

*REALLY*  
How to  $\wedge$  Use a Parent  
on Your Team

*Early Hearing Detection & Intervention*

*Chicago, Illinois*

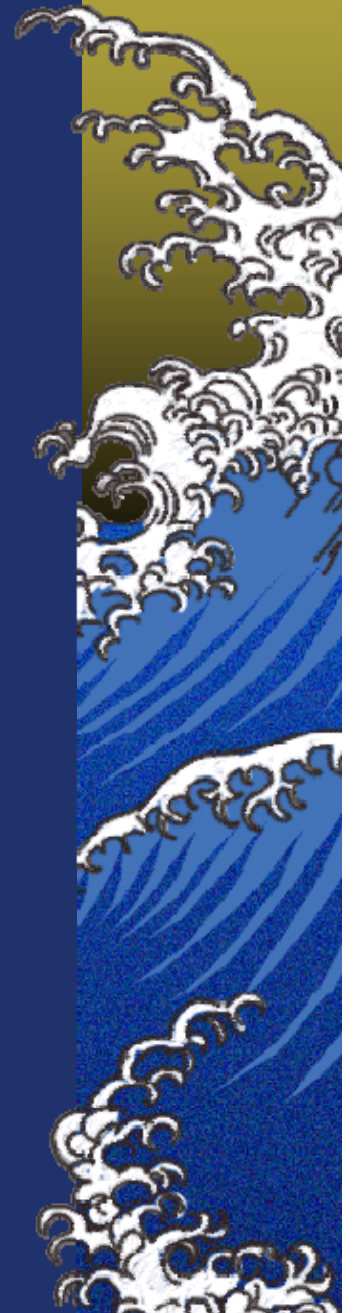
*March 1 – 2, 2010*

*Amanda Kaahanui*

*Baby HEARS **Parent** Coordinator*

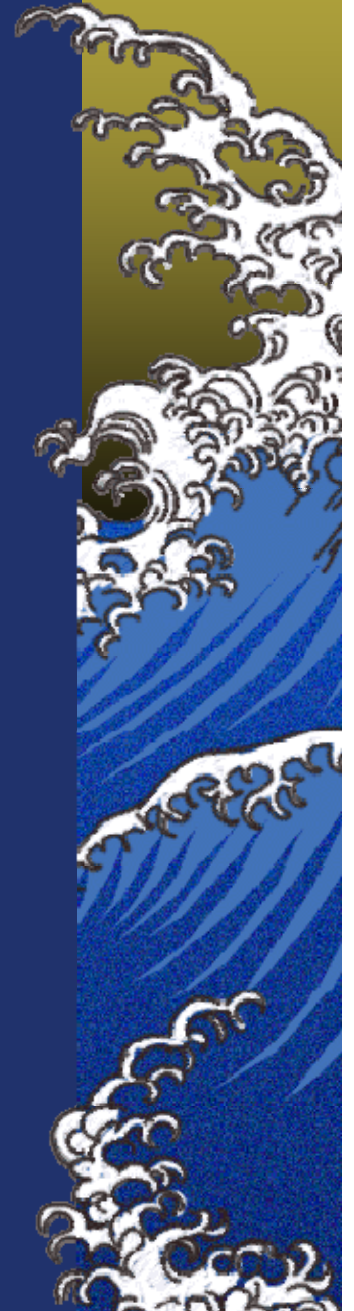
*Newborn Hearing Screening Program*

*Honolulu, Hawaii*



# Why Use Parents?

- ▶ *Parents offer a **unique** personal experience that will add value and significance to any advisory board, focus or work group*
- ▶ *They are often **fresh** and ready to hit the ground running*
- ▶ *Parents are on the **front line** of receiving services; dealing with doctors, vendors, providers, insurance and multiple agencies*



# Education vs. Experience

(not to say that parents are not educated, but they didn't get their BA in "Raising a Special Needs Child")

- ▶ *I went to school for this vs. I'm living through it*
- ▶ *Delivering services vs. Receiving services*
- ▶ *Tell you what to do vs. This worked for me*
- ▶ *Expert in the field vs. Expert with my child*
- ▶ *I can sympathize vs. I can empathize*



# Parents as Teammates

- ▶ *Involve* parents and ask them to be part of the solution instead of the “Squeaky Wheel” wanting things to be fixed for them
- ▶ They know how the system is working now, as opposed to how it’s supposed to be working: they can help bridge the gap
- ▶ Parent have *ideas*, contacts and connections that can be outside the box



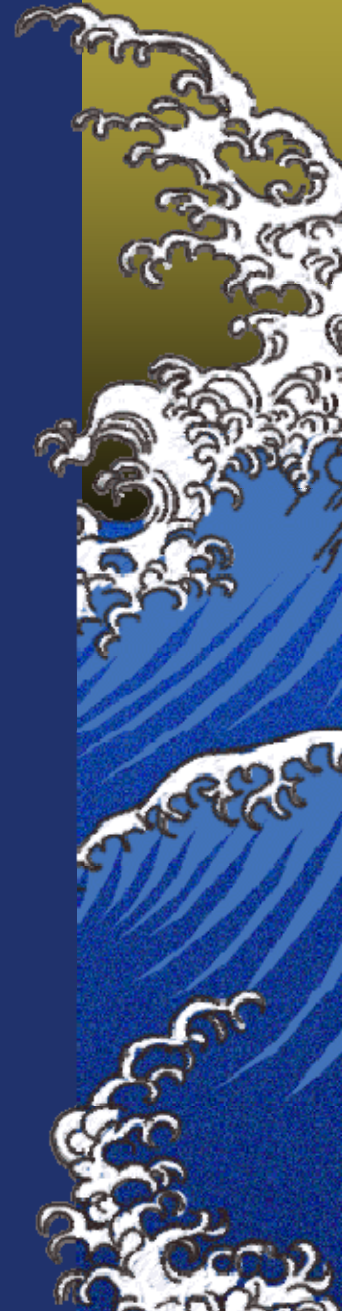
# Bonus Points for Parent Professionals

- ★ *Offer a parent a job, interacting and supporting other parents and you have a better representation of stories and experiences: not one perspective, but many – the **Village Speaker***
- ★ *The “Trickle-Up” and “Trickle-Down” effects*



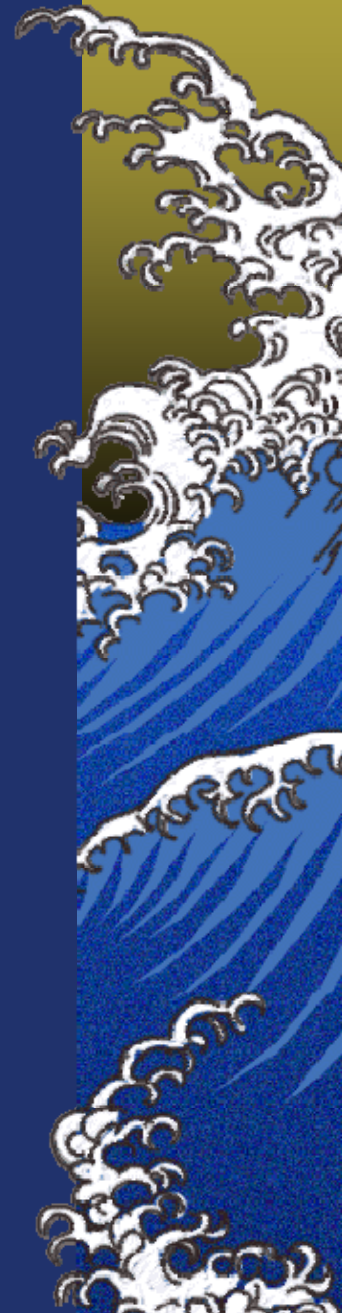
# *Really* Involve Parents in Training & Advisory Meetings

- ▶ *In-service to EI (or DOE, DOH) staff*
  - ▶ *Parent perspective, how we cope (or not), prioritizing services, day to day life*
    - ▶ *Example: PHN staff meeting resulted in 2 parent referrals in the first week*
- ▶ *Local, state, national advisory boards*
  - ▶ *If you invite us, **listen to us** & validate our experience by taking us serious!*
    - ▶ *Example: Before I had a “confident voice”, some members of a state team would ask “what do you think parents would feel about this issue”*

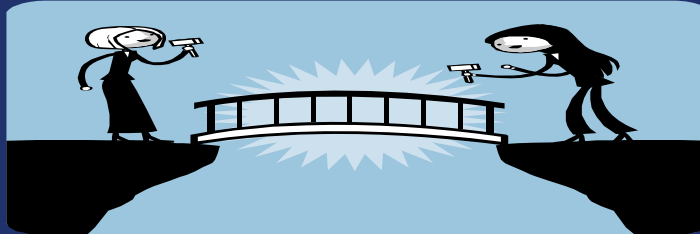


# Parents Leaders Can Make a *Really* Big Impact

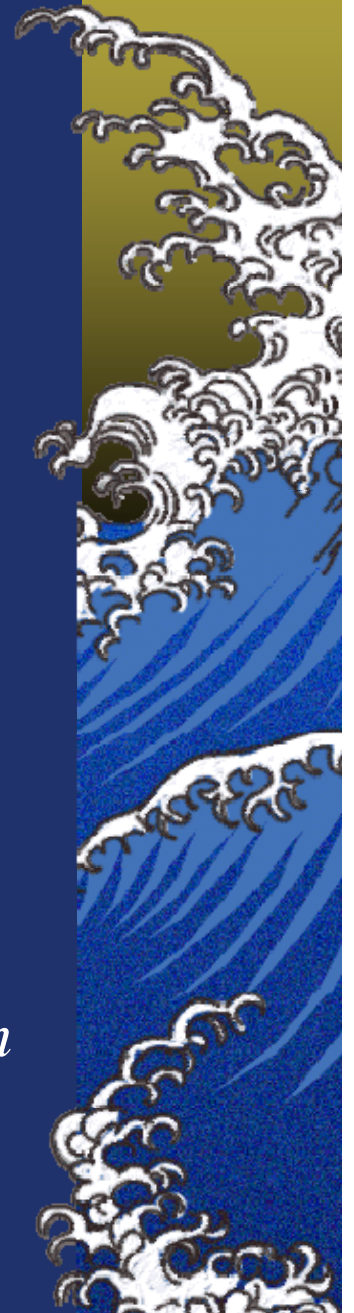
- ▶ *Talking to a “difficult parent”*
  - ▶ *I share my experiences of tests & EI – the “I’ve been in your shoes” parent connection*
  - ▶ *I’m not telling them what to do – I’m empowering them with information*
- ▶ *Using the 3 E’s: Embrace, Encourage & Enlist to support families*
  - ▶ *Example: Mom of 11 yr old C.I. w/ new hh baby – never talked with another parent, now enrolled in EI, attended her first parent training and is talking to other families!*
- ▶ *Bonus: Involved parents tend to make better informed choices for their own children*



# Parents **Can** Bridge the Gap



- ▶ *Our children continue to grow and move from one program to another while professionals tend to stay put and have limited understanding of the scope of services available beyond the child's current program*
  - ▶ *Example: At a recent training open to families of all ages and the professionals who serve them, a rep. from the Deaf School attended and was a hit! Now we have a rep. come for each meeting to mingle with our EI families and staff and we are exploring more opportunities for future collaboration: meeting space, training, school visits, etc.*





Mahalo for your attention,  
you were *Really* great!

