

Early Language Working Group

August 25, 2017, 3:00-5:00 p.m.

HawaiiUSA Federal Credit Union Conference Room
1126 College Walk, Honolulu Hawai'i

MEETING MINUTES

Attendance:

Working Group Members: Jennifer Blohm, Ed Chevy, Carole Duran, Kari Fillinger, Amanda Kaahanui, Nikki Kepo'o, Coleen Momohara, Emily Jo Noschese, Gwen Palmer, Angel Ramos, Charlene Robles, Jill Taosaka, Jennifer Hokulani Tarnay, Julie Whitaker, Colin Whited.

Facilitator: Leolinda Parlin

Observers: Patty Dong, Tabitha Ganitoen, Patricia Heu, Cassandra Kwilit, Linda Lambrecht, Steve Laracuente, Keiko Nitta, PoKwan Wong, Angela Nagata, Isabel Ramos.

1. Introductions

Attendees introduced themselves by name and indicated which role they were representing.

2. Minutes – 7/14/17 meeting

To be discussed at next meeting.

Member suggested a process check to see where the group is meeting the deliverables of the legislative report. An Early Language Working Group (ELWG) summary document was shared. Working Group would like it populated to see where we are for deliverables for Legislative report in January. Group was reminded that under the bill, the purpose of the group is to make recommendations to the Legislature.

Jill Taosaka asked for clarification on what the intention of the group is so that the group knows where they are at and how far they need to go. What is the purpose of this group?

Leolinda: The purpose is to make recommendations... the "what", not the "how". The directories and data that have been compiled are to be used in making decisions on what recommendations to make... for gap analysis... what is missing on neighbor islands? What about confidentiality of parents/families being on a list that is available to the public?

Specific language in Act 177: Establish a working group for the purposes of investigating issues related to resources and tools for parents of children who are deaf, hard of hearing, or deaf-blind and improvements to the statewide system of services that support age-appropriate language development for children from birth to age five who are deaf, hard of hearing, or deaf-blind. The department of health, department of education, and executive office on early learning shall establish and convene a working group for the purpose of making recommendations to the legislature on issues related to supporting age-appropriate development for children from birth to age five years who are deaf, hard of hearing, or deaf-blind.

Julie would like a road map of what has been done and what still needs to be done. Timeline and milestones will help to bring back the main points to who what progress has been made.

Leolinda: Report needs to be in by December, and as late as January. There are 3-4 more meetings. The group is on schedule. Will work on transition in September.

Colin wanted clarification on whether ELWG is making recommendations on solutions or on the problems that need to be addressed.

Leolinda: The group identifies the “what”, let the state design the “how”. The group makes recommendations on what they want it to actually look like. Make it broad enough that the possibility exists to work with existing groups, to support them. The recommendations could be financial, statutory, policy, resource allocation.

Coleen M. wants to know if there is an agency or group that is a logical place that may be the solution.

Nikki felt that the DOH is the organization that can help to reinstate the deaf mentor program and to produce the guide, and be responsible.

Julie states that we first need to categorize and prioritize the “what”. Leolinda reminded group that they can address the “what” but not the “how”.

Nikki stated that when a baby is determined to have a hearing loss, the next step is to set up the ENT appointment. There is no discussion on language, just medical information. In the interim, the family should be given the resource guide to help them make decisions and for help along their journey.

Colin feels that family should be given the opportunity to sit down with someone who can provide neutral, impartial information about their options.

Charlene suggests to look at the current resource guide and identify what is missing.

Angel Ramos states that Hawaii needs a center for the deaf similar to the John Tracy Clinic, for parents of children who are deaf, that includes curriculum and resources.

Coleen M. feels that it needs to go beyond a specific place because it may not be in a family’s culture to seek out these places. There should be a system of support that can help these families. A center might be a part of it, but also need to change the culture. Need to have policy and legislation for this to work across systems, like DOH, DHS, other agencies. Need interconnections between different agencies to reach the diversity of people that exist. How will people statewide access this system? That is beyond a physical place.

Julie agrees that services need to be state-based, and not just a center in Honolulu. What are the tools that can be furnished to the entire state, including Neighbor Islands, and areas in rural Oahu.

Jill thinks there should be a flow chart that will direct parents to resources according to their choices. Regardless of what medical professional is involved in the first contact, families all start at the same entry point, to lessen the effects bias of that medical professional. Families will have one place to go to explore their different options. Resources should be available online so that regardless of where I live, I could still access it.

Ed feels that there is a larger number of hearing families with a baby with a hearing loss who may need help. Deaf parents already know what to do. Parents are told of their baby's hearing loss by different people (audiologist, Newborn Hearing Screening Program, etc.) so they need to be directed to a starting point.

Angel Ramos wanted to take a vote on what we want the center to offer, about curriculum and partnerships in this center. He wants a vote to find out if the group wants a center or not.

It was discussed that more information is needed, such as whether it is a physical structure or virtual. A flow chart is needed so people can see what it is we are voting on. Everyone is seeing a different vision.

The following is a summary of the discussion related to possible recommendations:

- Starts at child's birth and helps move the family through utilizing community and state resources. It is an entity not a place.
- Single point of contact or single point of entry? For birth to 5 years of age. That will allow for consistency. Each family will get the same information.
- Is there an agency/group that's a logical solution?
- Need a deaf mentor program.
- Need an entity where parents and deaf community members can reach out to the family at birth with the Newborn Hearing Screening Program and with the hospitals, to guide them on their journey of getting a rescreen, diagnostic testing, referral to Early Intervention, connect them with the deaf community, help them understand their language, getting them a physical resource guide, help them understand the system as they move into DOE.
- It's a system that starts at birth.
- Newborn Hearing Screening Program might be a point of contact because they have contact with the families who fail screening.
- Different cultures so need flexibility and sensitivity. Can it be called family-centered?
- Need capacity to collect data.
- Impartial presentation of continuum of choices. Include options, technology, therapy.
- Family gets to choose whatever method with all options available to them.

- Families can continue to re-enter and find support.
- Door can't close, need multiple paths which can cross.
- Need resource center to see options in the community.
- Information should be comprehensive.
- Resource guide should be language based.
- Offer choices to parents so they can research and make decisions.
- Point of entry emphasizing value and necessity of interactions with the child thru language. Need to address power of interactions thru language.
- Need to work on misconceptions.
- Resource guide to identify what's there and what's missing and where the gaps are.
- Resource guide not just for families but also professionals, educators.
- Education and training is needed to ensure workforce is adequately and appropriately trained. Need training, certification, qualifications.
- Registry of service providers for children who are deaf.
- Specialized field could partner together. Mentorship training.
- Training from a mentor for professionals is very valuable.
- One stop shop where there is a guarantee that the family will be referred there. Families would get information, they are not doing this on their own, where they will have access to all information.
- It's a process starting from the newborn hearing screening, then people come into the process that will help you decide what path to take.
- Need some kind of curriculum to train the parents in the choice they make.
- Need to change the assumption that people want to go to a place. Change the culture of the way the state operates. Need to create a system where expectation that this is what we want for our families.
- Hawaii culture is that the system is critical in separating out bias. This is how we can help and negate the emotional impact.
- Education and high school to address how the system can build awareness of how to communicate with baby. Already have language delays with children who can hear – how do we as a community support language.
- State-based across the state. Implement cultural change not only one geographic region – look broader.
- Buckets
 1. Single point of entry
 2. Resource guide
 3. Deaf mentor for families
 4. Mentor/Train professionals
 5. Curriculum for families
 6. Mentor for children who do not go to a deaf school

3. Resource Guide for Families

Group discussed the need for developing a resource guide for families so there is consistent impartial information to assist families so child enters school language ready for kindergarten. Current task is to identify where data resides and what are the boundaries and parameters around data. Small group will work on the Work Flow (Flow Chart). Need to make sure it addresses all children who are deaf or hard of hearing (congenital and acquired) and those who move to Hawaii. Amanda and Leolinda will work on the flow chart.

4. Future meetings in 2017

Next meeting will be September 15, 2017, 3:00-5:00 p.m. at the HawaiiUSA Federal Credit Union Conference Room at 1126 College Walk, Honolulu Hawaii. Other dates: October 20, November 9 (location to be determined), December 1 or 15. Need to work on the Flow Chart, vote on the Resource Guide, review the matrix, look at assessment and planning tools, begin discussion on Transition, discuss data and look at absence of data.

5. Public Comment

Public member shared appreciation for opportunity to support children in Hawaii.

Isabel Ramos would like to include children grades K-5 that acquire hearing loss, and not just focus on newborns since hearing loss can happen later. The system/center needs to address information for K to 5 and include the continuum of when hearing loss may occur, including when infants/children are no longer newborns and are older. The deaf mentoring program should address 0-5, since in those first five years are essential for learning language and 0 to 3 is not enough. In deciding on the mode of communication, it is important to have activities (e.g., gesturing, sign language, people using that mode, going to HSDB), so that it is not just abstract information and the family can observe or experience the communication.

Meeting Adjourned.