

# **Supporting Parent Participation On LICCs**

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## **Overview**

Early Intervention services arose from a belief that children with or at risk for disabilities and their families need support within the community that enhances the developmental, health and educational lives of children and families. Repeated studies have documented the benefits of such services. The degree of family involvement has been shown to be one critical component that increases the effectiveness of Early Intervention service delivery.

In much the same manner, the Local Interagency Coordinating Council also benefits from parental involvement. Family members of the LICCs are visible and verbal reminders of "family friendly." They can make simple, down-to-earth suggestions that stimulate new ways of thinking. Asking "Why?" is a natural role for parents, and this question often challenges providers to reflect and respond in different ways. Consumer experience and active involvement at the local level help to create programs that respond to the needs of the community's citizens. Families must be a part of the process to aid the creation and revision of positive, appropriate service delivery systems.

Parents also enhance the two-way exchange of information through the community. Formal and casual parent networks improve communication. Various topics of interest (e.g., legislative issues or classroom overcrowding) will disseminate more rapidly and more accurately if parents are participants from the beginning.

It is important to acknowledge that the role of parents on the LICC comes at a price to families. Sacrifices made that enable parents to participate in the LICC should be appreciated and respected by all group members. Parenting a child with a disability frequently consumes more time than if the child were typically developing.

There are a variety of terms used to identify parents who participate on LICCs, such as "parent representatives", "family advisors" and "family advocates". All of these terms will be seen in this section and the appendix on parent participation.

## **Principles Of Family/Professional Collaboration**

In order to work effectively, families and professionals need to form an equal partnership which is mutually respectful of the education and expertise of both partners. Principles of Family/Professional Collaboration must include:

1. promoting a relationship in which family members and professionals work together to ensure the best services for the child and the family;
2. recognizing and respecting the knowledge, skills and experience that families and professionals bring to the relationship;
3. acknowledging that the development of trust is an integral part of a collaborative relationship;
4. facilitating open communication so that families and professionals feel free to express themselves;

5. creating an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored;
6. recognizing that negotiation is essential in a collaborative relationship; and
7. bringing to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special needs and their families.

## **Responsibility Of LICC To Parent Representatives**

1. Support parental participation on the LICC in addition to recognizing parents as necessary team members based on their field of expertise (i.e., actually living the life experiences that professionals are trained for), LICCs can also provide more tangible and necessary supports to parents.
2. Include the Parent Representative in all LICC activities and treat the Parent Representative as an equal team member and valuable consumer consultant.
3. Remember that being a parent on the LICC may not benefit that parent's child and in some cases may be a hardship for the family.

The involvement necessary for parents of children with disabilities is often beyond the role of typical parenting and therefore not part of the "job." Therefore, serving on the LICC is indeed just that – serving – and that involves sacrifice and time. Make parents' time and involvement worthwhile and provide feedback regularly.

## **What LICCs Can Do To Enable Effective Parent Representation**

1. Provide a stipend to compensate parents for their time and to cover their travel and child-care expenses. Identify a staff person to be primary contact for reimbursement and who understands that timeliness is essential.
2. Provide child-care at the meeting site or referrals for appropriate child-care providers.
3. Provide transportation if necessary.
4. Schedule the LICC meetings at convenient times for the Parent Representative, adjusting the regular schedule as necessary.
5. Provide personal orientation before the Parent Representative's first LICC meeting including a copy of the LICC Handbook and other orientation materials in the families' preferred language. Recognize that some family members may require more support than others.

6. Offer partnering the parent with a veteran parent or professional (including accompanying new Parent Representatives to their first LICC meeting) to ensure that new members feel supported in their roles as advisors and have the opportunity to share their ideas.
7. During and after meetings, specifically recognize the value of family participation.
8. Wear name tags and repeat introductions frequently for the benefit of all new members of the LICC.
9. Provide ongoing education and information regarding available programs and resources.
10. Provide scholarships and other financial support for parents to attend state or regional workshops.
11. Include Parent Representatives in specific projects in significant ways, remembering to balance membership on committees between families and professionals. Committees should be encouraged to have more than one family member.
12. Encourage several parents to become members of the LICC either at the same time or on a rotating basis. This helps cover family emergencies and also helps avoid the perception of being “the token parent” on the LICC. It will also give families the opportunity to share ideas and impression with other parents.
13. Ensure diversity among the membership by recruiting broadly from the community and the population the programs serves.
14. Broaden the prospective pool of parent members to include parents of children who have already graduated from early intervention (e.g., parents of children with disabilities aged 12 years or younger).

## **Strategies For Working With Families Who Speak Languages Other Than English**

1. Identify someone who is of the family’s culture and speaks the family’s language to facilitate family participation.
2. Provide explicit instructions about what the family will be expected to do.
3. Ask the family if they want an interpreter and involve them in the selection of interpreters. Strive to offer interpreters for all the program’s activities, not just at special times. Use the same interpreter at each meeting so that a new interpersonal relationship does not have to be established each time. Identify interpreters who understand the subject matter being discussed – for example, someone they know to interpret if they prefer.
4. Invite a bilingual veteran family member to sit with a new family participant to translate and offer support during and after the meeting.

5. Provide all written materials in the family's preferred language. In addition, materials can be offered in other formats, such as videotape and audiotape.
6. With families' permission, tape record sessions and meetings in addition to keeping minutes; some families may not be literate in their own language.

*Adapted from: Essential Allies – Families As Advisors, E. Jeppson & J. Thomas, Institute for Family-Centered Care, December, 1995*

### **Tips For Recruiting Families**

1. Ask other families who are already involved if they have a friend who might be interested.
2. Ask providers to identify families, have providers talk to families about participating on the LICC.
3. Use "key informants" --- people in the community who are knowledgeable about children with special needs and are a link to other families and family groups.
4. Contact local or statewide parent-to-parent organizations.
5. Ask families who participate in parent and support gatherings.
6. Develop radio and TV public service announcements in the language of the communities you are trying to reach.
7. Place a story in the community newspaper.
8. Develop posters and place in community locations:
  - Recreational and social service programs serving children and families,
  - child care facilities,
  - physician offices, community health clinics
  - libraries

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## Checklist for Involving Families on Local Interagency Coordinating Councils

This checklist is a tool to help think about ways that families are participating on your LICCs. Rate each item and then cite specific examples that illustrate how your LICC is involving families. Use this tool to imitate new opportunities to work in partnership with families or expand on current activities.

	not doing well	doing okay	doing very well	Examples
We recognize and respect the expertise of families as LICC members.				
We are vigilant about seeking opportunities to involve families in LICC activities.				
We seek to involve families who reflect the racial, ethnic, cultural, and socioeconomic diversity of families currently served in the community.				
We use a variety of strategies to identify and recruit families to serve on the LICC.				
We demonstrate appreciation for the contributions families make to the LICC.				
We have developed both short term and long term roles for families.				
We create opportunities for families to participate that are consistent with their cultural practices and individual personalities.				

## Checklist for Involving Families (continued)

	not doing well	doing okay	doing very well	Examples
<p>We have developed a range of ways for families to participate as members including:</p> <ul style="list-style-type: none"> <li>- participating as trainers in staff orientation and in-service programs</li> <li>- reviewing written and audiovisual materials developed by the LICC</li> <li>- conducting evaluation activities</li> <li>- participation in focus groups</li> <li>- serving as members of committees and task forces</li> <li>- reviewing grants</li> <li>- developing educational and informational materials for other families</li> </ul>				
<p>We support families serving on the LICC by:</p> <ul style="list-style-type: none"> <li>- reimbursing their travel and child care expenses</li> <li>- offering a stipend of honorarium for their participation</li> <li>- providing mentors</li> <li>- offering training programs and workshops</li> <li>- providing secretarial support</li> <li>- facilitating networking with other families</li> <li>- being aware of parental burn out</li> </ul>				
<p>We provide training to staff on working collaboratively with families.</p>				
<p>We have a Family Advisory Council or committee.</p>				
<p>Membership on the Advisory Council reflects the diversity of families served by the program.</p>				
<p>The Family Advisory Council reports to the LICC.</p>				

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## Sample Parent Invitation Letter

Insert LICC Header here

Dear            Parent Name

The Local Interagency Coordination Council is composed of members community and parents with an interest in quality services for children with special needs in our community. Everyone who attends meetings does so on a volunteer basis. Everyone brings a valuable point of view to the group. We would like to invite you to participate in this group. The parent members have a very important contribution to make to the LICC: your opinion and personal expertise!

Since you and your family are the recipient of services provided by the state and local agencies, you are the "customer". This is an excellent opportunity to offer suggestions to improve the services that you receive. Parents have the power to change things and get things done! Don't hesitate to speak up about the issues discussed at LICC meetings. Voice your concerns regarding your family and especially your child with special needs. It's also a good time to express your satisfaction with the services you receive. If you have had a good experience with a particular service or agency, let it be known. Praise goes a long way! Don't hesitate to advocate for your child, as ALL children with special needs will benefit! Doing so is the greatest service you could offer to the community. The primary purpose of parent advocates is to assist the professional members by offering ideas to better serve families of special needs children in the area. Your input is necessary and valued to ensure that the efforts of the LICC reach families, like yours, of children with special needs.

Your time is valuable. Your involvement with the LICC is very much appreciated and will not be taken for granted. We count it an honor that you would take time out of your busy schedule to join with us in our pursuit to reach all families of children with special needs. We meet on            day/month/time at            location. Our next meeting is            date. Please call me at            LICC contact with any questions you may have. If you are interested in the LICC but are unable to attend meetings due to work or other obligations, please let me know so that we can discuss other ways for you to become involved. Thank you for your consideration and I look forward to hearing from you soon.

Sincerely,

Name  
Professional Co-Chair  
LICC Name