

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 Mario Capecchi Drive, Salt Lake City, Utah, Main Conference Rooms
December 2, 2009 // 9:30 a.m. – 12:00 p.m.

Attendance: Cheryl Alexander, Debbie Ballard, Paul Carbone, Carol Cerna, Tandi Cichoski, Eileen Chamberland, Louise Dunn, Debbie Justice, Kimberly Morris, Sue Olsen, Angie Pinna, Harper Randall, Dinah Weldon, Shylo Wheeler

Attended by Phone: Susan Fox, Todd Houston

Excused: Joyce Dolcourt, Connie Nink, Gina Pola-Money, Patti Van Wagoner

Absent: Jeff Dean, Jana Homer, Kreig Kelly, Lynette Rasmussen, Sen. Stephen Urquhart

BWEI Staff: Brent Baum, Josiah Hawks, Catherine Hoelscher, Vanya Mabey, Lynne MacLeod, Susan Ord, Debra Titmus

- I. **Welcome and Introductions** – Meeting conducted by Shylo Wheeler. Members and guests welcomed.
- II. **Minutes** – Read and approved minutes of September 23, 2009.
- III. **Public Comment Period** – No public comment received.
- IV. **Membership** – This is Shylo Wheeler's last day on the ICC, as she has moved out of state.
- V. **New Member Training** – Training for new members moved to before the ICC meeting on January 27, 2010 at 8:30 am.
- VI. **Baby Watch Report** (Susan Ord)
 - a. **Staff Change** – Josiah Hawks has replaced Brent Baum to support the ICC as the ICC State Contact.
 - b. **ARRA** – Baby Watch has been awarded approximately \$6.2 million from ARRA funds. Susan Ord will give a more detailed report about the use of those funds in the January meeting. So far, \$2 million has been granted to the EI contractors, \$400,000 has been allocated for the development of BTOTS Web, \$50,000 for a

hearing aid bank, \$30,000 has been spent on State training activities, and \$11,800 is allocated for the University of Utah contract to help with Baby Watch cost study.. This leaves 3.75 million to spend by 09/30/2011. Ideas for future allocations are Baby Watch early intervention program grants, a State annual report estimated at \$6500, and funding additional State training and indirect costs.

VII. **Autism Screening Presentation** (MaryAnn Hunter)

- a. **Introduction** – MaryAnn Hunter is a Masters of Public Health student at Brigham Young University, and was an intern at Baby Watch during summer 2009 as part of her degree requirements. She conducted a study to determine the pros and cons and feasibility of systematic screening for Autism Spectrum Disorders (ASDs) and presented her findings.
- b. **Methods** – As part of MaryAnn’s project, she interviewed 14 community providers who would be affected if Baby Watch started systematic screening, surveyed the EI providers in the state, and held three focus groups with parents. Although there were concerns, the general attitude was favorable for systematic screening by Baby Watch.
 - i. Concerns from the EI providers were which screener to use, the proper procedure/training for using the screeners, and financial and personnel concerns.
 - ii. The interviewees gave mixed responses as to whether the community in general was ready for systematic screening done by Baby Watch, and one person was concerned that it wasn’t part of Baby Watch’s legal mandate. Some thought screening belonged in the medical home. However, several interviewees also said they thought the M-CHAT tool would be best for use by Baby Watch because it’s free, short, simple, commonly used, and available in Spanish.
 - iii. The parents in the focus groups were generally agreeable to Baby Watch screening for ASDs, but decided that it shouldn’t be mandatory and should be done in conjunction with the medical home. Parent education would be essential to help parents understand the difference between screening and diagnosis.
- c. **Conclusions** – The attitude overall was generally in favor of Baby Watch conducting systematic screening for ASDs under certain conditions; eg., information for parents on the nature of a screener, explanation to parents about the difference between screening and diagnosis, optional and at the parent’s discretion, training for personnel on administration and scoring of screening, and a standard way to discuss results with parents. Baby Watch would need to have a specific plan and policies in place for screening, and would need to provide a list of resources for parents for support, diagnosis, etc. The general consensus among

those surveyed was that the M-CHAT would be the best screening tool, and that there would need to be additional training to make sure providers were using the follow-up step of the M-CHAT.

- d. **Discussion** – The ICC discussed the implications and logistics of implementing statewide ASD screening. The ICC wanted to make sure there is no duplication of services with the medical home, and also making sure that no diagnoses take place in EI. We would need to implement sufficient training to make sure EI programs use both parts of the M-CHAT assessment, not just the initial screener. Concern was expressed about the M-CHAT being a level 1 screener, meant for the general population, rather than a level 2 screener meant for at risk populations, which could potentially increase the number of false positive results. One member suggested that we work with the CSPD/Best Practices committee to determine further action.
- e. **Action** – Harper Randall proposed the use of ARRA funds to further investigate the logistics and best practices for implementing an autism screener, and answer the questions that were discussed. It was decided that it would be best to hire someone specifically to work on this, to help coordinate between various providers and community experts. Debbie Justice thought the idea was too vague and wanted more specifics before making a decision. The motion was put forward and seconded. The motion passed. Susan Ord will give a preliminary report about hiring someone in the January meeting, but Baby Watch likely won't start working on it until after the Annual Performance Report (APR) is submitted.

VIII. Annual Performance Report (APR)

- a. **Introduction** –Early Intervention provider agency representatives joined the ICC meeting to review and discuss the APR. Catherine Hoelscher presented the draft APR by reviewing all indicators. She discussed the general measure of each, whether or not the state met the indicator, and whether or not further action was required on each indicator. An in-depth discussion was held on the following two indicators:
- b. **Indicator 2: Percentage of infants and toddlers with IFSPs who primarily receive early intervention services in the home or community based settings** – Lynne MacLeod explained 618 reporting, which includes the December 1, 2008 child count, settings in which children received services on this date, and other data included in reporting. She then presented detailed information about how the 618 settings data is used for Indicator 2 calculations. The ICC discussed ways in which progress on meeting the target indicator's target could be met. Questions were raised about why this indicator is calculated the way it is (see APR handouts), and why the targets are set at the levels they are, and whether we as a state should reset the targets to a level that we could meet. EI providers cited a lack of personnel and training as possible causes for the low indicator level. Programs also have a hard time recruiting because they find it difficult to pay

competitively. EI providers were encouraged to use the ARRA funds to expand their personnel bases. It was also suggested that we need to work closer with college and universities who train students in special education/PT/OT, and make sure they are coming out of college with the skills necessary to work in an early intervention setting. The ICC wondered if it has been shown that children receiving services primarily in home and community based settings have better outcomes than children in other settings, and also whether children who have better outcomes have met their IFSP goals. Discussion was raised about completing such a study, but time was short, so discussion was moved to the next indicators.

- c. **Indicator 5: Percentage of infants and toddlers birth to 1 with IFSPs compared to National data (1.04%) and Indicator 6: Percentage of infants and toddlers birth to 3 with IFSPs compared to National data (2.66%)** – Lynne MacLeod explained the method for calculating these indicators, including that each state’s program is now compared to the national average, which includes states with less strict eligibility requirements and those who serve at risk infants and toddlers as well as delayed infants and toddlers. However, Baby Watch’s percentage of children birth to 1 served has been decreasing over the last few years although the population is increasing, and the percentage of children birth to 3 has increased, but not as much as the national rate. The floor was opened for suggestions, but the meeting was scheduled to end at 12:00 p.m., so participants were encouraged to email or call Baby Watch with any suggestions for improvements for these indicators.
- d. The ICC had previously decided that the APR that Baby Watch prepares would also be their report to the governor as part of their ICC requirement. The final APR will be submitted to the ICC and discussed at the January meeting.

IX. **Next ICC meeting** will be January 27, 2010 at 9:30 a.m.

X. **Adjournment:** The meeting adjourned at 12:05 p.m.

APPROVED AS TO FORM:

Debbie Justice, for the ICC Tri-Chair

MINUTES SUBMITTED BY:

Josiah L Hawks, ICC State Contact