

Interagency Coordinating Council (ICC) on Early Intervention
Thursday, January 19, 2023
Zoom Meeting
Time: 9:00 a.m. – 3:30 p.m.

Link to Zoom Recording [January ICC Meeting - Day 1 - Zoom](#)

Opening

Dr. Marie Kanne Poulsen, ICC Chair, called the meeting to order at 9:02 a.m.

Housekeeping Items

Zoom instructions, ASL/Spanish interpreter instructions and etiquette were reviewed.

Roll Call

The roll call was conducted.

Review Agenda & October Meeting Minutes

No corrections made to the October meeting minutes it was approved.

Part C Literacy Article

Recommendations for Peer-to-Peer Support for NICU Parents by SL Hall, DJ Ryan, J Beatty, L Grubbs

This article focuses on the growing number of evidence that peer psychosocial support can provide great benefits to parents of neonatal intensive care units (NICUs) and mothers of children with special needs. In California, there are 165 NICUs with over 3,700 beds. There is a growing body of evidence, that besides addressing the complexity of professional medical health care, there are significant benefits that peer psychosocial support can provide to these parents. In 2012, the American Academy of Pediatrics recommended that peer support, as a core principle of family-centered care, should be an integral component of every NICU family support program. Parents who receive peer support have increased confidence and well-being, problem-solving capacity, reduced anxiety, and adaptive coping. Peer support offers a unique form of assistance that is not typically met by the formal service system. In an ideal model, veteran parents are closely matched on as many dimensions as possible (including, language, culture, education & income level, baby's diagnosis, family lifestyle, etc.). Size and budget of a NICU often determines what level of formal support can be provided to families and determines if there is time and space for training and meeting and if there are staff resources available to do outreach to ensure the recruitment of veteran parents or through making referrals to community organizations. There are also barriers families may experience in accessing supports offered. Within the NICUs, some parents do not want to spend time away from their babies' bedsides to meet for

individual peer support or families may experience a lack of NICU attendance due to transportation or childcare needs. However, peer support can also be offered by telephone, community groups or the internet. This article offers comprehensive guidelines for developing access for peer support within the NICUs.

Programs using veteran parents for peer support should provide a comprehensive training program. This document has set procedures and standards for training of peer mentors including:

- Defining the role
- Expectations of a parent mentor
- Development of an essential skill set
- Parameters for matching parents

In California, family resource centers (FRCs) are significant sources of support to the NICUs. We just need to ensure a match between the FRCs and the NICUs across our state.

DDS Updates and Information – Nancy Bargmann and Maricris Acon

Ms. Acon introduced Nancy Bargmann, Director of the Department of Developmental Services (DDS). As a developmental services system, DDS has put forward many proposals/efforts and has seen more proposals within the disparity grants and federal dollars from the American Rescue Plan Act (ARPA). There have been many initiatives in response to lower intake and connections to the community at the onset of the pandemic. In 2020, there was a significant decrease in Early Start referrals and participation. Due to community response, regional centers, service providers, and everyone's outreach, there was a relatively quick response to that. In 2021, there was an increase of intake and Early Start participation, and in 2022, there was also an increase in Lanterman Act services. The current year's projected increase to include intake assessments of 20,000 individuals.

While it's not within Early Start, the provisional eligibility initiative introduced last year was extremely important. This year's budget proposal shows, for current year, that they are asking for an adjustment that would be a higher number of children than would be participating. This was the first time a new category for Lanterman Act services for 3- and 4-year-old kiddos who did not meet Lanterman Act criteria, but there are concerns for some delays. In the past, the regional center would have them come back after exiting Early Start due to not meeting Lanterman Act eligibility.

DDS is looking into separating and identifying communication as two distinct areas to monitor for eligibility: expressive language and receptive language. DDS is looking into this data. The governor's budget is to build on those important initiatives within developmental services and other state departments. Statewide, the revenues coming in are less than anticipated. The State is looking at priorities of what can be funded. They are looking at delays within the Department of Health & Human Services (DHHS) and statewide. DDS has done extremely well with proposed budget, but only 1 item was

delayed for DDS i.e. proposal to help support preschool children, 3 and 4 years old. The other high priority item is service access and equity. As DDS looks at services access and equity are making sure that all individuals (race, language, etc.,) can access them. We need to challenge ourselves and look at those populations which may not access services.

Ms. Bargmann presented DDS's 2023-24 Governor's Budget. The DDS budget for current year 2022-23 was \$12.4 billion (regional centers (RCs) caseload 400,485) and 2023-24 is projected at \$14.2 billion (RCs caseload 420,927). The caseload includes Early Start caseload. DDS had approval for The Home & Community-Based Services Spending (HCBS) Plan funds available through March 2024 (\$1.8 billion).

Ms. Bargmann discussed American Rescue Plan Act (ARPA) updates for Early Start - Part C, \$26.9 million through January 2024. There are funds to pilot Family Wellness, Develop Culturally & Linguistically Sensitive Services, Outreach, Technology, Technical Assistance and Monitoring, and initiatives in collaboration with the California Department of Education (CDE). A few RCs were chosen to carry the initiatives.

Ms. Bargmann reviewed the Lanterman Act Provisional Eligibility, \$41.4 M GF (\$15.8M increase). Regional center operations (OPS) \$9.3 million and regional center purchase of services (POS) \$32.0M. Delayed implementation of the Early Start Preschool Inclusion Grants (-\$10 million General Fund); latter is expected to be in budget 2024-25. Ms. Bargmann briefly spoke of the regional center 2022-2023 significant one-time policy reminders of the Workforce Development, Resources for Individuals Who are Deaf, and Work Activity Program. She also provided an overview of updated the regional center OPS and POS 2023-24.

Ms. Bargmann indicated DDS is supporting Trauma-Informed Services for Foster Youth. It's important for the ICC to help track how we are helping and supporting foster youth (birth to 3 years old). Timing of accessing Early Start services and supports is slower for foster youth. DDS wants to help regional centers get additional staff to work in collaboration with counties to get attention to foster youth. This may be worth a separate conversation and for ICC to consider.

Lastly, Ms. Bargmann discussed the Safety Net Plan Update which includes establishing an Autism Services Branch at DDS, \$1 million total fund, \$0.8 million general fund. Autism is the largest growing population. Ms. Bargmann also reviewed the 2023-24 remaining state operated facilities & DDS Budget Concept Proposals (BCPs). This is part of the governor's proposed budget. Discussed future fiscal issues for coming year.

DDS Updates and Information – Nathaniel 'Nate' Taleon

Mr. Taleon reviewed the Early Start fiscal year 2021 preliminary data for the Annual Performance Report (APR). Any State that receives funds under Individuals with Disabilities Education Act (IDEA) must have an APR that evaluates the efforts to

implement the requirements and purposes of IDEA - Part C (Early Start program). Information will be submitted to Office of Special Education Programs (OSEP) on February 1st.

Mr. Taleon presented compliance scores for fiscal years 2020 and 2021. In 2021, COVID-19 exasperated exiting barriers and adding stress to systems lacking resources and coordination. The COVID-19 pandemic affected many services and timeframes, which impacted compliance indicators in timely provision of services and Individualized Family Services Plan (IFSP) in 45 days. Regarding transition indicators, timely IFSP conference had a slight increase. DDS has taken steps to mitigate and address the issues related to meeting the compliance measures.

Mr. Taleon presented the Early Start Family Outcomes (indicator 4). Parents surveyed and care providers to see how they know their rights, how family communicates their child's needs, and a family helping the child learn and develop. Data compiled from surveys distributed in October 2022 for families which had received services in fiscal year 2021. It was distributed to 8,000 families which reflected California's census population. They saw increases in 11.7 percent response rate increase from African-American and Hispanic families. DDS implemented and enhanced an online completion option for family survey to ease access. An outside contractor was used. Each letter had a Quick Response (QR) code. Participants were also able to complete the survey on the DDS website and on paper. Additionally, the survey had eight optional languages. A PDF version of the survey was included.

The full Annual Performance Report will be posted on the DDS website (late spring/early summer) <https://www.dds.ca.gov/service/early/start/state-performance-reports/>

The data will be broken down by regional center.

Public Input

Linda Landry stated that a parent-to-parent support match needs to be a parent trained in providing support; they do not diagnose or prescribe but listens. The family resource centers are the best to do parent-to-parent training. When a parent has a child with disability or preterm baby, the focus should be for all family members (mother, father, aunt, grandparents, etc.).

Pablo Velez stated lower income families discontinued therapies due not being able to access telehealth during COVID pandemic. Many families of color in the state had limited social support and financial support. He asked how to capture that data in these statistics; this may skew progress. Mr. Taleon stated that they are in the process of investigating this further, especially children/families who exited the system before the 3-month mark. DDS is looking at the current data now and will then investigate capturing that other data. Douglas Erber agreed with Mr. Velez and stated this is one of their concerns as well. Ms. Bargmann stated the initiatives set forth during the pandemic

was to help with the technological divide. She encouraged them to provide examples of what has worked; they want to look at what they can explore, have a best practice, and learn from some of that response.

Michelle added that the providers also need support. Dr. Poulsen stated that being licensed in California does not mean they have experience with working with young children. For example, insurance covered providers may not have pediatric expertise. Parents do not know to return to the regional centers. Dr. Poulsen suggested a policy whereby if the provider hired by the insurance does not have expertise, for the regional center to pay for it.

Voices from the Field

- ***Infant Development Association of California (IDA) - Frances Chasen***
Ms. Chasen shared some concerns about the use of insurance. The first concern is the use of insurance causes family to wait to approval to begin service. Even if the regional center might cover a deductible or co-payment, it's not often as seamless and timely process. The second concern is additional costs for managing to access private insurance for families in the Early Intervention program. The service by insurance utilizes the medical model of care vs developmental approach, and the services are child directed vs family centered. The question they want to raise is how utilizing a medical model approach will assist regional centers with meeting Early Start family outcomes. Often time the use of insurance is not provided by hospital or clinical settings. They are not sure it's always the best for families. Depending on the facility, parents may not be involved in the session. The purpose of Early Start is to train and educate parents to be able to care for their children more effectively. Another question they want to raise is how will social, emotional, and cognitive development be facilitated using a rehab approach to care. In terms of update, the California Little Hoover Commission has looked at DDS and implementation of the Lanterman Act in October. She will provide links to access this report. IDA is hosting its 8th annual IDA policy updates on Monday 1/23/23. Next step update for Feb 9th 12:00 p.m. – 1:00 p.m. for the event. It's their kickoff of IDA's 50th anniversary. Check www.idaofcal.org
- ***The Arc - Teresa Anderson (not present)***
- ***California Disability Community Action Network - Marty Omoto (not present)***
- ***FRCNCA - Robert Rochin, Director***
The Family Resource Center Network of California (FRCNCA) represents the 47 DDS funded family resource centers. Their steering committees from nine regions meet monthly. The Early Start family resource center attended two webinars in the last quarter. The webinar was presented by Teresa Anderson

with The Arc. The second webinar was on Early Screening/Better Outcomes by First-Five LA in partnership with LA Children's Hospital. A brief update about Service Access and Equity (SAE) funding opportunity they got for FRC SAE. Their project was focused on transitions for Black and Hispanic students with DDS and it addressed systemic barriers to Lanterman Act needed supports to produce family-friendly, transitions where families and professionals work together to ensure positive outcomes. As evidenced by pre/post surveys, the event increased cultural awareness, family-centered supports, and understanding of available services by these professionals. A pamphlet was created for participants (not final version). Encouraged any input.

Mr. Rochin reported that their Community Navigator Program (CNP) is up and running. They have been working on providing guidance to the 21 Lead FRCs and each of the 21 RCs. Each of the 21 Lead FRCs submitted a catchment area plan that identified language and population priorities and activities that will assist in building trust and effective working relationships with individuals and families served by the regional centers. They conducted 2 webinars for the CNP this past quarter. One was a Special Ed overview presented by Amber Fitzgerald from UCD MIND Institute and Bonita Shaw (parent). The second webinar provided an overview of the developmental system with focus on the Lanterman Act. The presenters were Leinani Walter, the Chief Equity Officer of Services, Access and Equity Division from DDS, Ernie Cruz from DDS, and Amy Westin from Association of Regional Center Agencies (ARCA).

Presentation – ARPA Initiative on Diversifying the ICC – Robert Rochin and Yvette Baptiste, FRCNCA

Ms. Baptiste gave a brief update about the ARPA initiative; it was funding provided to improve community capacity and diversify faces/places of representation on the ICC. Ms. Baptiste skipped some slides but will provide access to the power point. The Family Resource Center will be working on the Family Resource Center Network. There will be 3 Lead agencies working to help with this project. They have the capacity to help, they are a statewide entity, and heavily engaged in ICC. They are either conveners or attendees at the Local Interagency Coordinating Council Agencies (aka LICCAAs) where they still exist. They want to engage participants locally or to the State ICC. For example, the Eastern LA FRC (project lead), Care Parent Network Northern Regional (lead), and Parents Helping of San Luis Obispo Southern Region (lead) will focus on two strategies to connect with early intervention. The activities will be in strategy one to have that local engagement. They want to identify target populations needed at ICC and have opportunities to create those connections/partnerships, develop resources and do those activities. At the end, they want to develop recommendations for DDS and ICC for future work. They will ask up to 14 FRCs for help. Ms. Baptiste thanked DDS and WestEd, as they have used the training tools given to them many years ago. The second strategy is to develop and deploy leadership training for community family members and even consumer parents to participate in local ICCs. They will develop an

easy training to use on their own time. They want participants to know what ICC does for the state.

Ms. Baptiste showed the “Module 3: Ensuring Relevant Participation” video. See presentation [link](#). Ms. Baptiste and referenced the circle of core group (slide). Ms. Baptiste stated their core team is Dr. Poulsen, DDS, CDE, and folks who plan and convene the group. For the second group, the key participants in the circle are appointed members and community representatives. The extended participants are connected in our communities such as those who are closer to the work, who work in the practice, and who benefit from Part C services. They tell us about the issues, and we take their information. It goes both ways. There are folks in the community who are good at this. Ms. Baptiste is encouraging everyone to question “who is missing from your key participants and advisors?” In the future, this could be a discussion. In the meantime, she recommended elevating that need and bringing it back to the core team. Second question, “who would you like to have as extended participants/feedback network?” Ms. Baptiste encouraged everyone to think about how to represent areas locally and provide input.

Public Input

Lilia asked how to connect with a Community Navigator. Mr. Rochin stated that they hope to get that information on the website real soon; this is a new program. Mr. Rochin asked Lilia to message him with the regional center catchment area and he will find the FRC lead.

****BREAK****

Presentation – Children’s Benefits – Dr. Pamela Riley, M.D., MPH, DHCS

Dr. Riley has been with Department of Health Care Services (DHCS) as Chief Health Equity Office and Assistant Deputy Director for Quality and Population Health Management. She also served as a Child Health Champion. She is very concerned about child wellbeing and is interested in advancing health outcomes and advance equity access for kids of families they serve. She intends to share about the work the DHCS does to provide Medi-Cal services for members/kids.

Dr. Riley presented the Medi-Cal Children’s Initiatives: Increasing Awareness of Early Periodic Screening & Diagnostic Treatment (EPSDT) services. EPSDT is their main tool to make sure children are getting screening and preventative services, and treatment services they need and are entitled too. They are about to launch an EPSDT toolkit at the end of the month. She wants to engage ICC as how to best disseminate toolkit and engage everyone.

The EPSDT is a Medi-Cal program aimed so that children and their families can lead long healthy lives and have health care that they need. They are undertaking a lot of initiatives largely through Cal AIM waiver. They are focusing on preventative care with

managed care partners to focus on kids and to hold managed health care plans accountable. The DHCS is going to work closely with managed care programs and ICC attendees to ensure that it reaches populations intended to reach. They are aware preventive care utilization outcomes is not where they want it to be; there was a 2019 audit showed that 2.4 million children enrolled in Medi-Cal did not receive required preventative services - roughly half of all children under age 21 in Medi-Cal. The pandemic took a toll, but it was also a challenge pre-pandemic. They have not seen full recovery of services post-pandemic. Per Dr. Riley, this is the foundation for setting-up children to live long healthy lives.

In March of last year, Medi-Cal released 'Medi-Cal's Strategy to Support Health and Opportunity for Children and Families.' This was to help do a better job to coordinate coverage, coordinate comprehensive services and strengthen accountability for those services. Part of that strategy is to increase awareness and use EPSDT benefit through EPSDT outreach and education toolkit. EPSDT is a federal program which guarantees services for children and youth under age 21 enrolled in Medi-Cal. Dr. Riley stated they want to communicate that it requires comprehensive age-appropriate health services be provided to all Medi-Cal enrolled children and youth under age 21. The EPSDT is more comprehensive than what is for adults. The goal is to ensure children receive "the right care, at the right time and at the right place." The intent of the EPSDT presentation is to increase awareness of EPSDT among children and families, health plans, and providers.

The DHCS' goal is to release at the end of this month an EPSDT Outreach and Education toolkit to increase awareness among members and Medi-Cal managed health care plans. They want to see improved outcomes in the preventative side. The EPSDT needs to shift gears to refer a new terminology for the benefit mostly for providers and plans because they need to point out that members are entitled to it. Dr. Riley reviewed the components of the toolkit: EPSDT renaming (more to come), EPSDT Enrollee Brochures (child and teen versions), EPSDT enrollee know your Medi-Cal rights letter, and EPSDT provider training. They will share brochures with stakeholders, ICC, and others. The brochures will be translated in threshold languages.

The DHCS wants to ensure they are getting it out most effectively. Dr. Riley thinks about it in two stages. First, get the information "out there" by the end of the month via the DHCS website. In the second stage, they welcome input as to how to get this information out to stakeholders, providers, Medi-Cal managed health plans, county offices, local health departments, and others. Dr. Riley welcomes input as to who ICC thinks DHCS should partner with to distribute this information. These brochures will also include a 'Know Your Rights' letter; it will be published on DHCS's website. There will also be a provider training kit. The providers need to understand what members are entitled to. As part of the new requirements beginning January 2024, Medi-Cal managed health plans must train their network providers, at least every two years, to ensure providers are able to support families in utilizing EPSDT services (including behavioral health). DHCS developed a training and will share training materials on their website and with managed care plans. They want to make providers aware of what

recourse they have if services are unavailable or denied. Main distribution will be from managed health care plans. They hope to target difference audiences (enrollee, provider, plans). All the information will be shared with each group.

In terms of timeline, they had a lot of stakeholder engagement and determining what level/type of information is still needed. DHCS conducted end-user testing with Medi-Cal members and families. They wanted to improve effectiveness of the materials they intend to distribute. The goal is to publish the toolkit in English on the DHCS website by the end of the month; in the next couple of months, they will then translate materials in all threshold languages. They will mail member facing materials for dissemination to childhood serving stakeholders and members by the end of the first quarter of this year.

Dr. Riley requested ideas from ICC regarding distribution plan, other audiences, and other communication/engagement tools to make this effective. Dr. Riley mentioned they will have an EPSDT webinar sometime this month; invitation will be shared with ICC.

Public Input

Mr. Velez stated that families in Ventura County are receiving EPSDT services because Gold Coach managed health care plan knows what families are entitled to. However, this does not happen in the rest of the state. Mr. Velez stated that when families finish Early Start, they do not have therapy services because the process is very difficult. Managed health care plans only approve urgent medical needs (e.g., broken leg). Mr. Velez stated that before guiding and educating families on their rights there should be a compromise with the managed care plans with their local entities to ensure they are adjusting rates and that they hire and contract with local providers to provide services. The concern is that when children turn 3 years old, they are not getting services, and school district services are minimal. Additionally, the local rates for therapists should be matched. There are several barriers to make this successful.

Dr. Riley agreed it's of concern for DHCS as well. They are building their population of health management. They have enhanced case management services that are targeting children with special needs as well as other specialized populations. This will only work if they have the right partners. There are some efforts through Cal AIM that somewhat align with helping local and regional populations. Dr. Riley stated there is more they can and should do. She wants to make sure plans are connected to the right community networks and supports to serve this population. Dr. Riley thanked Mr. Velez for the feedback.

Samantha Hebermehl, a parent representative, wants to know if DHCS can help give information for families who do not qualify for Medi-Cal due to income restrictions. For example, how to access Medi-Cal waivers and making those Medi-Cal waivers more accessible for families. In Ms. Hebermehl's case, her children are not with the regional center but she has been trying to get the on the Medi-Cal waiver since July 2022. She has not made progress. According to Ms. Hebermehl, a lot of families are unaware about that Medi-Cal waivers. Ms. Hebermehl asked if there is anything that can be done

to make those barriers less difficult.

Dr. Riley acknowledged there is a problem beyond getting to those services and even “getting into the door.” She will take it to the eligibility team who focus on clarifying eligibility.

Yvette Baptiste indicated she is a Family Voices Council Member Agency. She serves in Los Angeles County for parents with special health care needs. She feels there is not a lot of support for that work from DHCS. There is a heavy reliance on the disabilities system which is underfunded compared to healthcare services. Ms. Baptiste added there is reliance on health care managed plans but there is the issue also noted by Mr. Velez. She stated that there is not enough knowledge about who is in the system by the practitioners to make those appropriate referrals. Ms. Baptiste encourages DHCS to focus on the family support component. All other systems have that attached to their department. She added that Family Voices participates in many of the DHCS activities but when it comes to supporting families the support dissipates. Yvette highlighted Samantha’s experience. Ms. Baptiste mentioned that Children’s Partnership did a great report; they did focus groups with families of color. It’s a great report which talks about the experiences in the community. She has been in the system 30 years and part of Family Voices for 20 years and has seen "no movement."

Per Dr. Riley, an approach they are trying is through their Population Enhance Care Management Benefit. It may not serve everyone but it’s the most intense level of case management care coordination their department will be offering to different populations (i.e. kids, including others who are more complex, medically, or socially). This benefit will be launched for most kids in July 2023. Dr. Riley also acknowledged suggestions in the chat and thanked ICC attendees for their input regarding who they are engaging in the EPSDT dissemination efforts.

Lisa Schoyer asked if there are any efforts to encourage pediatric development screenings. She thinks that the states percentage is hovering around 25 percent. Dr. Riley confirmed that it’s one of the issues they are trying to target with their efforts by increasing awareness of developmental screenings in kids are entitled to as part of the EPSDT benefits. Dr. Riley stated they need to increase awareness and utilization of that benefit. They will also need to think about what additional barriers/ challenges to get developmental screenings and other preventative services.

Brief Announcement

Marcy Okada stated that this presentation and other presentations will be posted on the DDS website. See link: <https://www.dds.ca.gov/services/early-start/state-icc-on-early-intervention-overview/>

Dr. Riley shared her work email should there be additional thoughts/comments.
Email: Pamela.Riley@dhcs.ca.gov

****LUNCH BREAK****

Announcement of Committee Composition and Goals

DJ Tomko reviewed how DDS would support the committees with agenda development, note taking, and tracking action items.

Committee Meetings

The following ICC Committees met for breakout sessions:

- Improving Systems
- Communications

**** END OF DAY 1 ****