### M I N U T E S

**Members Present:** Jason Maga (Chair), Bobbie-Jo Moniz-Tadeo (Vice-Chair), Ku’ulei Arceo, Michael Fahey, Lindsay Heller, Keri Kobayashi, Bernadette Lane, Doug Mersberg, Lauren Moriguchi, Sandra Pak, Toby Portner, Amy Tamashiro, Sharon Thomas, Kerrie Urosevich

**Members Absent:** Lori Goeas, Ashley Anne Diaz, Senator Josh Green, Adam Huillet, Sabrina Kehau Golis, Representative Bertrand Kobayashi, Lisa Lemon, Dayna Luka, Leah Muccio, Danette Wong Tomiyasu

**Ex-Officio:** Charlene Robles, Patricia Heu

**Guest:** Ann Sasuga, Sue Brown, Christine Jackson (EOEL), Christina Tydeman (DOE)

**Staff:** Aya Aoki, Michelle Matsuoka

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<thead>
<tr>
<th>TOPIC</th>
<th>DISCUSSION</th>
<th>DECISION/ FOLLOW-UP</th>
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<tr>
<td>1. Call to Order</td>
<td>Chair, Mr. Maga, called the meeting to order at 8:39 a.m.</td>
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<tr>
<td>a. <strong>Introductions</strong></td>
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<td>b. <strong>Review Agenda</strong></td>
<td>Agenda reviewed. No additions or comments.</td>
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<td>c. <strong>Review Minutes from May 30, 2018 Quarterly Meeting</strong></td>
<td>Minutes were reviewed and approved.</td>
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<td>2. Early Intervention Parent Sharing</td>
<td><strong>Miki’s story – Ku’ulei Arceo</strong></td>
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<tr>
<td>a. <strong>Miki’s story – Ku’ulei Arceo</strong></td>
<td>Arceo shared her daughter, Miki’s, Early Intervention (EI) story. She will be turning five this year. She and family received services from Hilo Easterseals.</td>
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● Arceo shared that psychological assessments/services from EI were limited (i.e. only available once a month, provider left job), they had to go outside to look for advice.
● Miki faced a difficult transition to DOE. Her preschool in Hilo was not very supportive of her learning (e.g. she received progress reports from teacher stating ‘N/A’, not included in water play, etc.).
● Their request for Geographic Exception (GE) for preschool was not accepted, despite Miki’s special needs. Family found a way to place her in an autism-center school in the area.
● Arceo shared the difficulty for parents to navigate through public and private systems financially to secure necessary services for Miki. For example, Miki qualifies for ABA services, though the process for obtaining services is complex and difficult. Also, the current system is based on the parents’ income level, while Arceo emphasized the importance of looking at financial support needs from the child’s life perspective – what happens when the child turns 18? How to continue necessary services?
● Due to regulations related to family rights and confidentiality, it is difficult for parents and families of special needs children to connect to each other and openly share information.

a. The Heller Family – Lindsay Heller

Heller shared her daughter, Bristol’s, EI story. She is five-years old now. She and her family received services from Hilo Easterseals.

● Heller shared that spina bifida is not recognized as a disability under the By-law of the Developmental Disability Council in Hawaii.
● When the family found out about their daughter’s spina bifida during pregnancy, doctors recommended parents choose either abortion or adoption. Family wished to keep their baby.
● Family found that fetal surgery would help reduce the severity of impaired motor and sensory function of legs. To qualify, the family relocated to Pennsylvania to begin evaluations.
● The family experienced gaps in Physical Therapy (PT). They went through four Physical Therapists, and at one point, there was no one available to provide Bristol...
with PT services. The family filed a complaint and EIS informed that there was no PT to service the area, but they were working on a solution. A short time later, a PT began flying over from Oahu. Now, there is no physical therapy on the Big Island that serves children with medical needs that are not school specific, so the family has flown to Maui twice for intensive physical therapy.

- Bristol received Occupational Therapy (OT) services from the same OT throughout her 0-3 Easterseals experience.
- Heller purchased a walker for Bristol, while doctors and her therapists thought a walker would be too early for a two-year old, but it turned out to be a success. Other families who have children with spina bifida on the Mainland start using this equipment much earlier on than is suggested by the doctors and therapists in Hawai`i. This experience told her that it is ok for parents to follow their instincts, as they know their child(ren) the best.
- The Heller family started EI services when Bristol was 2 months old. Doctors had told the family that she would never walk. By the time she turned 2 years old, she was walking up and down the stairs. Heller also shared that EI services gave parents knowledge of how to help Bristol develop various skills. Now at 5 years old, she can run around and does not need any support other than special shoe soles.
- The transition experience was difficult for the family. While Bristol does not have any intellectual delays, no preschool would accept her. To overcome this, family tried to obtain an IEP for her. Neither EI care coordinator nor DOE evaluators were helpful in her transition process to preschool. Many preschools are afraid of liability issues and hesitant of accepting special needs children. The family was told they were not eligible for the Headstart program due to their income level.

Based on the presentations, Fahey suggested to include ‘transition’ in future HEICC discussion agendas, and to inform the transition difficulties with the SEAC (Special Education Advisory Committee).

| 3. Early Intervention Section Update | **Early Intervention Section Update** – Charlene Robles  
[Refer to Early Intervention Section Update handout]  
|  
| a. Part C Update | Part C grant increased to $2,301,533.33.  
| b. Budget | FY19 supplemental budget of $2,716,006 is approved and this would be added to the EI base budget (State General Funds) beyond FY19.  
|  
| To revisit transition as a discussion item at a future HEICC meeting. |
c. **Positions** - Robles shared that vacancies exist across the state and are seriously affecting the provision of EI services. EIS is looking into contracting providers from the mainland and how to use tele-practice as an alternative method to delivery services.

d. **State Systemic Improvement Plan (SSIP)** - Professional development: developing a training and mentoring plan to support the Primary Service Provider (PSP) & Coaching model.

Fiscal/Staffing: developing strategies to address financial and system issues affecting recruitment and retention of staff.

Data for program improvement – working with families to obtain and use data.

e. **Initiatives and Activities** - EIS awarded contract for the development of a new web-based data system.

f. **Program Measures Dashboard with Complaint Summary**  
[Refer to HEICC Program Measures at A Glance Dashboard handout]

- Urosevich asked why the Child Welfare Services (CWS) referral number is very low. Robles explained that it is possible referrals are counted as pediatrician if the child is referred to their pediatrician after a developmental screen vs directly to EI.
- The council discussed the importance of looking into the Dashboard Measure #4 Referral Agents together with the Child Find data, to better understand where EI children are coming from and identify where the gaps may exist.
- The council also discussed Measure #8 Status of new referrals to EI programs prior to IFSP. Reasons for ‘unable to contact families’ are unknown. A question was asked if ‘decline referral (family not interested)’ is among those who are eligible.
- Discussion about dashboard data lead to discussion about the new data system.
  - Robles explained that there are three committees to spearhead and oversee the web-based data system development.
  - Heller suggested having data by geographic locations (neighbor islands, different areas in Oahu) would be useful to analyze EI needs and issues and develop strategies to respond.

Robles/Aoki to check:
- if Measure #8 ‘decline referral’ is after eligibility determination;
- for Measures #5b and 6b, what are the main reasons included in ‘other’ category for program reasons for late MDE & IFSPs.

By the next meeting, council members to prioritize what data would be useful for the HEICC to best support EI program moving forward, by reviewing the Dashboard data, HEICC priorities.
Robles explained the difficulty of meeting the OSEP timelines of 45 days (from referral to timely IFSP development) and 30 days (from the initial IFSP to complete all first services listed on IFSP) with all the vacancies.

Moniz-Tadeo shared the difficulty of retaining EI staff, even if programs were able to recruit them from the mainland.

Urosevich suggested looking into the possibility of approaching students from Hawaii in EI related disciplines (particularly PT and OT, as these are not taught in Hawaii) who are attending colleges on the mainland, offer tuition support followed by job opportunities in EI. Brown shared that EI used to offer a stipend program for PT students, approved by legislature, and suggested to revisit such possibilities. Pak shared that DOH Children’s Mental Health has a partnership with UH to accommodate fellows on DOH sites, which is helping students gain motivation to stay in the HI health system that they became familiar with during fellowship. Arceo suggested to share EI info with high school health pathway students and try early recruitment.

Measure #10 Children Exiting from EI Services: Pak suggested to rephrase some categories in more positive terms, e.g. ‘successfully exited Part C.’

The council discussed the importance of obtaining both positive and negative feedback from families on EI services to improve the program and communicate that negative feedback would not mean ‘failure’ but can help improve the services. Exit surveys may help so families would not feel that their services would be affected by sharing negative feedback.

### 4. Council Business

#### a. Legislative Update

Urosevich shared that the Action Strategy conveners put a place holder for EI as one of the policy priorities for the next year. She will be able to share more about priorities at the next meeting.

#### b. Early Learning Board

*Refer to Early Learning Board Mission & Vision handout*

Fahey shared the ELB Mission and Vision statements as well as the roles and responsibilities of its three committees: 1. EL System Mapping and Relationship Building; 2. Expand Beyond Public Pre-K; and 3. Policies and Processes. He invited anyone interested to join the committees.
The council discussed some of the challenges of coordinating services between different departments for children (e.g. DOH and DOE) and the importance of ensuring smooth transition for the children and families.

c. **HEICC Priorities**
   [Refer to HEICC Priorities handout]

**Sustainable Funding and Staffing for EI Services**
Maga shared that the Executive Committee and EIS have revised the HEICC priorities document to better reflect the council’s current priorities as well as action items/updates. He explained that the council’s number one priority remains as securing sustainable funding for EI, as EI staff’s salary level continues to be at a very low level compared to other states even with a $2.7 million increase. Robles explained that the intent for $2.7 million supplement is to increase the reimbursement rates for EI Purchase of Service (POS) program providers, though the detailed allocation is still being worked out.

Brown asked a question regarding the status of Medicaid reimbursement for EI. Robles explained that about 40% of the EI children are covered under Medicaid. Medicaid and EIS have a close working relationship and are trying to make necessary adjustments such as inclusion of tele-practice in the MOU. EIS is also researching how Medicaid reimburse EI services in other states. Robles shared that there is a 40% federal match that the state has to pay back for Medicaid claims, so EIS would only receive about half for reimbursement claims.

Arceo shared her experience with unclear coverages by private insurance vs. public services, particularly related to ABA services. She also shared the difficulty in obtaining ABA services for many families that request such services, both in terms of financing and availability of services (no weekend provision, not being able to receive services at school due to provider credential requirements, etc.).

Moriguchi shared information about the Leadership in Disabilities and Achievement of Hawaii that they could be a resource for parents on insurance coverage, apart from insurance companies and organizations.

Maga asked a question regarding FY20 budget request plans and if we could further analyze the salary study to help Hawaii’s EI salaries and rates move up beyond the 10th lowest out of 11 comparable states. Robles explained that EIS is trying to move some of
the federally supported direct services staff salaries to the state general funds, so that Part C funds could be used for professional development and other needs. He recommended to further utilize the salary study for continued efforts to obtain additional funding for EI.

Unmet Needs
Robles shared “Sharing Our `Ulu” resource list for children age 0-5 years and their families. The resource list has DHS, DOH, DOE, & EOEL programs that support children’s health and development. The website link: [http://health.hawaii.gov/cshcn/ulu/](http://health.hawaii.gov/cshcn/ulu/)

Urosevich asked a question that when a child is not eligible for EI services, who is responsible for following up? Robles explained that DOH shares Hi’ilei developmental screening services and other referral information with families.

d. **HEICC Orientation Plan**

Moniz-Tadeo shared about the HEICC Orientation, scheduled on October 22, from 8:30-11:30am in the same location, and requested members to send any request for coverage to Aoki.

e. **HEICC/Exec Committee Appointment and Vacancies**

Maga shared that Urosevich has joined the Executive Committee. Aoki shared that there are four new members who joined the council and three others have renewed the membership. The council has one parent vacancy, and the members are requested to send recommendations to Aoki.

5. *Public Comment*
No public comment.

6. *Announcements*
Council members, please receive parking passes for the next meeting from Aoki if needed.

7. *Future Meeting*
The next Quarterly Meeting will be on November 28, 2018.

8. *Adjourn*
Maga adjourned the meeting at 11:20 am.