

INTERAGENCY COORDINATING COUNCIL ON EARLY INTERVENTION

GENERAL MEETING

SEPTEMBER 24, 2004

MEMBERS PRESENT:

Raymond M. Peterson, M.D; Chair; Sylvia Carlisle, M.D; Arleen Downing, M.D; Bob Evans, on behalf of Jim Bellotti, representing CDE; Hedy Hansen; Gretchen Hester; Rick Ingraham, representing DDS; Cynthia Jaynes, representing ADP; Hallie Morrow, M.D; representing DHS; Marie Kanne Poulsen, Ph.D; Theresa Rossini; Cheryl Treadwell, representing CDSS; and Luis Zanartu, representing DMH.

MEMBERS ABSENT:

Marcy Gallagher, Toni Gonzales, Thomas McCool, Ed.D., Beverley Morgan-Sandoz, Elaine Fogel Schneider, Ph.D.

OTHERS PRESENT:

See Attachment A.

RECORDERS:

Cheryl Holden
Cheri Schoenborn

WELCOME AND ANNOUNCEMENTS

Dr. Peterson called the meeting to order at 9:00 a.m. and welcomed everyone in attendance. ICC members and the audience provided self-introductions.

First time meeting attendee Jacqui Kerze from Comfort Connection Family Resource Center attended the Newcomers Orientation meeting. Ms. Kerze was introduced and welcomed to the ICC meeting.

Dr. Peterson also welcomed newly appointed Community Representatives Edward Gold, Susan Graham, Al Millan, and Letha Sellars. He also introduced Bob Evans, the new Part C Liaison from the California Department of Education (CDE) Special Education Division, who was participating on behalf of Jim Bellotti.

Dr. Peterson acknowledged Department of Developmental Services (DDS) and WestEd, Center for Prevention and Early Intervention for the development of the 2004-2005 Early Start Statewide Institutes Catalogue. The catalogue of Early Start training events sponsored by DDS and coordinated by WestEd includes a calendar format that provides event dates for the upcoming Core Institutes,

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Service Coordination Institutes, and Supervision Institute. Scholarship and registration information is also included in the catalogue.

AGENDA REVIEW

The agenda was reviewed and Rick Ingraham agreed to present a brief report on the Annual Performance Report in Ken Freedlander's absence. Mr. Freedlander will be asked to present the report in more detail at the November ICC meeting. The agenda was approved with this amendment.

APPROVAL OF MINUTES

The minutes summarizing the May 21, 2004 ICC meeting were approved as written.

EXECUTIVE COMMITTEE REPORT

Executive Committee Chair Hedy Hansen reported on the Executive Committee meeting held on Thursday. Rick Ingraham provided assurances that DDS is committed to providing the ICC with data and information needed to support the development of recommendations in the ICC's priority areas. The Executive Committee Workplan was reviewed and it was agreed that the Standing Committees would continue to address the priority areas identified in the plan.

The Executive Committee discussed future ICC agendas. In November 2004, Cheryl Treadwell, CDSS, has agreed to arrange a special presentation on the Child Abuse Prevention and Treatment Act (CAPTA) including collaboration activities with DDS and at the local level.

The Executive Committee discussed strategies for assuring collaboration with Early Start Family Resource Centers (FRCs) when agencies release Requests For Proposals (RFPs) to establish new or expand existing entities to provide services similar to what Early Start FRCs provide. The Executive Committee assigned the Family Resources and Supports Committee (FRSC) with the task of developing recommended strategies to ensure collaboration with Early Start FRCs.

CHAIR'S REPORT

Dr. Peterson reported that California's 2004-2005 Budget did not include reductions in the Early Start program thereby allowing continued maintenance of the program. He noted that cost shifting from other programs that have received budget reductions might impact some services.

Dr. Peterson thanked the DDS staff for providing each of the Standing Committees with data and information resources in response to their requests. The Standing Committees can now proceed with reviewing the additional data along with information from Site Monitoring Reports and other sources and develop recommendations with measurable outcomes.

Dr. Peterson announced that the Budget Act Trailer bill authorizes the Department of Health Services' Genetic Disease Branch (DHS - GDB) to expand the newborn screening program to include congenital adrenal hyperplasia, and disorders detectable using Tandem Mass Spectrometry (MS/MS). DHS - GDB anticipates identifying 45 different disorders, in addition to PKU, by MS/MS. The effectiveness of the MS/MS pilot project conducted in California from January 2002 - June 2003, showed the value of the screening program. This expansion is consistent with a national movement lead by parents, community agencies, health professionals and the Federal Government, aimed at promoting comprehensive newborn screening for all babies.

STAFF REPORT

ICC Staff Manager, Cheri Schoenborn reported the next ICC meeting would be November 18-19, 2004, at the Radisson Hotel in Sacramento. ICC members and community representatives were encouraged to contact the Radisson Hotel directly at 916/922-2020 or 800/333-3333 to make their reservations by October 18, 2004, to ensure receiving the Government rate. Members needing assistance with travel arrangements or a travel advance may contact Barbara Ferreira at 916/654-1596. All other questions about the meeting can be referred to Ms. Schoenborn at 916/ 654-2767.

Ms. Schoenborn reported that the ICC's Committee Staff are working together to ensure collaboration across each of the ICC's priority areas (Early Entry, IFSP, Transition and Interagency Collaboration). Staff received an "Information and Data Resources Binder" which compiles all the data transmitted by DDS to all of the committees. ICC Staff and DDS Liaisons will be working together to support the Standing Committees and their Chairs. ICC Staff are available to arrange conference calls and prepare draft materials for Committee review. If additional staff support is needed, contact Ms. Schoenborn.

SPECIAL PRESENTATION: Fetal Alcohol Spectrum Disorder

Cynthia Jaynes, ADP representative, introduced Dr. Susann Steinberg the Chief of Maternal and Child Health Branch, Office of Family Planning for the California Department of Health Services. A summary of Dr. Steinberg's presentation and her slide presentation is included in Attachment B.

Cynthia Jaynes also introduced Dr. Edward P. Riley, recent chair of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects. Dr. Riley serves as the Co-Chair of the Steering Committee for the Substance Abuse and Mental Health Services Administration (SAMSHA) sponsored FAS Center for Excellence. Dr. Riley is a professor of psychology and the Director of Behavioral Teratology at San Diego State University and is an eminent researcher in the field of FASD. A brief summary of Dr. Riley's presentation and his slide presentation is also included in Attachment B.

FAMILY RESOURCE CENTERS NETWORK OF CALIFORNIA (FRC/N-CA) REPORT

Debbie Sarmiento reported on the activities of the FRC/N-CA meeting held on Wednesday. The minutes are included as Attachment C.

ACTION ITEMS

1. *2005 ICC Meeting Schedule*

Dr. Carlisle made a motion to accept the 2005 Meeting Schedule as proposed. The motion was seconded by Dr. Poulsen. Proxy votes were submitted by absent ICC Members: Marcy Gallagher, Thomas McCool, Beverley Morgan-Sandoz and Elaine Fogel Schneider. The motion carried with 16 votes approving the meeting schedule as recommended and one abstention.

2. *Preferred Practice Patterns for Speech-Language Pathologists In Service Delivery to Infants and Toddlers and Their Families: Guidelines for Intervention Planning and Delivery*

Dr. Downing made a Motion to accept the recommendation to forward the document as written to the Department of Developmental Services as a preferred practice. The motion was seconded by Ms. Hester.

Dr. Downing explained that 2002, Ruth Harris, M.A., CCC-SLP, of the California Speech-Language-Hearing Association (CSHA) requested the Health Systems Committee review and provide input to the *Preferred Practice Patterns for Speech-Language Pathologists In Service Delivery to Infants and Toddlers and Their Families: Guidelines for Intervention Planning and Delivery* position paper. The Health Systems Committee provided valuable input that was incorporated into the position paper. In late 2003 and early 2004, the Integrated Services and Health Committee revisited the recommendations and the position paper was amended to address the role of the speech-language pathologist with a young child with hearing loss or deafness.

Proxy votes were submitted by absent ICC Members: Marcy Gallagher, Thomas McCool, Beverley Morgan-Sandoz and Elaine Fogel Schneider. The motion carried unanimously with 17 votes approving the recommendation.

COMMITTEE REPORTS

Each of the Standing Committees reported on the progress made on activities identified in their Workplans. Each of the Standing Committees continue to assume lead responsibility for one priority area as identified in the Executive Committee Workplan. The Standing Committee reviewed the "Process and

Timeline for Submitting a Recommendation to the Department of Developmental Services”, with the understanding that it is a guideline for completing work assignments that could be modified and individualized for each committee’s needs.

As directed by the Executive Committee, each of the Standing Committees reported progress in the following areas:

- Review of the Committee’s workplan.
- Clarifying the purpose for each recommendation to be submitted.
- Discussing how to measure the impact of the recommendation.
- Plans for the next phase, including activities to be accomplished prior to the November 2004 ICC meeting.

Please see the Standing Committees’ minutes and workplans included in the ICC meeting packet for additional information related to each committee.

PUBLIC INPUT

Julie Woods, Community Representative, stated that although she is no longer affiliated with an Early Start FRC agency, she continues to work with young children and their families in her local community. Ms. Woods suggested that the ICC provide information about current legislative efforts that could impact infants and toddlers with disabilities and their families at each meeting.

Chris Nelson, Public Health Nurse from the Butte County Department of Health expressed a concern that Fetal Alcohol Spectrum Disorders be properly diagnosed early in a child’s life to ensure proper treatment. She emphasized the importance of a diagnosis in the medical model of care.

Jean Brunelli, Past Chairperson of the Infant Development Association (IDA) provided information about up-coming training events sponsored by IDA including:

- ❖ *Foundations for Interacting with the World: Sensory Integration & Sensory-Motor Tools for Young Children with Autism and Other Developmental Disabilities;*
- ❖ *Infant’s and Children’s Bodies: Seeing and Healing Trauma;*
- ❖ *Building the Future: Growing Thriving Early Childhood Communities.*

Additional information about these events can be found in Attachment D and on the IDA website at www.idaofcal.org. The website has complete descriptions of training offered and supports on-line registration.

Terry Colborn, Community Representative, provided information about the Supported Life 2004 Inclusion Celebration and Dessert Social to be held on October 6, 2004, in Sacramento. He invited all to attend and celebrate the outstanding role models who make a difference for individuals striving to belong to inclusive communities including Honoree Ken Freedlander, Chief, Early Start Local Support Section, in the Department of Developmental Services.

Kathleen Sandou provided information about an Infant Symposium sponsored by California First 5 on November 5, 2004. The guest speaker is Sharon Walsh.

CALIFORNIA EARLY START ANNUAL PERFORMANCE REPORT

Rick Ingraham provided an overview of the California Early Start Annual Performance Report (APR). This report details the current status of the State's program under Part C of the Individuals with Disabilities Education Act and is required by the United States Department of Education, Office of Special Education Programs (OSEP) as a condition of federal funding. Mr. Ingraham discussed OSEP's priorities and long-term strategies for Part C programs. He also discussed each of the APR cluster areas including:

- General Supervision;
- Public Awareness and Child Find;
- Family Centered Services;
- Services in Natural Environments and;
- Early Childhood Transition.

Data tables from the APR were displayed and Mr. Ingraham discussed how the information contained within these tables frequently serves as a proxy for some of the questions under consideration by the ICC's Standing Committees. It was agreed that Ken Freedlander would provide an in-depth presentation on this topic at the November ICC meeting. Additional information is also included in Attachment E.

AGENCY REPORTS

DEPARTMENT OF HEALTH SERVICES (DHS)

Dr. Hallie Morrow reported that the enacted budget for DHS includes \$36.3 billion (\$12.6 billion General Fund), an increase of \$4.2 billion above the revised 2003-04 Budget level. DHS administers a broad range of public health programs and the California Medical Assistance Program (Medi-Cal), which provides health care services to qualified low-income persons and families.

The Budget includes \$2.7 million from the Genetic Disease Testing Fund to expand the Newborn Screening program to include Tandem Mass Spectrometry, which will provide for screening of an additional 30 genetic diseases by August 2005. The current program screens for four treatable genetic diseases. It is anticipated that this expansion will also result in significant cost avoidance in Medi-Cal, special education, and developmental services.

Effective June 1, 2004, eligible infants can be enrolled into full scope, no share of cost Medi-Cal through the Child Health and Disability Prevention (CHDP) Gateway, without completing a joint Medi-Cal/Healthy Families application. Currently 6,000 infants are being enrolled each month.

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As of September 1, 2004 there are 174 hospitals certified by DHS to participate in the Newborn Hearing Screening Program (NHSP). There are three hospitals awaiting certification at this time.

The Children's Medical Services Branch is implementing Enhancement 47, an upgrade to the case management system, CMS Net. Challenges identified during implementation include provider acceptance, county program acceptance and making the system more user-friendly.

DEPARTMENT OF SOCIAL SERVICES (CDSS)

Cheryl Treadwell announced that Bruce Wagstaff has been appointed as Deputy Director of the Children and Family Services Division. Mr. Wagstaff previously served in the Welfare to Work Division. Ms. Treadwell is preparing to brief Deputy Director Wagstaff about the ICC and its importance for young children with and at risk for disabilities and their families.

CDSS is continuing with the implementation of the Child Welfare Services Redesign, beginning with 11 counties, as well as moving forward with the action steps identified in the federal Performance Improvement Plan (PIP) focusing on improvement of federal outcomes in the areas of safety, well-being and permanency. CDSS is currently mid-year in a three-year improvement plan process.

CDSS and DDS continue in their efforts to recommend enhancements to the current procedures for referrals to Early Start under CAPTA. CDSS will participate as part of a workgroup to begin to identify appropriate tools for Child Protective Services (CPS) workers to use for screening referrals to Early Start. It is anticipated that these efforts will remain a focus for the rest of the year. Next steps include convening a workgroup to identify best practices and procedures that exist within regional centers and county child welfare offices. CAPTA assurances were signed in August 2004, and submitted to the federal government for approval. Ms. Treadwell will provide additional information about CAPTA in a special presentation to the ICC at the November 2004 meeting.

DEPARTMENT OF ALCOHOL AND DRUG PROGRAMS (ADP)

Organizational Change

Cynthia Jaynes reported that the Program Operations Division and Prevention Services Division have been merged into the Program Services Division with separate branches for prevention, treatment, the Governor's Mentoring Partnership, and the new Office of Problem Gambling. The Office of Perinatal Substance Abuse will remain as part of the treatment branch.

Budget

Release of the 2004-2005 Budget indicated ADP will continue at the previous funding level. The Department has received \$7.6 million to implement the President's Access to Care Voucher Initiative, now called California Access to

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Recovery Effort (CARE). The federal grant will benefit youth, aged 12-20 and will allow clients to choose from several types of substance treatment, based on assessment.

Fetal Alcohol Syndrome (FAS)

ADP worked with California FAS on a campaign to recognize the problems of FASD with a Governor's Proclamation and a gathering on the steps of the Capitol on September 9 at 9:09 am.

There will be a national conference on Fetal Alcohol Spectrum and Neurobehavioral Disorders in Riverside, CA, on October 28th & 29th, 2004. For information on attending this conference call 888/818-6298.

DEPARTMENT OF MENTAL HEALTH (DMH)

Luis Zanartu reported that ADP and DMH are pleased to announce that two informational meetings have been scheduled to obtain public comment on the proposed merger of DMH with ADP as described in the *California Performance Review Report, Recommendation HHS15: Consolidate the State's Mental Health and Alcohol and Drug Programs to Better Serve Californian's*.

The two meetings are scheduled as follows:

- ▶ Tuesday, September 28, 2004, 10:30 a.m.-1:30 p.m. The Alhambra, 1000 South Fremont Avenue Alhambra, CA 91803
- ▶ Wednesday, September 29, 2004, 10:30 a.m.-1:30 p.m. State Personnel Board, 801 Capitol Mall Sacramento, CA 95814

Public Hearings regarding Proposition 63 will begin on September 29, 2004. Proposition 63 proposes to expand mental health services in California and to pay for it by taxing individuals who earn over \$1 million a year. An unusual feature of Proposition 63 is that it targets a narrow segment of the population with a special tax. With taxpayer groups stiffly opposing the proposition and mental illness advocates enthusiastically endorsing it, Proposition 63 is one of the more controversial of the 2004 ballot propositions.

Public Hearings will also be held regarding the Home and Community Based Services Waiver for specialized mental health services, including therapeutic behavioral services. The Home and Community Based Services waiver under Section 1915(c) under Federal Medicaid law gives states a policy option to allow children with a mental or physical disability to be enrolled in Medicaid even when their family income would normally exclude eligibility. For more information about the Public Hearings contact Luis Zanartu at 916/654-1889.

LEAD AGENCY - DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

Rick Ingraham provided information on the Early Start Family Resource Centers/Network Special projects. Thirty-eight grants were awarded with projects focusing on the following areas:

- Parent-to-Parent Support: 14 projects

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- Information Dissemination and Referral: 17 projects
- Transition Assistance: 5 projects
- Targeted Public Awareness
 - Parents: 4 projects
 - Medical Communities: 5 projects
 - Underserved: 14 projects
- Family/Professional Collaboration: 2 projects

Some projects have an overlapping focus; therefore numbers above do not total 38. Additional information about the Early Start Family Resource Centers Special Projects can be found in Attachment F.

DDS continues to collaborate with CDE around transition and family surveys. A joint grant proposal was submitted to develop child outcomes and study longitudinal data regarding children's progress.

DDS submitted the California Early Start Annual Performance Report to the United States Department of Education, Office of Special Education Programs (OSEP) and is awaiting their feedback.

The Early Start Personnel Development Fund scholarship activity summary for July – September 2004, is included in Attachment F.

CALIFORNIA DEPARTMENT OF EDUCATION (CDE)

Bob Evans reporting on behalf of Jim Bellotti stated that the California Deaf and Hard of Hearing Early Start Workgroup convened meetings in July and August. The group is developing proposed standards for the provision of services to deaf and hard of hearing infants and toddlers and their families, and recommending curriculum and assessment tools to be used when providing services to this population. Statewide trainings will be provided on the standards and on the curriculum and assessment tools. For more information contact Nancy Sager at 916/327-3868.

Mr. Evans reported that CDE has been working with DDS on a new version of the "Early Warning Signs" brochure, which is now titled "Reasons for Concern." Various individuals representing the field of Early Start, including FRC parents and the ICC Public Awareness Committee were invited to give input on the revisions. This publication is expected to be available in early 2005. English, Hmong, Chinese, Vietnamese and Spanish translations will also be provided.

CDE was awarded a new State Improvement Grant (SIG 2) in the amount of \$2,079,000 per year for a three-year period. The press release announcing this award is available on the CDE website. More information is also available at www.calstat.org.

The CDE website has been updated. Special items of interest are:

- Special Education Hearing Office 2003-04 Quarterly Reports
- Evaluation of the California Educational Review Process
- Special Education 2004-05 Budget Items
- Training on Writing IEPs Based on State Standards
- Request for Proposal to evaluate the Family Empowerment Centers.

Current legislation affecting state and federal special education law are listed in Attachment G. Assembly Bill 2909 (Salinas) was signed by the Governor, and requires CDE to conduct a study of the current methods of providing special instruction and other services to infants and toddlers who are deaf or hard of hearing, and report back to the legislature by January 2006 (Attachment H). For more information contact Nancy Sager.

The 2004 Budget Act did not significantly impact the Special Education Division's (SED) state operations budget. There were no personnel reductions. Changes to the SED budget are as follows:

1. Funding for the Focused Monitoring Pilot Program is authorized at \$881,000 (an increase of \$38,000 from last year).
2. Funding for dispute resolution services is authorized at \$10,140,000 (a decrease of \$123,000 from last year).
3. Supplemental funding for Ravenswood Elementary School District special education program is authorized at \$1,480,000 (a decrease of \$220,00 from last year).
4. A one-time allocation of \$180,000 is provided to evaluate the 12 Family Empowerment Centers on Disability as required by law. CDE is required to contract with an external entity for this evaluation.
5. Funding for the Early Education Program is authorized at \$74,980,000. Of this amount \$14,395,000 is deducted for reimbursements received from DDS for the Part C program. In total, the 2004-05 allocation for the Early Education Program represents an approximate \$2 million increase from fiscal year 2003-04.

ADJOURNMENT

With no additional business the meeting was adjourned at 1:30 p.m.

Attachment A

STAFF AND OTHERS ATTENDING ICC GENERAL MEETING

ICC STAFF

Cheryl Holden
Cheri Schoenborn

ICC COMMITTEE STAFF

Peter Guerrero
Angela McGuire
Stephanie Myers
Elissa Provance
Virginia Reynolds

COMMUNITY REPRESENTATIVES

Jean Brunelli
Toni Doman
Sandy Harvey
Ed Gold
Susan Graham
Laurie Jordan
Julie Kingsley
Al Millan
Robin Millar
Peter Michael Miller, M.D.
Lois Pastore
Kristine Pilkington
Letha Sellars
Julie Woods

DEPARTMENT LIAISONS

Rosa King, DDS
Nancy Sager, CDE
Dennis Self, DDS
Pat Widmann, DDS

GUESTS

Gretchen Cypin, Alta California Regional Center
Chris Nelson, PHN, Butte County Health Department
Susan Steinberg, M.D., DHS
Ed Riley, Ph.D., San Diego State University
Jamie Sullivan, El Dorado County Office of Education
Sue Winar, DDS
Michael Zito, CDE
Sharon Rea Zone, DDS

Attachment B

Summary of Special Presentation on Fetal Alcohol Spectrum Disorder:

Dr. Steinberg presented information on Fetal Alcohol Spectrum Disorder. Prenatal exposure to alcohol can cause a spectrum of disorders. One of the most severe effects of drinking during pregnancy is fetal alcohol syndrome (FAS). FAS is one of the leading known preventable causes of mental retardation and birth defects. FAS is characterized by (1) abnormal facial features, (2) growth deficiencies, and (3) central nervous system (CNS) problems. People with FAS may have problems with learning, memory, attention span, communication, vision, and/or hearing. These problems often lead to difficulties in school and problems getting along with others. FAS is a permanent condition. It affects every aspect of an individual's life and the lives of his or her family. Many terms have been used to describe children who have some, but not all, of the clinical signs of FAS. Three terms are fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). FAE has been used to describe children who have all of the diagnostic features of FAS, but at mild or less severe levels.

Children with FAS are at risk for psychiatric problems, criminal behavior, unemployment, and incomplete education. These secondary conditions are problems that an individual is not born with, but might acquire as a result of FAS. These conditions can be very serious, yet there are protective factors that have been found to help individuals with these problems. For example, a child who is diagnosed early in life can receive early intervention services provided with social services that can help the child and his or her family. Children with FAS who receive special education are more likely to achieve their developmental and educational potential. In addition, children with FAS need a loving, nurturing, and stable home life in order to avoid disruptions, transient lifestyles, or harmful relationships. Children with FAS who live in abusive or unstable households or become involved in youth violence are much more likely to develop secondary conditions than children with FAS who have not had such negative experiences. Dr. Steinberg's slide presentation is attached.

Dr. Riley provided information about the teratogenic effects of alcohol on the brain and behavior. Alcohol use during pregnancy is a leading cause of preventable birth defects and developmental delays. Fetal Alcohol Spectrum Disorder (FASD) refers to the full range of these problems. A diagnosis of Fetal Alcohol Syndrome (FAS) requires:

- a confirmed history of maternal alcohol exposure;
- evidence of facial dysmorphism (distinctive facial features);
- growth retardation;
- central nervous system (CNS) dysfunction.

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FASD is caused by prenatal exposure to alcohol; however, effects on the fetus vary widely and are difficult to predict. The cognitive (thinking and learning), behavioral, physiological or physical impairments that may occur with FASD have implications for the individual over his or her lifespan, as well as for the family, the community and society as a whole. Dr. Riley's slide presentation is also attached.