

INTERAGENCY COORDINATING COUNCIL ON EARLY INTERVENTION

GENERAL MEETING

MAY 21, 2004

MEMBERS PRESENT:

Raymond M. Peterson, M.D.; Chair; Jim Bellotti, representing CDE; Sylvia Carlisle, M.D.; Arleen Downing, M.D.; Hedy Hansen; Gretchen Hester; Rick Ingraham representing DDS; Cynthia Jaynes, representing ADP; Thomas McCool, Ed.D.; Beverley Morgan-Sandoz; 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, Elaine Fogel Schneider, Ph.D.

OTHERS PRESENT:

See Attachment A.

RECORDER:

Cheryl Holden

WELCOME AND ANNOUNCEMENTS

Dr. Peterson called the meeting to order at 8:45 a.m. and welcomed everyone in attendance. ICC members and the audience provided self-introductions.

First time meeting attendees, Edward Gold, Valerie Vosberg, Brenda Kosen and Anne Struthers, were welcomed to the meeting and Dr. Peterson thanked them for attending the Newcomers Orientation meeting.

AGENDA REVIEW

The agenda was reviewed and it was agreed that the format for the standing committee reporting would be revised for this meeting, thereby allowing each committee to report on their recommendations for the four ICC priority areas: Early Entry, IFSP, Transition and Interagency Collaboration.

APPROVAL OF MINUTES

The minutes of the February 27, 2004, ICC meeting were approved as written.

EXECUTIVE COMMITTEE REPORT

Executive Committee Chair Hedy Hansen reported that the Executive Committee met on Thursday, and that in preparation for this meeting, the Executive Committee members participated in two conference calls. During the April 2, 2004, conference call executive committee members reviewed a detailed matrix

displaying information developed by the ICC standing committees over the November 2003, and February 2004 ICC meetings. The Executive Committee asked DDS to revise the ICC's comprehensive list of goals and activities according to DDS' priorities as the lead agency. The *"Priority Recommendations for Outcomes, Activities and Data Sources"* were developed and shared with the Executive Committee on April 26, 2004 (Attachment B). The *"Priority Recommendations"* document was reviewed and preliminary committee assignments were made during a subsequent executive committee conference call on May 14, 2004.

Ms. Hansen asked Dr. Peterson to report on the Executive Committee meeting held on Thursday. He reported Rick Ingraham provided additional information on the data previously provided on the Site Monitoring Reports. The data findings are now linked to each of the 21 regional centers. Dr. Peterson noted that this information was shared with the Association of Regional Center Agencies (ARCA) and they agreed that identifying regional center catchment areas would help to identify best practices in the Early Start community. The revised reports were included in the May meeting packet. The Executive Committee also discussed strategies for reviewing the data in the standing committees and assigned lead responsibility for each of the ICC priority areas: Early Entry was assigned to PAC, Individualized Family Service Plan (IFSP) to QSDSC, Transition to FRSC and Interagency Collaboration to IHSC. The charge to the committees was to review the proposed measurable outcome, review applicable data, identify additional data or resources needed, and develop a workplan to complete the proposed assignment.

Dr. Peterson reported the Executive Committee discussed future ICC agendas and acknowledged that Cynthia Jaynes was making arrangements for a presentation on Fetal Alcohol Spectrum Disorders for the September 2004 meeting. It was agreed that for the November 2004 ICC meeting, Cheryl Treadwell will be asked to make arrangements for a presentation on the new requirement added to the Child Abuse Prevention and Treatment Act (CAPTA), which requires CDSS to have provisions and procedures for referring children with substantiated abuse and neglect to Part C, and Beverley Morgan-Sandoz, will be asked to make arrangements for a presentation at the January 2005 ICC meeting on Early Head Start.

CHAIR'S REPORT

Dr. Peterson discussed the provisions of the Governor's Budget May Revision on health and human service programs. The May Revision provides detail on the Administration's proposals to restructure and reform a number of health and human services programs including Medi-Cal, In-Home Supportive Services (IHSS), CalWORKS, Foster Care, services provided to people with developmental disabilities, and Healthy Families. The Administration has convened a number of key stakeholder meetings and prepared reform proposals that strike a responsible and reasonable balance between maintaining essential services for California's most vulnerable and at risk residents, while implementing

strategies to better manage and control program costs over the long term. Several proposals introduced in January 2004 have been withdrawn, including:

- Medi-Cal Provider Rate Reduction.
- Enrollment Caps and Co-Payments for Various Health and Human Service Programs.
- Block Grant for Immigrants program.
- Healthy Families Two-Tiered Benefit Proposal.
- Elimination of IHSS Residual Program.
- Update EPSDT Maximum Provider Rates.

STAFF REPORT

Cheri Schoenborn reported the next ICC meeting will be September 23-24, 2004, at the Lake Natoma Inn in Folsom. ICC members and community representatives were encouraged to contact the Lake Natoma Inn directly at (916) 351-1500 to make their reservations by August 22, 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 Cheryl Holden at (916) 654-2809 or Ms. Schoenborn at (916) 654-2767.

Ms. Schoenborn distributed a proposed ICC meeting schedule for 2005, for discussion (see Attachment B). The 2005 ICC meeting schedule will be an action item at the September ICC meeting.

The ICC Annual Report is in response to Title 34 Code of Federal Regulations (CFR) §303.654. The next report is currently under development will provide information for Fiscal Year (FY) 2002-03 and FY 2003-04. It is anticipated that a draft of this report will be available for ICC input at the September meeting. The target date for report completion is November 2004. Ms. Schoenborn explained that the ICC's Annual Report is different from the data DDS, as lead agency, is required to submit annually. The U.S. Department of Education, Office of Special Education Programs (OSEP) has a prescribed reporting structure for a State's Annual Performance Report (APR). The APR is responsive to the requirements under Title 34 of the Code of Federal Regulations (CFR) §303.540. OSEP does not have content or formatting requirements for the Annual Report submitted by the ICC. The ICC's report is for the Governor and OSEP and is a report on the status of the early intervention program under Part C of the Individuals with Disabilities Education Act (IDEA).

Ms. Schoenborn announced that Shelia Wolfe, staff to the Integrated Services and Health Committee (ISHC), will be leaving WestEd in June. Peter Guerrero, WestEd, will provide staff support to ISHC. Angela Maguire, WestEd, will provide staff support to the Quality Service Delivery Systems Committee (QSDSC). Elissa Provance and Stephanie Myers will continue their assignments with the Public Awareness Committee (PAC) and Family Resources and Supports Committee (FRSC), respectively. Committee staff and DDS liaisons can arrange

conference calls if committees require additional discussions in order to complete assignments between ICC meetings.

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

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

**SPECIAL PRESENTATION: NATIONAL EARLY INTERVENTION
LONGITUDINAL STUDY: CHILD AND FAMILY OUTCOMES AT 36 MONTHS**

The ICC welcomed Dr. Kathleen Hebbeler from SRI International, who provided information on the National Early Intervention Longitudinal Study (NEILS). NEILS is a longitudinal study that is following more than 3,338 children with disabilities or at risk for disabilities and their families through their experiences in early intervention and into early elementary school. The study provides information about the characteristics of children and families, the services they receive, and the outcomes they experience.

A nationally representative sample of 3,338 children between birth and 31 months of age and their families who began early intervention services for the first time between September 1997 and November 1998 were recruited for the study. The sample families were recruited in 3 to 7 counties in each of 20 states.

The study asked the following questions:

- Who are the children and families receiving early intervention services?
- What early intervention services do participating children and families receive, and how are those services delivered?
- What are the costs of these services?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics and services provided?

Telephone interviews were conducted with families to obtain information about child and family characteristics, child functioning, and families' perceptions of services. Families were interviewed when their children entered early intervention, annually on the anniversary of their entry, when their children were 3 years old, and again when they enter kindergarten.

Preliminary findings from the NEILS with emphasis on functional results at exit from early intervention were discussed. Additional information is available on the NEILS website, www.sri.com/neils and in Attachment D.

COMMITTEE REPORTS

Each of the ICC Committees discussed all of the ICC priority areas and the Committee Chairs provided input to the “lead committee” for that priority area. Recommendations included ways to make outcome measures more sensitive, and strategies to increase family-centered care and cross-committee collaboration. Additional details are contained in the standing committees’ minutes and specific workplans.

PUBLIC INPUT

Jean Brunelli, Past Chairperson of the Infant Development Association (IDA) provided information about the 12th IDA of California Conference, *Building the Future: Growing Thriving Early Intervention Communities*, scheduled for April 21 – 25, 2005, in Los Angeles. This biennial conference provides a forum for training and interchange among a broad range of disciplines, across agencies, and among family members and advocates who are involved in improving outcomes for infants, toddlers and their families throughout California. Additional information about this conference and training events for 2004-2005 are available on the IDA website at www.idaofcal.org. The website has complete descriptions of training offered and supports on-line registration.

Debby Reath, Early Start Local Support Section, expressed her gratitude to the Exceptional Family Resource Center in San Diego for their invitation and hospitality toward the site monitoring team while they used the FRC to conduct the Family Interview portion of the site monitoring visit. Ms. Reath extended her appreciation to Dr. Peterson and the San Diego Regional Center for their warm welcome and participation. She also thanked Lois Pastore of the San Diego County Office of Education for providing local education agency representation.

AGENCY REPORTS

CALIFORNIA DEPARTMENT OF EDUCATION (CDE)

Jim Bellotti reported that CDE, like other state agencies, continues to operate under a hiring freeze. The Part C position in CDE continues to be vacant.

On May 13, 2004, the Senate approved HR 1350, which would reauthorize the Individuals with Disabilities Act (IDEA), by a vote of 95-3. The House passed this last April by a vote of 251-171. Of the six amendments debated on the Senate floor, the two full funding amendments drew the most partisan debate.

The Governor’s Budget May Revision restores \$107 million for deferred maintenance, \$100 million for instructional materials, and \$28 million for revenue limit equalization of the reductions proposed in April. Revenue limit funding increased by \$169 million to reflect a higher cost of living allowance (COLA) and decreased by \$118 million to reflect slower enrollment growth. Increased federal funds and Proposition 98 funds are provided for various special education purposes including Licensed Children’s Institutes (\$38 million), mental health services (\$31 million), and COLA (\$21 million).

CDE has reconfigured their website. The new address for the Special Education Division (SED) is www.cde.ca.gov/sp/se/. The Child Development Division (CDD) website is www.cde.ca.gov/sp/cd/.

Senate Bill 1343 (Escutia), would require CDE to develop a master plan for infant and toddler care for children birth to three years in consultation and collaboration with a task force to be established by the superintendent and comprised of prescribed members indicated in the legislation. The plan would be submitted to the Legislature on or before January 1, 2006, and would then be updated every 5 years thereafter, providing for public input. The bill indicates that the Legislature will appropriate \$100,000 in FY 2004-05 through a subsequent measure for development of the plan if another \$70,000 is raised from non-state sources for the same purpose.

In response to a request from First 5 California, the Superintendent has designated Chris Drouin, SED and Mary Smithberger, CDD, to represent CDE on the Special Needs Project Advisory Committee. Sonoma State University's California Institute on Human Services is administering the Special Needs Project. The purpose of the project is to strengthen the First 5 School Readiness Initiative, Preschool for All, and Health Access for All Children 0-5 by demonstrating and disseminating effective practices for programs and systems serving young children with disabilities and other special needs.

The Early Start Deaf and Hard of Hearing Workgroup will have its first meeting in June 2004, to develop standards for assessment and service provision for deaf and hard of hearing infants and toddlers. The workgroup is being funded by a grant from the federal Maternal and Child Health Bureau.

DEPARTMENT OF HEALTH SERVICES (DHS)

Dr. Hallie Morrow reported that Governor Arnold Schwarzenegger announced the appointments of Sandra Shewry, as Director of the Department of Health Services, and Dr. Richard Jackson, as State Public Health Officer, completing the senior management team of the Department. Ms. Shewry returns to state service after having served for many years as the executive director of the Managed Risk Medical Insurance Board. Most recently, she has been with the National Governors Association Center for Best Practices. Dr. Jackson returns to DHS after ten years with the Centers for Disease Control and Prevention. As DHS Director, Ms. Shewry will provide overall leadership for and management of the programs and activities of the Department. Reporting to the Director, Dr. Jackson, as State Public Health Officer, will be responsible for providing leadership and oversight of the Department's public health related activities.

Dr. Maridee Gregory retired from state service on April 30, 2004. Dr. Marian Dalsey has been appointed Acting Chief over the Children's Medical Services Branch.

The Governor's Budget May Revision has:

- Eliminated proposed caps on California Children's Services enrollment.
- Eliminated proposed caps on Healthy Families enrollment; increased the monthly premiums to \$15 per child and \$45 for 3 or more children.
- Does not include Medi-Cal reform or departmental reorganization. The Medi-Cal Reform Report will be announced in August 2004.

Dr. Morrow also reported that it is anticipated the California Performance Review will also be released in August.

As of May 7, 2004, there are 164 hospitals certified by DHS to participate in the Newborn Hearing Screening Program (NHSP). There are 14 hospitals awaiting certification and it is anticipated that these will be completed by July 2004.

The World Council on Hearing Health has released the Annual State Report Card on Newborn Hearing Screening. California was one of three states with an unsatisfactory ranking. An unsatisfactory ranking is given to those states that screen less than 80% of all infants born in the state. A total of 66% of infants born in California were screened. Based on data from the Hearing Coordination Centers, California had a 5% lost to follow-up rate compared to 30-50% in other states. When the NHSP is fully implemented, California will be screening about 400,000 infants, more than any other state; however this number is approximately 75% of the total births statewide, therefore will receive an unsatisfactory rating. It is important to note that the Report Card does not evaluate the quality of the screening programs or success in providing identified infants with services - it only measures number of infants screened.

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. Eligible infants are those under one year of age whose mothers had Medi-Cal eligibility at the time of delivery, who lived with the mother during the month of birth, and continue to reside with the mother in California. This includes infants whose mothers were enrolled in a Medi-Cal Managed Care plan and those whose mothers had Medi-Cal with a Share of Cost that was met at the time of birth.

The Children's Medical Services Branch is providing training on policies and procedures related to Enhancement 47 (E-47). E-47 is an upgrade to the case management system, CMS Net. E-47 will be implemented on July 1, 2004, and conversion will require modifications to some existing business processes. E-47 will allow CCS providers to electronically bill for authorized services. Providers at a Special Care Center (SCC) must be listed in the SCC directory in order to be reimbursed for services authorized to the SCC.

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Dr. Morrow distributed a handout, "Children's Medical Services Branch Policy and Program Letter" (Attachment E). Policy and program letters are posted online at www.dhs.ca.gov/pcfh/cms/onlinearchive.

DEPARTMENT OF SOCIAL SERVICES (CDSS)

Cheryl Treadwell shared that she participated on an Early Start site monitoring visit in San Diego and encouraged ICC members to participate in this educational and informative experience.

The Governor's Budget May Revision provides an increase of \$135.2 million to pursue a federal Independence Plus Waiver for the IHSS Residual Program in lieu of eliminating the Residual Program. The Waiver will allow the federal government to pick up a share of cost for the program estimated at \$264 million in the 2004-05 budget year and leave the IHSS program in tact.

The IHSS Quality Assurance (QA) Initiative will receive funding for four positions to monitor implementation of QA procedures. When QA procedures are fully implemented in every county, annual on-going savings are estimated to be \$92.3 million General Fund beginning in FY 2006-07.

The May Revision continues a series of new foster care reforms proposed in the Governor's Budget to promote the care of more children in a family home environment and to shorten the period of time children spend in foster care, particularly in more restrictive placements such as group homes. Foster care caseload projections have decreased significantly from the Governor's Budget, indicating reduced entries and increasing exits from the system. This positive change is partially due to the implementation of reforms initiated by the Adoptions and Safe Families Act, California's Improvement Plan, and the new California Child Welfare Outcomes and Accountability System.

CDSS is analyzing the potential impact of the Child Abuse Prevention and Treatment Act (CAPTA): Keeping Children Safe Act of 2003. CDSS and DDS staff are completing an analysis of current practices and developing recommended enhancements to the current procedures for referral to Early Start.

Ms. Treadwell provided an update on the status of the Child and Family Services Review (CFSR), also known as the Outcomes and Accountability System. The counties are in the process of completing a self assessment that provides information on the outcomes of safety, permanency, and well-being of children and families.

DEPARTMENT OF ALCOHOL AND DRUG PROGRAMS (ADP)

Cynthia Jaynes reported that Michael Cunningham has been appointed as Deputy Director of the Program Operations Division. Mr. Cunningham worked with ADP in several capacities over many years and has been part of Center for Substance Abuse Treatment's workgroup on Fetal Alcohol Syndrome (FAS) issues.

The Governor's Budget May Revision indicates the ADP may undergo a slight reduction. The Office of Perinatal Substance Abuse (OPSA) Branch has taken the lead on applying for the President's Access to Care Voucher Initiative. If successful in its application, California will receive up to \$15 million to fund clients, rather than programs. The grant proposal was written to benefit youth, ages 12-20 and will allow clients to choose from several types of substance abuse treatment.

A Conference on Fetal Alcohol Spectrum and Related Neurobehavioral Disorders called *On the FAS Track to Understanding* will be held October 28 - 29, 2004, at the Riverside Convention Center in Riverside, California. A call for workshop proposals is included as Attachment F. For information on attending this conference call (888) 818-6298.

DEPARTMENT OF MENTAL HEALTH (DMH)

Luis Zanartu provided a summary of adjustment to the 2004-05 Governor's Budget included in the May Revision related to community services for young children and their families:

- A reduction of \$46.5 million in reimbursements from DHS for the Early, Periodic, Screening, Diagnosis, and Treatment (EPSDT) Program.
- A reduction of \$48.9 million in reimbursements from DHS for the EPSDT Program in the current year. This is a result of a decrease in the total cost of settled claims from the amount used in developing the funding request included in the 2004-05 Governor's Budget based on more current claims information.
- A General Fund reduction of \$480,000 following adjustments for the Managed Care Program.
- An increase of \$275,000 in reimbursements from DHS to reflect caseload adjustments for the Healthy Families Program.
- A decrease of \$31,000 in reimbursements from DHS to reflect caseload adjustments for the Healthy Families Program in the current year.

LEAD AGENCY – DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

Data and information. Rick Ingraham stated that, "Personal stories are the harbingers of change. Good data provides the leverage for change." As California's lead agency for IDEA, Part C, DDS seeks to provide the necessary data and information to equip the ICC and the standing committees in their mission to advise and assist the lead agency. To this end, several important reports were included in the May meeting packet including:

- Annual Performance Report for the State of California 2002 – 2003; page 135
- Down syndrome data – age at entry into the regional center system; page 189 (including a correction sheet as a meeting handout)
- OSEP Monitoring and Intervention Priorities and Methods: Questions and Answers; page 191, and
- California Early Start Monitoring Tool; page 197

Comprehensive System of Personnel Development (CSPD). Mr. Ingraham provided an update on the activities. The Service Coordination Institute: Advanced (SCIA) will be held on May 26 – 28, 2004, at the Sacramento Hilton. A new section of the *Service Coordinator's Handbook, Generic Services and Resources*, will be highlighted during the training.

Service coordinator training. The three Core Institutes for Early Start service providers are being reorganized based on input from prior attendees. The three-day institutes are going to be shortened to two days and will be held during the week, rather than on a Saturday. The end result will be four two-day institutes. In addition, the curriculum is being updated to reflect the latest evidence-based practice. The Core Institutes will be presented from October 2004 through March 2005. The proposed timeline for the Early Start Training Institutes are included as Attachment F.

The **Personnel Development Scholarship fund** has awarded \$255,758 through April 2004, resulting in 2930 personnel trained this fiscal year. There remains a balance of \$45,000. The Awards Activity Report is included as Attachment G.

Physician/health practitioner Training. The Regents of the University of California, San Francisco, Office of Continuing Medical Education (UCSF CME), under contract with DDS, conducted a two-day training, *Developmental Disabilities: An Update for Health Professionals*, on March 12-13, 2004, at the UCSF Laurel Heights Conference Center.

Health care professionals were asked, "How will you incorporate what you have learned in this course in your patient care?" Some of the responses included: "I can now better help these clients and their families with my knowledge and compassion and with providing resources and info." And also, "Be more aware of the signs and symptoms that may suggest a medical/dental problem." A compilation of feedback addressing this question is included as Attachment H.

Site monitoring visits. The Early Start Local Support Section has completed a site monitoring visit to San Diego Regional Center. Mr. Ingraham encouraged ICC members and others to attend an Evaluator Training session and participate on a monitoring team in order to develop a full appreciation for the Early Start program.

CAPTA (federal Child Abuse Prevention and Treatment Act). Mr. Ingraham mentioned DDS' survey of the regional centers regarding CAPTA. That is, what are the counties and regional centers currently doing to refer and serve 0-3 yr. olds in the Child Protective Services program with the counties? DDS is summarizing that data for release.

ICC membership. DDS has discussed ICC membership with the California Health and Human Services Agency (CHHSA) and the Governor's Office. A

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notice to the Early Start community will be sent when DDS receives approval to seek applications for appointment to the ICC.

Public information /outreach. Mr. Ingraham discussed inquiries received on the Early Start toll-free telephone information line. The “Babyline” Router System can be reached at 1-800-515-BABY (2229). The activity report is included as Attachment I.

State budget. The Governor’s Budget May Revision includes total DDS expenditures of \$3.5 billion, an increase of \$68 million above the Governor’s Budget released on January 10. The May Revision provides additional detail on the \$100 million savings for proposed cost containment measures in the regional centers purchase of service budget. The FY 2004-05 savings are associated with the following:

- Statewide Purchase of Service Standards;
- Family Cost Participation Program;
- On-going impact of temporary cost containment measures implemented in FY 2003-04, including but not limited to freeze on resource development at the regional centers, rate freezes, etc.
- Decrease rate of program growth; and
- An offset from increased federal funds.

However, everyone needs to recognize that the budget is far from final with the legislature just starting the discussions on the Governor’s May Revision.

OTHER BUSINESS

Linda Landry announced that at the 6th Annual Conference of Early Start Family Resource Centers and Networks, ICC Member Marie Kanne Poulsen, Ph.D., received the Distinguished Professional Award, honoring “her unyielding commitment to children and families.” Community Representative Kathleen Colvin was honored for her commitment and individual efforts toward the advancement of the FRCs. The Support for Families Family Resource Center received the FRC Advancement Award.

Teresa Rossini reported that the FRSC has become aware of other statewide agencies and organizations that are working to establish new or expand existing family resource services/centers. Ms. Rossini requested that the ICC/DDS consider sending a letter to agencies planning to release Requests for Proposals (RFP) highly recommending collaboration with Early Start Family Resource Centers as a condition of funding or awarding extra points to those applicants who include collaboration with the Early Start FRCs.

ADJOURNMENT

With no additional business, the meeting was adjourned at 1:16 p.m.

Note: Electronic copies of minutes do not include attachments. For a copy of attachments, please contact earlystart@dds.ca.gov.