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ABSTRACT

This issue of the "Early Childhood Bulletin" summarizes the main issues discussed during the first National Meeting of Parent Members of state Interagency Coordination Councils (ICCs), held in Washington, D.C., in June 1989. Some of these issues include: (1) processes for influencing state policies; (2) tips for helping families in rural areas access services; and (3) suggestions about how to promote cultural sensitivity in serving families. Five priorities for strengthening the ICC Parent Member network are listed, and the issue of reimbursement and compensation for parent ICC members is discussed. Also includes contact information for ICC Parent Steering Committee members. (SG)

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NOTES ON THE FIRST NATIONAL ICC
PARENTS' MEETING

By

SHEILA WESTPHAL

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Notes on the First National ICC Parents' Meeting

by Sheila Westphal,
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At the first National Meeting of Parent Members of state Interagency Coordinating Councils (ICC), parents identified an urgent need to be in communication with their fellow parent ICC members across the country. This "Bulletin," to be published with each issue of the *Coalition Quarterly*, is intended as one vehicle to help meet that need. It will be prepared by Sheila Westphal and Martha Gentili, Executive Director of Washington PAVE, a Parent Training and Information Center.

Serving as one of three parent representatives on a state Interagency Coordinating Council can seem overwhelming. Even parents accustomed to working closely with other parents and professionals in their own states may find the experience of participating in a national meeting a bit daunting. It may seem as though the other members have been acquainted for a long time, know the issues thoroughly, and are highly experienced in such activities.

At the same time, parents are eager to interact with each other, and are exhilarated by the opportunity to share their stories and to discover common areas of concern. This desire to connect, and the commitment to join together with other parents soon became the dominant motivation of the parents who attended the first national meeting for ICC parent representatives in Washington, D.C., in June 1989. The meeting was held in conjunction with the Partnerships for Progress III conference sponsored by the Federal Early Childhood Interagency Coordinating Council (FICC).

Prior to the meeting, parents had an opportunity to select their top priorities for topics to be covered by responding to a survey. A discussion of some of the workshops held in response to the priorities parents' selected follows:

A Process for Influencing State Policies

James Gallagher, Director of the Carolina Institute for Child and Family Policy, and Patricia Place, from the National Association for State Directors of Special Education, described a policy analysis process designed to facilitate discussion around policy options that states may select for implementing P.L. 99-457. The process is a systematic way to consider a full range of options and their possible consequences.

Following the description of the process, small groups convened to try it out. Two parent representatives then described their experiences in influencing policy on their state ICC. Judie Walker emphasized how important it was to "share my values with decision-makers and be real clear about it." She recommends that parents share personal experiences about their children when making a point about policy.

Phil Davis, father of two children with disabilities, said, "As a parent in an Interagency Coordinating Council forum, you need one essential characteristic: a belief that you can make a difference. Without it, you won't be an agent of change." He recommended that each state ICC have a procedure for discussing and developing policy alternatives which allows for a range of opinions to be presented without resulting in disagreement or a need for participants to defend their positions.

Delivery of Services in Rural Areas

Tips for helping families in rural areas were provided by: Gwen Jensen, a Wisconsin ICC Parent Representative; George Jesien, Director of Project LIFT, serving rural families; and Barbara Semrau, Director of Focus, a Parent Training and Information (PTI) project in Arkansas, and Lizzie Campbell, a teacher in the Focus early intervention program serving rural Arkansas.

In Wisconsin, the ICC members are trying to change the fact that parents have to move to get services. Services for families should not depend solely on where they live and the severity of their child's disability. One panelist summarized the problem as the "Mecca Syndrome: What families need is always somewhere else and they must pack up and go to the source of help." He suggested that a more family-centered strategy would be to "look at how Mecca can go to the community."

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An advantage to living in a rural area is that one major barrier to integrated programs is automatically eliminated. Center-based programs are simply not an available option for isolated rural families in most instances.

Policies to Meet Various Cultural Perspectives

A wealth of suggestions and information about how to understand one's own culture and how to promote cultural sensitivity in serving families was provided by a panel of experts. These included Kathleen Curry, who works with early childhood programs in the Pacific Territories; Florene Poyadue, director of a Parent Training and Information project in San José, California; Debi Tisdale, a parent member of the Washington ICC; and Philomena Milong, chairperson of the Palau ICC. They had three major suggestions for states to consider in developing policy and programs:

- look at serving children in the natural environments of the culture
- be constantly flexible in designing early intervention services
- look at needs in economic, social, and occupational terms instead of by "African-American" or "Asian" terms.

Structuring a Network for ICC Parents

Martha Ziegler, Executive Director of the Federation for Children with Special Needs in Boston and Director of the TAPP Project, helped the group identify the next steps needed to strengthen the ICC Parent Member network. The group selected these priorities for immediate action:

1. To have the ICC Parent Members meet at the beginning of the Partnership for Progress Conference in 1990
2. To prepare a complete list of all ICC Parent Members
3. To establish within the National Network of Parent Centers a "Division of Early Childhood"
4. To include an insert for ICC Parent Members in each edition of *Coalition Quarterly*.
5. To establish a steering committee

All of these activities are being implemented.

What Is Your State Doing?

In the next Early Childhood Bulletin, we would like to report on a number of approaches states are using to reimburse and compensate parent Interagency Coordinating Council members.

P.L. 99-457 requires each state to have a Coordinating Council with at least three parent members. The Regulations for that law state that "the Council shall reimburse its members for reasonable and necessary expenses for attending meetings and performing Council duties." In addition funds may be used to pay compensation "if a Council member is not employed or if a Council member must forfeit wages from other employment when participating in official Council meetings."

Some of the questions which have emerged around this issue that we would like to gather information on are:

- How much compensation is appropriate?
- Which activities are reimbursable?
- Where do "self employed" people fit?
- Is a person who works only a few hours a week considered employed?
- What are reasonable reimbursements?

We would like to have information from all over the nation. If you can help, please send information to Sheila Westphal, Washington PAVE, 6316 South 12th Street, Tacoma WA 98465. Also please feel free to call Sheila at (206) 522-2266. If you write, please include your own phone number so we can get back to you with further questions. And thanks.

Funding Ideas?

The next issue will also include an article on funding sources to help parent ICC members attend the next Partnership for Progress Conference. Writer Alixia Pichette, would appreciate your ideas and suggestions. Please contact her at 714 6th Avenue, Helena Montana 59601; telephone (406) 442-8309.

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