



IDEA

INFANT & TODDLER

COORDINATORS ASSOCIATION

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MESSAGE FROM THE PRESIDENT

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The IDEA Infant and Toddler Coordinators Association is organized as a not-for-profit corporation to promote mutual assistance, cooperation and exchange of information and ideas in the administration of Part C and to provide support to state and territory Part C coordinators.

On behalf of the members of the Board and especially from me, I would like to take this opportunity to thank the membership for your support and enthusiastic participation in all ITCA activities during the annual meeting in December. Once again, the spirit, dedication and camaraderie we have as Part C Coordinators and as an Association came through.

I remember as if it was yesterday, attending my first national meeting as a new Coordinator where the association was conceptual and a new work in progress. The achievements of the association since that time are impressive and are a result of the dedication and hard work of the board members and membership. Vision, creativity and commit-

ment are qualities that have and will continue to serve us well as we address the ever changing challenges of Part C.

The agenda we face during this year includes the second year of state determinations, the long anticipated release of Part C regulations, a Presidential election and transition in administration, increasing economic concerns across the nation, implementation of Medicaid rules and the next reauthorization of IDEA. The ITCA needs the involvement of all of you as members to actively participate with and support the work of the ITCA committees. These committees always need new members to ensure broad input to address critical issues and meet our association goals.

A high priority is the need to identify one or more Congressional heroes to champion increase funding for Part C. The years of doing more with less have reached a crisis level. The question being asked is how we can be expected to continue to meet the increasing compliance and administrative requirements with less funding. Even more concerning is the trend toward the reality of doing less with less and the impact this may have on maintaining compliance and improving quality of services for children and families. Help us find the congressional champions we need to weather these times.

On a sad note, I want to recognize the passing of two individuals, Pat Trohanis and Lois Taylor, who dedicated





EIFA Debuts at OSEP Conference

In December at the 2007 OSEP Early Childhood Conference the Early Intervention Family Alliance (EIFA) made its debut. This year's OSEP conference brought together some of the original proponents of early intervention, researchers and providers both new and experienced, and parents both new and experienced.

During the plenary sessions Bobby Silverstein spoke of the early days of drafting this trailblazing legislation. Mr. Silverstein discussed how at the time, passage of Part H seemed impossible, yet he and other like-minded individuals hunkered down and focused on the importance of providing a legislative framework for delivering supports and services to infants and toddlers with disabilities and their families. He recounted how this legislation repeatedly referenced the importance of families. And further how drafters envisioned that the legislation was only the

first step to changing how society viewed people with disabilities. The drafters knew that this legislation would have an impact not simply on services and supports for infants and toddlers, but it would provide improved supports to their families and that support would buoy social change across other systems.

In a joint meeting between ITCA and EIFA, presenters discussed the challenges and promises of Early Intervention. Twenty years later we continue to grapple with issues related to ensuring statewide systems, coordinating services and supports, and funding. Presenters reminded us that these same issues threatened to derail the original legislative effort, yet parents, providers and legislative staff stayed the course and passage was assured.

As parent leaders, the board of EIFA came together to en-

sure that the original promise of early intervention continues for all infants and toddlers with disabilities and their families. Some of our members have children who would have been recipients of early intervention had it existed thirty years ago, still others of our members are the proud benefactors of that advocacy. Together we want to ensure that as research has caught up to what the original advocates knew intrinsically, that we continue to strive to ensure that the promise of early intervention remains available to every infant or toddler with a disability and their family. We believe that families need to be meaningfully involved at all levels of policymaking. This involvement can ensure that states maintain a comprehensive system of early intervention services and that federal regulations address the issues that are challenging states in implementing the law as it was intended.

We know that legislators need to hear from families about how this system has benefited them and why it is essential to provide appropriate funding for Part C activities.

In these tough fiscal times it is more important than ever that groups like EIFA and ITCA work together to advocate for comprehensive, multidisciplinary statewide systems of early intervention services for infants and toddlers with disabilities and their families. Membership in EIFA is free for families currently receiving early intervention services and only \$25 for families who have transitioned from early intervention; we also welcome professional or organizational memberships. We have members across the country and it is our aim to keep them informed about national issues and trends related to Part C.

Maureen Casey
President

President's Letter ...

their lives to improving services and supports for children with disabilities and their families.

On behalf of the ITCA, Sharon Walsh and I attended a memorial service for Lois Taylor in January 2008. The service was a wonderful tribute to Lois and the relationships she established with friends and colleagues. Lois was a well respected OSEP

team leader who was known for her spirit and sense of humor. The tributes to her dedication, hard work, commitment to children with disabilities, and love of a life filled with fun and friendship reflected a life well lived. She will be missed.

Referred to as the "Ambassador of Part C" Pat Trohanis leaves behind a legacy of leadership, support and friendship that he

cultivated with NEC-TAC and throughout the IDEA community. Pat always supported Part C and provided us with encouragement as we struggled to obtain the awareness and respect as the new or evolving program competing for attention and recognition with the more established and larger Part B system. Those of us that had the pleasure and honor of knowing Pat over the years will Forever miss his pres-

entations where his unique sense of humor amused, motivated and entertained us. Pat has truly left this world a far better place and will forever hold a place in our hearts and in our ongoing efforts on behalf of young children with disabilities and their families. The ITCA renaming of the public service leadership award to the Trohanis Leadership Award is a testament to Pat, his work and is our way to honor a dear friend and supporter.



Pat's family at the ITCA/EIFA Awards Reception, accepting the inaugural *Pascal Trohanis Leadership Award*.

In closing, I am honored to serve as your President and look forward to working with the Board and membership as we continue our endeavors to meet challenges and realize achievements.

Terry Harrison
President

ITCA Committee Reports

Membership Services

The Membership Services committee held its first meeting on March 31 at 2:30 PM Eastern Time. Erin Kinavey, Part C Coordinator for Alaska and Mary Ann Disenza, Part C Coordinator for Virginia will co-chair the committee. ITCA received a positive response regarding committee membership with members representing five of the RRC regions as well as the diversity of the Association's membership.

The committee will focus on continuing the mentorship program to support new Part C Coordinators, developing strategies that support professional development, a coordinated system of technical assistance based on levels of need, updating the ITCA website and links to existing websites based on individual coordinators needs, and facilitating teleconferences and contacts with OSEP and key TA providers around areas of in-

of interest to Part C Coordinators.

The committee used its first meeting to establish priorities for the coming year around orientation, professional development, and mentorship and develop activities to support the annual membership survey, website review and topical leadership series.

Part C Coordinators are invited to send representatives to serve on the committee.

Data Committee

The Data Committee has continued to focus on the review and streamlining of the national survey database. The committee has reviewed the results of the recent national survey that provided data on content priorities to identify the topic areas within the national survey database that are most important to the membership.

Topics or questions that have other data sources such as the State Performance Plan, Annual Performance Report and 618 data collection are being streamlined or eliminated from the national database. The priority topic areas under discussion include personnel/credentialing, family involvement, service coordination, service delivery, and financing.

The committee currently has membership from eleven states with a significant representation of data managers. If you are interested in participating on this committee, please contact the ITCA office or Terry Harrison who is chairing the committee. The committee meets by conference call on a bi-monthly to quarterly basis.

2008 Members

- Alaska (7)
- American Samoa (8)
- Arizona (8)
- Colorado (5)
- Connecticut (8)
- Delaware (8)
- District of Columbia (5)
- Florida (6)
- Guam (7)
- Hawaii (8)
- Idaho (8)
- Illinois (7)
- Indiana (8)
- Iowa (7)
- Kansas (8)
- Kentucky (5)
- Maryland (8)
- Massachusetts (8)
- Minnesota (3)
- Missouri (6)
- Nebraska (4)
- Nevada (7)
- New Hampshire (8)
- New Jersey (8)
- New Mexico (8)
- New York (5)
- North Carolina (8)
- North Dakota (8)
- Northern Marianas (7)
- Ohio (7)
- South Carolina (5)
- South Dakota (4)
- Texas (8)
- Utah (8)
- Vermont (8)
- Virginia (4)
- Washington (8)
- Wisconsin (7)
- Wyoming (4)

The number in parens indicates the number of years of membership.

Federal Update

Budget Resolution Top Priority for the Congress

The Congress returned to Washington D.C. the first week in April with the federal budget at the top of the agenda. A major battle with the White House is almost certain as the House and Senate both have already signaled plans to spend more in the upcoming federal fiscal year 2009 (FFY'09) than the President requested in his budget request of February 2008. The FFY'09 year begins October 1, 2008 but there are still many steps to be completed and agreements to be reached before that date. The FFY'09 process determines the level of Part C funds states will receive July 1, 2009.

The next step is the development of a compromise Budget Resolution that must be approved by both the House and the Senate. The Budget Resolution is a non-binding blueprint that sets the federal budget for 5 years and determines the amount of money

each of the 12 appropriations committees are allocated to distribute to individual programs. The President does not sign the final Budget Resolution.

Before the spring Congressional break, the House passed its version of the '09 Budget Resolution containing \$22 billion more in discretionary funds than the President requested. The version passed by the Senate included \$18 billion more in discretionary funds than the President's budget. Unfortunately, the final Senate Budget Resolution did not include the \$32.5 billion amendment introduced by Senator Bernard Sanders (I-VT). That amendment would have included an additional \$10 billion for IDEA but the full Senate did not approve it. The Senate did approve an amendment offered by Senator Dodd to increase the funding for the Maternal and Child Health Block Grant.

These early actions for FFY'09 are similar

to the steps that occurred last year that ended in a major confrontation between the Congress and the White House over FFY'08 funding levels. The final days of the first session of Congress came to a close in late December 2007 with passage of a \$555 billion Omnibus Appropriations bill, H.R. 2764, that cut many federal programs, including Part C, in order to avoid a second presidential veto. The President had vetoed an earlier version of that spending bill that funds all labor, health and education programs and had included increased funds for many programs, including Part C. The House was only 3 votes short of overriding the veto. Despite the strong bipartisan support for the compromise funding measure, there was not quite enough support to obtain the 2/3 majority needed to enact the measure into law despite the President's objections.

The final FFY'08 funding level included an across the board cut for all programs that resulted in \$435.7 mil-

lion. The President has requested a freeze of Part C funding at the FFY'08 level of \$435.7 million.

Many in the Congress voice strong determination that this year's process will not have the same loss of funding for domestic programs. There has even been some talk of waiting until after the 2008 election if necessary to ensure adequate funding for domestic programs.

More Congressional Action To Stop Medicaid Regulations

Despite strong bipartisan objections from the Congress and continuing concern expressed by the governors, state and local governmental agencies, and numerous advocacy groups, the Medicaid Targeted Case Management regulations went into effect March 3, 2008.

However, aggressive Congressional efforts continue to place moratoria on

Federal Update continued

these and a number of other Medicaid regulations despite the Administration's continued refusal to withdraw or postpone them. The Senate Budget Resolution contains a Sense of the Senate expressing concern about these regulations and both the House and Senate Budget Resolutions contain a provision for reserve funds necessary for the postponement of the regulations. The latest effort to postpone the Medicaid regulations is H.R. 5613, "Protecting the Medicaid Safety Net Act of 2008", introduced by John Dingell (D-MI), Chairman of Committee on Energy and Commerce. Representative Tim Murphy (R-PA) co-sponsors the bill that establishes a moratorium on seven Medicaid regulations through March 2009. This one-year moratorium would include the targeted case management regulations, rehabilitation regulations and school claiming regulations.

On April 3, 2008 the

House Health Subcommittee held a hearing on the bill. Chairman Dingell opened the hearing with a statement on the importance of the legislation, "The Administration's arguments for supporting these regulations do not hold water.

These regulations go beyond any justifiable point to curb any abuses in the system and instead would shift costs to the States and prohibit Federal support for legitimate expenditures on behalf of Medicaid beneficiaries."

Voicing his reasons for co-sponsoring the bill, Congressman Tim Murphy indicated "The cuts to Medicaid target those who need help the most: children, and the mentally and physically disabled. ...By eliminating preventative healthcare programs and assistance, there could be a devastating effect on the long-term healthcare of Medicaid patients. This would only lead to higher costs in the future, and put the health of millions at risk."

Barbara Coulter Edwards, interim director of the National Association of State Medicaid Directors, testified at the hearing expressing strong disagreement with the regulations and detailing states' concerns on a number of issues including the lack of state fiscal resources to fill in for the loss of federal funds, the lack of time to implement the regulations and the lack of guidance states have been given from the federal agency.

During the hearing, numerous letters supporting the bill were presented to Chairman Dingell. One of the letters had over 1150 organizations signed-on, including ITCA. Another support letter was from the National Governors Association.

Markup of the bill is scheduled for the week of April 7th. A full House floor vote is expected the 3rd or 4th week in April. If the bill can achieve strong bipartisan support, it can be attached to a major legislative vehicle going through the Congress this spring.

A companion bill, "The Economic Recovery in Health care Act of 2008" was introduced in the Senate April 3, 2008. This bill includes a year moratorium on Medicaid regulations including the ones addressed in the House bill as well as a one-year moratorium on the August 17, 2007 directive limiting states' flexibility to provide services to children under SCHIP. The Senate bill, S. 2819, also includes among other fiscal relief measures, provisions that would give qualifying states that meet established criteria an increase in federal matching Medicaid payments and targeted state grants.

The bill was introduced by Jay Rockefeller (D-WV), Olympia Snowe (R-ME), and Edward Kennedy (D-MA). "This is the wrong time to impose regulations that will shift additional financial burdens to states that cannot afford it," Senator Snowe noted. "Rather than identifying the ways in which we can work

Federal Update continued

to better serve those who rely on Medicaid – our states are faced with the prospect of being forced to implement regulations that will cause them to fall through the cracks.”

A summary of state-by-state impacts of the seven Medicaid regulations is included in a March 2008 report issued by the House Committee on Oversight and Government Reform. According to Chairman Henry Waxman (D-CA), the results of the survey of state Medicaid directors indicates that the proposed regulations would reduce federal Medicaid payments to the states by \$49.7 billion over the next five years, which is more than three times the Bush Administration’s projected estimate of \$15 billion. The report can be found at:

<http://oversight.house.gov/documents/20080303111450.pdf>

Targeted Case Management Regulations In Effect

In the meantime, as states are well aware, the revised Targeted Case Management regulations have gone into effect. Along with many other organizations, ITCA provided written comments asking that these regulations be withdrawn but to no avail. ITCA members are encouraged to work with their state Medicaid agency on how best to address these new regulations especially to determine what is now a billable service and to ensure that billing is occurring in 15-minute increments. ITCA continues to believe there are at least three major problem areas with the interim final regulations:

1. The requirement that only one case manager can bill Medicaid (this includes all Medicaid programs including waiver programs, managed care etc.);
2. The elimination of several IDEA Part C functions (IFSP

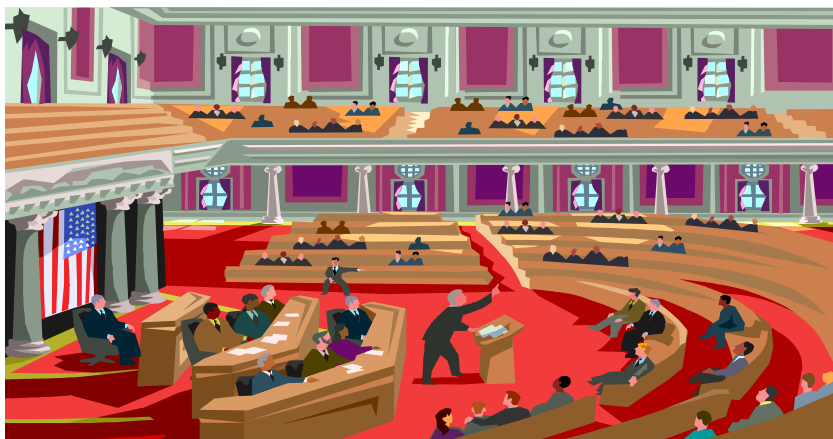
Development, prior written notice, preparing for or conducting the IFSP meeting, scheduling or attending IFSP meeting) as reimbursable; and

3. The requirement to bill in 15 minute increments (eliminates all other reimbursement methodologies);

Part C Regulations

Based on the most recent statements from representatives of the OSERS, it is expected that the final Part C regulations will be published sometime in late summer or fall of 2008. The public reporting period for the Notice of Proposed Rulemaking (NPRM) for Part C regulations closed July 23, 2007 and according to staff from OSEP, over 3,000 comments were received on the NPRM. ITCA remains concerned about the lack of Part C regulations since this December will be the 4th anniversary of the passage of IDEA 2004.

For further information, contact Sharon Walsh, ITCA Consultant at walshtaylo@aol.com



CDC Child Development Campaign Targets More Than 400,000 Child Care Facilities Nationwide

The Centers for Disease Control and Prevention (CDC), in collaboration with a coalition of national partners, launched a new phase of the "Learn the Signs. Act Early." public awareness campaign. This childhood development campaign is designed to help increase awareness about the importance of tracking a child's social and emotional development, including the potential early warning signs of autism and other developmental disabilities.

and client factors) affect his or her participation in specific areas of occupation.

The new phase targets more than 407,000 child care facilities in the United States and will provide free materials to help child care providers and preschool teachers educate parents about child development and autism.

More than 8.7 million children younger than five years of age in the United States are in some type of child care arrangement," said Alison Johnson, acting director of CDC's National Center on Birth Defects and Developmental Disabilities.

"Child care providers and preschool teachers are in a special position to watch for delays and to promote early identification and action when a delay is suspected. In fact, because they see children interact in peer groups, child care providers can be the first to observe early warning signs of a developmental delay such as autism."

The "Learn the Signs. Act Early." campaign* has developed a free resource kit of materials on child development and autism for day care providers and teachers to share with parents of children in their care.

The kit, available in both English and Spanish, includes a CD-ROM containing fact sheets on age-specific developmental milestones and on developmental disabilities such as autism, a growth chart that allows parents to track specific developmental milestones along with the height and weight of the child, and educational posters. These materials are available at www.cdc.gov/actearly under the "Child Care Provider" section.

**"Learn the Signs. Act Early." is a collaborative effort of the U.S. Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention (CDC), the American Academy of Pediatrics (AAP), Autism Speaks/the National Alliance for Autism Research (NAAR), the Autism Society of America (ASA), Cure Autism Now (CAN), First Signs, the Interagency Autism Coordinating Council (IACC), and the Organization for Autism Research (OAR).*

Please consider sharing these valuable resources with your state early care and education partners. We know many states have goals to increase knowledge of developmental delays among child care providers and preschool teachers. These materials can assist you in achieving these goals. ITCA will send you an e-mail with an attachment to ease your efforts.

Learn the Signs.
Act Early.



Parent Leadership Award



The recipient of the 2007 IDEA Infant and Toddler Coordinators Association's (ITCA) National Parent Leadership Award is Darla Gundler from North Adams, Massachusetts. Darla and her husband Greg are the parents of Zachary, 19 and Tiffany, 14. Their daughter Tiffany was born prematurely and as a result has a profound bilateral hearing

loss. Tiffany participated in early intervention for 3 years, then attended The Clarke School for the Deaf for 10 years where she was one of the graduation speakers. She is currently a sophomore at Drury High School participating in Honors Classes and is on the High Honor Roll. Tiffany is very active she plays high school soccer, softball, bowling and competitively figure skates when she is not studying or listening to music on her iPod.

As a result of her experience, Darla became a very active and effective voice on behalf of families. She has been the Director of the EI Parent Leadership Project in Massachusetts

Darla works with the early intervention system to continually create a well informed parent constituency throughout the Commonwealth of Massachusetts. Most recently Darla has taken her understanding of the Part C system and her experience as a family leader to assist in forming the Early Intervention Family Alliance (EIFA). Darla is a founding member and board member of EIFA. After many years of feeling the family voice slipping from the national discussions, Darla chose to be proactive and begin the formation of a national family group that would bring the family voice to the policy makers within the Part C arena.

The following is an excerpt from one of the nomination and support letters:

"Darla is a true collaborator and partner. When asked to participate, she only considers how her involvement can help shape the system for better, not how much time will it take or what's in it for her. Again, this is proven not only by her constant leadership in the National ICC meeting planning group, but by her affiliation with other national groups like Parent to Parent, AG Bell Association for the Deaf, Division of Early Childhood (DEC) and Family Voices."

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