

Two Molds are Better than None: A Model of Successful Intervention

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- In the past 12 months, I have not had a significant financial interest or other relationship with the manufacture(s) of the product(s) or provider(s) that will be discussed in my presentation.
- This presentation will (not) include discussion of pharmaceuticals or devices that have not been approved by the FDA or if you will be discussing unapproved or “off-label” uses of pharmaceuticals or devices.

Amanda Kaahanui



- Live on Oahu, Hawaii
- Instructor at Honolulu Zoo for past 8 years
- Currently enrolled in ASL Interpreter program
- Teaching beginning sign language to EIS and other families

Chelsea Courtney M.A.



- Grew up in Riverside, California
- B.A. in Deaf Education, Fresno State University
- M.A. in Deaf Education, San Diego State University
- 2 years with Hawaii Dept. of Health Intervention Section

Ikaika: Hawaiian for Strong

- Born October 13, 2003
- Full term, 38 weeks
- Taken to Kapiolani Children's Hospital 6 hours after birth for strider (loud breathing)
- Went in for a few days, stayed in four months



Multiple Testing for Multiple Symptoms

- Sedated MRI (brain)
- 3 sedated CT scans (chest, nose, ears)
- Ultrasound of kidneys
- EKG (for murmur)
- Ultrasound of heart
- 4 barium video x-ray of stomach and throat
- Multiple Endoscopic bronchoscopies
- Multiple chest x-rays
- 2 eye exams
- Neural-behavior testing
- Genetic testing
- Newborn hearing screen
- 4 ABR tests (non-sedated)

Multiple Surgeries



- T.E. Fistula repair (10 days old)
- G-Tube (3 weeks)
- Tracheotomy (2 months)
- Nissen (3 1/2 months)
- Choanal Stenosis (10 mo)
- Stent removal (12 month)
- Skin flap removed from vocal chords (16 months)
- Nissen redo (2 years)

Official Diagnosis

C olombona

H eart anomalies

A tresia of nose

R etardation of growth
&/or development

G enital or urinary track

E ars & balance

- Charge Association (Ikaika has A & E)
- Reactive Airway disease (asthma)
- Acid Reflux disease
- Moderate to severe mixed hearing loss

Parents' Diagnosis

- Happy, healthy child who happens to have a trach and g-tube
- Hearing loss that is aided to near-normal
- Language & cognitive development are age-appropriate
- Typical 2-year old!



Early Detection of Hearing Loss

- Newborn hearing screen - 1 month - failed
- ABR testing: test 1 - not in deep enough sleep for good results, test 2 - no response in right ear, test 3 - moderate to severe in his left ear, test 4 (outpatient) - same results for both ears
- Tympanic testing: results were conflicting with physical exam and prompted us to get a CT scan for definitive results

Results of Hearing Tests

- Mixed hearing loss
- Without aids, right ear is a 90 dB loss, left ear is a 50 dB loss
- Conduction loss is about 30 dB in each ear
- Aids bring hearing up to near normal levels
- Tympanic tests showed fluid or wax
- CT tests showed no fluid or wax, bones and cochlea are intact
- Revealed he is missing 2 of the 3 semi-circular canals that provide good balance

Parents' Response to Early Hearing Testing



- We had an inkling and were relieved to know for sure
- Our grieving process was shorter and less intense
- Received early support
- Jumped right into learning ASL and other tools to help Ikaika learn language

Early Intervention - Hospital

- Diagnosis: ABR showed hearing loss in both ears
- Result: Bedside visits by Audiologist and SLP explained test results, his degree of loss & began teaching basic ASL words, ABC's and songs
- Used an F.M. system to introduce Ikaika to the sound of our voice and get responses from him



Early Intervention: Outpatient



- Diagnosis: Continued tests showed hearing loss stable and would be improved by hearing aids
- Result: Fitted with new ear molds coupled with behavioral testing continuing every 3 months

Early Intervention: Home OT/PT



- Helped Ikaika roll onto tummy, crawl, walk, use a crayon, stack and other things he didn't want to do
- Once a week for 18 months, bi-monthly till age 2, now once a month

Early Intervention: Home Speech Language Pathologist



- Once a week visits
- Works on ASL signs & spoken language
- Eating and swallowing
- Cognitive development
- Passy-Muir trials for eventual safe removal of trach tube
- Support and guidance

Early Intervention: Home Deaf Educator



- Once a week for 6 months, now bi-monthly
- Teaches new signs to Ikaika and our family
- Explains tests, aids, Deaf culture
- Assesses & monitors language development
- Provides parent support & guidance

Early Intervention: Home Deaf Mentor



- Visits bi-monthly
- Signs with Ikaika and parents
- Provides a male role model
- Gives Ikaika a Deaf role model
- Offers support and boosts confidence in our signing at home

Support Services: Audiological

- Supportive, knowledgeable partner
- Always makes time for us
- Explains test results
- Enables us to make the right choices for our family
- Respectful of our choices for communication



Support Services: Parent to Parent

- Ohana Time - a quarterly family support meeting for children with hearing loss
- Parent meetings sponsored by KMC Mobile Team and our case management agency
- Parent Leader conference in S.F. sponsored by H.E.I.C.C.
- Through support of our Deaf Educator, received a contract to teach basic ASL to other families in Early Intervention

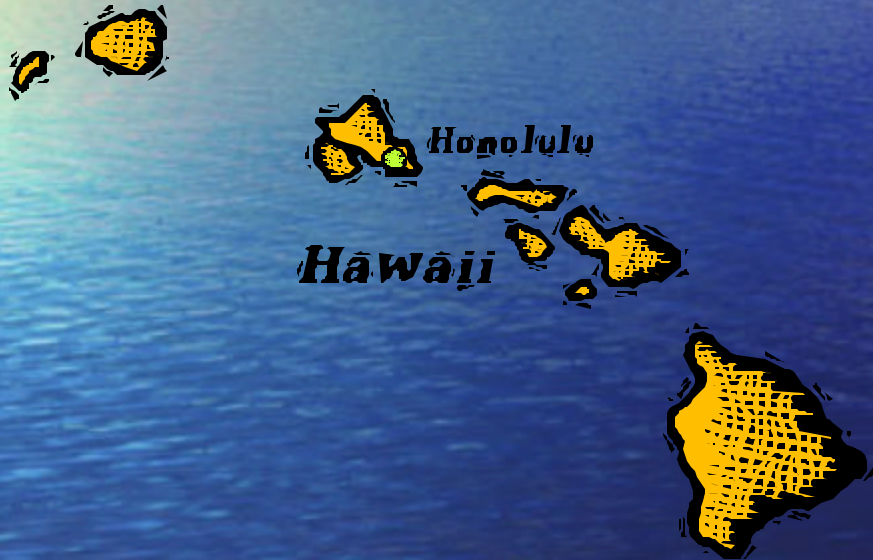
Ohana Time

Mission:

To provide a foundation for parent to parent contact

Steps:

- Develop quarterly meetings on Oahu
- Identify parent leaders
- Provide information to parents from parents
- Introduce new program ideas
- Model support and expand to neighbor islands
- Allow parents to take ownership



Goal: For Hawaii to have a parent driven parent to parent network

Parent Responses



- "I learned that being hearing impaired is alright"
- "It was inspiring to meet other parents are in the same position as us"
- "Talking with others and sharing experiences is VERY valuable"
- "I learned that singing can start at any age and have real benefits"
- " I learned there are many resources available"
- "It's okay to push for your child's needs and advocate"

~ Ohana Time - What's Next...



- Continue ongoing quarterly meetings
- Increase frequency of meetings in rural parts of island
- Encourage local chapter of national support organization

Our Outlook on Early Detection and Intervention Services

- We've been extremely satisfied with services
- Appreciate the partnership between parents and professionals
- Gratifying to contribute to parent support
- Only drawback, having to wait to get aids until we got home



Ikaika's responses to EHDI



- Early exposure helped him adapt to aids and sound
- He responds well to both sign language and speech
- Over 135 expressive signs
- He loves visits from his "aunties" & "uncles"
- Ikaika is a happy, healthy child expressing age-appropriate language

Mahalo Nui Loa!

