

## Recruiting and Retaining Diverse Parent Representation on Interagency Coordinating Councils

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### Background

In 1997, Congress reauthorized the Individuals with Disabilities Education Act (IDEA), which grew out of the Education for All Handicapped Children Act of 1975. Congress stated that there was a need to “enhance the capability of state and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner city and rural populations.” The 1986 reauthorization of the law had created the Infants and Toddlers with Disabilities Program and state interagency coordinating councils (ICCs) as one of the required components. The law mandated that at least 20 percent of the members of these councils be parents of children with disabilities. State ICCs strove to meet the need to enhance services to under-served groups within their locales by encouraging the participation by diverse citizens on the councils and committees.

This document describes several ways ICCs can encourage and expand diverse parent representation on councils and committees. Although it specifically concerns parent members, this paper can also be useful for general recruitment of diverse members.

There are two important factors that affect participation on ICCs—recruiting effective new members to the board, and retaining them.

This paper was developed with ideas from the references cited below and from numerous first-person stories and experiences of parents. NECTAC is grateful to the parents described in the “Family Stories” (Please see Appendix 1)—and to all the other parents of children with disabilities—who shared their experiences as members of state ICCs. We hope their experiences help other ICCs increase their effectiveness in recruiting, retaining, and involving parents from diverse groups.

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## Purpose

ICC members and staff must have a compelling interest in and belief that diversity is indeed a civic value that is essential to excellence and equity in the development of programs and services and their delivery to clients.

Members from under-served groups can help the council identify appropriate methods of reaching diverse families and community groups, which in turn can improve the likelihood that services meet the cultural needs of families and their children. By adapting services to the needs, preferences, and values of diverse families and by tailoring messages to make families feel comfortable in seeking early intervention services, state ICCs can achieve their goal of better serving not only diverse families, but *all* families.

State leaders and state ICCs can set the tone by demonstrating the importance of cultural diversity in their membership, particularly in recruiting parents. But their participation should be active, effective, and open. Members should value the expertise and knowledge of all participants and encourage and solicit the observations of all. Simply adding parents to state councils in order to meet the legal requirements for parent participation or diversity of representation is not enough.

For active—and effective—parent participation to occur, the parent members must believe they will have a voice in the discussions and that their opinions will be heard and respected. In many other settings and situations, family members have shown themselves to be effective advocates and partners with agency representatives and service professionals in designing, implementing, and evaluating programs.

Some parents are established leaders in their family units. Others have had experiences that prepare them to move easily into their roles as ICC members. And still others need ongoing individual support, mentoring, or leadership training to participate on the council effectively.

Consider this word of caution. No parent—nor any member—should be expected to speak on behalf of all families. Instead, the parent member should be recognized as part of a group of family members who broadly represent the demographics of the state.

Culture, ethnicity, and previous experiences in groups influence how a person participates on an ICC. When members exhibit genuine interest in each other's background, new members will probably feel respected

and valued, which will help ensure that parent members from diverse backgrounds find a comfortable setting in which to talk about their experiences, values, and expectations.

## Recruiting diverse members—especially parents

In order to increase participation by diverse parents, we suggest that state ICCs study and adapt the following strategies, techniques, and principles to develop their policies. We have taken them from the reference sources cited below and from the experiences of parents who have served on ICCs and other advisory boards.

### *Prepare*

#### ★ Evaluate the council's mission

What do the council members know about addressing diversity issues in the development of policies, structures, and practices, and what is their commitment to it? A strong mission statement, for example, can be an effective framework for recruiting and retaining diverse members on the ICC.

Evaluate the purpose and rationale for ensuring diverse representation. Is it an effort to comply with legal requirements or is it an effort to develop the skills to respond to broad community needs? What goals will be achieved by ensuring that the ICC has diverse parent membership?

#### ★ Discuss state and local demographics with ICC members

What do current ICC members know and understand about the diverse groups and their demographic distribution in the state? Do these groups have different interests and needs? Do the ICC members know what they are? What do the board members need to improve their understanding of diversity issues?

#### ★ Get training for ICC members on diversity topics

Learn how diversity has an impact on programs, including such matters as stereotyping, communication, cultural norms, etc. For example, although the majority culture in general places a high value on timeliness, eye contact, firm handshakes and the opportunity to disagree publicly, these may be unimportant to others. Or a minority member, raised to expect that it is disrespectful to disagree with others in public, may find the board meetings uncomfortable and resign without contributing his or her insights.

### *Contact the communities and constituents*

#### ★ Talk to community leaders

Describe and explain the council's approach to diversity to leaders of the different local groups and cultural communities. Tell the leaders that the participation and contributions of all ICC members is sought out and welcomed, and that all perspectives are weighed and considered. Reaching out like this to community leaders can engender their confidence in the ICC, and they may refer parent leaders to the ICC and its committees.

#### ★ Describe how vacancies occur and how they are filled

Explain to community leaders and others how vacancies occur on the state ICC and your own state's procedures for filling them. The procedures vary from state to state, but in all states, the office of the governor appoints members of the state ICC. (See Shackelford, J., *State ICC Overview* (2003), pp. 1–7 for a state-by-state summary of these procedures.)

#### ★ Contact local and regional councils and agencies

Find out how they identify and nurture natural leaders. Local agencies are in a good position to have connections to diverse parents through such things as local parent leadership training sessions, training of trainers, and other meetings and focus groups. Local agencies also may have conducted trainings based on parent interests and needs, or may have offered other opportunities for parents to work with the council.

#### ★ Establish alliances with local agencies that provide services to families.

Connect with community leaders and tell them your desire to encourage diverse representation on ICCs. Focus your outreach efforts on schools with very diverse populations, hospitals and clinics, faith-based groups, and businesses that work with or have committees made up of potential candidates for board membership.

Many states have community-based parent resource centers or projects that address special populations. These projects—many of them funded by the Office of Special Education Programs in the U.S. Department of Education—offer information and training to parents of children with disabilities.

#### ★ Get out into the communities

Networking in many communities often occurs by word of mouth. Being visible and known in communities is an important way for ICC members to learn about possible candidates and to meet interested individuals. It also demonstrates in a concrete way that the ICC values diversity of ideas and perspectives and the contributions that members of the community can bring to the council.

#### ★ Describe the qualifications and commitment your candidates should have

What knowledge, experiences, and skills are you looking for? Would the various communities served by the ICC agree that these are necessary skills? Should the prospective parent member be knowledgeable about community issues? Should the candidate be bilingual? Should the candidate represent a particular ethnic group to ensure balanced representation?

### *Act*

#### ★ Actively ask for names of potential board members

Ask others, such as parents, advisory board members, and individuals in the community, to help you find candidates, and also to encourage individuals to make themselves and their interests known to the council.

#### ★ Recruit the candidates

After you have identified possible candidates for the council, current members and ICC staff should contact them directly, either in person or by telephone or email. Direct contact in this way shows overt respect for their contributions and representation. This approach general has more impact than writing a letter of invitation alone, and it also gives the council members an opportunity to answer any questions a candidate may have about serving on the board.

### **Strategies for retaining parent members**

#### *Introductions and transitions*

#### ★ Begin with smaller roles and responsibilities

Introduce candidates to the work of the ICC before they actually become members, beginning with small assignments, such as serving on a committee, to build up their familiarity with the work of the ICC and the practical skills they will need, such as expressing one's position effectively in a group, building rapport with other members, and feeling pride in civic involvement. By the same

token, these kinds of introductory assignments are ways for the council members to evaluate the candidates' contributions to the council and to enhance their ability to serve as full members.

★ Give new parent members an effective, thorough orientation

A good orientation gives new members an opportunity to learn about the mission of the council, its lead agency, how it conducts its business, and what is expected of the members. Explain any existing ground rules the council has adopted for conducting its meetings. It is a time to lay the foundation of positive relationships among members and to discuss with the new members their preferred methods of communicating, meeting schedules of the council, how to ensure full and active participation, and leadership training opportunities. Thoroughly explain to new members any acronyms, technical terms, and special language that is used on the board. Prepare a glossary of frequently used terms, with interpretations for members who do not speak English or for whom English is a second language.

Explain the long-term nature of the work of the ICC. That will go a long way to dispelling the disappointment some members have felt when their and the council's work did not produce immediate results. In the past, some members have left or stopped participating, discouraged by the apparent lack of effectiveness of their contributions.

### *At the meetings*

★ Prepare members before the meetings

Inform members in advance of the major agenda items and their political context. Circulate detailed supporting information about issues to be discussed. Give members time to prepare reports and to ask for input or assistance from others. Review, if necessary, procedures to put an issue on the agenda or bring up at a meeting.

★ Establish a positive working atmosphere

Studies have shown that the climate of a meeting can be as influential in generating a level of quality of participation by diverse members as the meeting logistics and structure. The ICC chairperson—or the meeting facilitator—should establish rapport with and build a caring relationship as a reliable ally with new members.

Make sure there is enough time at meetings for discussion and reflection. Recognize the different forms that participation can take, from intentional listening, to ask-

ing question, interjecting ideas, and offering informative input. Respect every member's opinions and encourage all members to contribute to the discussion. Incorporate diversity issues throughout the agenda, not just isolate them in one or two items.

Family issues or personal reasons may inhibit a member from participating actively. Be sensitive to how a member receives a question or comment. For example, in some cultures, it is considered more appropriate to phrase questions indirectly, such as "What would families you know think about this?" rather than "What do you think about this?"

★ Guide meetings for full participation

Skillful facilitation is the key to a good, productive meeting. The ICC chairperson (or facilitator, if there is one) should follow established techniques of facilitating a meeting to elicit the opinions and perspectives of all participants, checking to verify everyone's understanding of what was said, and helping to clarify statements when needed or encouraging members to ask questions or volunteer information that will help clear up areas of possible misunderstanding.

Many groups, including ICCs, have already established ground rules that govern their meetings. When new members join the council, the leader or facilitator should review them in a meeting.

As part of good facilitation, the chairperson or leader should not only pay attention to members who seem to control the conversation, but also encourage members who have not spoken up to offer their views on the topics at hand. This includes giving members enough time to respond to issues or questions under discussion and to review technical terms and jargon, if that seems to be a difficulty.

### *After the meeting*

★ Conduct individual follow-ups

The ICC chairperson, facilitator, designated member, or mentor should contact new members after each of the first few meetings, either in person or by phone or email, to see that the new members have a good understanding of the issues and discussions that took place in the meeting.

★ Plan for absences

Set up an alternate way to inform a member of what happened at a meeting when a member cannot attend. Send the absent person information in the form of

another member's notes, a telephone conversation, or more formally in a report or the minutes of the meeting.

★ Compensate members for their expenses

Establish a stipend or other form of compensation for the time, travel expenses, and childcare for members who are not otherwise reimbursed (e.g., an employee whose agency pays salary and travel costs). More than two-thirds of state ICCs offers some form of compensation to parent members.

★ Recognize good work

Demonstrate the ICC's appreciation for good work, both informally and formally. An occasional note of appreciation creates renewed energy. At other times, a more formal acknowledgement may be appropriate, such as a framed certificate (which, if displayed on the wall at home or in the office may prompt others to ask about the ICC).

★ Evaluate the council's effectiveness in embracing diversity

Periodically, evaluate how effective the council has been in including multiple perspectives in decision-making policies, in supporting and assisting new members, and in assessing the value brought to the discussions from new diversity members. Continue talking to new members about ongoing needs.

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## Notes

For contact information for State ICC Chairs, see <http://www.nectac.org/contact/iccchair.asp>.

For more information about each state's community parent resource centers (CPRCs) and parent training and information centers (PTIs), visit the web site of the Technical Assistance Alliance for Parent Centers at <http://www.taalliance.org/>

## Appendix 1

### Family Stories

The following three family stories illustrate how several of the strategies were used to recruit new parent members to the ICC.

The first story focuses on an issue that a number of ICCs have experienced—difficulty in recruiting parents who represent diverse cultures because of the issue of citizenship. Nanfi's experiences demonstrate how these parents can be involved even without official citizen status. In the second story, because the father's voice is rarely heard, Michael's experiences demonstrate ways to involve fathers and include their perspectives. In the third story, Ginger combines her expertise as a parent and her experiences in working with diverse cultures to enhance the work of the ICC in helping families to access services.

All three stories illustrate the importance of a mentor in recruiting and retaining members to the ICC. They also demonstrate the unexpected but welcome outcome of parent leadership in that both Nanfi and Ginger have become employed in positions working with families of young children with disabilities.

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#### Nanfi's Story

Nanfi L. is a parent from Connecticut. Having come to the United States from Uganda, she has had resident status, but as of 2003 is not yet a citizen. Her 4-year-old daughter began receiving early intervention services as an infant. In talking with one of her daughter's therapists, Nanfi indicated an interest in becoming involved in some way in her local community. The therapist did some research and consulted with the program director. She told Nanfi about the local Birth-to-Three committee and their need for parents to become involved in the work of the committee, as well as some training opportunities that would be available to her.

Through her involvement at the local level, Nanfi became aware of the state ICC and set a goal of one day becoming involved at that level. She had become acquainted with a parent member of the ICC through her work on the local committee. As her daughter grew older, Nanfi began to feel more comfortable and in a position to increase her level of involvement. After two years of receiving services and becoming familiar with the system, the parent member of the ICC contacted her and encouraged her to apply as an alternate. This parent then provided ongoing mentorship and nurturing that allowed Nanfi to feel comfortable attending meetings.

When she first was selected to serve as an alternate on the council, there were very few other parents on the council. She felt that perhaps she was there "simply as a token minority representative." She did not feel valued as a parent. It was "intimidating" for her and the other two parent members to voice their views. At that time,

they felt "outnumbered" by the agency representatives on the council. As her confidence grew and she was able to form connections with other parents, she began to feel more comfortable in expressing her opinion. As other parents were recruited and the parent voice grew, it became easier to speak on issues. It was the family-to-family connection that provided her with the support and encouragement to ensure her ongoing work with the council.

Because of her citizenship status (she was not then a U.S. citizen), Connecticut state law prohibited her from being appointed to the council. Nanfi began by serving as an alternate, non-voting member, rather than as a full member of the ICC, which still allowed her to speak on behalf of other families. In order to support her attendance at council meetings, Nanfi was provided with childcare and mileage reimbursement for council activities. Without this it would have been very difficult for her to participate, despite the fact that she was committed to the work of the council and it was a goal of hers to serve on the council.

Nanfi now works as the project director for the Birth-to-Three Family Leadership Project in Connecticut.

#### Michael's Story

Michael J. is the parent of a 4-year-old daughter with a disability. When he became involved with the local Baby Net Council, he became recognized as a parent who was willing to speak and give valuable opinions on issues that affected families. He felt that the father's voice was often unheard. He was recruited at the local level and

encouraged to apply for membership on the South Carolina ICC. He was appointed to the Council and currently serves as the vice-chair.

When Michael was first appointed, the Part C coordinator, another member of the ICC, in South Carolina worked with the new members and provided an orientation about the work of the council. Through ongoing communication, primarily through email, he was able to participate actively as a council member. Michael and the other parent members of the council keep family issues at the forefront of the council's agenda. As new issues are brought forward, members of the council actively seek parent input, and Michael feels that his input is valued and acted upon.

When asked for advice for recruiting other parent members, he suggested directly asking parents who are active at the local level and who have demonstrated some leadership skills. To retain new members, Michael suggested that council members limit the use of acronyms as much as possible so that all members know and understand what is being discussed and are not faced with a confusing "alphabet soup" of terms that can often accompany council discussions.

Because he is employed by the South Carolina Department of Mental Health and therefore considered a state employee, Michael is not reimbursed separately for his time or expenses on the council. Instead, his supervisor has made it a part of his job description to attend the meetings; therefore, he is paid for his time as part of his employment.

### Ginger's Story

Ginger K. has been actively involved in the early intervention services system in the state of Washington for the past six years, since her son was diagnosed with autism. She has become a strong family advocate for parents in the SICCC for the past four years.

On the professional level through The Arc of King County, Ginger works with many families of children with disabilities from diverse cultural backgrounds, particularly from the Asian community. She conducts regular workshops and training sessions on issues related to serving people and families in cross-cultural situations.

Ginger became aware of the state ICC from working with The Arc and serving as a parent representative at the local ICC. Another parent who was involved in both local and state ICCs introduced Ginger to family leadership

team members, many of whom were parents whose children had been in early intervention programs. They encouraged her to apply for membership on the state ICC. Upon being selected, she was given an orientation and was also mentored by the team coordinator.

The Washington ICC has a family leadership subcommittee and a family involvement coordinator, who conducts outreach activities to culturally and racially diverse communities to involve families at the local level and to encourage leadership. Ginger is currently the co-chair of this committee.

Ginger feels her role on the council gives her the opportunity to share her perspectives and speak on behalf of underserved families. She helps raise the issues of language and cultural barriers that families from diverse cultures face in accessing services. Because of the issues raised by Ginger and other council members, the ICC agreed to fund a half-time position to work with families from diverse cultures and to train early childhood professionals on the issues of cultural diversity. Ginger has recruited parents from various communities to attend these trainings as well so that they can share their stories with the professionals. Many parents have become trainers and presenters.

Parents on the Washington ICC receive per diem payment for meals and are reimbursed for travel and childcare expenses.

## Citation

Please cite as:

Swett, J., Xiong, D., Ayankoya, B., and Shackelford, J. (2004). *Recruiting and retaining diverse parent representation on interagency coordinating councils* (NECTAC Notes No.17). Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center.

This document appears at <http://www.nectac.org/pubs/pdfs/nnotes17.pdf> and updates to the data herein will be announced at <http://www.nectac.org/pubs/>.

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## Acknowledgments

Michael Brady, of the Publications Office at the FPG Child Development Institute, edited this paper and the authors appreciate his contributions.

Joan Danaher, Associate Director of NECTAC, provided technical edits. Caroline Armijo, NECTAC Publications Coordinator, was responsible for design and production. All NECTAC products are reviewed by our Contracting Officer's Representative, Peggy Cvach.

*NECTAC Notes* is produced and distributed by the National Early Childhood Technical Assistance Center (NECTAC), pursuant to contract ED-01-CO-0112 with the Office of Special Education Programs, U.S. Department of Education (ED).

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