

Approved on 04/30/2010

**INTERAGENCY COORDINATING COUNCIL ON EARLY INTERVENTION  
GENERAL MEETING**

**February 25, 2010**

**MEMBERS PRESENT:**

Theresa Rossini, ICC Vice-Chair  
Jill Abramson, Designee for the Director (DHCS)  
Susan Burger, Designee for the Director (DMHC)  
Arleen Downing, M.D.  
Gretchen Hester  
Janet Hill, Designee for the Director (DPH)  
Rick Ingraham, Designee for the Director (DDS)  
Heidi Lange, substitute for the Designee for the Director (DMH)  
Marie Poulsen, Ph.D.  
Pamela Quiroz, Designee for the Superintendent of Public Instruction (CDE)  
Elaine Fogel Schneider, Ph.D.  
Cheryl Treadwell, Designee for the Director (DSS)

**MEMBERS ABSENT:**

Toni Gonzales  
Madeline Journey-Lynn, Designee for the Director (DADP)  
Beverley Morgan-Sandoz

**OTHERS PRESENT:**

Linda Landry  
Debbie Sarmento  
Patric Widmann, ICC Supervisor  
Stacie Byrne-Reed, ICC Coordinator  
Elissa Provance, WestEd, Recorder

Refer to Attachment A for a complete list of attendees.

**CALL TO ORDER**

Theresa Rossini called the meeting to order at 8:40 a.m.

**INTRODUCTIONS AND ANNOUNCEMENTS:**

Self-introductions were made. No announcements.

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### **AGENDA REVIEW:**

The agenda was approved with the following changes:

- The Chair's report will come before the Executive Committee report.
- Elaine Fogel Schneider asked for a review of the Birth-5 Reasons for Concern posters during Other Business. Linda Landry asked if one of the posters could be signed to present to Dr. Peterson at the Family Resources and Supports Institute.

### **APPROVAL OF NOVEMBER 2009 MINUTES:**

Minutes were approved with the following changes:

Susan Burger reported that on p. 24, Knotts-King Act should be changed to Knox-Keene Act.

Rick Ingraham reported the following changes:

p. 30, strike "Thus far, DDS' position is that the law is silent and it is up to local regional centers on this point."

p. 31, "regulatory requirements" should be "Part C regulatory requirements"

p. 31, delete "DDS felt they were not being as scientifically rigorous as originally agreed to."

p. 31, the DDS Stakeholder Budget committee that developed budget is now known as the DDS Budget Advisory Committee.

Peter Michael Miller reported that on p. 23, brain development should be changed to early brain and child development

### **EXECUTIVE COMMITTEE REPORT**

Marie Kanne Poulsen reported that there was rich discussion about numerous topics as follows:

- DDS and ARCA established the ES Quality Assurance Advisory Committee.
- Update about the prevention program and issues confronting regional centers re policies and procedures as well as families and communities
- Affirmation about the need to educate communities, families, and providers
- The monitoring process resumed in January
- Update on SPP indicator changes
- Committee structure was discussed, i.e., membership needs and scopes of work
- Scheduled ICC presentations were reviewed and DDS is still asking for ideas to enrich our council meetings
- Issues re underrepresentation and outreach workgroup and the newcomers meeting
- Acknowledgement of Dr. Mac Peterson's contribution
- Data presentation by DDS and CDE

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### **ICC CHAIR REPORT**

Theresa reported that Mac Peterson had personally written letters to each ICC Member about his resignation. Theresa will be chairing ICC meetings and covering Chair responsibilities until the governor appoints a new Chair. The Executive Committee Chair position will rotate among existing ICC Standing Committee Chairs. This month, Marie Kanne Poulsen chaired the Executive Committee. In April, Beverley Morgan-Sandoz will cover the Executive Committee followed by Arleen Downing. Theresa said she appreciated everyone's assistance.

Theresa spoke with Mac who stated his life has turned in a different direction and he will be advocating through a different path. Linda Landry said Mac will be presented with a Lifetime Achievement Award at the Family Resources and Supports Institute (FRSI). Mac has agreed to attend a future ICC meeting so he can be honored by the ICC for his dedication and contributions to young children and their families. Rick anticipates that DDS may be asked for a short list of ICC Chair candidates.

Theresa asked for updates to the ICC and Community Representative rosters.

Jill Abramson, a pediatrician with the Department of Health Care Services, Children's Medical Services, who is the head of policy development and High-Risk Infant Follow-Up Program, was introduced. Jill is replacing Hallie Morrow.

### **ICC STAFF REPORT**

Stacie Byrne-Reed reported the following:

- A request was made for members to submit airline itineraries when submitting receipts and always use Southwest Airlines SWABIZ.
- Travel advances will not be issued if you have more than one travel advance claim outstanding so try to submit travel claims as soon as possible.
- A new form will begin in April regarding hotel booking reservations. All ICC meetings for this year are at the Doubletree. An occupancy tax waiver form to reduce the hotel cost will be sent via email and will be included in future ICC packets.
- The next ICC meeting is scheduled for April 29-30.

### **FAMILY RESOURCE CENTERS NETWORK OF CALIFORNIA**

Linda Landry reported (Refer to Attachment B for details) that FRCNCA has an administrative body that is paid through non-DDS grant monies; allowing some activities to focus on children beyond 3 years of age and their families.

Two grants sources:

1. California Consumer Protection grant: Using this to host a variety of webinars. The latest one was about stress management.
2. Partners in Policymaking Collaborative: Members include the Arc of California, California Empowerment Center, Family Voices. And FRCNCA. The fourth training

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will begin at the end of the month. The collaborative has 18 self-advocates and 18 family members. It will likely be the last training due to budget issues. At that time 120 families and self-advocates will have been trained throughout the state. Graduates sit in area boards, advisory boards on hospitals, etc. Linda also reported on a variety of additional outreach activities.

FRCNCA is looking forward to its 12<sup>th</sup> Director's Forum, which involves family resource center directors who receive training, discuss issues and future directions. It is held the day before FRSI. Linda thanked Patric Widmann for shepherded through a grant proposal to help fund the Director's Forum. The annual meeting will be held on the second day of FRSI. So far, more than 150 people have registered from a variety of entities: regional center, medical, etc.

### **PUBLIC INPUT**

Shane Nurnberg: Parent and Community Representative from Redding asked about the Policy Topics Committee's comments regarding the insurance industry and said he believes that the whole system needs to be reformed. He also asked for clarification about the Policy Topics Committee's reference to the term "denial." It was explained that what is really needed is "authorization." Regarding the comment about developing a brochure about accessing insurance, Shane asked if it is the ICC's responsibility to inform parents about how to access insurance companies?

Mara McGrath: Parent and Community Representative from Palo Alto, explained that it should not be a parent's job to chase insurance companies. If one brochure could be developed, it could be taken to the provider and start a chain reaction. Medical providers are so confused about the issues. It is easier to provide a brochure to parents.

Laurie Jordan: Parent and Community Representative from Oxnard read letters from mothers of children with Down syndrome who participate in a support group. The mothers have kids in Early Start and are Spanish speaking only. The comments were all positive and Laurie said although there is a lot going on, we need to remember we're doing really good things for families and Early Start is having a good impact on families.

Fran Chasen: Community Representative from Santa Monica thanked Marie for mentioning reaching out to professional organizations. Many organizations are looking at how to better communicate Early Start changes. IDA is looking into sharing information and doing a collective survey. She agrees that services are still being delivered but there are many complications that need to be addressed. The current service delivery system is disintegrating. Families are unaware of the richness of the Early Start service system and don't even know that changes that are taking place. Fran also presented information about statewide trainings.

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Peter Michael Miler: Community Representative from San Anselmo announced that in 1991, the head of the Department of Health services received a grant. AB99 looked at coalescing programs. He said it is crazy that programs have separate systems of billing and that all bills should go to the state and the state should figure out who to pay. This issue might be considered in the Policy Topics Committee. Dealing with insurance issues and forms doesn't help anybody.

Nancy Sager: ICC Liaison from the California Department of Education read a letter from Diane Black, who has two children who are regional center clients. She is grateful for the assistance from the regional center and school district. She does parent coordination for the Southern California Hearing Coordination Center. She is concerned about the lack of screening for babies until 18 months in some areas and the 45-day timeline is not being honored. She thanked Patric Widmann for listening to her concerns during a recent teleconference.

Tony Anderson: Community Representative from Sacramento announced an action alert going out today regarding SB 2860 and HR 4247, bills that addresses the dangers of the use of restraints and seclusion in schools and that needs sponsors on the Senate side. He also mentioned AB 1694, which creates a \$.05 alcohol mitigation fee and AB 2702, which clarifies the discussions and decision making process that can be made in IFSP and IPP team meetings. This bill dispels any misinterpretations of how decisions are to be made.

Arleen Downing: ICC Member from Santa Ana discussed the issue of completing evaluations and assessments of hearing during the 45-day timeline, especially for children with insurance. This was a problem because regional centers would fund audiological evaluations in order to meet timelines. She also announced an article in the October issue of *Pediatrics* about hearing assessments and recommendations. The article said every child with one or more risk factors should have ongoing developmentally appropriate hearing screening and at least one diagnostic assessment by 24-30 months or age. In addition, any parental concern about hearing loss should be taken seriously and requires objective hearing screening of patient.

### **PRESENTATION – PRENATAL DIAGNOSTICS INCLUDING AUTISM**

Rick Ingraham introduced Dr. Shirley R. Korula, a consultant in genetics at several Los Angeles hospitals and South Central Los Angeles Regional Center (SCLARC), who presented on *Prenatal Diagnostics Including Autism* (Refer to Attachment C for PowerPoint). Dr. Korula has also been medical director at San Gabriel-Pomona Regional Center, an advisor on the Association of Regional Center Agencies (ARCA) Prevention Committee, and is a member of several medical organizations. She recently presented at an international conference in India.

Dr. Korula reported that when the incidence of autism began climbing, geneticists were given the job of trying to find cause. Very few geneticists are working in the field of developmental disabilities. Autism is a neuro-developmental disorder displayed by

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impairment in social interaction; impaired verbal/nonverbal communication; and restricted and stereotypic patterns on interest, behavior, and activities.

Dr Korula identified disorders of Autism Spectrum Disorders (ASD), the incidence of autism, causes and diagnostic yield for autism. She stressed that an accurate evaluation is needed before diagnosing autism. You need a formal diagnosis by clinical specialists, preferably by a team evaluation and a hearing evaluation. Evaluations need to be tiered, not a shotgun approach.

Rick asked what regional center and service coordinators can do to advise parents about the University of California Davis article stating that autism is more common with older parents. Dr. Korula replied that most children with autism are actually being born to younger parents. If you are seeing families with multiple kids with autism, they need to be referred for family studies and genetic counseling. Standard recommendations cannot be made.

### **STANDING COMMITTEE REPORTS**

Quality Data Committee: Gretchen Hester reported that the Committee made suggestions regarding the Early Start Report draft, (i.e., Mental Retardation should be changed to Intellectual Disability).

#### *Highlights:*

- The Committee looked at using CDE's DRDP *access* instrument and identified that a time period of direct exposure to the child was needed to use this instrument. The committee decided that it wasn't a viable option. Something more universal is needed.
- Members determined that it would be good for data systems to be constant throughout the agencies and getting data from different agencies would be good. They also looked at coordination among agencies and what should be worked on immediately.
- Arleen added that for the next meeting, members will be look at the APR, especially indicator 3, and develop questions for DDS regarding what we might want to know more about and what might show areas of improvement.

Policy Topics Committee: Elaine Fogel Schneider thanked her Committee for spirited discussion and reported that Tony Anderson should be added to the Committee list in the ICC packet.

#### *Highlights:*

- The Committee is looking at accessing services and how policy changes are affecting a family's ability to receive services.
- The primary focus of discussion was about the impact on families who are required to access their insurance.
- Delays in service provision due to families having to show denial of service before regional centers will officially provide services.

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- Instead of using the term ‘denial’ regional centers should use “notification of benefits” to explain activity on claims
- The impact of co-pays and deductibles for families may significantly impact a family’s budget resulting in some opting out of services.
- Is it cost effective for regional centers to require families to access insurance?
- Medic-Cal codes were also reviewed.
- Vendors don’t understand the process or the words to use and need to receive training.
- Timeliness of services and standardization of services.
- Development of an information brochure re insurance questions.
- Parent Leadership Award responsibilities will be transferred to the Child and Family Outcomes Committee.

Child and Family Outcomes Committee: Cheryl Treadwell reported that the Committee looked at APR Indicators 3 & 4. Dale Sorbello, DDS, and Debbie Benitez, WestEd Center for Prevention and Early Intervention, presented details of the Early Start Family Outcomes Survey. The Committee decided to plan for the next meeting re bringing forward additional questions for the survey to be disseminated July-Aug.

*Highlights:*

- Discussed supporting the FRCNCA becoming a voting member of ICC.
- There should be increased information regarding the Prevention Program and eligibility changes the community and state partners.
- Rick said the Family Survey (3 questions) was done quickly to meet Federal requirements. The response rate is upwards of 30%, which is an excellent return rate. The Committee will explore developing additional questions. Debbie said it could be discussed at the April meeting and come as a recommendation but they are not asking for ICC approval of questions as an Action Item.
- Theresa asked about asking an open-ended question so people can add their own concerns. You would get what people are truly concerned about, not what you’re looking for.
- Pamela Quiroz suggested a presentation about the DRDP access tool.

Qualified Personnel Committee: Marie Poulsen reported the purpose of the committee is to ensure infants, toddlers, and families receive quality care, services, and support.

*Highlights:*

- All Early Start Institutes have incorporated information about Early Start changes. IDA and SEECAP have also integrated information. Local regional centers are having meetings in communities. FRCNCA offered webinars in collaboration with DDS. There is a need to contact professional organizations in our communities. Members should contact a minimum of five entities and clarify what’s going on.

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- There is a need to contact pediatricians and hospitals regarding clarification of information.
- Reviewed the 3-5-year TTA plan. An overview and update of the CSPD will be presented at the April meeting with special attention to the revised ESPM, which includes competencies for early intervention professionals. The Committee wants to analyze public input collected over the last few years to decide implications for TTA.
- Requested that Mike Fuller from First 5 be appointed as a Community Representative to QPC. Regional center and special education local plan area representation is also needed.

### **AGENCY REPORTS:**

**Department of Alcohol & Drug Programs (DADP)** – No report.

**Department of Mental Health (DMH)** – Heidi Lange, who is filling in for newly appointed member, Lois Williams, reported that Lois will participate in April and provide a report at that time.

**Department of Managed Health Care (DMHC)** – Susan Burger reported on the following:

As Regional Center and Early Start consumers and their families begin to request authorization for medical care from private insurers, the Department of Managed Health Care (“DMHC”) continues to respond to and evaluate the potential impact of the implementation of Trailer Bill ABX4 9 on health care service delivery for affected managed care enrollees. Related activities include, but are not limited to, the following:

- Continued processing of complaints filed with the DMHC Help Center that are related to the Trailer Bill Language policy changes. In order to more effectively assist callers, Call Center staff also received guidance on the recent policy changes specifically related to requesting treatment authorizations for medical care from private insurance carriers.
- Increased effectiveness in tracking and trending inquiries and complaints received by the Help Center related to the implementation of the Trailer Bill Language. The Help Center revised its data collection system process to ensure that all calls and complaints related to the recent policy changes are captured in its tracking report.
- Continued outreach efforts to educate individuals on services available from the DMHC’s Help Center, including information on how managed care enrollees can access basic health care services and medically-necessary treatment from their health care service plans. Help Center staff accepted the following speaking invitations:

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- The 2010 Advanced Practice Institute (API) and the Early Start Managers' Symposium (February 2, 2010; Redondo Beach)
- 2010 Health Summit sponsored by Family Voices of California (March 2, 2010; Sacramento)
- Early Start Training and Technical Assistance Collaborative (March 4, 2010; Sacramento)
- The 2010 Early Start Family Resources and Supports Institute Conference (March 17, 2010; San Diego)
- Family Voices of California - Monthly Brown Bag Lunch Webinar (April 7, 2010)
- Early Intervention: Practices that Make a Difference Conference – sponsored by The Infant Development Association of California and the Riverside County Office of Education (April 22, 2010; Riverside)

The Department reiterated that the DMHC Help Center provides a free consumer service that is available 24 hours a day, seven days a week to answer consumers' questions regarding accessing health care services from managed care health plans. The Help Center receives and resolves enrollee complaints to ensure that enrollees receive all the necessary medical and mental health care to which they are entitled and provides referrals to community and other government organizations, when applicable. If medical treatment has been delayed, denied, or modified, managed care enrollees have the right to an Independent Medical review (IMR). If families are uncertain about how to proceed with a health plan dispute or are having other problems involving a health plan, please contact the Help Center at **1-888-466-2219**, **TDD: 1-877-688-9891**, or visit the Department's website at [www.healthhelp.ca.gov](http://www.healthhelp.ca.gov). The Help Center can provide help to consumers who speak any of 100 different languages.

**Department of Developmental Services (DDS)** – Rick Ingraham reported on the following:

- The entire department is wrestling with several challenges:
  - Trailer bill changes affecting Early Start and other departments in DDS.
  - In addition, there is a plan to close the Lanterman Developmental Center and transfer residents to other centers.
  - The Children and Services Branch will be releasing the best practice guidelines for intervention re ASD, a five-year project culminating in the review of articles. Rick knows that the guidelines need to be revised due to continually emerging research.
- The Prevention Program has been launched. The number of kids is well under projections: just more than 3,000 kids for the 'at risk' category. As soon as they show delays, they will be transferred to Early Start. Early Start numbers are down from 36,000 to 28,000 (point in time data).
- It has been difficult to quantify savings re the trailer bill language. OSEP has questions about implementation of some of these measures and will be sending questions to Rick for responses.

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- Early Start monitoring has resumed and DDS is continuing to work with regional center representatives re the Early Start Quality Assurance Advisory Committee.
- DDS is finalizing revisions of the Early Start report form. Once launched, there should be universal reporting on many required data elements, including child progress.
- The new APR is posted on the website.
- Elise Parnes is the new nurse consultant.

**Department of Education (CDE)** – Pamela Quiroz reported on the following

The CDE website is current and special areas of interest are:

- information related to disproportionate representation of student by race and ethnicity receiving special education services
- updates about student participation in statewide assessment
- Focus Monitoring and Technical Assistance (FMTA) unit consultants assignments by county, local education agency (LEA)
- program summaries and information on specified federal grants allocated to provide services to individual disabilities
- information about the advisory Commission on Special Education (ACSE)
- National Autism Center Standard Projects that provide critical information about which treatments is shown to be effective for individual with Autism Spectrum Disorder

### **Legislative Updates**

- CA Assembly Joint Resolution (AJR) 31 Memorializes Congress and the President to enact House of Representatives (HR 1102) This Joint Resolution requests the President to fully-fund the Individuals with Disabilities' Act the resolution is currently in the Education Committee
- The CDE will be pursuing the parental consent legislation as a State Superintendent of Public Instruction sponsored bill. Lily Baird, Executive Fellow in the Legislative Affairs Division, will be the primary contact and staff for this legislation. Lily has submitted the language to the Legislative Counsel and she is currently looking for a bill author. Representatives from our division will soon be meeting with Lily about special education issues
- CDE met with Epilepsy California representatives to discuss the status of possible legislation to address the administration of Diastat to some children with epilepsy who are susceptible to prolonged seizures and require access to a life-saving emergency medication. It appears that a federal solution may be the best direction to take at this time

### **Budget Updates**

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- A summary report of the Governor's proposed State Budget for 2010-11 for special education and related budget items provides \$3.2 billion from the General Fund and \$1.2 billion from federal IDEA funds for special education. As part of the General Fund Budget item for special education, the sum of \$65 million is available pursuant to legislation enacting a settlement agreement for the Behavioral Intervention Plan mandate.

### **Interagency Collaboration Activities**

- The California Early Learning Quality Improvement System (CAEL QIS) Advisory Committee submitted their 2009 Interim Report to the Governor's Office. The purpose of the CAEL QIS Advisory Committee is to develop a plan to improve outcomes for children and promote school readiness by improving the quality of early learning and care programs for children from birth to five years old
- The California Department of Education Head Start Interagency Agreement approved the CDE Head Start Interagency Agreement
- In collaboration with the Head Start Collaboration Office, Pamela Quiroz will participate in a video conference about the CDE-Head Start Interagency Agreement. The video conference will be on March 16, 10:30-12:30. The purpose of the video conference is to provide support to LEAs, Head Start and Early Head Start programs to develop an Interagency Agreement at the local level
- Joan Hirose met with the Fetal Alcohol Spectrum Disorder (FASD) Interagency Work Group met to discuss and develop deliverables around fetal alcohol spectrum disorder
  1. Develop a map of resources for pregnant women and families impacted by FASD.
  2. Include information on FASD at all of our departments/agencies conferences.
- The CDE submitted the State Performance Plan on time.

### **Personnel Updates**

- The Administrator 1 position for the NPS unit in the Special Education Division remains vacant
- Mary Hudler, CDE-SED Director will retire from the CDE the end of March

**Department of Health Care Services (DHCS)** – Jill Abramson reported on the following:

### **CMS Branch Staffing**

- The Branch Chief position is still vacant

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## **CCS**

- Handout of recent Numbered Letters provided
- CCS Redesign
  - Part of 1115 Waiver renewal
  - Reports of the assessments available on the DHCS website ([www.dhcs.ca.gov](http://www.dhcs.ca.gov)) – click on Waiver Renewal
  - Technical workgroups: CCS, SPD most relevant. BHI and HCCI. Minutes from meetings on website
  - Several demonstration projects proposed by director
  - Variations of Medical Home Model: EPCCM (by county or MCO, or accountable care organization). One report found at: [http://www.dhcs.ca.gov/provgovpart/Documents/Enhanced%20Medical%20Home%20\(CHCS-posted\).pdf](http://www.dhcs.ca.gov/provgovpart/Documents/Enhanced%20Medical%20Home%20(CHCS-posted).pdf)
  - Current waiver expires August 31, 2010
- Title V Needs Assessment
  - Five year needs assessment for the Maternal and Child Health Block Grant
  - Identify priorities for the next 5 years for CCS, California's Title V Children with Special Health Care Needs program. Evaluation by FHOP
  - Stakeholder meetings were held and several workgroups are meeting
  - Key informant interviews and focus groups have been completed
  - Online surveys will be conducted in 2010 – if you have thoughts on reaching CCS/CHSCN families for online survey, contact Jennifer Renks at [Jenrenks@aol.com](mailto:Jenrenks@aol.com)
- Pediatric Palliative Care (Partners for Children)
  - Program began in October, has enrolled several children
  - Can enroll up to 300 children in the first year
  - Taking applications for hospice and home health providers to become palliative care providers – [www.californiapartnersforchildren.org](http://www.californiapartnersforchildren.org)
- Neonatal Quality Improvement Initiative
  - 14 Regional NICUs to focus on reducing blood stream infections, other infections, and antibiotic stewardship. Audits of compliance with bundles (CLBSI – hand hygiene, line insertion)
  - Breast Milk collaborative – 11 regional and community NICUs – increase # of VLBW infants discharged on breast milk
  - Will continue through 12/31/10

## **High Risk Infant Follow-up (HRIF) program**

- Electronic data collection system
- 4565 infants in registry, born after 1/09
- 60 actively participating centers – 21 Regional and 39 community

## **NHSP**

- 2008 data analysis: 93% of infants born in California were screened.
- Still certifying last few hospitals

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## **Budget**

- Governor's proposed budget released 1/8/10:  
<http://www.dhcs.ca.gov/provgovpart/Documents/2010-11%20Governor%20Budget%20Highlights.pdf>
- Reduction in HF to 200% FPL
- Trigger reductions if inadequate federal aid include:
  - Elimination of CHDP
  - Elimination of Healthy Families
  - Elimination of Medi-Cal optional benefits

**Department of Social Services (DSS) – Cheryl Treadwell** reported on the following:

## **FEBRUARY IS PARENT LEADERSHIP MONTH**

Parent Leadership Conference is convening today in Ontario, California. Co-sponsored by our Department along with First Five, County Welfare Directors Association, and Parents Anonymous, Inc. Any follow-up materials can be found at [www.parentsanonymous.org](http://www.parentsanonymous.org)

Improving CAPTA compliance. CDSS and UC Davis for Family Focused Practice continues to offer a series of Webinars to assist the counties with training staff on the developmental screening tools that can be used for young children. Training on ASQ will be offered March 8-9<sup>th</sup>, and PEDs training will be offered on 3/15<sup>th</sup>. Priority given to county teams, public health nurses and trainers committed to training others in their counties.

New Federal Initiative announced : TeXt4Baby Webinar to be held on 3/17<sup>th</sup> and will introduce the initiative that will provide free health related text messages to new mothers and pregnant women. It is sponsored by the National Healthy Mothers and Healthy Babies Coalition. You can visit the website at: [www.hmhb.org](http://www.hmhb.org)

New Website: Launched by California's Youth Law Center = [www.justbeginning.com](http://www.justbeginning.com) which specifically focuses on birth to six children in foster care. The site focuses on child psychology research, how to reduce the trauma of removals and transition for babies and toddlers in foster care and more.

## **Relevant Budget Update**

### **Children's Services**

The May Revise Budget proposes funding for Children's Services in the amount \$350 million redirection from First Five/Prop 10 funding to several social services programs. This would target resources to high-priority programs that would otherwise require General Fund (GF) support. Budget proposes increasing Federal Financial Participation for all foster children and finally should these or other proposals not be

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approved, it triggers other reductions, such as elimination of CalWorks, and severe reduction to In Home Supportive Services.

High Note: Our average monthly caseload has decrease slightly from 68,800 in FY 2008-09 to 67,500 in FY 2009-10, a reduction of 1.8 percent and is on the steady decline. This is good news.

### Partnering and Collaboration Activities

CDSS is a partner with Alameda County and other State Departments on the Project Launch project, which a five year grant to improve outcomes from young children.

Working with the Co-investment Partnership (comprised of several foundations) on their Early Care and Education Collaborative to promote readiness for foster children to succeed in school. The purpose is to bring renewed focus to the needs of young foster children.

### **Department of Public Health (DPH) – Janet Hill reported on the following:**

No changes in the amount that was eliminated from the MCAH budget. The Governor eliminated 100% of State General Funds from MCAH programs for a total of \$27.7 million, which included federal matching dollars. However implications of the cuts have become known:

#### **IMPACT:**

- \* decreased capacity of local health jurisdictions to coordinate services for their MCAH population, including for low income pregnant women and infants
- \* decreased outreach activities, including less prenatal referrals
- \* decreased SIDS prevention and follow-up services
- \* decreased home visiting, breastfeeding support, child safety, oral health and substance abuse activities
- \* decrease of over 6000 pregnant teens receiving case management support from the Adolescent Family and Life Program (AFLP) and a waiting list of over 1100 in the counties. Implications include increased repeat teen pregnancies, fewer developmental screening of at-risk infants
- \* decrease of 2000 pregnant and postpartum African-American women receiving Black Infant Health support to decrease black infant morbidity and mortality. implications include increased prematurity and low birth weight, fewer referrals for services.

#### **Summary of the impact of the budget cuts:**

1. Funding cuts have devastated many local MCAH, AFLP and BIH programs
2. Local agency funds have filled some gaps
3. Reduced services will result in increased public costs to treat short and long term

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preventable complications

4. Some programs are threatening closure if they do not receive adequate funding in FY 10/11

#### CURRENT ACTIVITIES:

BIH: On a positive note, the BIH curriculum is being revised and young children's development is being addressed.

Project LAUNCH: MCAH continues to lead the \$4.2 million dollar 5 year federal grant that will promote and support the developmental growth of children, 0-8 years of age. Funds will be used to provide home visitations, mental health consultations in early childcare and education, developmental screening and behavioral consultations in primary care, and will use the Strengthening Family framework, which has been shown to reduce child abuse and increase family resiliency. Our pilot area is East Oakland, and there will be plans to work with the East Bay Regional Center to identify system barriers and solutions around implementation of the recent changes to the Early Start Program. The local pilot will inform the state to create the systems changes necessary to sustain and promote the developmental growth of children statewide. There are 2 full-time employees to coordinate these activities- one at the local level and the other at the state. The Statewide Screening Collaborative will serve as the state Council for the Project.

#### INTERAGENCY COLLABORATIONS:

The Statewide Screening Collaborative is working with Med-iCal FFS on how to streamline reimbursement for developmental screening and Medic-Cal MC on how to incorporate developmental growth questions on the pediatric Staying Healthy Assessment questionnaires which are currently being revised. Both provide opportunities for system changes to promote early identification and referral.

The SSC also launched the California Screening Initiative, an outreach campaign to increase awareness of the importance of early identification and intervention. The resources, such as the state discount flyer for ASQ and PEDS, will be posted on the MCAH website soon so anyone can participate in their communities.  
<http://www.cdph.ca.gov/programs/eccs/pages/default.aspx>

The Developmental Screening website for California Kids is continuing to evolve. Child welfare and early child care and education pages have been developed. Also, the number of counties providing their system of care profiles is increasing. Go to [www.first5ecmh.org](http://www.first5ecmh.org) <<http://www.first5ecmh.org/>>

Lastly, the SSC will help coordinate California's participation in the National Children Mental Health Awareness Day, set for May 6, 2010.

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**OTHER BUSINESS:**

Elaine said one of the Reasons for Concern developmental posters will be signed and presented to Mac at FRSI. Elissa Provance gave background information on the workgroup and process for development of the poster series.

**ADJOURNMENT:**

The meeting adjourned at 1:25 p.m.

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**ATTACHMENT A**

**STAFF AND OTHERS ATTENDING ICC GENERAL MEETING**

**THURSDAY, FEBRUARY 26, 2010**

**COMMUNITY REPRESENTATIVES**

Tony Anderson  
Fran Chasen  
Bev Ching  
Terry Colborn  
Stephanie Pringle-Fox  
Edward Gold  
Susan Graham  
Laurie Jordan  
Dwight Lee  
Kat Lowrance  
Mara McGrath  
Peter Michael Miller  
Shane Nurnberg  
Lois Pastore  
Kristine Pilkington  
Sherry Torok

**GUESTS**

Natalie Harlan  
Bethany Kavrik  
Shirley Korula, MD  
Elise Parnes

**DEPARTMENT LIAISONS**

Michelle Donahue  
Erin Paulsen  
Nancy Grosz Sager

**WESTED STAFF**

Debbie Benitez  
Peter Guerrero  
Angela McGuire  
Stephanie Myers  
Virginia Reynolds



## Family Resource Centers Network of California

### Report to the Interagency Coordinating Council on Early Intervention

February 26, 2010

The Family Resource Centers Network of California (FRCNCA) Steering Committee met monthly via conference call, web conferencing or face to face.

The FRCNCA Directors' Forum will be held March 16<sup>th</sup>, prior to the Family Resources and Supports Institute in San Diego. The FRCNCA is very appreciative of a training grant from WestEd to help support the Forum.

The **Partners in Policymaking California Collaborative** (PIPCC), funded by the State Council on Developmental Disabilities and made up of the FRCNCA, The Arc California, Family Voices of California and the California Association of Family Empowerment Centers, holds conference calls twice monthly to oversee the implementation of Partners in Policymaking California. The Partners in Policymaking 2010 class has been selected and will meet for the first time on March 26, 2010. The 2010 class is made up of participants from Mono, Inyo, San Bernardino, Riverside, Imperial, San Diego and Orange Counties.

**Outreach and collaboration activities** have included outreach tables at Early Start Essentials and the Supported Life Institute Information Fair. FRCNCA representatives participation on the DDS Budget Workgroup, the Tarjan Center UCEDD Advisory Committee, the MIND UCEDD Consumer Advisory Committee, USC UCEDD Advisory Board, the Prematurity Coalition, the Arc of California Board and the Supported Life Institute and Family Voices Health Summit Planning Committees. FRCNCA representatives also attended the California Parent Center Staff Day and the California Family Resource Association Workshop on MHSA.

A second year of funding by the **California Consumer Protection Foundation** for a **Webconferencing** grant began in September. The FRCNCA, working in collaboration with Family Voices California and the California Association of Family Empowerment Centers, will develop a comprehensive series of web-based trainings designed to enhance the skills of collaborative partner staff, other community-based organization staff, and family members to (1) increase the ability of centers and agencies to provide timely information, education, support, and linkages to appropriate services for hard-to-reach families, and (2) provide job readiness and professional development opportunities to families of children with special health care needs, including transitioning youth. This grant will meet several of our Strategic Plan goals and will build on our previous work and allow us to present eight web-based trainings. To date we have presented three webinars: two on the Prevention Program featuring Julia Mullen and Rick Ingraham; a Caring for the Caregivers webinar on stress reduction.

The FRCNCA is participating as a member of the **California Consortium for Emergency Preparedness and Developmental Disability**, a project of the Tarjan Center for Excellence in Developmental Disabilities. The project is being funded by the Administration on Developmental Disabilities.

**Shirley R. Korula M.D.**  
**Los Angeles, CA**

# AUTISM

DEFINITION : A neurodevelopmental disorder with the following features

- Significant and sustained impairment in social interaction
- Impaired verbal and nonverbal communication
- Restricted and stereotypic patterns of interests, behavior and activities

# AUTISM SPECTRUM DISORDERS

- PDD - NOS
- Autistic Disorder
- Asperger Syndrome

# ASD

- Incidence : 1 in 150
- M:F is 4:1
- Complex inheritance with marked genetic heterogeneity
- 70 - 90% concordance in monozygotic twins depending on whether or not a broader phenotype is used
- Heritability is approx. 90%

# ASD

CLINICALLY THERE ARE TWO FORMS

SYNDROMIC

NONSYNDROMIC

# ETIOLOGY OF AUTISM

- CHROMOSOMAL ANOMALIES

Fragile X Syndrome

47, XYY

Marker chromosomes: idic 15;15(q12;q12)

Folate sensitive sites: 2q13, 6p23, 12q13

Deletions and duplications of 15q and 22q

17p11.2

Subtelomeric deletion of 2q

# ETIOLOGY OF AUTISM

- GENETIC SYNDROMES

- Tuberous Sclerosis

- Neurofibromatosis (NF 1)

- Fragile X ; ARX gene

- Sotos

- Banayaan Riley Ruvalcaba (BRR)

- Angelman

- Smith Lemli Opitz

- Rett

- Smith Magenis

# ETIOLOGY OF AUTISM

- METABOLIC DISORDERS

- Phenylketonuria

- Mucopolysaccharidoses

- Disorders of purine and pyrimidine metabolism

- Sulfation defects

- Disorders of GABA metabolism

- Disorders of creatine metabolism

- Mitochondrial abnormalities

# DIAGNOSIS IN AUTISM

## DIAGNOSTIC YIELD :

Nonsyndromic: 8-10%

Syndromic: 40%

50% (aggressive testing)

# EVALUATION OF AUTISM

## PRE-EVALUATION

- Formal diagnosis of Autism by clinical specialists preferably a team evaluation
- Hearing evaluation

# EVALUATION OF AUTISM

## TIER 1

- Significant number of diagnoses are made by history and dysmorphology evaluation alone

# EVALUATION OF AUTISM

- History often reveals:
  - Advanced paternal age
  - Prematurity
  - Prenatal infections
  - Prenatal substance abuse
  - Family history of OCD, anxiety bipolar and mood disorders

# EVALUATION OF AUTISM

## TIER 1 (continued)

- IF CLINICAL INDICATORS PRESENT:
  - Standard metabolic screening
  - Rubella titers
  - Mitochondrial disease workup
    - Serum lactate, pyruvate, ammonia
    - Serum creatine, acyl carnitine
    - Urine organic acids

# EVALUATION OF AUTISM

## TIER 1 (continued)

- IF A SPECIFIC DIAGNOSIS IS SUSPECTED, THEN GO TO TARGETED TESTING

# EVALUATION OF AUTISM

## TIER 1 (CONTD)

If no specific diagnosis is suspected :

- Prometaphase chromosome analysis
- DNA studies for Fragile X studies

# EVALUATION OF AUTISM

- 25% have associated macrocephaly
- In those with macrocephaly, increasing head size noted in the first year of life and less so in the second year
- Stabilizes after that
- Abnormalities noted in the frontal lobe, cerebellum, hippocampus and limbic system

# EVALUATION OF AUTISM

## TIER 2

If microcephaly or macrocephaly present :

Brain MRI

If seizures are present :

EEG / Brain MRI

Chromosome microarray analysis if  
chromosomes are normal and in the  
presence of dysmorphism / MR

# EVALUATION OF AUTISM

## TIER 3

- MECP 2 gene testing (in females)
- Chromosome 15 methylation studies
- Serum and urine uric acid
  - if increased, HgPRT & PRPP synthetase
  - if decreased, purine / pyrimidine panel

# EVALUATION OF AUTISM

## TIER 4

- Specific gene testing for :
  - UBE 3 A (Angelman)
  - PTEN (BRR)
  - FMR 1 gene sequencing
  - NSD 1 (Sotos)
  - Mitochondrial genes
  - Neurologin (X-linked MR)
  - Screening for folate sensitive fragile sites
  - Advanced metabolic work up

# EVALUATION OF AUTISM

## REFERENCES:

Genetics in Medicine 2007; 9:268-273

Gail E Herman et al

Genetics in Medicine 2006;8:549-556

Schaefer GB & Lutz RE