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## ABSTRACT

This issue of the "Early Childhood Bulletin" highlights some of the major concerns raised by parents during the second national meeting of parent members of state Interagency Coordinating Councils (ICCs) for early intervention, which was held in conjunction with the Partnerships for Progress Conference IV in Crystal City, Arlington, VA, in July 1990. The most pressing concerns parents raised were in the areas of family support, funding for PL 99-457, networking, legislative issues, and parent/professional collaboration. Each of these concerns is described and the recommendations that were generated during the conference are then presented. Parents' reaffirmation of family-centered community-based programs was a central, recurrent theme throughout the conference. Parents presented their vision of being equal partners with the other planners of PL 99-457 and of receiving support for themselves and their families where they live, where they work, and where they play. (SG)

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EARLY CHILDHOOD BULLETIN

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PARENTS SPEAK OUT

By

SHEILA WESTPHAL

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# EARLY CHILDHOOD BULLETIN

News by and for Parent Members of State Interagency Coordinating Councils

Winter/Spring

Prepared by NEC\*TAS Parent Network Staff

1991

## Parents Speak Out

by Sheila Westphal

Early Childhood Resource Specialist

The second national meeting of parent members of state Interagency Coordinating Councils (ICC) for early intervention was held in conjunction with the Partnerships for Progress Conference IV in Crystal City, Arlington, Virginia, in July 1990. At the conclusion of the conference, one parent summed up how crucial it is for parents serving on their state ICC to meet with their counterparts from across the nation: "Getting together with other parents has been great to strengthen the vision and the support network." It was exciting and enlightening to hear from so many parents — over 100 parents from 49 states and territories were present.

Throughout the conference many concerns and recommendations were shared by both parents and professionals as we worked together to continue planning for full implementation of the early childhood provisions of

PL 99-457. The most pressing concerns parents raised were in the areas of family support, funding for PL 99-457, networking, legislative issues, and parent/professional collaboration.

This *Bulletin* highlights these major concerns, and gives the recommendations generated both at the parents' meeting and throughout the conference. Parents' reaffirmation of family-centered community-based programs was a central, recurrent theme throughout the conference. Parents are doing what they are doing on ICCs because they have a vision that parents will be equal in partnership with the other planners of P.L. 99-457 and that communities will support them and their families where they live, where they work, and where they play.

## Concerns & Recommendations Family Support Issues

### ▪ Family-centered services

**Concern:** Parents strongly endorse the concept of family-centered services and see themselves as playing an important role in supporting this new direction in their state early intervention programs and services. There is considerable concern, however, about the newness of the direction in the overall scheme of services. Families are saying, "We know we are having an impact on birth-to-three services, but what will happen when our children turn three and enter the school system?" Families are anxious to have more definition and clarification of what "family-centered" means. They want to be able to carry the message to new service environments they and their children will encounter and to maintain their sense of competence and power.

**Recommendations:** One of the best ways to master a subject is to let others know about it, to teach it. Those of us involved primarily in education need to find ways to extend the message of family-centered

services into the schools. Families may have a heightened expectation for teamwork and partnership, for example. Parents should be supported in their efforts to carry these expectations and skills to the next school environment.

There is a need to compile an annotated bibliography of clearly written materials that describe family-centered principles and practices and to make them available to ICC parent members and to other parents.

### ▪ Family assessment

**Concern:** Parents are concerned about the language requiring "assessment of families" because of the possible implication that their families will be judged from a "pathology" or "deviance" perspective, either psychologically or sociologically. In some states parents are hearing of plans for pre- and post-test comparisons of family cohesion.

**Recommendation:** Follow California's proposal to do away with assessment of family strengths and

EC 308553

needs. Instead, identify family concerns and priorities for their children, then assess the availability and adequacy of resources as they relate to addressing those concerns and priorities.

#### ▪ Case management

**Concerns:** Families are wary of the perception that they or their children are "cases" in need of management. Families are not cases, and do not want to be managed. A related concern is that case management may add yet another layer of bureaucracy between families and the services they need.

**Recommendation:** Continue to clarify the meaning and intent of family-centered case management as a resource to parents, a support for them in coordinating and managing a fragmented system. To help clarify the intent, many organizations, including the parents, recommend that the term be changed, possibly to "care coordination."

## Parent Networking/Involvement Issues

#### ▪ Interagency Coordinating Councils

**Concern:** There are no established communication links and channels to insure a flow of information from the parents, to the state ICC, to the FICC, back to state ICCs, and to local or regional ICCs.

**Recommendation:** Establish formal channels for communication and foster informal ones.

Parents reported the following grassroots efforts: In California, the ICC initiated a statewide newsletter as a way to include and inform families across the state.

Washington state includes parent support networks in their mailing list.

Florida has initiated the Parent Resource Organization (PRO) so parents from all over the state can get together and discuss what is happening on the ICC.

Pennsylvania is sponsoring a "Leadership 2000" initiative to generate more public awareness about disability issues and foster more parent involvement.

Massachusetts is funding the establishment of regional early intervention parent advisory councils. Each of the five ICC parents is responsible for parent networking in a region of the state. (The state lead agency is very supportive of parent participation, and has proposed an increase in ICC parent representatives from five to eight.)

The NEC\*TAS list of ICC parents is a useful resource for helping parents network nationally.

**Concern:** A few states do not have the three parents on the state ICC required by law.

#### ▪ IFSP

**Concerns:** How do we protect and nurture the spirit of the law so that we are not just signing our names on lines and in boxes? How do we make the IFSP an invention that allows for family dreams to be expressed and furthered? Parents are concerned about the efforts spent to make IFSPs imitate current IEP protocol. The challenge is to build in accountability and procedural safeguards sufficient to protect the rights of children and families, yet avoid an overly legalized, adversarial system.

**Recommendations:** Encourage parents to consider that the IFSP belongs to them and their family. It may be useful to look at it as a management tool for clarifying roles and relationships of team members, charting progress and identifying problems.

Rights under PL 99-457 must be spelled out, possibly in the IFSP. A system independent of the lead agency is needed to teach parents about their rights, the laws and what constitutes a good IFSP.

**Recommendation:** Identify the source of the problem. Is there a lack of commitment at the state level? Are recruitment activities sufficient? Are adequate supports in place for parents who may want to participate? Enlist the support of the state Parent Training and Information (PTI) Center if needed.

**Concern:** Parents are not given sufficient preparation to allow them to participate optimally on the ICC.

**Recommendation:** Information is essential to equipping parents to serve effectively. An ICC orientation for all parents by parents was recommended, as was fostering mentoring relationships among experienced and new parents. An orientation manual should be developed and made available to ICCs. [Note: A future issue of "Early Childhood Bulletin" will address this need.]

**Concern:** Some parents are concerned that, by the time they *do* become familiar with how the ICC works, it is time to retire because their child has exceeded the age limit. This requirement also deprives the ICC of experienced parents.

**Recommendation:** ICCs should have a percentage of parents with children under five years old and a percentage with children over five.

**Concern:** There are insufficient financial and family supports for parents who serve on state ICCs. Parents find that the time commitment often requires them to take time off from work, thus losing a day's pay. Some must pay for child care out of pocket, or are forced to use scarce respite care services while

they attend ICC meetings. While professionals attend ICC meetings as part of their jobs, reimbursement for expenses and compensation for time policies are not in place for parents. Less than 20% of the ICCs are set up so that parents will be fully reimbursed for their expenses.

**Recommendations:** ICCs should make a financial commitment to at least cover parents' expenses incurred as a result of participation on the ICC. Child care expenses should be reimbursed for the actual costs of services, not at a set rate. Without these supports in place, only a select group of parents will be able to be involved to any significant degree. (See "Early Childhood Bulletin," Spring/Summer 1990, for more discussion of this topic.)

**Concern:** There is inadequate representation of the diversity of families in states.

**Recommendations:** Put in place the supports that will allow for true representation of all the kinds of families who use early intervention services.

Adopt an "Essential Policy" that states that all policies and procedures must have considered and been adapted to address the unique characteristics of diverse families. Establish the procedure of reviewing all new policies against the "Essential Policy." At every meeting, display the Essential Policy on the wall and assign someone to be a monitor. Design or adopt new policies that will address the unique needs of diverse families. Be able to say, "These policies and procedures are sensitive to the unique needs of these families."

## Funding Issues

**Concern:** There is great concern about the impact of the federal deficit and national economy on funding for PL 99-457. Many states are facing severe deficits. Funding for early intervention must compete with basic health and human service needs.

Some states are concerned about census-based funding. Alaska, for example, is concerned about how to reach a small population in a very large state.

**Recommendations:** Congress has demonstrated

strong commitment to Part H by nearly doubling the appropriations for FY 1991. Because of the economic climate, it is crucial that this federal support continue as states move toward full implementation. Supporting coordination across systems—state and federal—is also seen as crucial to maximizing and generating funding.

Investigate the feasibility of allocating funds according to child count rather than census.

## Legislation Issues

### ▪ Timelines

**Concerns:** Federal timelines are fast approaching for states to ensure that all eligible children and their families are receiving all the services identified in their IFSPs. There is concern that states which have proceeded in good faith but which are facing budget deficits may not be able to enact enabling legislation within the timelines. Many parents feel that their states are just getting started on enabling legislation and are looking for the timelines to be extended.

Other states are asking that timelines *not* be moved back because they are useful for creating the urgency needed to get legislative action.

**Recommendations:** Timelines should be moved back for states which truly need more time. Provide incentives for states ready to implement.

### ▪ Public Awareness

**Concerns:** Parents noted that a recent Mental Health Law Project survey of eleven states on the progress in state early intervention program planning under Part H found "... the lack of public awareness and organized advocacy on behalf of early intervention as *extremely alarming*, since the support of top

state officials is needed soon to enact and fund state-wide programs."

**Recommendations:** NEC\*TAS and the PTIs (Parent Training and Information Centers) must be given the support they need to train ICC parents and those in early intervention in the skills they need to build a base of support.

Participants offered a number of concrete suggestions for increasing public awareness, including:

- Work at the town meeting, budget committee level in your community.
- Establish a telephone tree to get information out quickly.
- Send information to legislators regularly and invite them to local and state ICC meetings.
- Take your senator/representative to visit a program. Get press coverage of the visit.
- Host a legislative breakfast or luncheon. (Get food donated or have it be potluck, with parents and students serving.)
- Invite your senator and/or representative to lunch or coffee—maintain personal contact.
- Sometimes less "polished" speakers have a greater impact on legislators. Use them.
- Be creative! For example, North Carolina

parents got Snickers bars donated by a local company. They added wrappers saying, "Losing federal dollars is nothing to snicker at." One was placed on each representative's desk before a vote on the issue.

- When in DC (especially with your child who has a disability), make an appointment to meet with your representative/senator, and have a picture taken with him or her and your child. Use the picture later as a reminder.

## Parent/Professional Collaboration

### ■ Interagency agreements/coordination

**Concerns:** In some states there is insufficient parent participation in "interagency workings." Turf issues may be a barrier, with agencies trying to hold to traditional role definitions. In this struggle, parents see themselves as impartial, keeping the interest of the child central.

**Recommendations:** Several states have addressed this concern: Virginia has an interagency agreement signed and would be willing to share it with others. New York's lead agency has produced a curriculum on partnering used for training parent/professional teams across the state. The Partners in Policy Making Workshop sponsored by the Minnesota Developmental Disabilities Councils is a good example of collaborative training.

### ■ Personnel preparation

**Concern:** Family-centered service design is a new approach. In practice, the traditional medical-model

and deficit-oriented approach to families is still prevalent. Many textbooks currently in use do not even contain the word "family." Parents are concerned with the lack of attention given to family-centered principles at the pre-service stage of teacher training and in inservice opportunities.

**Recommendations:** Innovative ways to prepare teachers, including firsthand experiences with families and using parents as teachers in university and college curricula should be encouraged. Competencies for teachers must be redefined according to family-centered principles.

**Concern:** There is a shortage of trained early childhood educators and specialists.

**Recommendation:** A national student loan program for the education of early childhood professionals with a "forgiveness feature" for years in the field (similar to the national defense loans of the 1960's for teachers) is needed.

**Evelyn Hausslein, Subcontract Coordinator of the parent component of NEC\*TAS at the Federation for Children with Special Needs in Boston, reports that many of the concerns raised by ICC parents in July may be addressed in the Reauthorization of Part H of PL 99-457. Testimony will be received by Senate and House Subcommittees in March, April and May 1991. Legislative aides for Senate and House leaders spoke at major conferences about Reauthorization. At the OSEP and NEC\*TAS-sponsored meeting in December 1990 for Part H Coordinators and ICC chairs, and at the TAPP annual conference in January 1991 for Parent Training and Information (PTI) projects across the country, areas of concern identified were: case management (care coordination), parent reimbursement, ages of children that allow parents to be eligible for ICC service, and federal timelines for implementation. Testimony on Reauthorization prepared by the National Parent Network on Disability will be included in the next issue of *Coalition Quarterly*.**

*This Bulletin, published with each issue of *Coalition Quarterly*, was prepared by Sheila Westphal, Early Childhood Resource Specialist at Washington PAVE, and NEC\*TAS Parent Network Staff. Sheila is the mother of two youngsters, Adrianna, age two and a half, and Travis, age six. Travis has Down syndrome.*

*Sheila welcomes your comments and views and is eager to include information from parents across the nation. Please send your contributions to Sheila Westphal, Washington PAVE, 6316 South Street, Tacoma, WA 98465. Also, feel free to call her at (206) 565-2266. If you write, please include your phone number.*



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