



Message from the President



Kim Wedel, President

Four and 1/2 years ago, I became the Part C Coordinator for Texas. While I had experience with leading programs that served children, families, and people with disabilities, I had no experience in the Part C system. I brought new perspectives and the staff in the Texas Early Childhood Intervention system worked hard to train me on our implementation of the system. The Association (each of you, Maureen, Sharon, the information in surveys) supported me in a way no individual could. You strengthened my ability to understand the range of possibilities for Part C and helped me accept the unique dynamics of the “glue money” and garnering support and re-

sources from other systems.

- ◇ The Association has supported me to increase my ability to lead and support the families and staff of the program.
- ◇ The Association allowed me to feel a part of a national Part C community.
- ◇ The Association guided me to be a part of the national agenda.
- ◇ The Association saved me time by analyzing documents.
- ◇ The Association armed me to answer questions from our state leadership.

You helped me to laugh when I wanted to cry and allowed me to vent privately so I could go back out and more appropriately address the challenges.

I am appreciative of the opportunity to be President during the year when we need each other most. (I am hoping it gets better soon.) We face unprecedented state and local funding crises and for most of us the glue is no longer enough to maintain the broad eligibility, free services or low family fees, adequate provider rates, and service

plans that do not need to be reviewed for appropriate efficiencies. We are making difficult choices. For many of us, we were excited to have jobs that focused on improvements but now find we are focused on taking steps to ensure the continuation of the program. We work to preserve the strengths of our state systems so that when times are better we can be positioned to broaden again.

I hope that the Association can support each of you in at least one of the ways you supported me. Your value of the Association is demonstrated in the high rate of continuing memberships. I ask you to participate in other ways:

- ◇ Is there a committee you can join?
- ◇ Would you like to start by being on a taskforce?
- ◇ Will you commit to answering the surveys?
- ◇ Do you have a staff member who could participate in any of these activities?

With your participation we can be stronger for children and families. I look forward to working with you in the coming year.

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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.

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Making Connections

ITCA Board Meets with OSEP Staff

On Friday afternoon January 20th, the ITCA Board met with Melody Musgrove, Director of the Office of Special Education Programs (OSEP) and Ruth Ryder, Director of the Monitoring and State Improvement Planning (MSIP) Division. Board members opened the meeting by describing the recent actions of states faced with financial challenges including:

- ◇ Narrowing eligibility criteria;
- ◇ Increasing family fees; and
- ◇ Decreasing reimbursement rates paid to providers.

We reframed our focus from “dropping out” of Part C to “carving out.” States are carving out children and families directly through narrowing eligibility and in some cases creating separate state programs. States carve out indirectly through decreasing provider rates, capping provider reimbursement, and instituting review procedures to ensure plans are efficient and appropriate. By directing resources to children with more significant disabilities and delays, these actions challenge the original focus on **early** intervention. We explained the confounding of Part C’s foundation being built on interagency collaboration and requiring a variety of funding sources. The services to families are constrained by cuts and revisions to other programs as well as Part C.

Melody and Ruth listened closely and took notes. They requested information on the impact of changes in Part C on future Special Education needs. **The Board is asking Part C coordinators to forward any information they have on increased needs for Special Education as a result of changes to Part C to Maureen Greer.**

Melody and Ruth said the OSEP re-

sponse to the ITCA/NASDSE letter regarding the Transition FAQ is in the review process.

Board members expressed their appreciation of discretionary grants that support Part C.

On Saturday morning Ruth graciously joined the Board for a more in depth conversation that addressed the following issues:

- ◇ Ruth shared her thoughts on the process MSIP will be using to implement their new focus on results. Ruth described their work with OSEP-funded Technical Assistance Providers and plans to include states in the development of the results process including the identification of potential barriers and alternatives. The results process will continue to be developed and improvements will be incorporated based on onsite experience. The design will be individualized, tailored to each state, and will incorporate existing systems including Annual Performance Reports (APRs), verification, and technical assistance.
- ◇ In addition, MSIP will use a risk assessment to identify states they deem as high risk. Factors will be based on existing information including audits, determinations, and verification reviews. These states will receive additional contacts.
- ◇ The Board shared the concerns of members regarding the clarifications that have come from 09-02, specifically on the disincentive for using a database for monitoring when 12 months of data must be used.
- ◇ Ruth said the Part C Regulations were “top priority” and are moving forward.

The Board expressed interest and support in OSEP’s role and participation in the Department of Education and Health and Human Services initiative related to the Early Learning and Development Inter-Departmental Initiative study groups.

ITCA looks forward to working closely with OSEP particularly to help them keep informed on the activities in states and the potential impact of OSEP actions on states.

Kim Wedel

Save the Date

ITCA Annual Meeting

Sunday, July 31

8:30 — 4:30

Topical Meeting

Saturday, July 30

1:00 — 5:00

Do you have an interest in Fragile X?

ITCA is looking for a motivated member to represent the Association in future collaborative efforts with partners who want to make systemic, life-enhancing changes to the FXS system of care for children and families.

Please contact Julie at Julie.Curry@iowa.gov or (515) 281-5437 for more information.

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Congress and White House Engaged In Two Major Budget Activities

This is a very unusual time in Washington DC. The President and the Congress are working on funding for both the 2011 and the 2012 federal fiscal years simultaneously and this can be very confusing to follow.

The most immediate need is to finalize funding decisions for FFY 2011 that started on October 1, 2010. The government is currently funded on a Continuing Resolution (CR) that expires March 4, 2011. The government will shut down if the Congress and the President do not complete the FFY 2011 funding legislation or extend the current CR until agreement can be reached. This effort is not going smoothly, major cuts are being proposed and agreement is far from sight.

At the same time, President Obama's release of his budget on February 14, 2011 signaled the beginning of the FFY 2012 budget and appropriations process. As soon as the budget was released, both praise and criticism began immediately signaling a difficult FFY 2012 process ahead. FFY 2012 begins on October 1, 2011.

Continuing Resolution for 2011 Set To Expire March 4, 2011, House Committee Proposes Massive Cuts

The full House is currently debating and considering amendments on H.R. 1 that would replace the existing Continuing Resolution (CR) scheduled to expire March 4, 2011. The existing CR can be extended past March 4th with agreement from the Congress and the President but ultimately agreement has to be reached on funding levels for the last seven months of the current year.

H.R. 1, as approved by the House Appropriations Committee, currently includes

significant cuts to many programs affecting young children and families including a billion dollar cut to Head Start and more than a half a billion dollar cut to Part B Special Education Grants. (See box below)

The full House and the full Senate must come to agreement on a bill to fund programs through the remaining 7 months of this year. The President must also sign a final funding bill into law for it to be enacted.

The full House is expected to vote on H.R. 1 on February 17th after several days of consideration of amendments. At that point, efforts will shift to the Senate. The

Congress is on recess the week of February 21st. Once the Congress returns to Washington, only a short time is available for final resolution of the CR before the March 4th deadline. If the CR expires without a replacement, the government will automatically shut down.

Significant advocacy efforts are underway to stop the House proposed cuts. Many associations and coalitions are urging their members and the public to contact their Representative in the House and tell them to vote against H.R. 1 and against these serious and unacceptable cuts to programs important to children and families.

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Continuing Resolution Proposed Cuts:

The following are several key proposed cuts recommended by the House Appropriations Committee related to children and families. If approved and signed into law, these cuts would be taken from FFY 2010 funding levels for these federal programs:

- ◇ WIC - (\$747.2 M)
- ◇ Community Health Centers - (\$1,000 B)
- ◇ MCH Block Grant - (\$50 M)
- ◇ Family Planning - (\$317.5 M)
- ◇ Head Start - (\$1.08 B)
- ◇ Low Income Home Energy Assistance - (\$390.3 M)
- ◇ CCDBG - (\$39 M)
- ◇ Community Services Block Grant - (\$305 M)
- ◇ Teen Pregnancy Prevention Community Grants - (\$110 M)
- ◇ IDEA Part B Special Education - (\$557.7 M)
- ◇ Striving Readers - (\$250 M)
- ◇ Even Start - (\$66.5 M)
- ◇ Statewide Data Systems - (\$58.3 M)

Making Connections

Fragile X Syndrome System of Care

By Julie Curry

What we know about Fragile X

Technology over the last two decades has increased significantly. According to the National Fragile X Foundation, fragile X syndrome is a genetic condition which is caused by a change in the FMRI gene found on the X chromosome and is inherited at the time of conception. This gene can now be identified by a blood/DNA test developed in 1991. **Fragile X Syndrome (FXS) is the most common cause of inherited mental impairment, yet often goes undiagnosed (especially when autism spectrum disorder is diagnosed first).** FXS is the most common known, single gene cause of autism or "autistic-like" behaviors. Associated disorders can include reproductive problems and early menopause in some female carriers (fragile X-associated primary ovarian insufficiency or FXPOI) as well as balance, tremor and memory problems in some older male gene carriers (fragile X-associated tremor ataxia syndrome or FXTAS).

What does early intervention have in common with genetic scientists and counselors, family leaders, Center for Disease Control, University Centers for Excellence, American Academy of Pediatrics, and disability researchers and foundations? A desire to lower the average age of diagnosis for fragile X syndrome (FXS) and to ensure that these children and their families have timely access to needed medical, early intervention, special education services and family support. Research studies by Dr. Don Bailey reveal there was no change in age of FXS diagnosis in the last decade. Families identified their first concerns at age 9-12 months; delays were confirmed at 15-23 months; EI services began 17-27 months; and FXS diagnoses at 34-40 months.

This knowledge was the impetus of the Fragile X Foundation's partnership with the Center for Disease Control and Na-

tional Center for Birth Defects and Developmental Disabilities who convened a May 12th *Surveillance and Early Identification of Fragile X and Related Disorders Meeting*. I had the honor of representing our Infant Toddler Coordinator Association, providing an early intervention voice among this collaborative group of advocates. The day was spent learning about research and problem solving how to improve early identification and connection to needed services.

In 2006, efforts were made to improve our nation's Fragile X system of care. The FXS Clinical and Research Consortium was organized by the National Fragile X Foundation to enable existing clinics to 1) provide individuals and families with evaluation and care supported by the latest medical, educational, and research knowledge available; 2) establish additional clinics throughout the U.S.; and 3) help existing clinics become more comprehensive in the delivery of their services; develop an infrastructure for shared research trials. Check out the website for locations and more information.

One important assumption during the May 12th meeting was it takes a combination of early intervention/special education (EI/SpEd), therapy, medications, and family support to improve outcomes for persons with FXS. Throughout the day we pondered, "What are the ethical considerations for improving diagnosis and early identification?" "What difference does diagnosis make; how accurate are screenings; and are needed treatments/services available?" Studies in new medical treatments show emerging, exciting results that have the potential of more significant impact on outcomes (could be as revolutionary as the PKU treatments). Early identification

of the syndrome can link families to EI/Special Ed and family support services. Diagnosis can enhance a family's knowledge when making family planning decisions, though informing immediate and extended family of the syndrome can be a complicated and delicate process. Dr. Don Bailey's research assisted us in examining the strengths and weaknesses of five plausible early identification methods including preconception carrier screening; prenatal screening; newborn blood screening; developmental screening surveillance; and genetic testing of all children with developmental delays).

Partners identified that the FXS system of care needs a more effective early identification system that includes:

- ◇ Anticipatory research of culturally sensitive early identification options to inform policy decisions;
- ◇ Well informed EI providers who can identify triggers for an FXS medical workup;
- ◇ Primary care providers who can refer to appropriate subspecialty medical clinics;
- ◇ FXS clinics that are equipped to conduct evaluations and make accurate diagnoses;
- ◇ Research to practice education regarding screenings, assessments, health treatments and learning interventions; and
- ◇ Relationships between EI/SpEd and families with FXS clinics/research projects.

This system of care is emerging in the U.S., yet more efforts are needed to make it comprehensive, accessible and affordable. Next steps were identified:

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Two New CDC Resources to Support Your Child

CDC's "[Learn the Signs. Act Early.](#)" program seeks to improve early identification of children with autism and other developmental disabilities so children and families can get the services they need. The health education campaign promotes awareness of healthy developmental milestones in early childhood, the importance of tracking each child's development, and the importance of acting early if there are concerns.

Two new resources for parents are available online:

[Milestone Moments](#) is a 42-page, full-color booklet that includes complete milestone checklists, tips and activities to help parents support their child's development from age 2 months to 5 years, and guidance about when and how to take early action for a developmental concern. The English version of the booklet is available now; the Spanish version will be posted soon.

[Track Your Child's Developmental Milestones](#) is a single-sheet, trifold, full-color brochure that includes a checklist of key milestones from 6 months to 4 years of age in a fun, gameboard design. It also includes a message for parents about the importance of tracking their child's milestones and provides information about what to do and who to contact if they are concerned about their child's development. State Part C programs who are interested in using the brochure for Child Find and other public awareness activities can add local contact information and logo. The pdf versions of the resources are available from the ITCA office.

To request customization send an email to ActEarly@cdc.gov. You will need to supply the local contact information and logos that you would like included. CDC will send you the print-ready file for you to have printed locally.

For more information, go to www.cdc.gov/ActEarly.

Fragile X Syndrome (continued)

- ◇ Explore the development of policy examples and guidance to be adopted by early intervention programs that call for automatic referrals of infants and toddlers with developmental delays for medical workup/evaluation including identification of fragile X syndrome.
- ◇ Strengthen capacity of pediatricians and family practitioners to conduct routine surveillance screenings and order medical workups of children without diagnoses.

This meeting was the launch of a long term partnership intended to improve functional outcomes in important domains for the populations we serve. Stay tuned for future developments as we figure out systemic changes that will help

us reach the goal of early identification and connection to appropriate services and treatments.

Fragile X Resources

- ◇ **National Fragile X Foundation** <http://www.fragilex.org/html/home.shtml>
- ◇ **Fragile X Clinical and Research Consortium** <http://www.fragilex.org/html/clinics.htm>
- ◇ **Centers for Disease Control** http://www.cdc.gov/ncbddd/single_gene/fragilex.htm
- ◇ **No Change in the Age of Diagnosis for Fragile X syndrome: Findings From a National Parent Survey.** *Pediatrics* (online) by Bailey, D., Raspa, M., Bishop, E. and Holiday, D. (July 5, 2009). <http://tinyurl.com/Fragile-X-research>

2011 ITCA Members

As of February 1, the following states have renewed their membership for 2011. We look forward to receiving your membership soon.

- ◇ Alaska (10 years)
- ◇ American Samoa (10 years)
- ◇ Arkansas (6 years)
- ◇ Colorado (8 years)
- ◇ Delaware (11 years)
- ◇ Georgia (11 years)
- ◇ Hawaii (11 years)
- ◇ Illinois (10 years)
- ◇ Iowa (10 years)
- ◇ Kansas (11 years)
- ◇ Kentucky (8 years)
- ◇ Louisiana (9 years)
- ◇ Maine (7 years)
- ◇ Maryland (11 years)
- ◇ Massachusetts (11 years)
- ◇ Mississippi (10 years)
- ◇ Missouri (9 years)
- ◇ Nevada (10 years)
- ◇ New Hampshire (10 years)
- ◇ New Jersey (11 years)
- ◇ New Mexico (11 years)
- ◇ North Carolina (11 years)
- ◇ Ohio (10 years)
- ◇ Pennsylvania (9 years)
- ◇ Rhode Island (10 years)
- ◇ South Carolina (6 years)
- ◇ South Dakota (7 years)
- ◇ Texas (11 years)
- ◇ Utah (11 years)
- ◇ Virgin Islands (7 years)
- ◇ Virginia (7 years)
- ◇ Washington (11 years)
- ◇ West Virginia (10 years)
- ◇ Wisconsin (10 years)

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President's Budget for FFY 2012 As Compared to FFY 2010 Funding

Federal Program	Federal Fiscal Year 2010	President's Budget for FFY 2012	Change
Part C of IDEA	\$439.4 million	\$489.4 million	\$50 million increase
IDEA Preschool 619 Grants	\$374.1 million	\$374.1 million	Freeze
IDEA Part B State Special Education	\$11.5 billion	\$11.7 billion	\$200 million increase
IDEA State Personnel Development	\$48 million	\$48 million	Freeze
IDEA Technical Assistance and Dissemination	\$49.5 million	\$49.5 million	Freeze
IDEA Personnel Preparation	\$90.7 million	\$90.7 million	Freeze
IDEA Parent Information Centers (PTIs)	\$28 million	\$28 million	Freeze
IDEA Technology and Media	\$44 million	\$33.3 million	\$10.7 million cut in earmarks
Special Education Research	\$71.1 million	\$58.1 million	\$23 million cut
IES Research	\$200.2 million	\$260.4 million	\$60.2 million increase
Race to the Top	-	\$900 million	Funded under ARRA
Investing in Innovation	-	\$300 million	Funded under ARRA
Promise Neighborhoods	-	\$150 million	Funded under ARRA
Early Learning Challenge Fund	-	\$350 million	New program
Statewide Data Systems	\$58.3 million	\$100 million	\$41.7 million increase
Head Start	\$7.23 billion	\$8.1 billion	\$866 million increase
CCDBG	\$2.13	\$2.93 billion	\$800 million increase
MCH Block Grant	\$661 million	\$654 million	\$6 million cut
Developmental Disabilities	\$187 million	\$163 million	\$23 million cut



Making Connections

Data Committee

The Data Committee was busy in 2010 and expects an even busier year in 2011. Alice Ridgway (CT) and Pam Roush (WV) were co-chairs of the Data Committee for 2010. They were joined by sixteen other committee members representing Part C Coordinators and Data Managers.

The committee accomplished a number of activities on behalf of the Association including:

- ◇ Review of the Transition FAQ and comments from the Legislative Committee. The committee provided recommendations to the Board regarding potential data gathering implications as a result of the FAQ which were incorporated into our response to OSEP.
- ◇ A compilation of current eligibility criteria for states and jurisdictions and established categories of eligibility that will be used for comparability purposes. Association members had indicated a desire to continue to provide data comparisons based on eligibility status and since OSEP is no longer providing a state list with eligibility status, the data committee made recommendations for criteria to continue categories.
- ◇ Gathered input and made recommendations if appropriate regarding consistency of SPP/APR technical assistance available to states. This was included in a session at the Data Conference.
- ◇ Developed the birth cohort survey to better understand the actual percentage of children that are touched by the Part C system during the three years of potential eligibility.

The Board charged the Data Committee with the following activities for 2011:

- ◇ Develop a template for State Profiles to reduce the number of surveys that states are asked to respond to;
- ◇ Conduct a survey on the status of state data systems; and
- ◇ Develop a method of identifying the impact of Part C eligibility changes on other systems and future eligibility in Part C, 619 or Part B.

The Data Committee will be chaired this year by Pam Roush (WV) and Lisa Balivet (AK).

Finance Committee

The fifteen member Finance Committee focused their activities this year in three areas:

- ◇ A recommendation for a revised allocation methodology in preparation for reauthorization;
- ◇ The data collection and analysis of fiscal resources utilized by states; and
- ◇ Recommendations developed with the Legislative Committee regarding the challenges related to Maintenance of Effort

The Finance will continue to be chaired by Ron Benham (MA) and Rick Ingraham (CA) during 2011. The committee is partnering with NECTAC to identify technical assistance needs and products to support states in dealing with their fiscal issues. In addition the committee will be monitoring the erosion of funding for Part C. The final activity for the committee in 2011 will be analyzing the impact of provisions of the Affordable Care Act on Part C systems.

Legislative Committee

The Legislative Committee, chaired by Linda Goodman (CT) has an active committee of sixteen representatives from Part C offices. The committee is charged with monitoring legislative activities as well as policy letters and NPRMs. The committee spent much of the past year on MOE issues and providing comments on OSEP discretionary priorities and the Early Childhood Listening Tour. The committee has begun a review of the statutory language for Part C to identify potential areas for revisions during reauthorization.

Kim Wedel (TX) will join Linda for 2011 as a co-chair of the committee. The Board charged the committee with:

- ◇ Preparing for reauthorization;
- ◇ Monitoring the Affordable Care Act statutory and regulatory changes;
- ◇ Monitoring the status of Part C regulations; and
- ◇ Monitoring legislative and regulatory actions.

Leadership Services

The Leadership Services Committee oversaw the development of a new product to support members. Chaired by Erin Kinavey (AK), this small (five members) but productive committee partnered with the TACSEI Center and the 619 Consortium to develop three webinars on the topic of the social-emotional development of young children. The webinars are posted on the ITCA website.

The Board has decided to take a different approach with this committee based on the successful webinar development. The committee will dissolve and be replaced with Task Forces that are organized around a specific topic or product.

If you, or a member of your staff, are interested in participating on one of the committees, please contact the office at ideaitca@aol.com or 317-251-0125.

All of the committee chairs would welcome your participation.

Major Budget Challenges (continued)

On February 14, 2011, President Obama presented his **budget for FFY 2012** that begins October 1, 2011. This is the first step in a long process that must conclude with agreement by the Congress and the President on funding levels for all federal programs beginning October 1, 2011. The next step in this 2012 process is for the House to develop a budget which is expected sometime in late March or early April of 2011.

The President's budget for Education is \$77.4 billion and includes an increase in early learning and K-12 programs. The budget includes a \$200 million increase for Part B State Grants and a \$50 million increase for Part C. Unfortunately, the budget also includes a freeze for the 619 Preschool Program and a cut in Special Education Research. Part D programs also were

generally held to a freeze except for cuts in the Media and Technology Program representing \$10.7 million in earmarked programs. The Congress and the President have publically agreed not to support any earmarks.

The Education budget also proposes to eliminate 13 programs and consolidate 38 programs into 11 new initiatives. One of the new authorities "Effective Teaching and Learning: Literacy" would include, among other programs, Even Start, Reading Is Fundamental and Striving Readers.

The President's Health and Human Services budget is \$79.9 billion, a slight increase to the FFY 2010 level. The budget includes increases for Head Start and the Child Care Development Block

grant but unfortunately also makes cuts to the Maternal and Child Health Block Grant and Developmental Disabilities. Details on other programs important to children and families are included on the chart on page 7.

The Congress and the President must agree to final funding before October 1, 2011 when the FFY 2012 year begins. These FFY 2012 funds will determine the amount states will receive for IDEA grants on July 1, 2012. The FFY 2012 process will most assuredly take many months to complete and significant disagreements are already in evidence.

Sharon Walsh

Governmental Relations
Consultant

The budget request includes a \$200 million increase for Part B State Grants and a \$50 million increase for Part C.

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