Early Intervention: The Missing Link
Researched, Composed, and Signed by Rachel Benedict
Produced by ASLized
Transcription Notes by Gina Oliva
www.aslized.org/ei

TRANSCRIPTION NOTES
This is has been prepared to help individuals who may not be familiar with sign language and/or the issues discussed herein to more easily grasp the message of the film.

The Missing Link - Deaf role models at hospitals - helping hearing parents with deaf newborns

0:13
There are many deaf people around the world who use sign language daily. We believe that we are not disabled, and that being deaf is not something to be upset or worried about. We believe we are perfectly normal, and have our own culture. But when hearing parents suddenly find themselves with a deaf baby, understandably they are quite surprised, even shocked. Those parents are not sure what to do with their deaf child -- the birth and revelation of a deaf baby is a confusing and overwhelming time for them.

0:40
Can we blame the hearing parents for being shocked or for their reaction? No, It is not their fault. Then whose fault is it? We can say it is probably the hospitals and the people who work in the early intervention, to name a few. The way they share information can really make the parents fearful.

0:57
"BAD NEWS"
For those hearing parents, this deaf baby is probably the first deaf person they ever met in their lives. Being shocked and uncertain is very normal for parents in this situation. Again, it isn't their fault here. Now imagine the very first meeting when the parents sit down with the doctors and the early intervention people -- the parents are outnumbered by the professionals, sometimes by as many as 7 to 2. Obviously at this point, the parents are scared because this big power imbalance suggests that something is seriously wrong with their baby.

1:36
"SOMETHING IS WRONG WITH YOUR BABY"
At this meeting, the very first thing the doctor typically says, with a very mournful face, is, "I am sorry."

” Sorry?" Why would the doctor say that?? Of course the parents are really scared now!!

1:52
“SORRY = FEAR”
Many terms doctors use have a huge negative impact on the parents. Everything is presented as negative.

2:09
“You think that is overwhelming? Naturally that's how the parents feel!”

The doctor says (with a very sad face), "Your child has been diagnosed." Wow, a strong word - "Diagnosed." That term is typically used for diseases, cancers, or illnesses that lead to death. Is "deaf" in this category of grave illnesses? No, it is not. Instead, the doctors could use the word, “identified,” as in “We have identified your child to be deaf.” (and say it with a smile!) The term, “identify,” seems more normal, acceptable, positive.

DIAGNOSED → IDENTIFIED

2:38
Then doctor says, “Your child has a hearing loss” (again with that sad facial expression) So it seems the child lost his hearing? The child probably never had any hearing to begin with. Instead, doctors could use terms such as, “hearing level,” and/or “hearing status.”

HEARING LOSS → HEARING LEVEL or HEARING STATUS

2:59
Next the doctor (or the early intervention specialist) would typically say, “since your child is deaf, we need to discuss communication options.” This is when parents receive the impression that they must pick **only one option** - they must pick sign language only, or spoken language only, a cochlear implant, or use cued speech, -- the strong implication is that they **must pick one of these options**. Of course this gives the parents intense pressure to **make a decision right now. Pick one!!!** Naturally the inexperienced new parents are unsure which option to choose, and how will it affect the child and their lives.

Instead, doctors could say, "There are communication opportunities. The child can learn to sign and also get a cochlear implant and learn how to speak." The doctor can assure parents that both of these opportunities are important. Emphasizing that the parents must select **one** "option" only serves to make the parents anxious.

COMMUNICATION OPTIONS → COMMUNICATION OPPORTUNITIES

3:40

Now here is another term that ought to be changed: In hospitals, the term "early intervention" is used -- this is recommend to the parents. Early intervention is a term used commonly all over America. However, the word “intervention,” suggests that the doctors are stepping in, in the midst of a huge problem to help the parents solve this terribly disruptive situation. This makes the parents feel helpless, that they have nothing to offer, and leads to their doubting themselves as good parents.

Instead doctors and other professionals should use a different term: “early involvement.” They should put more emphasis on saying things like “we are here to support you,” and “we are here to provide you with information however the decision is still yours.” This approach would be less invasive.

INTERVENTION → INVOLVEMENT

4:17
Here is another example of negative terminology: The audiologist would say, “Your child failed the hearing test.” Another strong emotionally loaded word choice. This says the baby has failed his first test ever! Imagine how the parents feel about this!
It isn’t the baby’s fault -- "failed" is the wrong term. Instead doctors could note, “refer with an explanation," e.g., to the early involvement (:-) personnel for follow-up. This means the doctors will discuss the tests with other professionals as well as with the parents.

FAILED HIS FIRST TEST → REFER WITH AN EXPLANATION

4:38
Doctors sometimes also say, “Your child may have vocational limitations,” and further suggest that the child’s future is uncertain - alluding to the fact that the child might not be able to attend college or find a job. Comments like this even further scare the parents. The truth is that a deaf child has “unlimited opportunities!!” And that should be said with a smile too!

VOCATIONALLY LIMITED → UNLIMITED OPPORTUNITIES

4:58
The doctors and/or hospital personnel typically also say, “we know you are grieving so we will get a counselor to work with you to discuss the grieving process.” This drives home the strong assumption that the parents are beset with a very serious situation, so serious that they are routinely told they need counseling. Again this puts the parents in the position of questioning themselves as parents. Why don't the doctors use the term, “journey”? They can say “having a deaf child is a journey in life,” and “you will learn a lot of new things on this journey.” By saying these things in a upbeat manner like they would after the birth of **any** child, they are helping the parents view the experiences they will have with their deaf child in a positive light.

COUNSELING → JOURNEY

5:28
Often we see and hear words such as disabled, handicapped, can't do this, can't do that, and other negative terminology applied to deaf people.

5:46
For example, parents are almost always told, “your child needs technology to function,” specifically that the child must have ear-related technology, such as a cochlear implant or a hearing aid. That kind of thinking is limited and narrow - focused only on the hearing mechanism. Instead doctors should say, there are visual and audio technologies.” This is good thing - it calls attention to the child's eyes, which can be used to advantage. Parents should be informed that there are visual technologies such as doorbell lights so the child will know if someone is at the door, and telephone lights as well.

NEEDS TECHNOLOGY TO FUNCTION → VISUAL AND AUDIO TECHNOLOGIES

6:10
Several research studies have shown that the typical first meeting with the doctor leaves the parents feeling overwhelmed with tons of unexpected information. They go home from the hospital with their newborn and numerous brochures -- they are frightened and uncertain what to do next.

Several research studies have also shown that if cultural aspects are discussed at the hospital -- if the doctors inform the parents that there are deaf adults who excel in higher education, that many deaf adults have full-time jobs in a variety of fields, and that many have doctoral degrees, the parents leave the hospital with a sense of relief. They leave with a positive idea that their child can have a normal life. This is in contrast to getting a sense that their child is viewed as "not normal" or "handicapped". These research studies also show that if an actual deaf adult "role model" meets with parents, it makes a huge difference in their thinking about deaf people. The conversation with a deaf adult makes the parents realize that deaf people are able to communicate, are intelligent, and are “okay.”

Deaf role models at hospitals are nonexistent and this is the missing link.