

## **Interagency Coordinating Council (ICC) on Early Intervention**

**Thursday, August 1, 2024**

**Zoom Conference Call**

**Time: 9:00 a.m. – 1:00 p.m.**

**Link to Zoom Recording:** [Thursday, August 1 Zoom Recording](#)

### **Opening**

Dr. Marie Kanne Poulsen, ICC Chair, called the meeting to order at 9:03 a.m. Dr. Poulsen expressed gratitude for all council members, WestEd, the Department of Developmental Services (DDS), and community members for their attendance.

Dr. Poulsen announced that Nancy Bargmann, Director of DDS, is retiring in September. Dr. Poulsen expressed gratitude for Director Bargmann's years of service to California's infants and toddlers with disabilities and their families.

### **Housekeeping Items**

DJ Tomko reviewed housekeeping procedures for Zoom and in-person participants. Zoom instructions, ASL/Spanish interpreter instructions, and meeting etiquette were reviewed.

### **Roll Call**

The roll call of appointed members was conducted by DJ Tomko.

### **Review Agenda**

Before beginning, Dr. Poulsen thanked the ICC Community Representatives who met to identify Early Start issues for the DDS master plan. Dr. Poulsen reviewed the agenda. No changes were made to the agenda.

### **Approval of the Minutes**

Motion to approve by Maricris Acon. Seconded by Susan Ducore.

### **Review of ICC Mission, Purpose, and Theme of Meeting**

Dr. Poulsen reviewed the mission and vision of the ICC. The theme of this month's meeting is Early Access.

### **Part C Literacy**

[2024 California Children's Report Card](#) by Children Now

The California Children's Report Card rates the state on its ability to support better outcomes for children and families based on passing and implementing state-level policies. There are over 13 million Californians from the ages of prenatal to 26. Of these 13 million, 16% are children and youth with special healthcare needs and 45% are from immigrant families. Early Intervention received a D because of the low percentage of enrollment in services compared to the overall population of eligible children. California has made an investment to help with early identification of eligible babies and toddlers,



but it does not make up for the years of underfunding. This report offers a lot of food for thought and calls to action.

### **Family Testimonial – Janneth Suarez, Parent from ELAFRC [Presented in Spanish]**

Parent of Samuel, who has autism and was in the NICU for 20 days because he could not eat on his own. At two years of age, Janneth noticed “something wasn’t right.”

Janneth had Samuel’s pediatrician do an evaluation and was sent to a regional center to get early intervention services. The importance of connecting to an FRC was a big deal to Janneth to get vital information about diagnoses and available services. Support groups like Mind the Gap were incredibly important. In the support group, Janneth learned why early intervention is so critical, which services are available and how to access them, and access to assistive communication devices. In Samuel’s case, after beginning Early Start, he was able to communicate much better, learned his ABCs in sign language, and could interact with other children. Samuel is interested in swimming, music, and communicating with his tablet – all thanks to Early Start.

- Nancy Bargmann thanked Janneth for her presentation. She asked, “What is the advice or guidance you would give providers to help families?”
  - Janneth answered [In Spanish], “First, think of your own child’s needs, and second, don’t be afraid to seek help.”

### **DDS Updates and Information – Nancy Bargmann and Carla Castaneda**

Carla Castaneda provided a budget update. DDS has a budget of \$15.9 billion which is an increase from the last budget year but still less than requested.

Nancy Bargmann provided updates on the DDS master plan. The membership for five workgroups will be announced this week. There were over 900 applicants. The first workgroup meeting is August 5<sup>th</sup>.

Director Bargmann reminded the ICC that the provisional eligibility budget is based on the fact that primarily Black and Latino children are entering Early Start older than two years, and the purpose of provisional eligibility is to retain the supports that families and children need through transition from Early Start. Nancy encouraged the ICC to continue to look at data to determine any needed recommendations. The service access and equity grants have been incredibly important to fund equity initiatives:

- Nearly all Regional Centers have achieved the lower caseload ratios required.
- Six regional centers have agreed to pilot a Chief Equity Officer position.
- Funding initiatives are working on developing NICU liaisons.

**\*\*BREAK\*\***

**Presentation: Honoring Your Learner: An Assent-Based Approach to Learning and Teaching– Liz Lefebvre, Octave Training**



Ms. Lefebvre is a behavior analyst specializing in autism. The foundational philosophy of Assent-Based Learning (ABL) is “the learner is always right”; that is, behavior is a function of the environment that supports that behavior and that learners are doing their best with what they have.

Ms. Lefebvre defined key terms: consent, assent, and assent withdrawal. Assent is further defined as a verbal or non-verbal demonstration of agreement to participate that is provided by those who are not of legal age or capacity to provide informed consent.

Ms. Lefebvre provided historical context of compliance, consent, and assent in education. Cultural norms and practices vary in how compliance is viewed, and therapies for children and those with disabilities have a history of being compliance-based to the point of being harmful. The pressure on teachers and service providers, like funding and productivity metrics, creates an environment for compliance rather than assent.

Ms. Lefebvre explained ABL as based on learner values, building self-advocacy skills, honors assent withdrawal, and requiring clear boundaries and instruction. The presenter explained in detail each component of an ABL approach.

#### Questions:

- Yvette Baptiste asked, is there a need for some kind of legislation change around the practice? What does the presenter see as the perspective of practice in the field to lean more towards things like consent and assent?
  - Ms. Lefebvre responded that the field has partially been responsive to this approach. As far as legislation goes, each state credentials applied behavior analysts, so it would need to happen at the state-level.
- An anonymous participant asked, do you see applied behavior analysis (ABA) practitioners adopting this approach?
  - Ms. Lefebvre responded that consumers of ABA services can look for things like compassionate-based approaches.
- Julie Eby-McKenzie asked whether there any move to disconnect from the terminology of ABA.
  - Ms. Lefebvre answered that many practitioners are working on educating themselves on the harms of ABA and learning more about ABL-aligned practices. She acknowledged that terms in the field need to be changed.
- Marty Omoto acknowledged his own initial resistance to this approach and appreciated this presentation. Marty sees this as a potential pathway towards equity. Marty asked whether the presenter noticed any gains in equity from this approach, and how this approach can become standard.
  - Ms. Lefebvre replied that the rapid shift in ABA is the result of autistic adults speaking out on their experiences, which has forced the field to make changes quickly, but there is not enough training to meet the need.



- Teresa Anderson commented on the importance of advocacy on increasing the uptake on adopting this approach. Teresa asked how this approach could be used in early childhood education.
  - Ms. Lefebre answered that it can be done in a systematic way in group settings, but every adult in the room needs training to support it.
  - Teresa asked if anyone is doing research studies on outcomes with ABL approaches. Ms. Lefebre responded that research in this field is new and literature is just starting to come out.

## **Voices from the Field**

- ***Infant Development Association of California (IDA) – Fran Chasen***  
Ms. Chasen reflected on the Early Start budget, mentioning the change to the implementation of the funding rate model. Ms. Chasen summarized some IDA accomplishments from the last year:
  - In coordination with Family Resource Centers Network of California (FRCNCA), IDA compiled an accurate list of current functional local interagency coordination areas (LICAs), which was submitted to FRCNCA and will be included with their report to DDS.
  - At the federal level, California Representative Jared Huffman continues efforts to get full funding for the Individuals with Disabilities Education Act (IDEA) in the IDEA Full Funding Act bill, with particular emphasis on recruitment of quality direct service providers. IDA will be working with Teresa Anderson (Executive Director of the Center for Intellectual and Developmental Disabilities) to implement focus groups around recruitment and retention efforts.
- ***California Disability Community Action Network – Marty Omoto***  
Mr. Omoto shared an update that the state legislature is in recess until Monday and will adjourn August 31<sup>st</sup>. Then, all passed bills go to the Governor. Any bill that is going to cost a lot of money and is not sponsored by the administration will have difficulty getting a signature from the Governor.

Mr. Omoto shared the details of the next informational hearing for the Early Childhood Policy Council under the California Health and Human Services Agency. Mr. Omoto also shared details about informational hearings on barriers and solutions to nonprofit participation in state government, facilitated by the California Senate and Assembly Select Committees on Nonprofit Sectors.

- ***Family Resource Centers Network of California (FRCNCA) – Ana Seda***  
Ms. Seda shared key accomplishments from the last year:
  - With support from the Lucille Packard Foundation, the Access to Care Project offered two webinars to share the results from a survey conducted with over 600 families about experiences with children's specialty care.



- In the last quarter, FRCNCA hosted support group facilitator trainings for 29 participants to enhance skills for creating safe environments for families in support groups.
- FRCNCA executed two standards of quality for family strengthening and support sessions. Thirty-four FRC staff attended and received certification. Ms. Seda shared a video produced with Options for All to promote Community Navigator programs.

## **\*\*LUNCH BREAK\*\***

### **Presentation: Fetal Alcohol Spectrum Disorder – Dr. Lucy Esralew, DDS**

Dr. Esralew began by defining and explaining Fetal Alcohol Spectrum Disorders (FASDs) as a spectrum of effects on the development of individuals prenatally exposed to alcohol resulting in brain damage and other lifelong mental and health conditions. Individuals with FASD are heterogeneous and do have many strengths, though this presentation focuses more on their challenges. Dr. Esralew then explained how individuals with FASD are often misdiagnosed due to stigma, lack of awareness among healthcare professionals, and overlap between neurobehavioral symptoms of FASD and other neurodevelopmental disorders. She then listed the types of diagnoses under the FASD umbrella to demonstrate the range of conditions that are in the spectrum.

Dr. Esralew described in detail Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD). Each of these can impact thinking and memory, behavior, and day-to-day living skills.

Dr. Esralew shared strategies for working with children with FASD: establishing structure and routine, using hands-on learning methods, remaining calm, keeping instructions short and simple, providing consistent and specific directions, and offering frequent check-ins.

Dr. Esralew described the effects of prenatal alcohol exposure in infants, toddlers, preschoolers, school-aged children, and adolescents. She provided case studies of an infant named John, who received Early Start supports for FASD, and a toddler named Miranda, who was not diagnosed with FASD but was otherwise eligible for Early Start services.

Questions from attendees:

- Yvette Baptiste asked whether a child could have the co-occurring condition of ADHD without the hyperactivity. Dr. Esralew confirmed this possibility. Ms. Baptiste continued with a situation with a former client who did not qualify for Early Start or Lanterman Act services despite having prenatal exposure to alcohol and related issues. She asked about the changes in the regional center clinical departments to identify these kinds of children, particularly those who have been in the foster/adoption system.
  - Dr. Esralew replied that often it is executive functioning that is impacted by FASD, which does not present until later in a child's life and is difficult to assess in infants and toddlers. Reducing the developmental delay criteria and



establishing provisional eligibility has been helpful in identifying these individuals.

- Yvette Baptiste added that FASD education is needed in the foster/adoption community. Dr. Esralew agreed and noted that child welfare departments have taken the lead on this.
- Gilda Giron thanked Yvette for her example and shared a similar struggle with individuals with spina bifida.
  - Dr. Esralew reminded the ICC that a diagnosis is not required for Early Start, including provisional eligibility, only the 25% delay in one or more developmental domains.
- Lisa Schoyer asked if there any strategies regarding ABA.
  - Dr. Esralew stated that ABA is very much based on individual assessment. She recommended getting a good functional behavior assessment by someone trained in FASD.
- Mica Harris asked whether there any key things service coordinators should look for if prenatal exposure was not disclosed by parent during intake.
  - Dr. Esralew noted that stigma is a real issue. It is a matter of having a sensitive conversation with parents to get consent for further evaluation.
- Teresa Anderson asked for some suggestions of how to get diagnoses, especially for adults.
  - Dr. Esralew answered that she is not sure. There are specific clinics in the state who can provide evaluation, assessment, and diagnoses. She will follow-up with Teresa and shared her email address to all ICC attendees if people want to get more information.

### **Review of Public Input Guidelines, Followed by Public Input**

Lisa Cooley asked about what is being done to help people with FASD as they age, specifically beyond the age of 40 or 50. DJ Tomko answered that Dr. Esralew will follow up.

Lisa Schoyer shared a case where a parent is trying to get ABA for her child under age 3 which HealthNet Managed Care insurance requires a diagnosis to cover. Insurance has a long wait, and the family doesn't have access to gap funding. She asked for any ideas to help this family. Suzanne Sherinian provided her contact information so she can assist with this issue.

Yvette Baptiste asked if Suzanne Sherinian can give a presentation again soon, as many insurers are not providing coverage for ABA. Suzanne agreed to do so and encouraged everyone to reach out to her directly for assistance.

### **Announcement of Committee Composition and Goals**

DJ Tomko provided a summary of committee composition and goals. He reminded everyone that only ICC members and community representatives are members of committees.

### **Subcommittee Meetings**

Meeting of the whole was adjourned at 2:25 p.m.; committees met separately.



**MEMBERS PRESENT**

**MEMBERS EXCUSED**

**MEMBERS ABSENT**

**COMMUNITY MEMBERS PRESENT**

**COMMUNITY MEMBERS ABSENT**

**DDS**

**WESTED**

**OTHERS PRESENT**

\*Parent