



FEDERATION FOR CHILDREN
WITH SPECIAL NEEDS

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“Who You Gonna Call?”

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A popular movie made that slogan familiar, but it is also familiar to many parents of children with disabilities and special health needs. Parents often are called upon to serve in capacities that go beyond representing the interests of their own family and child. They may be asked to collaborate with professionals in efforts to improve or redesign services, programs, and policies that impact many families. Committees, task forces, and program administrators may look to parents and family members to help guide their efforts to be more family centered. The parents reading this article are likely to be the ones called by other parents, community leaders, or professionals who are looking for parents to fulfill a variety of roles, from providers of information to serving as committee chairpersons.

When parents become active in Interagency Coordinating Councils (ICCs) because of some interest in programs for their children, they take on a new public identity. They became known not just as “Jason’s or Isabelle’s parents,” but as parents knowledgeable about or representing a particular disability, health condition or service need. That association often leads to invitations—and expectations—about other things that “Jason’s or Isabelle’s parents” might like to do.

Often parents do not need an invitation from another parent or program staff member to become involved; their own experiences compel them to action. One mother of a child with cardiac problems learned from a consumer group about a parent advisory council at the hospital where her child had surgery and was receiving ongoing care. She was eager to join the council so that she could learn

more about the hospital and offer the administrators her suggestions for possible improvements. Her participation helped change hospital policies, such as sibling visitation hours; provided guidance on renovation decisions; and led to new and better ways of getting valuable feedback from parents on the care that was being provided. Other parents hear about pending legislation and feel that political involvement is the best way for them to help their own child as well as all the other children with similar conditions.

No matter what compels parents to contribute to these larger efforts or where they choose to devote their time, such activities inevitably bring parents into new arenas. As they become known and recognized as resources, available to share their views and their time with other parents and with professionals seeking consumer views, parents may find that they are being deluged with requests.

Here are some things to consider when deciding to participate. First, rather than agreeing immediately to take on new tasks or to represent families on a new committee or task force, ask how soon a reply is needed. Parents may wish to ask for more information about the purpose and time commitment involved and may wish to talk with others first, including their spouse, to see whether it fits in with other commitments. Using the time available before a response is important for weighing the pros and cons, allowing for a parent to make a more informed decision. Volunteers have the luxury of picking and choosing only those activities that seem relevant to them or that offer them the chance to learn valuable information. They also learn to keep handy the names of other parents who might be interested in participating. Declining gracefully while offering a referral to another parent keeps the door open for other opportunities that might be of greater interest or that might come at a better time for the family.

Finding the “Right” Parent

Officers and board members of parent groups are always looking for others to share the workload and to help the organization be effective. High on their list of desired attributes are enthusiasm, a certain level of organization, and good communication skills. Parents who have a perspective gained from firsthand experience over time are essential, as are parents of younger children who lend a fresh viewpoint and new energy to the organization’s efforts. In the same way, professionals see the value of bringing to their parent-professional collaborative activities the viewpoints of parents of young children, parents whose children are newly diagnosed, and parents who have already shown their leadership qualities through their own parent organization activities.

Different viewpoints exist about what characteristics are most important and about how to select parents to join with professionals on committees and on task forces. The range of viewpoints was crystallized for me while conducting a telephone survey of state health departments in 1987. The intent of the survey was to discover how state health department officials identified parents to serve as consumer representatives on their department advisory committees. I had just completed a call with one official who was clear that the best path was to find parents who were already active. These

parents, he felt, would be comfortable in forums with professionals and would have gained some perspective about their own child's situation. Professionals would feel comfortable with parents who already knew some of the special terms and who had experience with committee work.

The next state health official I interviewed, who worked in a state contiguous to the first one, exclaimed, "Spare me the professional parents!" She preferred that only those "fresh from the experience" of either diagnosis or hospitalization be invited to participate. What was each official seeking, and what was each hoping to avoid?

In many circles, the "professional parent" label is not meant as a compliment. The terms "active parent" or even "parent activist," by contrast, bring to mind other types of activists in our society championing such causes as civil rights and protecting the environment. The term "professional parent," however, implies a parent who has had lots of experience representing parents, but who has lost touch with the day-to-day reality of other parents and the parenting experience. In an extreme expression of this point of view, one professional said that, in her opinion, after a few years of involvement a parent was not useful any more as a parent representative! Parents, of course, know that they gain valuable new perspectives from the many changes and challenges they and their children experience over time.

If professionals select only very active and involved parents with a proven ability to collaborate, how will new parents be considered for participation in the planning of policy and programs? Does the "professional parent" join the professionals in deciding what all parents need?

On the other hand, some professionals believe that parents of newly diagnosed children are in the best position to evaluate available services and programs. However, the newness and even shock of a diagnosis or experience of hospitalization needs to wear off before many parents are able to figure out what to do next about their own family's situation, let alone evaluate a program affecting many families.

How then can you find the right mixture and balance both for professionals seeking family input and for parents wishing to participate and wondering how they can best make a contribution that will be satisfying for them? Asking two questions may spur a dialogue between those asking for parent involvement and among parents seeking to become partners in improving programs and policies for families of children with special needs:

- Does the definition of the "right" parent depend on the length of involvement in activities and organizations or the level at which parents are ready to take on new commitments?
- Is the parent connected to other parents and parent organizations and interested in networking with parents?

How these questions are answered by the professionals will determine the success of attempts to establish stronger links and ties to families. The answers also will affect future opportunities for participation by a diverse group of parents.

Parent Participation in State Title V Programs

Many of the early successes in getting special education laws passed and in teaching parents about their rights were done by parents as volunteers. Gradually a few parent centers received U.S. Department of Education funds, and over the years, support for parent programs has grown. As progress was being made to expand the role of parents in education, the Federation for Children with Special Needs was working simultaneously to bring about similar changes in health care.

The Federation's Collaboration Among Parents and Professionals (CAPP) Project conducted a survey in 1992 to gauge the involvement of parents with their state health department programs funded by Title V. The report was published as ***Families in Program and Policy: Report of a 1992 Survey of Family Participation in State Title V Programs for Children with Special Needs*** (Wells, Anderson, and Popper 1993). Program staff from the state Divisions for Children with Special Health Care Needs (CSHCN) replied to questions about the amount and type of parent participation at the program and policy levels. Since health departments are critical collaborators in early intervention systems—often serving as lead agencies for Part H—the results were instructive for those seeking to create new opportunities for parent involvement in early intervention.

CAPP asked states about the extent to which family members were being included in committees of state health programs and whether or not any family members had been hired as staff or as consultants. We learned that almost every state had invited parents or other family members to become involved in committees, task forces, or as advisers in some fashion (50 of the 51 respondents—all but one of the 50 states and the District of Columbia—have parents on committees).

In addition to the questions about the nature and degree of parent involvement, the survey included questions about the benefits and difficulties of having parents participate. Typical answers to the questions about the benefits of having parents participate on committees were that the parents enhanced the state's ability to carry out its mission, increased the understanding of family needs, improved planning, improved family/professional communication and increased the empowerment of family members. When responding to the questions about the difficulties of involving families, state departments most often mentioned difficulties in finding suitable meeting times, long distances to meetings, lack of transportation, inability to find child care, and the unpredictability of children's health.

The survey also asked if states offer support for parent activities or to parent organizations. Of the 92% per cent (47/51) of states offering support for parent activities or groups, 85% offered travel money for parents to attend meetings and conferences, 47% paid for child care for meeting times,

38% paid parents for their time or services as advisers, and 41% hired parents as paid staff or consultants. States are increasingly aware that families can donate some of their time, but will need some assistance with travel and child care (both of which are becoming better supported).

In 2002 Family Voices carried out an update and expansion of that survey titled ***Families in Program and Policy: Survey of State Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) Programs*** (draft 9/04, Family Voices, www.familyvoices.org). Results showed that between 1992 and 2002, hiring family members as staff or consultants had grown from 41% of the 51 respondents to 79% of the 53 responding states and territories. The report also indicates that programs for children with special needs which employ parents consider it their job to: provide information and support to families; facilitate collaboration between families/family organizations and state Title V programs; assist in program development and planning for families; and to provide a parent/family perspective to Title V. State program staff were asked questions (adapted from the 1992 survey) about the benefits of family involvement in their programs. All of the following were reported by the majority of states as being at a medium or high level: increased responsiveness to federal requirements, increased availability of families to participate, increased parent/professional communication, improved understanding of programs and services, responsiveness to family needs and awareness of family issues.

In the fall of 2003, the National Parent Leadership Development Project for ICCs conducted its own survey of state ICC programs in order to collect information about parent involvement in early intervention programs. Some of the responses from the fourteen states are included below:

- Over half of the respondents expressed difficulty in retaining parent involvement.
- Eleven states said they could use (and some reported getting) help with developing parent leadership.
- Nine states reported “fair success” in achieving diversity among parents in leadership positions. Two responded “good”; two, “excellent.” (One survey was left blank.)
- Eight states (57%) had hired parents for their expertise as parents in part-time or full-time positions.
- Most states paid expenses for parents for travel, meals, and child care for meetings. Five pay stipends from \$55-150 for attending the SICC meeting, and many paid parents for attending committee meetings.

- Comments on the advantages of having parent involvement:
 - *“The parent voice heightens understanding of parent needs and perspective.”*
 - *“Parent input assists the EI system in hearing the needs, concerns, and strengths of families.”*
 - *“Involvement keeps program design and policy focused on family-centered principles, the real intent of the program.”*
 - *“Families are partners (by law and philosophy).”*
 - *“Strong parent support is essential when dealing with funding issues.”*
 - *“Parents know what is working and what needs work, and they have strategies.”*

- Comments on the difficulties of parent involvement:
 - *“Time commitments, travel, family situations, comfort levels of parents in policy work all impede involvement.”*
 - *“There are struggles chairing committees, running meetings, following protocol.”*
 - *“Flexibility and consistent participation is needed to participate in meetings.”*
 - *“Reimbursement policies are hard for low income families.”*
 - *“Other programs also are looking for parents.”*
 - *“Keeping parents actively involved is always a challenge.”*

These survey results from health departments and early intervention programs are an important indication that parents serving at the program and policy levels are receiving greater recognition. This recognition should lead to even more opportunities for parent participation in a wide range of volunteer and paid capacities. The survey findings also indicate that families value the opportunity to assume new roles, and often overcome many difficulties to participate.

Here are some questions that may be useful in setting your own criteria and guidelines for participating in your ICC and in related activities:

- 1. *What have you decided are your own goals or reasons for accepting any new involvement offered? Does this new invitation fit in with your goals?***

Goals: educating myself, getting to know the players, considering new career, advancing the goals I have for my child, making changes in the system

- 2. *What barriers to being able to fulfill any new commitment do you see ahead?***

Barriers: time limitations, scheduling hassles, child care arrangements, expenses of travel and parking, other family obligations

- 3. *What resources are being offered, or what can you request, to help you balance a new set of tasks with your other responsibilities?***

Resources: money (stipend, salary, consulting fee), reimbursement of travel and parking costs, child care costs

- 4. *Who is available to help you learn more about the new expectation? Are formal orientation sessions provided? By whom?***

Helpers: experienced parents, professional staff members, mentors

- 5. *How will you evaluate whether your efforts are being successful and whether the rewards continue to outweigh the difficulties?***

Evaluation: personal checklist of goals for regular review

- 6. *What would convince you either to increase or cut back on your level of activity?***

Reasons for Changing: success of efforts, feeling encouraged/discouraged, camaraderie, fatigue, family needs, children's activities, needs of parent group

- 7. *What plans have you made to help you pace yourself?***

Pacing supports: regular exercise and relaxing time, support of spouse, buying a filing cabinet

- 8. *Will you have opportunities to share your ideas and impressions with other parents, and perhaps be able to bring along a "partner parent" who also could substitute for you when you are unable to be available?***

Being the only parent can be uncomfortable since we all know our experiences and opinions aren't representative of all families