



IDEA Infant Toddler Coordinator Association Annual Business Meeting November 2, 2003

Member States Present: Alaska, American Samoa, Arizona, Connecticut, Delaware, Florida, Georgia, Guam, Hawaii, Idaho, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Puerto Rico, South Carolina, Utah, Vermont, Virgin Islands, Washington, West Virginia, Wisconsin, Wyoming

Member States Absent: District of Columbia, Illinois, Mississippi, Northern Marianas, Pennsylvania, Rhode Island, Texas

Guest States: Alabama, Arkansas, California, Colorado, Michigan, Minnesota, Missouri, Montana, South Dakota, Tennessee, Virginia

Welcome and overview of status of ITCA - Duncan Munn

- Duncan provided a review of the Board's activities since the 2002 meeting.

Professional Development Opportunities - Stephanie Moss/Andy Gomm

- Update on Leadership Academy: ITCA solicited input on what states would be interested in attending the Leadership Academy. An interest survey is in the meeting packet. States should complete the form if they are interested in attending the Academy. State budget constraints were identified as the reason that coordinators could not participate in the 2003 Academy. If states would be more able/likely to attend if the expenses were paid (and Part C coordinator then only contributed "personal or vacation" days, please note that on the interest form. The Academy is usually planned for summer but is not locked into that; if there is a particular month that is better note that as well.
- Mentorship: ITCA is attempting to develop a formalized mentor program for new Part C Coordinators; sometimes there are 10 or 12 new coordinators per year (this year 3). The mentorship concept is intended to provide support for coordinators in their first year because there is so much to learn. In order to accomplish mentor program ITCA will:
 1. Identify (volunteers) willing to commit to be a mentor for a year (12-15)
 2. Identify new Part C Coordinators (in a member state) willing to be mentored
 3. Identify a Mentorship Coordinator: to identify a match (see criteria in handout)

4. Support mentor relationship with a Mentor Coordinator on board or staff to ensure regular communication between two is maintained/follow up on issues of concern; be resource for mentors

The question was raised "Could a secondary phase of this be a mentorship for those Part C coordinators who are not "new" but still need some support? " The response was "sure". Participants were requested to provide some input on the handout sheet provided and remember to check web site.

Family Cost Participation: Sue Mackey Andrews

In response to request from last year to have more information about how states are doing FCP, ITCA commissioned a study by Solutions to investigate the FCP issue.

Key findings:

- Doesn't seem to be a relationship between services and fees
- Doesn't seem to be a relationship between funding source accessed and FCP
- Few states could explain in detail amount of income from insurance since it is typically collected at the local level; States with insurance legislation are accessing significantly more insurance revenue than those without.

Next steps: To incorporate into the National Survey; Verify data; ITCA web with Resource Material; additional analysis. States will not be identified individually until verified and or agreed to by state.

Have collected for each state: policies/regulations/forms/procedures/ and will post on ITCA web site. This is such a volatile topic and changes so significantly that there is no guarantee that what is posted will be accurate at the point you view it. Between April when 11 states were surveyed for MO and August when remainder were surveyed, 5 of the 11 changed their policies.

Get demographic information in order so you can better understand what your state looks like in terms of federal poverty level, number of military bases, reservations and other resources that effect your access to these funds.

Prevalence Standard: Duncan Munn, Ron Benham

The Board of the Association supports getting 2% of the birth population into Part C.

Question we need feedback on: Do you support the 2% floor? ITCA does, OSEP has said states should decide themselves. Do you believe all states should use as goal to serve 2% of the 0-3 population?

Q: What does being served mean?

A: All children with IFSP at the given point in time (Dec 1) (OSEP)

Q: Could someone talk about rationale for excluding the at risk children in these figures?

A: There are two charts (one with/one without)

Q: Which is OSEP criteria?

A: The one without.

Hawaii: OSEP was just in Hawaii and looked at children without (risk) and excluded our environmental factors

Arkansas: OSEP told us although we are serving 2% we could not tell which children in which region were over the 2 % and we had to show each county/area was over 2%.

New Mexico: We are way below on at risk but we set a target that we all feel comfortable with it as a benchmark even though we know it is not epidemiologically correct.

South Carolina: I worry that if you set 2% you are setting ceiling instead of floor. When you put a base number, folks are going to say that is the minimum I have to do.

Florida: 5% of population is eligible in Florida because we ran the data and a regression and we are doing a follow up to that study but we are serving more.

North Carolina: We are doing an Ages and Stages on all kids; have folks stationed in the pediatric units and are finding 90% of kids eligible.

State Issues: Duncan Munn

Each year the Board engages in a strategic planning process that determines what our services and products are for the coming year based on input from member states. What can the Association do for you?

Issues identified:

- Neils data
 - this data needs to be published faster;
 - concerns about the average cost data;
 - need average costs for non Part C programs as comparison
- Annual Performance Report
 - Issues with formatting and the content
- CAPTA
 - mandatory referral/enrollment of substantiated cases of abuse and neglect);
 - financing potential through EPSDT;
 - existing partnerships with child welfare;
 - professional development; and

- effective ways to get information out to states.
- Child Outcomes
 - How to identify appropriate outcomes for kids

Regional Resource Centers: Jim Henson

An overview of the Regional Resource Centers was provided.

- Products: customized products, information and services on variety of topics
- Provide TA on Federal priorities:
 - SIP and data systems
 - Monitoring of local districts re: IDEA
 - Due process
 - Parent involvement
 - Child identification
 - Systemic issues/needs
- Structure of RRC TA" (chart) ranging from just a consultation to having a TA agreement, which is implemented and then evaluated.
- Historically staff just worked with Part B but RRCs are trying to expand that so C can access more. Each RRC may have different approach.

NECTAC: Tal Black

- October 1st began 3 of 5 year contract.
- Added staff Linda Fletcher, Ann Lucas, Sharon Ringwalt, Christina Kasprzak
- Focus shifted to individual work with states around a specific issue on implementation of 619 and early intervention. (Session in conference re this topic)
- Still an information resource for states; have website
- New: Communities of Practice for OSEP; New initiative of 6 "communities of practice": e.g. Settings (natural environment) paired with a NEC*TAC staff member and an RRC.

Q: What's the goal of CP?

A: In terms of giving states adequate support, there ought to be a mechanism for states to help each other and address these things; initiative to allow and create a system for states to learn from each other.

Good News Document: Duncan Munn

We want to create a paper that identifies good things have resulted from Part C whether it is kid outcomes, child care connections, improved relations, whatever, so if you have some good news from your state, get them to Maureen and we'll develop a briefing paper so you can show your legislature.

National Survey: Stephanie Moss, Andy Gomm, Karleen Goldhammer

Goal: update national survey and avoid all the surveys we get weekly. The Board wanted to improve the access and utilization of the survey, so you had current information and could easily make changes. The Association issued an RFP to develop the web based application. This information is going to be critical for states and at national level. States are encouraged to update and complete (will cut down on the work later)

Member Version of National Survey:

Full function
All data tables
Password Protection
Data Entry
Summary Reports
Detailed Reports
State responses

Non member Version:

Limited function
Summary tables
Data entry
Summary reports

New design (web based) eliminates some barriers: installing a program; is more accessible; has frequently asked questions including what some of the questions MEAN so you can respond appropriately; one function is ability to email questions not on Frequently Asked Questions;

Time line:

- 10/03: contract; incorporate other surveys/create data entry pool
- 11/03: final question edits; test data entry; invite Part C Coordinators to respond, web site development; print responses
- 12/03-1/04-Full reporting and query capacity developed and implemented(with full protection of the state level detailed reports so only what states want to share is available.)

States can choose to update only one section of survey without having to do whole thing.

The Association has developed criteria for when anyone on the board is contacted for some grant: you have to use ITCA data before you contact individual states. We do want to give supports to RRCs but we may establish some fee for more detailed data...in some cases we cannot share data, in some we cannot share the detailed data, in others we can share for a fee....but we are thinking about a fee structure for non members.

Early Childhood Issues Panel: Opportunities for Collaboration

Each representative identified current issues and opportunities from their organizational perspective.

- **Dan Berland, NASSDDS Federal Policy Analyst**
 - We polled our membership to identify 5 priorities for our strategic plan
 1. Strengthening system wide quality assurance/quality improvement

2. Research goals Charlie Laiken at University of Minnesota to create national research agenda
 3. Supporting people with unique needs in the community: working with mental health directors/continued research on this
 4. Developing a skilled workforce: current or impending crisis in direct support workforce -Re-inventing Quality Conference always focuses on this
 5. Developing responsive finance: tracking state budgets, Medicaid
- Just completed an individual projects study. In most states that use individualized budgets, they can use it as a way for families to have control over the funding (direct and manage services available) for their children. Provides information (report available).....on variety of finance characteristics. Implications: are budgets data based; are spending caps used; See web site: NASSDDS
Book handout: Strategic Plan and Project Agenda.

▪ **Meg Booth, Association of Maternal and Child Health Programs**

- Main Goals: Strengthen national policy and increase resources for maternal, child and family health programs through our Washington presence and build the capacity of state family health programs by linking states to one another, identifying model programs and providing technical assistance
- Priorities: prenatal health, child health, adolescent health and through the span of women's health
- Title V block grant: There will be 30 states that lose block grant funding under current Congressional proposals. If the President's budget request had been fulfilled, only 11 states would lose funding.
- Nearly half the Part C programs are in state health departments, many within the MCH program. Care Coordination is a strong function of most state MCH/CSHCN programs and is an important role our members play in the Part C system.
- New MCHB funding -- SECCS grants (State Early Childhood Comprehensive Systems): will be phased-in to replace the Healthy Child Care America CISS grants: The SECCS grants are currently two year planning grants to 51 states and territories (48 states, DC, Puerto Rico and Palau):. States are required to develop a statewide strategic plan around 5 identified priorities (access to a medical home, early care and education/childcare, mental health/social-emotional development, family support and parent education). The National Center for Infant and Early Childhood Health Policy was created to assist states with the new grant. The National Center partners include UCLA Center for Healthier Children, Families and Communities, Johns Hopkins University Women and Children's Health Policy Center and AMCHP.

- AMCHP recently started a new project funded by The Commonwealth Fun to look at state Title V funded hotlines mandated to provide information on prenatal care. AMCHP is looking specifically at the extend information provided by the hotlines on early childhood development and services. We are doing 10 state case studies to see if they are using their 800 line to link in or coexist with other agencies. A 50 state survey will go out in the next two weeks. A parent has been commissioned to call all state hotlines to see where they get referred. Documents on this project should be released on the web by this summer.
 - Infant Mental Health Video: AMCHP recently released a video highlighting the importance of early childhood social emotional health and the role of Title V.
 - The 2004 AMCHP Annual Conference (February 28-March 3) will focus on mental health.
 - AMCHP depends on numerous coalitions and partnerships, they are critical to our existence because we deal with so many issues. Some examples of our partnerships for children with special health care needs include the Consortium for Citizens with Disabilities, Family Voices and families.
 - A successful partnership for adolescent health includes AMCHP's work with state Adolescent Health Coordinators; the partnership has show how to merge health related and educational projects and school based teen pregnancy prevention programs.
 - Women's Health Partnerships: Safe Motherhood partnerships to reduce infant mortality.
 - Other important issues we work with other organizations and coalitions include: Medicaid reform and immigrant health, etc.
 - All partners and more information on AMCHP on web site: www.amchp.org
- **Cindy Oser: ZERO TO THREE**
 - ZERO TO THREE Priorities: 25th anniversary; strong focus on science base of early childhood development; not a membership organization. Current issue of the journal highlights past contributions of "old timers" and IDEA article.
 - Head Start: we focus on prenatal to 3 (Early Head Start - EHS); we worked to keep EHS out of the block grants to states, since states did not have to adhere to standards; want set aside increased for EHS and overall HS appropriation increased; requirement for testing of all 4 year olds controversial - it has to be developmentally appropriate; Child care/TANF should continue to allow exemption for parents of infants (one proposal increases the work requirement to 40 hours a week with no child care)
 - Part C: maintain so it is not taken apart, that mental health is a viable part; include funds for teaching people about socio-emotional development.

Worked to include language (based on National Academy of Sciences recommendation) that children involved in substantiated cases of abuse or neglect be referred to Part C. Must now work to assure that all funding resources are used to support that process. Infant mental health - working with National Prevention Coalition to have impact on President's New Freedom Commission; Pre-K: Governors and state departments of education see promise in programs for 4 year olds (to improve school readiness and narrow the achievement gap) but this may take money away from other things so we want to emphasize; continue to build bridges to encourage people to work from birth to five to get children ready for school.

- State Early Childhood Policy Forum: Working in partnership with the National Governors Association to support a small group of state-level early childhood policy leaders (13 individuals in the first class, and 11 current fellows). Fellows are usually in charge of Governor's Pre-K or early education initiatives; the Forum help them get their systems in place and allows us to talk to them about 0-3 and birth to five systems (see www.zerotothree.org/policy).
- National Infant and Toddler Child Care Initiative to work with 18 states and child care coordinator to improve infant toddler childcare. They understand Part C, 619, early childhood and will be including these programs in their new searchable data base at <http://nccic.org/itcc>.
- Better Baby Care Campaign: Advocacy effort to improve care for infants and toddlers in partnership with the National Association of Child Care Resource and Referral Agencies (NACCRRA) and Voices for America's Children. BBC gives grants to state groups to work on grassroots advocacy; get out media messages and create a national network of baby care advocates. State by State data sheets posted on their web site (www.betterbabycare.org).
- *Growing Up Healthy*: A new short and punchy piece to get county commissioners, mayors and city councils involved in health and development of infants and toddlers; highlights babies with special needs throughout. A joint effort by ZTT, the National League of Cities, and the National Association of Counties. Available to download at www.zerotothree.org/policy
- *America's Babies: the ZERO TO THREE Policy Data Book*: A new publication highlighting a variety of baby data, family and economic data and other related statistics; Part C coordinators will receive a free copy.

Legislative Update: Sharon Walsh

See Handout: What's Happening in Washington? DEC October 13, 2003 and Nov 03 ITCA newsletter

- Reauthorization will not be completed this session. We are currently waiting on the Senate committee report

- CAPTA-this is not going to stop; introduced in multiple bills, we'll put a link on our web site for you. *Consider this from "consent to refer" policy in your state, surrogate parent issue, foster parent issue, and other strategies for continuing dialogue.
- Head Start Reauthorization
 - House Bill passed but Senate bill awaiting reauthorization.
 - Head Start testing going on now: scores due in two weeks. Some bills would stop and others delay the testing. Very controversial
- Commission on Mental Health: "Traditional reforms are not enough...recommends fundamentally transforming how mental health care is delivered in America"
- No budget for FY04-extended to Nov 7. Danger is HUGE pieces of legislation with all kinds of things in them.
- FOA Family Opportunity Act: creates options for families with children with disabilities to apply for Medicaid and still work.
- CCDBG and TANF-Increased work expectations and no child care.
- Optional Birth to Six - State Option
 - Parents in Part C, eligible for 619, could stay in C IF there are pre-literacy, language, and numeracy skills.
 - If you do this, it will be run according to Part C not 619. Trick is will states still have to run a 619 program.

National Center on Child Outcomes

Awarded October 1, SRI is the Prime grantee, Frank Porter Graham, University of Kansas, NASDSE and Mary Beth Bruder in conjunction with Don Bailey

5 year Center for Research, TA and Collaboration

- Office of Management and Budget critical of OSEP for not having outcome data on birth to three
 - May take some small set of outcomes to fast track and a larger set to be developed more slowly and develop more fully.
 - Has dual goal of meeting states' needs (for their own decision making, to report to their legislature and to OSEP) and OSEP's needs to report to Congress
 - Advisory Board: We are working with OSEP toward representation of perspectives. This group is like a standing stakeholder group: first level of response followed by "going public" on web site for comment (remember it's a fast track so don't wait to comment-decisions will be made fast)
 - Technical Work Group

ISSUES INPUT

The Board will be meeting with Ruth Ryder and OSEP staff to inform them of some of the key issues. If you have any areas of interest or concern that we can bring up with the staff, please identify:

- Annual Performance Report and Neils study
- Different interpretations to relationship between the annual performance report and those of us states who have improvement plans with quarterly reports due, everything in our improvement plans are part of the quarterly report (one due in Nov and one due in DEC)
- If we are going to do data point changes, we need at least a year to make those changes and they cannot make those changes and expect us to report on them in the same year.
- Bring in family involvement to these conferences should not be responsibility of only the state, NEC*TAS should step up and OSEP should step up.
- Could there be one day at the meeting where the states could meet for a couple hours with their OSEP representative to follow up on unresolved issues.
- How about some clarification on the issues of confidentiality and conflict of interest between HIPAA, CAPTA, FERPA?