Catch Them on the FLIP Side

Supporting and Empowering Parents of Children Who are Deaf with Disabilities (Deaf+)

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Parent Guide, Illinois Hands & Voices Guide by Your Side

When we learned of our son's diagnosis with severe - profound hearing loss, it didn't feel like a big deal.



About Me

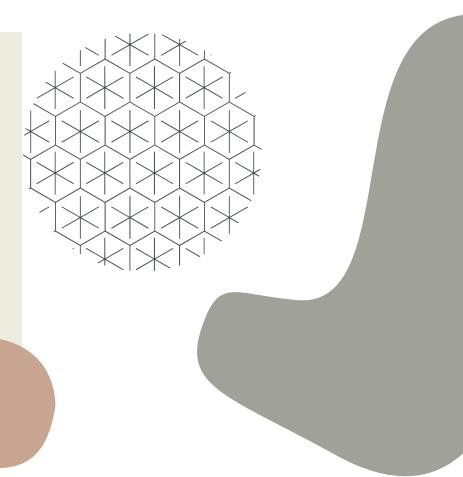
- Parent of a child who is Deaf+
- Former middle school teacher, current adult ed teacher
- Parent Guide with ILHV-GBYS
- Parent Facilitator with ISRC

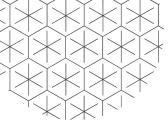
Presentation Objectives

I will reflect on ways my current practices could change to better meet the needs of families of children who are DwD in order for them to achieve their highest potential, now and in the future. I will gain a deeper understanding of the unique challenges parents face when raising a child who is DwD.

Important Things to Note

- Criticism doesn't equal lack of respect and appreciation.
- The language I use may not be the language you are most comfortable with.





40-60 %

of children with hearing loss have additional health challenges outside of their hearing.

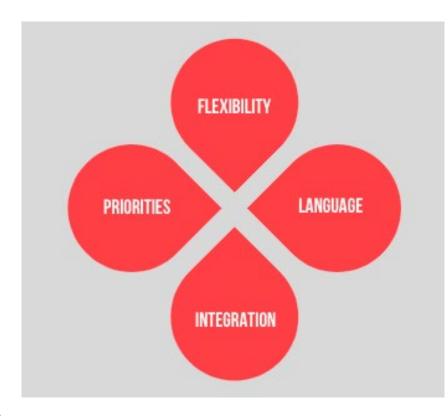
Many Forms of Deaf+

Examples		
Cognitive	Learning disabilities	Developmental disabilities
Motor	Low muscle tone	Cerebral Palsy
Medical	Vision impairments	Seizure disorders
Emotional	Anxiety/depression	Behavioral disorders

The combinations are endless!

Each of these is a lot to deal with on its own...

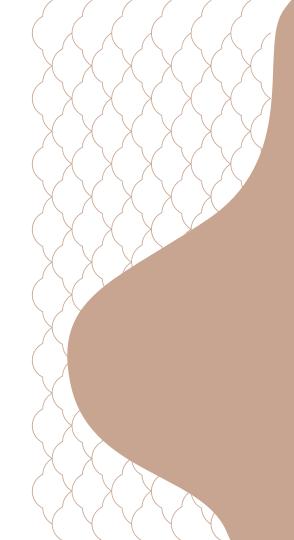
THE FLIP APPROACH





Am I being flexible?

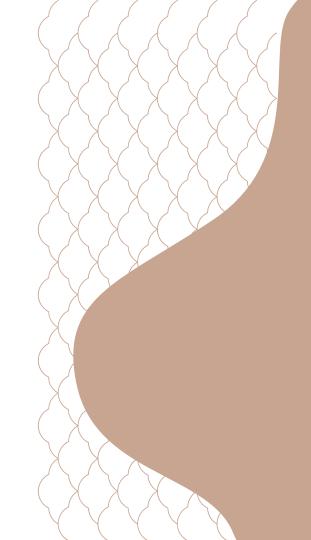
- Thinking outside the box when it comes to communicating with families
- Being willing to try new things in order to get families involved
- Scheduling



Am I challenging my assumptions?

Am I *promoting* flexibility?

- Emphasizing to families that the communication mode they choose doesn't have the be the only option for all of eternity
- Making sure families know there are options (taking an advocate role)
- Acceptance of communication choice regardless of opinion





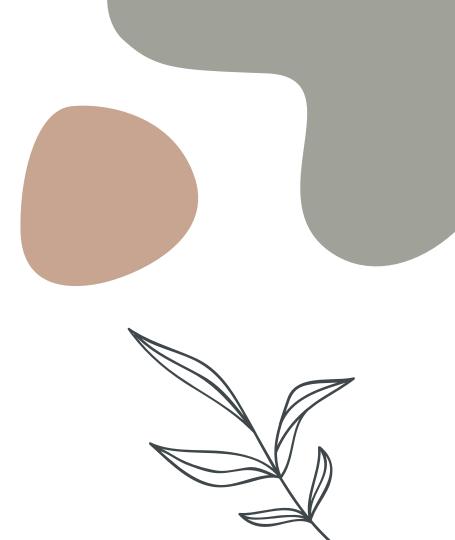


Is this my label or theirs?

- Don't assume a label is acceptable
- Labels need to be explained/defined
- Families choose the label, not professionals
- Labels and diagnoses are not
 the same

Am I saying more than I mean?

- Be aware of the way your words can make a parent feel responsible or defeated
 "Were you able to
 - _____ this week?"
- Doesn't mean sugar-coating everything or not asking



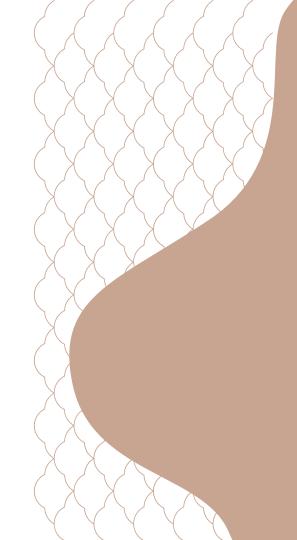
Am I being clear in the context? • Don't assume they know what something means

- Don't skip over it either
- Provide a glossary
- Explain when a label means something specific in certain circumstances



Am I seeing the big picture?

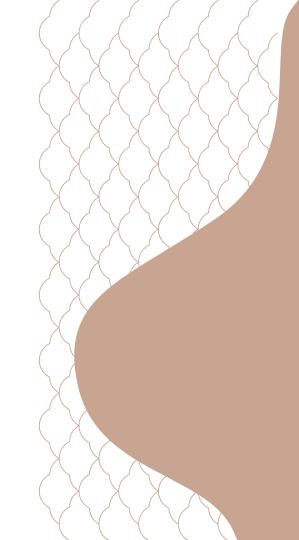
- It really is all connected
- Assessments/evaluations integrated as well



Am I stuck in my lane?

Am I engaging the team?

- Communication!!!
- Take the initiative & reach out
- Parents count too--Get updates even when you don't "need" them Asking for updates often means you won't get bombarded later.



Priorities

Am I understanding what is most important here?

- There are many times when hearing/devices/etc. aren't the main priority for a child/family.
 - That doesn't mean these things don't matter to us!
- ASK the family what their priorities are!
 - Once is not enough.
- Decision fatigue is real.
 - That might mean presenting resources and then leaving a topic for a while.
- There are times when you simply WON'T understand, and that's ok.
 - ...As long as you're giving grace and communicating!

Families need you to meet them where they are. With families of kids who are DwD, that's probably a place you have never been.



Resources

- Berke, Jamie. "7 Reasons Why Using Sign Language Helps Families of Deaf Children." VeryWell Health, 29 Apr 2020. https://www.verywellhealth.com/parents-of-deaf-children-not-learning-signlanguage-1049359.
- Ching, Teresa YC *et al.* "Factors Influencing Parents' Decisions about Communication Choices During Early Education of Their Child with Hearing Loss: A Qualitative Study." *Deafness Educ Int,* 2018, 20(3-4), pp 154-181. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6411083/
- "Deaf/Hard of Hearing Plus." Hands and Voices, <u>https://www.handsandvoices.org/resources/dhh-plus.html</u>. Accessed 4 Feb 2022.
- DesGeorges, Janet. "Avoiding Assumptions: Communication Decisions Made by Hearing Parents of Deaf Children." AMA Journal of Ethics, 18(4), 2016, pp. 442-446. https://journalofethics.ama-assn.org/article/avoidingassumptions-communication-decisions-made-hearing-parents-deafchildren/2016-04

Thank you!

Do you have any questions/comments, or just want to connect?

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