were 'other parents like me'. I knew that I was not born a natural advocate, and had learned the ropes along the way. I have also seen many families over the years who would be considered 'out of compliance' with treatment recommendations. Those same families eventually move forward into meaningful collaborative partnerships with professionals, seeing their children beginning to make effective progress. For many parents, significant involvement in their child's interventions may not occur naturally, but is something that is learned over time and modeled by other parents and the professionals that serve them."

Introduction

Family involvement is universally acknowledged as one of the primary components needed to achieve successful outcomes for children who are deaf and hard of

hearing. This is true in the early intervention years, as well as through the school age years (Sass-Lehrer et al. 2000). Many studies have been conducted over the past 30 years that identify parent involvement as the most important factor in student success in school (Henderson and Berla 1994; Hoover-Dempsey and Sandler 1997; Epstein 2001). Benefits of parent involvement include higher reading scores, higher grades on homework, improved attitudes towards school and improved relationships between parents and teachers (Donahoo 2001).

Most practitioners serving families of children who are deaf or hard of hearing have the experience of working with one or more families who could be considered 'challenging' and/or 'under-involved.' This manuscript will define, identify and provide strategies for service providers in order to increase meaningful involvement of families.

What is a 'Challenging' Family?

There are some basic characteristics of families that lead to successful outcomes for children who are deaf or hard of hearing. These include: successfully dealing with the decisions regarding communication, language development and technology in the context of the needs of the family and child; having emotionally healthy attitudes regarding the acceptance of their child's hearing loss and the ability to move forward; and surrounding themselves with appropriate information, services, and resources in order to receive the help needed to find success. Service providers can become frustrated when working with a family who does not seem to be engaged and/or making progress in these areas. Terms like 'challenging,' 'under-involved' and 'out of compliance' are often used to describe these families. Other definitions for these words include:

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- Challenging: demanding, taxing, testing, difficult, tough, exigent, not easy, tricky;
- Under-involved: under concerned, no follow through, apathetic, lazy, bored, indifferent;
- Out of compliance – opposite of compliance (obedience, conformity, submission, acquiescence).

Often-heard comments about challenging families can be observed by the following statements:

- “They are not complying with treatment recommendations.”
- “They don’t show up for appointments and/or they are always late.”
- “Those parents are ‘deadbeat parents.’”
- “They don’t even bring in the equipment to the appointment.”
- “The family isn’t following through on their own choices” (regarding signing, technology, therapy etc.).
- “They ask too many questions”, “They don’t ask any questions.”
- “They show too much emotion”, “they show no emotion.”
- “Those kids/families (referring to identifiable demographics) just don’t do as well.”
- “The family is questioning my expertise.”

The comments above tend to reflect the experience from the practitioners’ point of view. The professional who has the ability to think about what is happening from the family’s point of view may begin to change their own attitudes and therefore utilize tools and techniques that can help a family make progress. Another way to think about families who challenge the professionals who are serving them may include the following reflections:

- “A parent who doesn’t think like I do.”
- “They don’t learn the way I teach.”
- “What they need is not what I have.”
- “They have more on their plate than just dealing with a deaf or hard of hearing child.”
- “The challenging behavior may have a root cause that we can address, if I take the time to find out” (i.e., emotional, cultural, past experiences).
- “Maybe just for today the family is going to cope in the best way possible.”

Why Attitude Matters

The importance of self-reflection for service providers concerning their own attitudes and assumptions about a family which is struggling is often the first

step towards helping that family move towards more effective involvement. There are families who are not following through – at the expense of their child’s ideal/expected development. There are also families that, due to certain identifiable demographics, have a more difficult time following through. In a study looking at rescreen rates for hearing loss in the state of Colorado, some of the statistics for lack of follow through could be tracked to such things as the mother’s age, education level, marital status, ethnicity (Thomson 2007). When a family is judged solely on these factors and assumptions are made that the family will not follow through due to these contributing factors, a breakdown in support often occurs. The essential role that the provider plays in a family’s life can be a catapult to help a family move up the scale to success. Families who are struggling due to these kinds of factors can benefit even more from a supportive relationship with the professionals who serve them.

The attitude of a professional is often the basis for the relationship with a family, as noted in this example of a diagnosing audiologist’s interaction with a mother. In the following story, one mother’s inability to comprehend an English word was perceived by the audiologist as denial.

“When [the doctor] told me, ‘He’s deaf,’ I did not understand the term ‘deaf,’ I was not familiar with it, I did not know what ‘deaf’ was. When he told me it was a ‘severe-profound hearing loss,’ then I could translate it word-by-word and I understood: severe-to-profound hearing loss, but I did not know what ‘deaf’ was. And I asked him, ‘Is there someone here that speaks Spanish? Because I do not understand.’ Then he [took hold of me] by the shoulders and said to me, ‘It is not that you do not understand, it is that you do not want to understand.’ (Steinberg, Bain, Li, Montoya and Ruperto 2002)

The Words we Use

One other area to explore is the use of semantics in the attitudes that drive professionals. As one family advocate reported, *“When I first started working as an advocate in systems change, I noticed a very unusual phenomenon among professionals. Often, when they were sitting in a group discussing a family they were working with, they would make comments such as, ‘Mom is coming in next week for an appointment’, or ‘Mom reports that the child is making speech sounds’. I was confused. I thought that clinicians were talking about their own mothers. I then realized, rather than using a parent’s name in their*

conversations, they actually called them 'mom' or 'dad'." This example is one in which conveys a lack of equality in the relationship by the words that are used. Basic respect for an individual is seen by knowing and using the name of the person when referring to them. Even adding the word 'the' in front of the term 'mom' in the case where anonymity is necessary enhances the respect for the individual. Why are the words we use important? The use of semantics is another way in which attitude can be passed on, and is also a basic, simple adjustment that can be made to ensure the integrity of the partnership with families.

Critical Components Leading to Successful Family Involvement

Professionals who have successfully explored their own personal attitudes, assumptions and pre-conceived ideas of families can then help a family who is struggling begin to succeed. The application of a positive attitude towards families also further enhances the relationship with families who are already on track. The support to families can now be enhanced through implementing some basic ideas and problem-solving tools.

Building the Parent/Professional Relationship

Families feel supported by professionals when they perceive the relationship to be a collaborative partnership built on trust (Stonestreet, Johnston and Action 1991). This process takes time and involves many things, including mutual respect, honest and clear communication, understanding, and empathy. Professionals who develop active listening skills help to create positive connections with families. This can be a challenge for professionals who are trained in the "craft" of service provision, but usually not given explicit training in the more esoteric art of "family support." Professionals who have the ability to incorporate dynamic family support and direct service provision congruently create a structure for success.

When the Cultural Mindset is Deference to Authority

Occasionally service providers encounter families who have been offered and encouraged to enter into a relationship of partnership and are faced with a cultural mindset of deference to authority. This can lead to an as-

sumption that it is impossible for families from these cultures to have an effective collaborative relationship with the professionals in their lives. Can and should families from this reference point still be encouraged to take on the role of an 'equal partner'?

This idea can be explored through an example from the book 'Outliers' (Gladwell 2008). The chapter entitled *The Ethnic Theory of Plane Crashes* creates a correlation that may be useful in this exploration of thought. Over a 20 year period, there was an airline that had the worst aviation record in the world – though they had good airplanes and qualified and well-trained pilots. When investigators went back and looked through the records it began to emerge that this airline was based in a country where deference to authority was a 'high value' within that culture. In the cockpit, in a relationship where a pilot and co-pilot are flying a plane, the co-pilot must be able to take over if the pilot is making mistakes. *"The whole flight-deck design is intended to be operated by two people, and that operation works best when you have one person checking the other, or both people willing to participate"* (Gladwell 2008). Information began to emerge that the co-pilot often hesitated to 'take over' when needed, due to his inability to override the authority in the cockpit – the pilot. The co-pilot's cultural propensity towards deference to authority – in this particular situation – did not work. In one instance, when investigators listened to the dialogue from the 'black box' between pilot and co-pilot in critical moments prior to crashing, this deference was noted by the inability of the co-pilot to speak his mind about what he knew. As he began to piece together the fact that the plane was on a clear path towards flying directly into a mountain, the co-pilot said, *"The radar has really helped us in the past" as opposed to "We are going to crash if you don't pull up – NOW!"*

Rather than living with the status quo of the mindset that existed in this culture, trainers were brought in. The trainers didn't come in and try to dismiss or devalue the cultural value of deference to authority, but they understood that this situation must change. They re-trained the pilots and co-pilots in the proper roles that must exist inside the cockpit. That airline turned around, and to this day has one of the best safety records in the airline industry. The lesson for professionals and parents is that inside the relationship for getting to success with children who are deaf or hard of hearing, deference to authority can be respected, yet parents can be supported in the much-needed ability to work as equal partners with the professionals that serve them. Families must have a safe place to talk openly and honestly with professionals.

Motivational Interviewing Techniques

Service providers can use some basic interviewing techniques with families to build conversations towards more active involvement by the parents. Motivational Interviewing Technique (Miller and Rollnick 2002) is a common method to elicit engaged conversation. Examples of these types of questions include:

- Asking permission: “Do you mind if we talk about [insert behavior]?”
- Questions that elicit change talk (by the parent): “What would you like to see different about your current situation?”
- Open-ended questions
- Reflective listening

Be empathetic, supportive, and encouraging; do a lot of listening! “Don’t just *do* something – stand there and pay attention” is a helpful approach to learning how to support a family. In working with infants, toddlers and families, less talking is usually more helpful. The impulse to protect, provide, or even to rescue is strong where babies or vulnerable adults are concerned. But you are more likely to make a positive difference in the development of young children and families if you refrain from “doing” and take time first to observe carefully...and ask questions that demonstrate your respect, interest and capacity for empathy” (Dean 1999).

Support, Information and Modeling

It is important for professionals who are providing services to children who are deaf and hard of hearing and their families, to help them connect with other families who can serve as a catalyst for those who are struggling to become appropriately involved in their own child’s care.

At Hands and Voices (www.handsandvoices.org), there are three basic components provided to families through this parent-to-parent organizational system: emotional support, information and resource dissemination, and modeling by other families. Supported families are emotionally healthy, and ready to face their responsibilities. Informed families have the resources to make good decisions, take ownership of decisions and outcomes, and understand why they are doing what they are doing. Finally, families learn skills, strategies and advocacy tools by being exposed to other families on the path of raising children who are deaf and hard of hearing. Programs often strive to connect families to one another through a variety of methods. Often this is

for emotional support and community opportunities. One of the frequently overlooked purposes of parent-to-parent connections is the opportunity for families to see positively-modeled behaviors of effective parent involvement and advocacy from their peers, other families. This seems to be true across the spectrum of the different types and diversity of families, including those from different cultures who are provided role models from the same cultures and backgrounds.

Conclusion

A family’s life is changed from the moment they receive the news that their child has a hearing loss. A family’s level of involvement is influenced by many factors. Most families are doing the best they can at any given moment. Families are not static. A family which is considered ‘challenging’ and ‘under-involved’ can move from that place to a more productive position of active involvement when surrounded by professionals and other parents who have positive attitudes and tools to help that family make progress and ensure that successful outcomes for children who are deaf and hard of hearing can be achieved!

References

- Dean, J. 1999. Principles of practice: Forming the foundation for creative infants and their families. Unpublished manual.
 - Donahoo, S. 2001. Perspectives on Charter Schools: A Review for Parents. *ERIC Clearinghouse on Elementary and Early Childhood Education* ED455973 Champaign IL.
 - Epstein, J. L. 2001. *School, family, and community partnerships: Preparing educators and improving schools*. Boulder, CO: Westview Press.
 - Gladwell, M. 2008. Outliers: The Story of Success. *The Ethnic Theories of Plane Crashes* (pp. 177–223). Boston: Little, Brown.
 - Henderson, A., and Berla, N. (eds.) 1994. *A new generation of evidence: The family is critical to student achievement*. Washington, DC: National Committee for Citizens in Education.
 - Hoover-Dempsey, K.V., and Sandler, H.M. 1997. Why do parents become involved in their children’s education? *Review of Educational Research* 67: 3–42.
 - Miller, W.R. and Rollnick, S. 2002. *Motivational interviewing: Preparing people to change*. New York: Guilford Press.
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- Sass-Lehrer, M., Mertens, D., and Scott-Olson, K. 2000. Sensitivity in the family-professional relationship: Parental experiences in families with young deaf and hard of hearing children. In P. Spencer, C. Erting and M. Marschark (eds.), *The deaf child in the family and at school*. Mahwah, NJ: Erlbaum Associates.
- Steinberg, A., Bain, L., Li Y., Montoya, L., and Ruperto, V. 2002. *A look at the decisions Hispanic families make after the diagnosis of deafness* (p. 18). Washington, DC: Laurent Clerc National Deaf Education Center, Gallaudet University.
- Stonestreet, R.H., Johnston, R.G., and Action, S.J. (1991). Guidelines for real partnerships with parents. *Infant-Toddler Intervention: The Transdisciplinary Journal* 1:1.
- Thomson, V. 2007. A programmatic analysis of a newborn hearing screening program for evaluation and improvement. Unpublished thesis, University of Colorado. Boulder, CO.
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