

I. ICC MISSION STATEMENT

"The mission of the Utah Interagency Coordinating Council for Infants and Toddlers with Special Needs and Their Families (ICC) is to assure that each infant and young child with special needs will have the opportunity to achieve optimal health and development within the context of the family."



MINUTES OF THE UTAH INTERAGENCY COORDINATING COUNCIL (ICC) FOR INFANTS AND TODDLERS WITH SPECIAL NEEDS AND THEIR FAMILIES Utah Department of Health, Division of Community and Family Health Services 44 North Medical Drive, Salt Lake City, Utah, Main Conference Rooms September 15, 2006 // 9:30 AM – 12 Noon

Attendance (alphabetical): Cheryl Alexander, Paul Carbone, Tandi Cichoski, Angelique Colemer, Karen Ekker, Kristine Fawson, Barb Fiechtl, Jana Homer, Debbie Justice, Catherine Nelson, Judi Nielson, Jill Oberndorfer, Sue Olsen, Susan Ord, Gina Pola Money, Marcela Rafide, Krissie Summerhays, Liz Kuhlman (proxy for Patti Van Wagoner), Shylo Wheeler, Holly Williams

Excused:

Other Attendees: William Greer, Dr. George Delavan, Lisa Morrise (Medicaid)

Baby Watch Staff: Brent Baum, Patrice Isabella, Vanya Mabey.

- I. WELCOME/INTRODUCTIONS.** The meeting commenced at 9:30 AM, conducted by Catherine Nelson. Introductions of new members and today's guests.
- II. MINUTES.** Read and approved for May 19, 2006. Suggested changes, motion to approve minutes with corrections, seconded, and approved by members.
- III. REVIEW OF MEMBERSHIP.** Cathy Nelson reviewed the required composition of the ICC and the requirements and duties of membership. New members were referred to Brent Baum for assistance in completing their membership applications and other related tasks. Members retiring from the ICC are Marcela Rafide (Parent Representative), Dr. Nancy Murphy (Provider Representative, Medical/Pediatrics) and Dr. Mark Valentine (Provider Representative, Medical). Members who have terms up for renewal are Barbara Fiechtl, Kristina Hindert, Debbie Justice, and Catherine Nelson. A number of current members have not received their appointment letters from the current or former Governors. Brent Baum will follow up and make sure that each member has the appropriate letter of appointment.
- IV. NOMINATION OF NEW MEMBERS.** Proposed that Paul Carbone (Provider Representative, Medical/Pediatrics), Angelique Colemer (Agency Representative, Mental Health) and Jenny Simmons (Parent Representative) be accepted as members of the ICC. Moved, seconded and approved to accept the 3 new members.
- V. NOMINATIONS FOR TRI-CHAIR.** Barb Fiechtl and Marcela Rafide will be stepping down from their positions on the Tri-Chair. Suggested that at least one member of the Tri-Chair be a parent. Marcella reviewed her experience as a Tri-Chair member, including the challenges and rewards of serving in that position. Tandi Cichoski nominated to fill the parent seat on the Tri-Chair, and nomination accepted by Tandi. Debbie Justice and Eileen Chamberland were nominated to fill the third position on the Tri-Chair and their

nomination biographies were reviewed by the membership. Nominations for Tri-Chair membership closed.

VI. VOTING ON NEW MEMBERS AND TRI-CHAIR. Tandi Cichoski installed as the parent member of the Tri-Chair by voice vote. Voting by ballot for either Eileen or Debbie resulted in a tie. Moved, seconded and approved that the absent ICC members be polled via e-mail to finalize the vote and break the tie. Voting will be finalized by close of business, Friday, September 22, 2006.

VII. SUB-COMMITTEE REPORTS.

1. **CAPTA Committee.** CAPTA was formed as a result of a federal mandate to define and develop procedures for referring all children under age 3 with substantiated cases of abuse and neglect to Early Intervention. Child Protective Services (CPS) adopted a screening tool that CPS workers who investigate an allegation of maltreatment use to perform screenings of target children under age 3 and refer them into Early Intervention. Utah is unique among all the states in that all reported children are screened whether their cases are substantiated or not, and for 2005 that number was over 5,000. In July and August, 926 children 0-3 years of age were eligible for screening by CPS and only 10 were eventually referred to Early Intervention services with CPS worker assistance. These findings are preliminary and only reflect 1 ½ month's data. It is too early to know if these figures are typical of the new procedure. The parents of the other children may have self-referred, and if referral source information was known and entered into BTOTS, BWEI may be able to match these children against the DCFS database. Parent involvement with Early Intervention remains voluntary, however CPS workers will assist parents in making contacts if requested.

Next steps: a.) CPS/DCFS will review and firm up processes to assure that children are not being missed in the initial screenings, b.) Follow up with CPS workers to determine whether they feel adequately trained in the referral and screening processes.

Please refer to the attached hand out, "Preliminary Report on Screening and Referral of Children 0-35 Months" for the committee's statistical report.

2. **FUN Committee.** The committee has created successful connections with the Family-To-Family Network (FTF), and has participated in joint teleconferences and training with FTF. The latest teleconference was a good jump-start for generating activity during the coming year. The FTF network is very open to hosting a joint open house for families of children with special needs. Lisa Madsen, an EI parent, serves as one of the chairs with FTF network.

Committee members participated in parent advocacy training and other activities. The committee set up a meeting with Dr. Sundwall, DOH Director. Three parents attended the meeting with two providers and a physician to speak on behalf of funding the Early Intervention program. Several parents attended the Department of Health budget hearing on August 31, 2006. Testimonies from EI parents were collected and presented. FUN sponsors a teleconference the first Wednesday of each month. September's topic was sibling issues. The

October 4th teleconference will cover Halloween safety tips and issues. November's teleconference will be on feeding issues. The committee is developing training for parents in Utah County EI programs led by Kris Fawson. There is also a possibility for a meeting with John Nixon, Director of the Governor's Office of Planning and Budget, Monday, September 25th.

3. **Transition Committee.** (See letter to Catherine Nelson and Transition Checklist handouts.) A small group of people was appointed to draft a transition activities best practices checklist for Early Intervention agencies, but it does not dictate exact policies or procedures for developing transition agreements. They decided that the Transition Interagency Agreement between Part C and Part B was a crucial tool in ensuring smooth transitions. In order to assist programs throughout the state develop effective interagency agreements they developed a checklist of topics that need to be discussed during the development of the agreement. The rough draft of this checklist will be sent to the Transition committee for additional input and revisions. The final copy will be sent to the Parent Committee for possible revisions then to the full ICC. Once approved it will be posted on the Part B and Part C web sites as a Technical Assistance tool.

During the summer of 2006 Part C and Part B staff collaborated on the development of a training presentation for developing a smooth transition process, which will be ready for review in September of 2006. The training tool will be available for programs to download from the Part B and Part C web sites. The training material will also be incorporated into a joint Part B and BWEI presentation to be given at the 2006 pre-school conference. BWEI will be working on updating relevant interagency agreements that affect transition. Although the transition agency agreements are crucial, drafting the agreements needs to wait until the final Federal regulation is issued.

4. **Medical Home Committee.** A total of 6 training sessions will be presented through the integrated services project at CSHCN and the University of Utah. The first session was an overview of the Medical Home project. As a result 11 new pediatric doctors are on board, the majority of which are in Utah County. The next session will focus on Early Intervention with emphasis on screening and giving referrals as opposed to the traditional wait-and-see approach. The first session in December will discuss early screening for mental health issues. Another successful component is introducing Early Intervention providers to the doctors, which seems to have enhanced the referral process in Utah County. Medical home efforts have become a huge part of getting EI to the children who need it. A retreat was hosted that involved parents with existing and new family home medical advocates. The committee will also be hosting a Summit, part of which will focus on further development of Early Intervention sites. They are working within a 5-year federal grant focused on systems integration and on early screening of mental health issues.

VIII. FINANCIAL AND FUNDING ISSUES AND PLANNING. (Please refer to handout titled "Draft Baby Watch Financial Action Plan Worksheet".) Financing EI has been an ongoing issue for 20 years. Growth of the program through the years has created a continuing need for annual increases in funding. For the past 4 years the Early Intervention

program contractors have operated at the same funding level. This under funding has resulted in a decrease in the services available to children. Previous budget requests have been funded at less than the requested levels or left at the prior year's level. EI is now at a crossroads; funding needs to increase or there will be consequences to the delivery of appropriate statewide services. EI providers have found that they are unable to meet all the needs of the children they serve and make their budgets stretch to cover the costs of operation. Those costs include recruitment and retention of clinical personnel, personnel benefits and mileage reimbursement, and caseload increases. Federal funding was reduced some this past year and future increases are not anticipated. Three years ago we tightened the eligibility requirements, which held caseloads at a manageable level for a year or two, but now caseloads are growing again due to general statewide population increases. Child find activities are very successful in identifying more eligible children. States with similar eligibility requirements are serving about 2.2% of the birth to three population and Utah is serving about 1.8%. Under federal mandate, our State Performance Plan requires us to look at that indicator exactly and have a plan for achieving a caseload of 2.2%.

The ICC has developed a Finance Committee to review all aspects of EI financing and explore funding avenues in addition to state and federal funding. The Baby Watch program applied and was selected as one of six states to participate in a symposium on EI funding at the national level. Susan Ord and Catherine Hoelscher from BWEI as well as Debbie Justice and Susan Olsen from the ICC Finance subcommittee attended. The Utah delegation focused on insurance billing and maximizing Medicaid funds. The delegation came away from the symposium with a proposed plan of action consisting of 5 priorities. The action plan represents the beginning action steps, timelines and responsibilities. Some elements have recently been completed, however, there are many more steps to add to fully explore each priority area. The Finance Subcommittee recommends that we form a committee to pursue each of the priorities; that the activities of each priority sub-committee be fast tracked as much as possible; and that the activities be accomplished simultaneously. The ICC agreed to the proposed action plan.

If the DOH funding request is not approved by the Governor's office and funded by the legislature, a fall back plan will need to be developed immediately at the close of the legislative session. BWEI will seek input from the ICC for its development. One choice is to make the program eligibility criteria more stringent, thus restricting EI services to those children scoring in the severe category. If current EI providers drop out, the state could seek other local providers who could provide the services within the available funding parameters, or make arrangements to provide services from the state level. However, the cost of services would remain the same and a lack of funding will be a significant barrier. A fee for service payment system may be another alternative, yet the rates may remain too low to provide adequate services.

The ICC feels that this discussion needs to happen much more broadly around the state, it needs to move out of the ICC and into the communities and legislature. Mr. Greer, the Legislative Fiscal Analyst, and the Governor's office need to understand the issues impacting EI. One message we want to present is "This is a workforce program, not a welfare program." 40% of EI children do not enter Special Education resulting in a significant cost savings over time. Additionally they are more likely to enter the workforce as net producers rather than net consumers of public goods and services.

Priority #1: Department of Health Building Block Request. Susan Ord presented information on the DOH funding request of \$2.6 million, which recently went to the Governor's office. ICC members asked questions about how the budget request amount was determined. The funding request can be divided into 3 portions. First, approximately \$1 million for maintaining the current contract rate for children. Second, \$1 million to cover an anticipated case load growth of about 6%, which has been the average rate of growth over the last few years. Third, approximately \$600,000 for a 6% increase in the provider rate to offset inflation. The current Medicaid provider rate is \$5,235, and Medicaid has provided increases of up to 4.6% annually. Six percent is a compromise number between the Medicaid rates and a catch up amount for inflationary costs, which have never been funded.

The ICC Finance Committee will meet with John Nixon and Dan Schuring in the Governor's Office of Planning and Budget. At this meeting the Committee will discuss the need to support the Department of Health's initial request for approximately \$2.6 million. Additional meetings will be held to reiterate the importance and purpose of EI to the fiscal decision makers.

Priority #2: Insurance Task Force. Use of family's insurance is allowed under the IDEA regulations. Information from the August symposium shows that insurance funding works best in states where legislation requires that insurance companies cover EI services. As an example, New Mexico's recent insurance legislation mandates yearly capped insurance coverage for EI. New Mexico has capped their insurance reimbursement at \$3,600 per year so insurance companies have an assurance that EI services will not present excessive costs to them. New Mexico organized a legislative task force of insurance companies, and other stakeholders, which studied the feasibility and mechanism for utilizing insurance. Case studies, actuarial projections and cost capitation all showed insurance companies and other stakeholders that costs are limited and that there is a direct benefit to insurers due to reduced future costs. Additionally, the national Blue Cross/Blue Shield organization is proposing an Early Intervention ICD 9 billing code. Initiating an insurance approach in Utah requires extensive study because we don't know how the costs and benefits will break out in our state. We recommend the establishment of a legislative study group to investigate the issue and to develop possible implementation scenarios.

Priority #3: EI Cost Study. There is a critical need to document the overall costs associated with EI, including overhead and hidden costs as well as direct per child services costs. There are several important purposes for this information including determining provider rates, Medicaid rates, and funding requests. The cost study needs to meet several criteria: a.) clarity regarding anticipated outcomes, b.) an unbiased yet focused structure to provide an accurate picture of EI funding in Utah, c.) be closely linked with best practices, and the state funding methodology, and d.) at least partially completed by an independent entity.

Priority #4: Medicaid. We need to develop methods, strategies and activities to assure that providers are appropriately billing Medicaid for all eligible children and services. About 30% of the children enrolled in EI are Medicaid eligible, but not all have billable services every month.

Priority #5: Early Intervention Foundation. The state and ICC need to examine the possibilities of developing a foundation to bring in additional funds. As an example the

Office of Child Care has a legislated 501 (c) (3) in which the director is the chair of the board. Another approach is to establish a foundation outside of government, or a combination governmental/private foundation. If adequately developed the foundation model may be a source of additional revenue for some Early Intervention activities.

- IX. AGENCY REPORT AND ANNUAL PERFORMANCE REPORT.** On October 5th Governor Huntsman will issue a proclamation designating October as Baby Watch Early Intervention Month. Providers and parents will be invited to participate in the signing. Others may go to the Capitol at 1 p.m. to witness the event followed by a parent event at Liberty Park at 2 p.m. The proclamation is very timely as 2006 is the 20th anniversary of the IDEA and the Part C program. We want to capitalize on the declaration and the 20th anniversary through special event provider activities around the state. The ICC extended a special thanks to Janet Wade for spearheading the proclamation effort.

BWEI conducted a survey to generate baseline data for Indicator 4 of the State Performance Plan, focused on how many parents know, a.) their rights and how many parents feel that EI has been effective in b.) helping them communicate their child's needs, and c.) helping their child learn and develop. BWEI purchased a nationally normed and validated survey instrument, which was delivered to all the programs for administration to the parents. They received a 25% return rate, which in terms of this type of survey is an excellent result. 74.1% of parents knew their rights, 73.2% could effectively communicate their children's needs, and 81.7% felt that EI helped their child's development and learning. This data will be reported as the baseline data for Indicator 4 on the Annual Performance Report (APR). BWEI will further analyze the responses to identify and address specific trends among the individual provider agencies. (See handout titled "NCSEAM Family Survey".)

The Annual Performance Report is due February 1st, 2007, and as in previous years the BWEI program will be relying on the ICC and providers for their assistance. The APR provides the Federal Government a yearly picture of our status in achieving our State Performance Plan (SPP) goals. The SPP is a six year plan, required by the IDEA and is built around 14 mandated indicators for which we are required to establish baseline data and performance targets. Targets should reflect an annual increase in each indicator from each baseline. The current SPP may be viewed on the BWEI website (<http://www.utahbabywatch.org/>). Patrice Isabella will collect the data, which shows the progress we are making towards the indicators and targets and then present the data to the ICC at the November meeting. The ICC will then make a critical examination of the data, identify where work needs to be done and develop ideas for strategies. Where targets were not met we will need to explain the slippage and review our activities and strategies toward meeting those targets in the future. The APR will be finalized in January 2007.

- X. NEXT MEETING:** November 17, 2006, 9:30 a.m. at the CSHCN Building, 44 North Medical Drive, Salt Lake City, UT.
- XI. ADJOURNMENT.** Thanks to Barb and Marcella for their service as Tri-Chairs, and to Marcella for her membership on the ICC. Appreciation also extended to today's special guests. The meeting was adjourned at 11:50 a.m.

APPROVED AS TO FORM:

Cathy Nelson, Chair for ICC

MINUTES SUBMITTED BY:

Brent W. Baum, ICC State Contact