

Early Language Working Group

September 15, 2017, 3:00-5:00 p.m.

HawaiiUSA Federal Credit Union Conference Room
1126 College Walk, Honolulu Hawaii

MEETING MINUTES

Attendance:

Jennifer Blohm, Carole Duran, Nikki Kepo'o, Emily Jo Noschese, Emily Jo Noschese, Gwen Palmer, Charlene Robles, Jill Taosaka, Julie Whitaker, Colin Whited.

Facilitator: Leolinda Parlin

Observers: Marisa Bolivar, Patti Dong, Tabitha Ganitoen, Patricia Heu, MD, Linda Lambrecht, Dale Matsumoto-Oi, Angela Nagata, Keiko Nitta, Po Kwan Wong, Cassandra Quilit

1. Introductions

Attendees introduced themselves by name and indicated which role they were representing. Facilitator oriented the group to the contents of the packet including the agendas, revised minutes, and the work group summary. Included in the packet is the homework assignment which was to draw out the work flow of what a potential one-stop resource entity might look like. There is also included an updated document on the data where a discrepancy was noticed that the newborn hearing screening program data does not reflect all children 0-3 in 2017 but only the births in 2015. It is not a running total of the births.

2. Minutes – 7/14/17 and 8/25/17 meeting

Minutes from the 7/14/17 and 8/25/17 were discussed since they were not reviewed at the last meeting. For the 8/25/17 minutes, there is a question on whether Gisella or Giselle was in attendance – it should be Isabelle Ramos. Clarification that the comments from Isabelle should be moved to the Public Comment portion of the meeting and that there were more comments that was shared at the end of the meeting.

3. ELWG Summary

The Early Learning Working Group Summary has been updated. Whatever is bolded is what was added to the matrix since the last meeting. New things added under the Resource for Families was some of the discussion on what the one-stop resource could look like. Other information added was under data and availability of data on language and literacy development. The third piece added was on improvements regarding the statewide system of services.

4. Resource Guide for Parents of Children who are Deaf, Hard of Hearing, or Deaf-Blind (D/HH/DB)

Amanda and Leolinda worked on a workflow of what a potential virtual one-stop might look like. Group discussed the draft "Virtual Resource and Support One-Stop for Families of Children 0-5."

Leolinda explained the Opt-Out referral where the referral could come from anywhere but that it would be an opt-out referral where the family has to indicate that instead of getting permission to make referral, they are automatically going to be referred unless the family says no. It is typically used when there is less inclination to say no. According to the diagram, regardless of where the referral came in

from, a family would receive the functions in the blue column (link to a resource and support coordinator and that there would be continuity across the 0-5 system continuum.

Leolinda explained the function of the Coordinator who would be responsible for what is in the right column. Options would be available for families such as local videos for each of the options with positive celebrations of children who have chosen different options. The Coordinator would help dispatch kupuna/Makua to the home and dispatch a peer parent support. Other responsibilities would be to maintain a resource guide, materials, handouts, and assist with professional development curricula. [Decision made at 10/13/17 meeting to use the term “mentor” instead of distinguishing between kupuna/Makua for the generational differences. Mentor also is distinguished from peer.]

In virtual one-stop schema, Coordinator would:

1. Receive referral
2. Set up face-to-face meeting with family
3. Connect family to supports and other resources
4. Ensure continuity across the continuum

Coordinator’s role:

1. First person to talk with family about deaf supports
2. Share what family is to expect from system
3. If still in screening/diagnostic stage, encourage family to get diagnostic eval
4. Help families articulate their priorities
5. Offer impartial education info on language options
6. If more info/support is needed, Coordinator would help family get info
7. Connect family with deaf Kupuna or deaf Makua
8. Promote family-to-family peer support
9. Help match resources to family
10. Do other coordination
11. Maintain resource guide
12. Maintain and update other materials, such as websites, handouts, sites
13. Generate professional development curriculum for audiologists and others

Deaf Kupuna and Deaf Makua

1. Go to home
2. Teach family how to communicate with child
3. Help parents develop skills
4. Involve peer parent support to share their experiences, information, support family

What is not on the draft is where do the Early Intervention Section (EIS) and Department of Education (DOE) fit because it was designed so that regardless of what the system is and where services are, this would be a stand alone that works collaboratively with the DOE and EIS but not necessarily dependent. This was designed so the resource could be a bridge and cover the age range from 0-5 regardless of whether the child is in a program, not in a program, or could potentially be in a program.

Jill Taosaka had a question on deaf kupuna and deaf support line and whether that is to support the child or the family. Leolinda clarified that it is to the parent and helping the family to develop their skills. Jill suggested that an “s” should be added to “skill”.

This draft includes children that may not be identified at birth such as children who have acquired hearing loss later or they may have moved from another state. This is why the referral bucket does not say “hospital” or “birthing center” at the time the referral is made. This way any child at any time could come into the resource. Any family could come into the one-stop and any family that needs access to information, education, etc.

Nikki’s concerned that there already are existing processes and the one-stop looks as though it is setting up another entity that will be responsible for all of it. Because these recommendations will be heard by the legislation, it would appear to be a heavy financial request. It doesn’t address preexisting processes and supports that are already have in place. There will also need to be more requests for qualified staff and more education. Concern that by setting up a whole other group may not necessarily get us what we wanted.

She expressed concern that we are moving towards a Center again. Wants to make sure there is contact with the family to say, “Congratulations, we’re here to help.” Concern that a large financial ask may not be justified if the Center is serving on the 74 children actually confirmed. Doesn’t want to make money request haphazardly and not get it. What about working with existing people, like Jennifer, and also educating audiologist?

Charlene stated that there are pieces, like the deaf kupuna that do not exist now. So that would still be needed. No matter if it’s the one-stop coordinator, or it’s in DOH EI or DOE, you’ll still have to fund the deaf mentor, you’ll still have to consider staffing, there will still be costs.

Leolinda clarifies:

1. Need to have a coordinator position
2. The function is to connect family to parent-to-parent support, hands-on resources, deaf mentor, etc.
3. The “HOW” is determined by the State
4. ELWG can determine the function of the coordinator

Charlene clarifies Jennifer’s role as hearing specialist for EI:

1. There are missing parts
2. Jennifer has done a lot of things beyond her role
3. Her role is to help build the capacity of EI staff
4. She goes out to consult with the Speech Path, PT, etc. of the children

Emily asked if there is money for more people. We’re talking about expanding, needing more people, opening a new position, etc. Emily is concerned about the budget, whether the legislature will approve such a budget.

Jennifer wants to know if the concern is that we are asking for something new, and therefore may not get it versus just asking for what we have to be amped up?

Other concerns included:

- Is it more creating or improving a system so we have more audiologists or more of a guide?
- We need resources and funding for more staffing. All the pieces are in the resource so it's both – a one stop or working within DOE or DOH/EIS.
- Use CSC or Flow Chart or Coordinator.
- Need to have a coordinator to help family guide through the system. The "How" part is for the state to design this and be agnostic to the department.
- Coordinator overlaps with what Jennifer already does. Need several more Jennifers. Can an MOU between entities be done? It's working it just needs to be expanded and may be done through inter-department agreements. Need critical mass within Early Intervention. It needs to go beyond Jennifer and build capacity with all staff.
- Deaf mentor system is already in place, need more Jennifers to improve what is already existing and can build and train on what is already working as opposed to what is there.
- Do we need a new position or funding? We need more people but is there a budget for people?
- Are we asking for something new or asking for something to be amped up? This is an opportunity to make a request. In an ideal situation, it will need to be cost out, and prioritized.
- Care coordination is the space between silos. How can we expand the safety net and expand capacity of the system of care. It is up to the state on how it gets done whether its contracted out or developed as a program.
- Need to ask for the moon given that we have the right data and backing of partners. The resource guide should not just be a guide but should educate families about options and connecting and bonding with the child. If a third party can help us get to that point or the family whether it's a new system or ramping up what is there, it doesn't matter. People just need to know what is there. Leolinda's response: Because recommendations are coming from the task force, there is a little more credibility than if it were coming off the street so this is an opportunity to be heard. The group may want to prioritize at some point but in the meantime the task is to lay it out there. The intricacies is that Part C has its statute of what it can do for children in their services so it becomes a question of whether this is entitlement or not. It is almost like trying to create a wraparound service or a support system to early intervention and to special education. It is like a big hug and how do we fill in the gaps.
- There is an implicit bias in many professionals, so the awareness is going to help, but it's not going to eliminate the bias. That is why you want a safe place to get to an impartial place. Family is the constant in the system. Providers come and go and how to make sure families get messages you feel are important to know.
- The purpose of the working group is looking at language but it is running across other issues.
- What's missing is the 3-5 age group. May need to ask deaf itinerant teachers to get a better picture. Carol was asked if a survey to deaf itinerant teachers can be done. There is a disconnect in the Special Education systems for kids deaf who qualify under multiple disabilities. There may be some *pukas* in itinerant teachers. DOE data governance can run the number of children eligible to deaf and hard of hearing as it is categorical and may have multiple disabilities. DOE does not list secondary eligibility although it is slowly trying to add that. May be able to get better information and numbers from itinerant teachers.

- Jennifer: If anything could be added, it would be to address the transition from early intervention to DOE so that there could be communication and flow.
- Charlene agrees that transition to DOE is an important piece. But need to be cautious you need to keep in mind Part C and Part B responsibilities. That will be how the two will merge. Maybe it's a systems thing and DOH and DOE just needs to sit down and talk.
- Colin wondered if consent to share information was an obstacle. Minnesota has legislation so that DOH and DOE could share info, that helped with transition. Charlene said that EI already uses signed consent to share info with DOE. Patricia Dong stated that some parents choose not to have their child go to DOE after EI, some wait to see how the child is doing first, and some opt out.
- Jennifer stated that if there was a coordinator position, and a family chooses not to enroll a child in DOE after EI, that position can help get the child into DOE.
- Jennifer stated that the Newborn Hearing Screening is an EHDI program that already exists, maybe the coordinator can be there. Leolinda states that the group can say that we need the coordinator, but where it will be, whether DOH or DCAB or wherever, is a "HOW", and the State will need to figure that out.

5. Tools Used to Assess and Plan Language Development Services for Children Age 0-5 Years who are D/HH/DB

Group discussed that it is important to have information across the range of hearing loss and chunking it down to milestones. Milestones were passed out at the last meeting and California legislation included the milestones which is in the public domain. Other tools that could be used are the HELP chart which was developed in Hawaii and there is an offer to have the ladies who developed it share at the next Task Force meeting. Concern that the HELP was developed for children in general. Since the ASL is its own language it is not necessarily the same as comparing it to English and or hearing. Concern to not reinvent something as it is more to develop it to the point where it's specific to the deaf and hard-of-hearing. There also needs to be a section for deaf-blind. Do milestones address just language or is it addressing everything? Can it be incorporated to the HELP chart or is it something different where it needs to be its own subset. If you identify that this particular child has hearing loss, this would be your second assessment tool for that.

Concern that there is already demonstration of children going to school language deprived. There needs to be other things that are part of the assessment. There is no simple assessment chart. DOE is always trying to find standardized assessment tools and tries to share. Need to take a wider look: are they babbling, are they looking at the face of the speaker, use broad range of skills – are they doing pretend play, are they following social routines. Some families are struggling to learn ASL, it's a process and assessment needs to look at a variety of things and try to be descriptive so the IEP team can take the assessment to make it a goal or objective.

Clarification on term assessment. Assessment is a formalized standardized normed tool with many years of research. Checklists or milestones give you more flexibility with clinical judgment to give more a range of what is happening. For Early Intervention, it is standard to get an accurate baseline. Besides the MDE, there could be a recommendation on this is what

you should use as a standard to start with which will help with starting at a level field and to determine progress. Best practice shows that the MDE should be used to get an accurate baseline.

This tool may need to be online for parents and others to use.

Concern that there needs to be a standard protocol to approach what the next milestone to watch for or work on. If a checklist was used, would that be a way to know if a child has met the milestone and to know what to look for in the next milestone? Regarding the sequence of activities, if a baby recognizes and responds to voice but is not vocalizing, is there stuff you pull out to do with this child? The BDI is not quite enough.

Needs to be a way to know specifically those foundation skills that the child needs. If there is a foundation then there can be qualifications to expand. SKI-HI has a range of things you can expect to see and you can see it at different levels and can be used as targets. There is a nice list of tasks to reach at different levels. Recommendation that SKI-HI is great but there needs to be training on this.

Qualifications on who is qualified to assess must also be addressed. Oftentimes many signs are overlooked. On the flip side, there needs to be attention paid to cochlear implant, ASL, deaf-blind, and speech evaluator. Even if we have the tools, we need to have appropriate and trained people to do the assessment,

Group decided: The group needs to look 1) what are the tools available, 2) what are the qualifications, and 3) what does it cost to implement. Jennifer to send out tools. Tabitha has the SKI-HI. Matrix may not be helpful because we haven't seen all the tools. Need to look at more than just SKI-HI. Need a separate work group and may have more time to work on these and other tools.

6. Data and Availability of Data on Language and Literacy Development for Children age 0-5 years who are D/HH/DB

Need to add on information from deaf itinerant teachers. Data is limited. It may be individual child information in the chart but it is not aggregated into the system. Don't have strong data and will need to address recommendations on data at the next meeting. Need to look at tools to get data consistent.

Carole will ask the itinerant hearing impaired teachers in DOE for data.

More discussion on tools will be done at the next meeting.

7. Transition from DOH Early Intervention Services to DOE

Will need to address at the next meeting. Send thoughts or comments on transition ahead of time. Will compile list of concerns on transition: pain points for families, EI, SPED. Will cluster, consolidate, and then send back to the Work Group.

8. Future meetings in 2017 – 3-5 p.m.

Next meeting needs to assign responsibility to an entity (DOH, not EI to know if there are needs for funding or not. Next meetings: October 20, November 9, December 1.

9. Public Comment

Concern that there are Ideas for assessment in 0-3 where there is a state team for assessment but for general Special Education, teachers are required to do assessment GOLD. It may be fine for physical movement but it is not good for language development. Brigance is not good for language cause only for spoken language. Public is glad that there is a team to propose something for deaf and hard of hearing to do look at assessment and want to be assured that whoever is doing assessment is qualified to get the report the teacher can actually use.

Meetiing Adjourned.