EXIT ONLY

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• Not on any map
• You can slow down, but you can not stop
• Unexpected, unfamiliar highway
• Decisions are required for testing, retesting, referrals, diagnosis
• As professionals be immediate, direct, and firm
• Acceptance of the diagnosis
• Understanding of the immediate implications
• Feeling alone
• Families are forced to stay on this road
• Focus on this journey
• Learn about this new landscape and environment –
  
  **Welcome to Holland**

  *Raising and Educating a Deaf Child* – Marc Marschark
Language choices
• Use of sign language
  • Bridge to English
  • Speech delay
  • Early access to communication
• ASL vs. signing English
• Cued Speech
• Oral only
• Parents most often do not choose this route
• We are blessed to meet those who have, merging in with us
• Small group of special people
• It is still our journey to make
• You are the first in-home source of information.
• Take advantage of the relaxed home environment.
• If you don’t know, find out, or find someone who does know.
• What kind of learners are the parents? What kind of teachers are they?
• Parents do not always know which questions to ask.
• No guidebooks available for what to expect at each mile marker
• Hard to tell how long some of these miles really are
  • One year’s growth in one year’s time
• No clear maps about junctions that lie ahead and how to get ready
• Share successful plans from other families
• Our IFSP or IEP map may be distorted
• Decisions based on bad information
• Not following good advice
• Try something and fail
• DO NOT wave this sign in front of us – you may get run over
• Tight turns, slow speed
• Rough road, level "B" maintenance
• Smooth, four lane open road
• Series of stoplights, traffic jams
IMPLANT OR NO IMPLANT

- Parents must decide for their infant child
- Older children can be given illusion of choice
- No indication of “road conditions”
- Research does not specify compliance
- Implant road does not bring back natural hearing
- Implant road is MORE work for everyone
- Expectations need to be realistic
- Decision is harder for some families than others
  - Current FDA guidelines, insurance, finances
- Consider the sources of information
  - Implant companies, implant centers, other families
The bilateral debate

• Insurance coverage
• Simultaneous vs. sequential
• Time between implants
• The risks, however small, are scary
• Gifts, cards, calls both before and after are appreciated
• Classroom presentation helpful for older children
• Once activated NO PARKING ANYTIME FOR ANYONE
• Processors must be kept ON and in working order
• Supplies must be kept on hand
• Everything becomes therapy
• Everyone can do therapy
• Other families join along the journey
• Professionals see the big traffic picture
  • Help us find each other out on the road
  • Support groups are important Hands & Voices
• Deaf adult connection
Two worlds for some deaf/HOH

- Not completely at home in deaf world
- Not completely at home in hearing world
- AEA workers – ITHI – parents – deaf mentors – friends
  All need to help bridge the gap
- Try to keep services going
• Real? Perceived? Surmountable?
• Creative problem solving, communication, support
Pull out services

- Are expectations appropriate?
- Has the bar been lowered? Why?
- Try shoving them back out into traffic
- Benefits vs. costs
• Help families see the joys and enrichment brought into their lives
• Knowledge and opportunities
• Perks
  Golden Pass, Civic Center seats
Is my low fuel light on?

• Take time to rest, refuel
  Kids, AEA, parents
• Vacation days, play days, party days
• Continuing education, trips to clinic
We need to dump. Now.
• Dump pain, anger, disappointment, fear, jealousy, anxiety
• Sometimes in the IFSP or IEP
• You don’t need to always clean it up – just allow the dump

You need to dump
• Remember we know each other – like small town
• We are not the only ones out here
• Demands on AEA staff, school staff, budget