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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

<u>Raising and Educating a Deaf Child</u> – Marc Marschark



Language choices

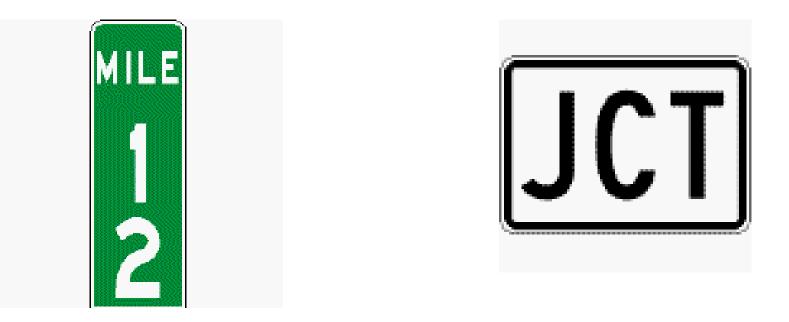
- •Use of sign language
 - Bridge to English
 - •Speech delay
 - Early access to communication
 - ASL vs. signing English
- •Cued Speech
- •Oral only



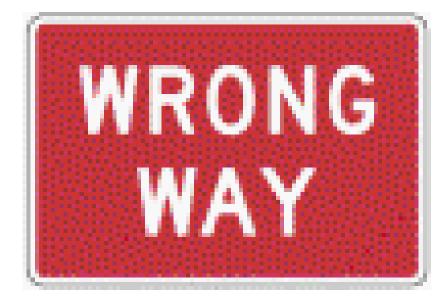
- Parents most often do not choose this route
- •We are blessed to meet those who have, merging in with us
- •Small group of special people
- •It is still our journey to make



- 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

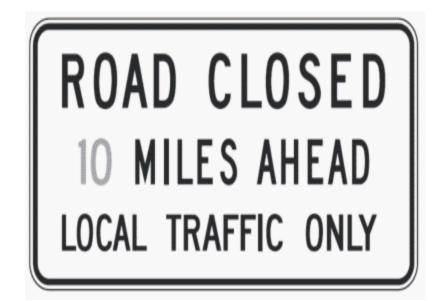


- •Once activated NO PARKING ANYTIME FOR ANYONE
- Processors must be kept ON and in working order
- •Supplies must be kept on hand
- •Everything becomes therapy
- •Everyone can do therapy





- •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

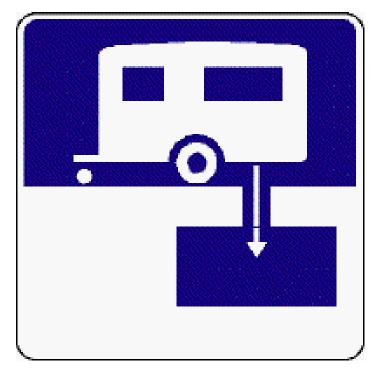




We need to dump. Now.

•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



