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ABSTRACT

This issue of the "Early Childhood Bulletin" identifies and discusses issues of concern regarding financial support for parent members of Interagency Coordinating Councils (ICCs). Information gathered via letters, conversations, and interviews with parent ICC members from around the country is summarized. The article consists of six sections: (1) How Much Reimbursement Is Enough?; (2) Should Parents Be Compensated for Their Time?; (3) Parent Support Policies Must Encourage Diversity; (4) Beyond Reimbursements & Stipends; (5) What Are States Doing To Support Local ICC Parents? and (6) For the Future. A directory of ICC parent steering committee members is included. (SG)

State Support for Parents on Interagency Coordinating Councils.

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STATE SUPPORT FOR PARENTS
ON INTERAGENCY COORDINATING COUNCILS

State Support for Parents on Interagency Coordinating Councils

by Martha Gentili

Executive Director, Washington PAVE

NEC*TAS Parent Network Staff

Across this country parents are requesting information about support for their work on state and local Interagency Coordinating Councils (ICCs). They want to know if parent ICC members in other states are reimbursed or compensated for their participation on the Council, the conditions for receiving this support, and why there are such wide variations from state to state.

While our own conversations with parent leaders and parent ICC members have revealed certain trends and issues, the need to deepen the inquiry and expand on the answers became apparent. To begin that process, we requested information from parent ICC members around the country. We received responses from seven states, and then made follow-up calls to get more information. This article summarizes what we have learned so far, both from ongoing informal conversations with parents and from the responses to our most recent request. It is not an exhaustive study, rather a beginning conversation, intended to prompt responses from other states, share ideas and possibilities, and assist states in their efforts to design the nature and extent of supports parents need to increase and enhance their opportunities to contribute. These conclusions are based in our conversations, letters and interviews to date:

- Most states reimburse parents at some level.
- Timeliness of reimbursements is as important to parents as the level of reimbursement.
- Not all states pay stipends, but some do.
- Parent reimbursement and support policies can limit which parents participate and how much participation is possible.
- Parent support includes in-service training, orientation, and providing mentor parents.
- In addition to ICC membership at the state level, there is a need to support parent participation on local Interagency Coordinating Councils.

Background

Parent involvement is extremely important as states plan for services and policies to provide early intervention for young children and their families. The Regulations for Public Law 99-457, Part H, §303.602, ¶(b) [2], state clearly that states may reimburse ICC members for their expenses and pay compensation for their time:

§303.602 Use of funds by the Council.

(b) Compensation and expenses of Council members.

(1) Except as provided in paragraph (b) (2) of this section, Council members shall serve without compensation from funds available under this part, but the Council shall reimburse its members for reasonable and necessary expenses for attending meetings and performing Council duties. Funds provided under this part may be used for this purpose.

(2) Funds under this part may be used to pay compensation if—

- (i) A Council member is not employed; or
- (ii) A Council member must forfeit wages from other employment when participating in official Council functions.

(Authority: 20 U.S.C. 1479; 1482 (c), (d))

However, there is considerable latitude as to how, how much, and for which activities parents on local and/or state ICCs will be compensated for their time or reimbursed for their expenses. It should not be surprising that any review of state practices reveals wide variety. The amount of Part H money states receive from the U.S. Department of Education depends on the overall infant-toddler (birth to age 3) population of the state. At the same time, each state must have at least three parent representatives on the ICC. Also, states' priorities for use of Part H money vary from an emphasis on direct services to children and families, to an emphasis on planning. States set priorities to meet their own unique needs usually balanced between major priorities.

How Much Reimbursement Is Enough?

Nearly every state has a reimbursement policy for one or more of these costs:

- child care,
- mileage,
- food,
- air travel (Some states have large geographical areas for parent to travel, while in other states the capital or location of most ICC meetings is no more than a two-hour drive from any border).

Some states have policies to provide support for ICC members as well as other parents who serve on task forces or focus groups. Some states have a parent mentor program which may also expand the number of parents receiving remuneration.

According to Marlene Morgan, former Part H Coordinator for Arizona, the ICC bylaws for that state provide that:

the Council will offset financial obligations that are incurred as a direct result of participation on the Council, and will develop policies and procedures for timely and expeditious reimbursement for travel expenses, reimbursement of child care, respite sitter and/or related special needs and services, will insure opportunities for in-state and out-of-state travel. We pay 85% of all travel reimbursement and per diem in advance of trips. This is state policy for all employees and has been extended to parents. We purchase the airline ticket in advance and pay for registration prior to conferences.

In at least one state, parents themselves opted to limit the amount of funds to be used to support parent participation on the ICC. Alicia Pichette, a parent and former ICC Chairperson for Montana, reports that her state decided to put nearly all the funds into direct services, thus allowing for 100 children ages birth to three to be added to the service system. Because of this priority, the Council decided to provide no stipends, no child care reimbursements, and to limit per diem and travel reimbursements to out-of-town parent representatives only. There is no budget for out-of-state travel for any ICC member.

One ICC parent representative wrote that her state reimburses tolls, parking and mileage at the rate of 18 cents per mile. When she requested child care reimbursements for "nonworking moms," she was told that only mileage expenses were authorized for reimbursement.

Timeliness

Timeliness of reimbursements is as important to parents as the level of reimbursement. When a parent

must travel by airplane to attend each meeting, the airfare, hotel and meals can be more than \$500 per trip. Family budgets often cannot advance that amount nor are credit cards always an option. Cassie Johnston, a parent on the staff of Washington state's Part H Planning Project, commented, "Many parents cannot participate unless we find a way to voucher for rooms and mileage. One parent said to me recently, 'The reimbursement came in the mail today, and it goes directly for my rent.' That is the reality of parent reimbursement."

Should Parents Be Compensated for Their Time?

In the three years that parents have served on state ICCs, they have found the demands on their time to be much greater than originally anticipated—and the demands are increasing. Most agency representatives who serve on a state's ICC or its sub-committees do so as a part of their regular work load, and receive salary for the time they spend. The question of equitable treatment for parents, in terms of stipends and honoraria, is one to which parents are devoting a great deal of attention. Some states have found creative methods to provide stipends, while others either have not made provision in their budgets or find that such stipends violate state policy regarding citizen councils or committees.

Several states stand out in the provision of stipends for parent members. According to Evelyn Hausslein, Early Childhood Specialist at the Federation for Children with Special Needs in Boston and Coordinator of the Parent Network component for NEC*TAS, Massachusetts pays both a stipend and mileage reimbursement. The Massachusetts Department of Public Health, the lead agency for birth to three services, uses Part H funds to pay a stipend of \$40 per meeting to parents who are serving on the ICC. This payment applies whether it is a three- or six-hour meeting, held in the day or evening. The purpose of the stipend is to cover expenses, such as child care, but the parent is free to use it for whatever is needed. Mileage is reimbursed in addition.

This Part H money is administered through the Federation for Children with Special Needs, a non-profit parent center. The contract stipulates that the funds be used "to provide direct assistance to parents to enhance their ability to participate on the statewide council." Deborah Walker, head of the Bureau within the Massachusetts Public Health Department that has initiated these stipends says: "We need to get many more parents involved with us in many areas beyond early intervention. Providing

direct support to participating parents is fundamental to that goal."

North Dakota provides a \$50 "child care stipend" to each parent attending the ICC meeting or subcommittee meetings.

Marlene Morgan reported a legal challenge to Arizona's procedure described earlier in this article.

We have in our by-laws a statement that we will pay parents reimbursement for travel and per diem. In addition we had decided to pay each parent a stipend of \$50 per day. The problem was that there was no in-state statute that would allow us to do this. We asked for a written informal opinion from our state attorney general. He referred to P.L. 99-457 which provides for compensation if ICC members must take leave or be docked for time, or if they are unemployed. Parent representatives who were self-employed or who worked part-time and therefore would not forfeit wages would not qualify. Our state attorney general, in an informal opinion, did not support paying people who did not fit the 99-457 Regulations. The lead agency deputy director decided we should comply with our attorney general's opinion.

In at least one state, parents are trying to seek additional parent support funds through their state legislature. Caroline Hyde, parent ICC member from Maine, reported:

At a recent monthly meeting of the Maine ICC, a motion was passed that every parent be offered a stipend for participation on the Council. It was understood that, while some parents might opt not to accept it, it should be available to offset hidden costs associated with their participation. The motion is awaiting action by the state legislature. The plan is to make Part H or interdepartmental funds available to parents through a contract with the Maine Parent Federation, the state's Parent Training and Information (PTI) Center. The Parent Federation would in turn contract with ICC parents to report back on ICC meetings. The Maine ICC also hopes to make funds available to the Maine Parent Federation to provide on-going support for parents to attend state and national meetings.

Parent Support Policies Must Encourage Diversity

Reimbursement and support policies for parents can restrict which parents participate and how much participation is possible. As states grapple with limited funds, they may decide to reimburse for only part of the costs of participation. One parent representative from the midwest wrote, "Because of restrictions in parent reimbursement, we do not have fair representation on the Council ... opening can only go to people who can afford to participate, i.e.,

middle and upper middle class mothers. No fathers, no lower income parents, no single parents, no one who works outside the home or outside of special education. When parents' expenses are reimbursed, the state reports it as income to the IRS!"

Beyond Reimbursements & Stipends

Parent support is a broader issue than simply providing the amount of reimbursements or stipends parents need to be able to participate in the first place. The quality of parent participation can and should be enhanced through in-service training, orientation, and providing for mentoring relationships with experienced parents.

In some states, an experienced parent is hired to recruit parents, and to develop workshops and retreats to make certain all ICC parent members are brought up to date in their information. Cassie Johnston, a parent/consumer staff person for Part H in Washington state, refers to ICC parent orientation and training as "the hidden truth about supporting parent involvement." Here is what she said about the kind of training ICC parents need:

Because parents' time and expertise are in the area of child-rearing, being part of planning and policy development with state agencies is not something they are necessarily familiar with. Orientation must be provided right away, and must include information on the structure of the Council and state services and how things work at the state and local levels.

Parents can't participate in the Council at the same level as state agency people unless they understand the 'inner workings and process.' An example is the 'Year Four Application process.' Since it is likely that new parents coming on board may have no idea what this means, we will have a workshop about how the process works. That way, parents will be prepared to take part in developing the overall plan and to vote on it when it comes before the Council. If you don't understand what the Council is doing or why, you can't really feel a part of it. When that happens, the feeling of being a 'token' can enter in, and then you don't really want to participate.

Providing in-service training for parents on the ICC reinforces and validates the value of parent involvement and of their perspectives.

What Are States Doing To Support Local ICC Parents?

A challenge facing Maine and other states establishing local or community-based Interagency Coordinating Councils is recruiting and sustaining parent involvement at the local level. Caroline Hyde from Maine commented:

Maine has a provision for three parents on each local ICC, and there are many parents floundering out there. We want to find a way to get these parents together to discuss issues and strategies so they can go to their local ICC and be empowered. One way we are addressing this need is through an annual state-wide meeting to be held in early Spring. The state ICC would provide funding for one parent from each local ICC and the three state ICC parents to participate. In planning the workshop and working on legislation, we are teaming up with the Association for Young Children with Special Needs (Maine Early Childhood Advocacy Group), and the Maine Parent Federation (Coalition of Maine Advocacy Groups primarily for school-age children at this time, but working more on early childhood issues).

Additional goals of the parent representatives on the Maine ICC are to provide funding through the Part H grant monies to the Maine Parent Federation for an Early Childhood Specialist to provide support and information to parents of young children. It is hoped that when local or state parent representatives have questions that come up during their participation, they can call the Maine Parent Federation to ask questions or gather backup information.

In Massachusetts a contract already exists with the Federation for Children with Special Needs to provide time for staff to work with community-based Early Intervention Parent Advisory Councils (PACs) to conduct training and develop training materials. These local PACs operate out of the various Early Intervention programs in the state and are a requirement for a program's eligibility for state early intervention grant funds. Technically, some of these training and support funds could be used to send a parent to the annual Partnerships for Progress Conference or for local PACs to bring in speakers, de-

velop materials, and meet other training and development needs.

One final issue around supporting ICC parents seems critical if long-range parent involvement in planning is to be assured. That is the issue of planning for a smooth transition from outgoing to incoming parent representatives on state ICCs. One promising model from Washington state involves linking outgoing or experienced parents with incoming parent members in a mentoring relationship.

For the Future

Wide diversity of states' policies toward parent support will probably exist for the near future. However, one parent suggested a need for a national policy to direct an appropriate amount of Part H dollars to support the participation of ICC parent members. Flexibility about how the money would be spent is needed to meet the unique needs of parents in widely diverse states.

*This "Bulletin," to be published with each issue of the Coalition Quarterly, is prepared by Martha Gentili and Sheila Westphal, Early Childhood Resource Specialist, NEC*TAS. Your comments and views are important to us. We would like 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 Sheila at (206) 565-2266. If you write, please include your own phone number so we can get back to you with further questions. And thanks.*

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