

Working with Challenging and Under-involved Families

Janet DesGeorges





**Thanks to Audiology
Online...**

**...and to my gang at
home that never
complains when I'm
gone...**





- Let's define 'challenging'... shall we?
- Facts and/or assumptions
- Cultural Responsiveness...or is it?
- Solutions that will help you next week



- **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



- “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”(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”



Thinking about families in a different mindset



- “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/hh 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 they can”



Assumptions



- “They are not involved because they don’t care”
- “They will not be involved because they are in the statistical representation of families who don’t follow through.”
- The ‘anti’-assumption’ - “I was surprised to find this family was a challenge...you should see the neighborhood they live in..”

One mother's inability to comprehend an English word was perceived by the physician 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.'

Facts



- There are some families that are not *following through* - at the expense of their child's ideal/expected development
- There are identifiable demographics relating to families who tend to have a more difficult time following through

Health Disparities at a Glance: Rescreening Statistics



- **Mother's age**
 - 11-19 Years
 - Population=8%
 - Not rescreened=14%
- **Marital Status**
 - Unmarried
 - Population=27%
 - Not rescreened=39%
- **Education Level**
 - 12 years or less
 - Population=48%
 - Not rescreened=64%
- **Ethnicity**
 - Hispanic
 - Population=32%
 - Not rescreened=46%

Objectives. The purpose of this study was to identify hospital and demographic factors that are associated with an infant not receiving a follow-up outpatient rescreen and identification of hearing loss by six months of age in the state of Colorado.



But I really want to help...

- ✓ Self- awareness and attitudes
- ✓ Assumption free
- ✓ BRING IT (don't avoid the challenge)
- ✓ Identify the 'challenge'
- ✓ Build on what is working
- ✓ Moving families up the scale
- ✓ Call in reinforcements

Solution Samples



- **Don't forget the basics** (*you may already have the tools that will work*)
- **Motivational interviewing techniques** (*gets to the root of the issue – from the parent's point of view*)
- **Equality of Partnership** (*solves discord and conflict*)
- **Mutual Mentoring** (*solves ownership and follow through dilemmas*)
- **The Hands & Voices mantra:** Support, information, modeling (*the parent-to-parent solution*)



Motivational Interviewing Techniques

- 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



Elements of Equality

- I am not your mom
- Change the words you use
- Families are not 'static'
- Medical model vs. holistic mindset





Cultural Considerations

...When **Equality of Partnership** is foreign to a cultural mindset

“Cultural Competency in the Cockpit”

The Ethnic Theory of Plane Crashes...
“Captain, the weather radar has helped us a lot.”

Outliers Pages 177 – 223, Malcolm Gladwell



Definition of Mutual Mentoring

- *Mentoring* has traditionally been defined by a top-down, one-on-one relationship in which an experienced ‘expert’ guides and supports the ‘protégé’
 - (in UNHS, who is the expert and who is the protégé?)
- “*Mutual Mentoring*” distinguishes itself from the traditional model of ‘top-down mentoring’ in that the relationship is a non-hierarchical, collaborative exchange in which no single person is required or expected to possess all the expertise and information.
- i.e. We need each other!



Support, Information, Modeling

- **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...
- **Modeling by other families** – families learn best by seeing other families in action

Parents have the right...



- ... to tell you they're not ready*
- ... to delay a decision*
- ... to drive the conversation*
- ... to change your agenda for the visit*
- ... to receive unemotional information*
- ... to be emotional*
- ... to not hear your bias or your issues*
- ... to be subjective*
- ... to be treated with respect*

The Stakes Are High



- Parental Involvement is the number one indicator of successful outcomes.
 - Research indicates that the single-most important factor in predicting successful outcomes of newly identified deaf/hh babies in early intervention is the active participation of their parents. (Yoshinaga-Itano, Coulter & Thomson, 2000)
 - Benefits of Parent involvement include higher reading scores, higher grades on homework, improved attitudes towards school, improves relationships between parents and teachers. (Donahoo, Saran, 2001)
- Parent involvement leads to advocacy, which leads to **self-advocacy** for the child.
 - Education, social/emotional
 - The end game statistics: underemployment, a society that discriminates.... (It's not about the 's' sound)

Remember...



...“Most families are doing the best they can, at any given moment.” (Isn’t that true of you, too?)





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Janet DesGeorges Outreach Director, Hands & Voices
& Executive Director, CO Families for Hands & Voices

**PO Box 3093
Boulder, CO 80307
303-492-6283
janet@handsandvoices.org**