

FAMILY SUPPORT GUIDELINES *for* EFFECTIVE PRACTICE

*in the Early Intervention Service System
for Families of Infants and Toddlers
with Disabilities or At Risk*

Recommendations of the
California Interagency Coordinating Council on Early Intervention

Approved January 28, 1994



FAMILY SUPPORT GUIDELINES
for EFFECTIVE PRACTICE
*in the Early Intervention Service System for
Families of Infants and Toddlers with Disabilities or At Risk*

was developed by the
California Interagency Coordinating
Council on Early Intervention
Family Support Services Committee

JANUARY 1994

ii

FORMER CO-CHAIRS:

Nancy Sweet
Diane Hall

FORMER COMMITTEE MEMBERS:

<i>Marion Karian</i>	<i>Bob Farran</i>
<i>Pat Hastings</i>	<i>Carolyn Jackson</i>
<i>Florene Poyadue</i>	<i>Lisbeth Vincent</i>
<i>Joan Kilburn</i>	<i>Lora Keller</i>
<i>Lori Antonino</i>	<i>Kate Warren</i>
<i>Miftah MacNeil</i>	<i>Shelly Cox</i>
<i>Sherry Torok</i>	<i>Barbara Tyson</i>

GROUP FACILITATION/DOCUMENT DEVELOPMENT
Linda Brekken, Ph.D., former Project Director,
California Early Intervention Technical Assistance Network (CEITAN)

Fourth Printing April 2003.
Disseminated by the California Department of Developmental Services.
For additional copies, call Early Start Resources at 916/492-9990 or 800/869-4337.

P R E F A C E

These *Family Support Guidelines for Effective Practice* were developed with the belief that, if used, they will make a positive difference in the early intervention services provided for families of infants and toddlers at risk of/or experiencing disabilities.

The intent of Part C of the Individuals With Disabilities Education Act is that early intervention services be coordinated and family-centered. This is a critical need and appears on the surface to be an easy enough goal. It can, however, become an enormous and daunting task for systems attempting to shape this intent into reality. Therefore, in support of the values of Part C, the California Interagency Coordinating Council (ICC) on Early Intervention Family Support Services Committee, developed definitions and guidelines for effective practice in family support services to provide a functional and practical resource document which can be used on a daily basis to ensure family-centered services in California.

It is hoped that the recommendations in this document will be infused into all areas of program and agency services. Families and service providers will be empowered to make informed choices for children if these guidelines are used when developing and implementing the goals of the Individualized Family Service Plan.

The *Family Support Guidelines* are divided into two sections: those for family resource centers and networks and those for agencies and early intervention programs. When utilized, both sections can create change in the way services are provided. The members of the California ICC would like to challenge both families and service providers to be creative in the use of these guidelines in order to experience the positive impact they can provide.

Thank you for your dedication to this cause and for the time devoted to the future of California which is vested in our children.



C O N T E N T S

PREFACE	iii
OVERVIEW	1
The Need for Family Support Services	1
Definition of Family Support Services	1
Family Support Services Available Through Part C in California	2
Other Needed Family Support Services	3
Agencies and Programs Affected by These Guidelines	4
How to Use These Guidelines	4
GUIDELINES FOR FAMILY RESOURCE CENTERS AND NETWORKS	5
1. Parent-to-Parent Support	5
2. Information and Referral Support to Families	6
3. Community Outreach and Awareness	7
4. Personnel	8
5. Personnel Development for Families and Professionals	9
6. Organizational Structure	10
GUIDELINES FOR AGENCIES AND EARLY INTERVENTION PROGRAMS	12
1. Procedural Guidelines for Family Support	12
2. Personnel Qualifications and Personnel Development	14
3. Family Support Service Settings and Environments	15
4. Family Empowerment Strategies	15
5. Family Support in the IFSP Process	16
RECOMMENDATIONS FOR IMPLEMENTATION	17
State Agencies	17
Family Resource Centers and Networks	17
Local Early Intervention Service Providers	18

APPENDICES 19
Appendix A: Mission and Values on Family-Focused Services 19
Appendix B: A Definition of Families 21
Appendix C: Family Support Principles 22
Appendix D: Performance Self-Rating and Planning Worksheets..... 23

O V E R V I E W

The Need for Family Support Services



California established an early intervention service system to assist infants and toddlers with disabilities or at risk, from birth through 36 months, and their families. These early intervention service systems interact with families soon after they have learned that their child has a disability.

Parents have dreams for their children. When a disability is identified, those dreams may be shattered, and families grieve the loss of those dreams. During this period of emotional stress, many parents experience feelings of isolation. Often families are in crisis and are facing a confusing array of services. Family support services at this time establish relationships that provide the foundation for emotional growth, the building of new dreams, and the development of new directions for the life of the child and family. Family support must occur as a central focus of all early intervention services. Powerful and long lasting support may often come from other parents.

Definition of Family Support Services

Implementation of Part C of the Individuals with Disabilities Education Act (IDEA) enables states to develop comprehensive early intervention service systems for all infants and toddlers with disabilities or at risk and their families. Family support services are included in these systems. In the law, “family support” refers to the enhancement of the capacities of the family to meet the needs of infants or toddlers with disabilities or special needs. To be effective, family support services *must* be flexible and individualized to the family’s concerns, priorities, and resources. Support for families of young children with disabilities has two interrelated components that add to and strengthen the existing natural supports in the context of the community:

- > emotional support for families (e.g., parent-to-parent support or emotional support provided by professionals) and
- > supportive services, delivered in a family-centered manner.

Family Support Services Available Through Part C in California

It is the intent of Part C that the early intervention system is family-centered and that it include as early intervention services such family supports as family training, counseling, and home visits to assist the family in understanding the special needs of the child and enhancing the child's development. Federal regulations note that early intervention services may include such services as the provision of respite and other family support services and that qualified personnel may include parent-to-parent support personnel. In California, the Interagency Coordinating Council (ICC) on Early Intervention has developed family-centered values and has focused on the development of a statewide implementation mechanism: the family resource centers and networks (FRC/Ns). The family resource centers and networks exist to meet the needs of Part C eligible families through parent-to-parent support and parent-professional collaboration.

A range of family support services exists in California. Emotionally supportive services include family counseling, family support groups, parent-to-parent support, and respite. Developmental intervention and consultation include speech and language services, occupational and physical therapy, counseling, medical and dental services, skill development, evaluation and assessment, nursing services, nutritional services, and other early intervention services. Families overwhelmingly express a need for access to information about their child's disability and available services, as well as access to contact other families who have had similar experiences. Families also express their need for assistance in accessing and coordinating services.

Other Needed Family Support Services

In addition, a broader range of family supports may be critical in assisting families to care for their children. The ICC's Family Support Services Committee developed a broad list of family supports that, although not provided through Part C, may be of vital assistance to an individual family's success in caring for their infant or toddler with disabilities or at risk:

- Natural supports including church groups, the family's circle of friends, whatever support systems exist in the community, and pre-existing supports.
- Child care.
- Environmental supports, such as adaptive equipment or home modifications.
- In-home services, including homemaker services, attendant, or home health services.
- There may in some cases be a need for a variety of extraordinary services, including transportation, vehicle modification to accommodate access for a family member who is disabled, diet and nutritional assistance, specialized clothing, utilities, health insurance, home repairs, and rent assistance. Financial assistance may be needed because of the financial impact of the family member who has a disability.
- Families who need early intervention services may also need assistance to secure supports that other families need (e.g., food, clothing, shelter, health care, family planning, recreation, drug treatment, mental health services, protection from domestic violence, job training, parenting supports, literacy development, translation for families who are non-English speaking, English-as-a-Second-Language [ESL] programs, adult education, family reunification, juvenile court, and probation).

Agencies and Programs Affected by These Guidelines

The Family Support Services Committee developed guidelines for effective practice in family support services for FRC/Ns and for state and local agencies and early intervention programs interacting with families of infants and toddlers with disabilities or at risk. The guidelines build on the California ICC Mission and Values on Family-Focused Services (see Appendix A), a definition of families (included in Appendix B), and the Family Support Principles developed by the California Family Support Advisory Committee to the Department of Developmental Services and the State Council on Developmental Disabilities (see Appendix C). The *Family Support Guidelines for Effective Practice* were developed for any public or private agency that receives Part C funds or provides services to Part C eligible infants and toddlers as a part of California's early intervention service system. This specifically includes regional centers and local educational agencies as the mandated providers of Part C family support services, as well as early intervention programs that provide direct services for infants, toddlers, and families.

How to Use These Guidelines

The *Family Support Guidelines for Effective Practice* are divided into two sections: those for FRC/Ns and those for agencies and early intervention programs.

The intent of Part C is that early intervention services are coordinated and family-centered. The California Interagency Coordinating Council has developed the *Family Support Guidelines for Effective Practice* to meet this intent. It is the vision of the ICC that local communities implement these guidelines in innovative ways, utilizing their unique resources.

GUIDELINES

for Family Resource Centers and Networks

PARENT-TO-PARENT SUPPORT

Parent-to-Parent Support Components

FRC/Ns should have parent-to-parent support components.

- ⊃ Parent-to-parent support should be provided by a parent of a child with a disability who has the ability to address the family's concerns, priorities, or resources (e.g., ethnic, cultural, linguistic or socioeconomic diversity of the family). In circumstances where culturally consistent parent support is not available, this support may be provided by an individual representing a cultural or linguistic area of the community until family leadership is developed to fulfill this need for parent-to-parent support.
- ⊃ Parent support should be provided by a parent with specific training in best practices in peer support.
- ⊃ Parent-to-parent support through FRC/Ns should be available from referral into the early intervention system through transition out of early intervention services.
- ⊃ FRC/Ns should offer families opportunities for a “feeling-focused support”¹ at the time of the initial contact. This may occur via a phone call or face-to-face at a location such as the hospital or the family home.
- ⊃ Ongoing support should be available on an individual and/or group basis to be determined by the family.
- ⊃ Family support should be available for eligible families who are not yet served or who choose not to access early intervention services.
- ⊃ FRC/Ns should have a formal system of support for those providing support to families.

¹“Feeling-focused support” refers to opportunities for families to share their experiences and feelings of parenting a child with special needs in a confidential, non-judgmental, safe setting. This process is facilitated individually or in groups by a trained peer parent who is culturally and/or linguistically appropriate.

Parent-to-Parent Support Services

A range of parent-to-parent support services should exist, based on the concerns/needs of the community, the preferences of the families served, and the resources and skills of staff.

- ⊃ Individual parent-to-parent support should be available through face-to-face or phone contact.
- ⊃ Parent/family support groups are available in the community, through other family support services or through the family resource center. If no support groups exist, the FRC/N may assist in developing support groups in the community.
- ⊃ FRC/Ns should help families identify natural supports. If those supports are not readily available, the FRC/Ns may prepare families for meetings and may be available to families as a support to attend meetings, within reason (e.g., Individualized Family Service Plan, transition planning, and medical appointments).
- ⊃ FRC/Ns personnel may participate on multiagency teams, providing the family's perspective.
- ⊃ FRC/Ns may facilitate and coordinate the family's participation in conferences, workshops, and trainings.

2 INFORMATION AND REFERRAL SUPPORT TO FAMILIES

FRC/Ns should have an information and referral component for both families and professionals that provides

- ⊃ free, basic information on community resources and how to access them
- ⊃ access to the community through regular hours, convenient location, and/or phone
- ⊃ a recognized resource to the community, staffed by trained individuals
- ⊃ responsive and timely services
- ⊃ family friendly, current, unbiased, accurate, and varied (print, audio, video — in appropriate languages) information
- ⊃ culturally competent services and resources

- ▷ linkages with other FRC/Ns — for information, resources, and additional sources of information
- ▷ linkages to local, regional, and national resources, including disability organizations
- ▷ information on trainings for parents and professionals
- ▷ information on parent support groups in the community and linked to *California's Early Start Program Central Directory of Early Intervention Resources*
- ▷ current information on legislation (state and national) and regulations
- ▷ information on advocacy organizations or resources

COMMUNITY OUTREACH AND AWARENESS

FRC/Ns should have a community outreach and awareness component that

- ▷ conducts activities based on available community needs assessments and ongoing self evaluation
- ▷ shares information from any needs assessments and uses them to develop a community action plan
- ▷ is linked with a variety of community resources (including for profit, as well as non-profit organizations) e.g., technology, home health care, adaptive equipment, and child care
- ▷ is actively involved in promoting family support systems in the community
- ▷ serves as a neutral resource for convening people and programs in the community around key issues
- ▷ promotes a “people first” attitude and disability awareness within the community
- ▷ serves as a voice for increased participation and acceptance of individuals with disabilities and their families in their community
- ▷ promotes the perception of families of children with disabilities as healthy, functional, and resourceful
- ▷ participates in the community's public awareness and outreach efforts through Part C

4 PERSONNEL

FRC/Ns should have personnel who

- ⊃ support the purpose and mission of the FRC/N
- ⊃ include parents of children with disabilities who are emotionally available to other families
- ⊃ are reflective of the community, including cultural and linguistic diversity
- ⊃ have training and support that include the following:
 - effective communication skills
 - coping skills, grief response, “feeling-focused support”
 - decision making and problem solving
 - enhancing natural support systems
 - helping families assess their strengths and priorities
 - respecting family’s values
 - parent-professional collaboration
 - community resources, both generic and specialized
 - recognizing situations which require referral to others and respecting limits/boundaries
 - increasing families’ self advocacy/empowerment
 - general knowledge regarding accessing information on disabilities
- ⊃ have skills and sensitivities to work effectively with families of infants and toddlers with disabilities or at-risk conditions
- ⊃ have skills in relating to the public, to families, and to agencies and programs in the community
- ⊃ have facilitation skills
- ⊃ embrace collaboration and family-centered values
- ⊃ join together with professionals to promote family-centered changes in the service system for the benefit of infants and toddlers with disabilities or at-risk conditions and their families

5 PERSONNEL DEVELOPMENT FOR FAMILIES AND PROFESSIONALS

Family/Professional Training Components

FRC/Ns should have training components for families and professionals that include:

- ⊃ family-centered services
- ⊃ peer support
- ⊃ relationship building
- ⊃ collaboration and partnership
- ⊃ cultural competence
- ⊃ accessing and participating in the system
- ⊃ service coordination
- ⊃ problem solving and negotiation skills

Characteristics of Personnel Development Activities

The personnel development activities should have the following characteristics:

- ⊃ address topics specifically requested by families
- ⊃ be responsive to the community's diverse cultural needs
- ⊃ be family and professional friendly
- ⊃ be unbiased, accurate, and timely
- ⊃ provide an ongoing process to support in-depth personnel and program change and development
- ⊃ be evaluated to determine quality and impact on personnel and program effectiveness

Optional Activities

The personnel development activities of FRC/Ns may also include:

- ⊃ training of trainers on effective practices in family support
- ⊃ resource pool of parent co-trainers
- ⊃ opportunities for pooled training, resource sharing, and networking among FRC/Ns

ORGANIZATIONAL STRUCTURE

FRC/Ns should have the organizational characteristics listed below.

Administration and Direction

- ⊃ A Board of Directors, Advisory Committee, or Governing Board should include representation of families of children with disabilities or special needs, community members, and the early intervention service system.
- ⊃ The management structure should be directed by parents of children with disabilities or co-directed by parent-professional partners.

Mission, Purpose, Goals, and Services

- ⊃ The mission statement, bylaws, or goals and outcomes should be consistent with ICC values and approved guidelines for family support.
- ⊃ The mission, purpose, and goals should include a clear statement of who is served and how services are funded.

Personnel

- ⊃ Hiring practices should give preference to parents of children who are disabled or at risk and who are culturally consistent with the community.
- ⊃ Personnel policies and job descriptions should be written for both paid and volunteer staff.
- ⊃ Systems for support of both paid and volunteer staff (addressing needs for child care, stipends, resource sharing, transportation) should be developed.
- ⊃ Systems of staff support, supervision, and consultation should ensure that parent-to-parent support providers are functioning within their capabilities and training and are able to recognize and address situations that require referral to other agencies or personnel, including mental health service providers.

Role within the Community

FRC/Ns should

- ⊃ provide “feeling-focused support” to families
- ⊃ model and provide training in parent-professional collaboration
- ⊃ provide access to information, resources and support, and establish and maintain linkages with other information and referral systems

■ *Guidelines for Family Resource Centers and Networks* ■

- ▷ serve as a neutral or “safe” place in the community for families and professionals
- ▷ provide training and support to families and professionals
- ▷ provide support to families who are eligible for early intervention services, but who are not currently receiving early intervention services
- ▷ work within the community to build awareness of the need for and the availability of early intervention services
- ▷ provide a vehicle for families’ voices to be heard within the community, in both specialized and generic services and resources
- ▷ promote the inclusion and valuing of family representation and perspectives in multiagency team processes
- ▷ participate in planning and implementing the early intervention system, including participating in local interagency groups
- ▷ be responsive to community needs (e.g., recognizing the diverse needs of rural and urban communities)
- ▷ collaborate and participate in the community needs assessment process
- ▷ assist the local interagency group in addressing Part C requirements at the local level
- ▷ augment professional resources for family support services within the community

Fiscal and Programmatic Accountability

FRC/Ns should have a

- ▷ role in decision making about distribution of FRC/N funds based on family input representative of the community
- ▷ mechanism for contracting for funds
- ▷ system for fiscal accountability, including methods
 - for ensuring that Part C dollars are spent on the birth to three population
 - to identify and track all sources of funds
 - to identify and track volunteer and in-kind contributions
- ▷ system for data collection

GUIDELINES

for Agencies and Early Intervention Programs

PROCEDURAL GUIDELINES FOR FAMILY SUPPORT

Intake

As part of the intake process, every agency should

- ▷ provide information about family support systems, including FRC/Ns

Individualized Family Service Plan (IFSP) Process

As part of the IFSP process, every agency should

- ▷ explore with families those existing supports that they are currently using, or might use
- ▷ provide information about the early intervention system and how to access services

Access to Family Support Services

Every agency should ensure access to family support services as defined by Part C through incorporating a family-centered service model into all interactions with the family by

- ▷ sharing information with families about family support services available in the community
- ▷ coordinating with other agencies
- ▷ training staff
- ▷ providing or ensuring availability of needed direct family support services such as:
 - counseling
 - home visits
 - support groups
 - parent training (e.g., conferences, workshops, trainings)
- ▷ including all appropriate family members
- ▷ providing culturally consistent services that match the cultural and linguistic diversity of the families served

Access to Information

Every agency should ensure family access to complete, objective information about

- ⊃ services required to be available under Part C
- ⊃ family support services available, including FRC/Ns
- ⊃ early intervention services available
- ⊃ disabling conditions and additional informational resources
- ⊃ intervention and treatment options
- ⊃ family roles and responsibilities
- ⊃ due process
- ⊃ culturally appropriate services available

Culturally Sensitive and Consistent Services

Every agency should take *demonstrable* steps towards achieving culturally sensitive and consistent family support services through

- ⊃ eliciting, respecting, and responding to expressed needs and support systems of families
- ⊃ selecting and training staff consistent with the population of families served
- ⊃ coordinating with other agencies and community groups
- ⊃ parenting efforts with culturally specific groups and organizations
- ⊃ providing or ensuring availability of direct services including translators
- ⊃ using trained volunteers and/or paraprofessionals
- ⊃ providing written and/or audiovisual materials in appropriate languages

PERSONNEL QUALIFICATIONS AND PERSONNEL DEVELOPMENT

Ongoing Training and Supervision

Every agency should ensure that all agency staff receive ongoing training and supervision in family-centered service delivery. Methods of achieving such personnel development include

- ⊃ co-training by parents as well as professionals
- ⊃ training in the philosophy and strategies of parent-professional collaboration
- ⊃ hiring qualified staff who are also parents of children who are disabled or at risk
- ⊃ using specialized consultants and program assistants who are parents of children who are disabled or at risk
- ⊃ technical assistance from FRC/Ns, the California Early Intervention Technical Assistance Network (CEITAN), and other family support resources
- ⊃ reviewing personnel development plans and materials for family-centered content
- ⊃ ongoing interagency, interdisciplinary communication and networking
- ⊃ training and consultation by culturally specific groups and organizations

Appropriately Qualified Personnel

Agencies that provide Part C family support services should have appropriately qualified personnel as follows:

- ⊃ Staff/professionals functioning as early intervention specialists or consultants must meet personnel standards specified in California's implementation of Part C.
- ⊃ Parents functioning in a peer support role should be parents of children who are disabled or at risk and should have both orientation and training and ongoing support as defined in guidelines for FRC/Ns. (See section beginning on page 5.)

- ⊃ Qualified professionals and peer support personnel may be provided through coordination with community agencies and/or outside professional consultants.

3 FAMILY SUPPORT SERVICE SETTINGS AND ENVIRONMENTS

Family support services should be provided by agencies in a choice of settings that are comfortable and accessible for families including

- ⊃ home
- ⊃ community or neighborhood
- ⊃ FRC/Ns
- ⊃ specific service delivery setting (e.g., early intervention program, hospital, child care, or child development program, drug treatment center, culturally specific service center)

4 FAMILY EMPOWERMENT STRATEGIES

Enhancing Skills and Using Existing Support Systems

Family support services should enhance families' skills and confidence in utilizing and developing their own support systems. Agencies should

- ⊃ listen to families
- ⊃ give families choices
- ⊃ assist families in identifying and accessing both early intervention and individual support systems (e.g., church, community, and extended family)
- ⊃ build on the family's strengths and resources
- ⊃ respect the family's decisions
- ⊃ provide training in advocacy skills

Parent-Professional Collaboration

Parent-professional collaboration should be in evidence in the following ways:

- ⊃ Families and professionals work together to develop, refine, and monitor family support services within the agency or program.
- ⊃ Families and professionals work together to develop, refine, and monitor early intervention services.
- ⊃ A mechanism for joint problem solving by professionals and parents is available for addressing individual service delivery problems prior to due process.
- ⊃ A mechanism for joint problem solving by professionals and families is developed and implemented for the overall service system.

5 FAMILY SUPPORT IN THE IFSP PROCESS

Agencies should ensure that the IFSP process is family-centered by

- ⊃ following Part C guidelines
- ⊃ providing families access to peer parents for support
- ⊃ providing families access to information
- ⊃ building collaborative relationships with families
- ⊃ allocating sufficient staff time, training, and resources to achieve the intent of the IFSP process as specified in Part C
- ⊃ respecting family choices
- ⊃ ensuring that intended IFSP outcomes are family generated and incorporated in the written IFSP document

RECOMMENDATIONS *for Implementation*



The California Interagency Coordinating Council on Early Intervention has developed the *Family Support Guidelines for Effective Practice* to meet the intent of Part C that early intervention services are coordinated and family-centered. These guidelines have application to four major target groups. The recommendations for implementation of the guidelines follow.

State Agencies

Each lead state agency (California Department of Developmental Services and California Department of Education) should require and assist local agency implementation and evaluation of family support guidelines as part of their responsibilities for administering and monitoring early intervention services and programs.

Family Resource Centers and Networks

Each FRC/N receiving Part C funding should develop and implement a plan that addresses:

- ⤷ Parent-to-parent support
- ⤷ Information and referral support to families
- ⤷ Community outreach and awareness
- ⤷ Personnel
- ⤷ Personnel development for families and professionals
- ⤷ Organizational structure

Local Early Intervention Service Providers

Each public and private non-profit agency, including regional centers and local education agencies, involved in the provision of early intervention services should develop and implement a plan which promotes family-centered service delivery in the following areas:

- ↳ Procedural guidelines for family support
- ↳ Personnel qualifications and personnel development
- ↳ Family support service settings and environments
- ↳ Family empowerment strategies
- ↳ Family support in the IFSP process

A self-rating tool is contained in Appendix D to assist FRC/Ns in determining the degree of success of implementation of these guidelines.

Appendix A

Mission and Values on Family-Focused Services of the Interagency Coordinating Council on Early Intervention

Throughout discussions of the various models and options, the Interagency Coordinating Council (ICC) on Early Intervention continually referred to the values expressed in its mission statement:

The mission of the ICC is to promote the creation of a coordinated interagency service delivery system for high risk and handicapped infants and toddlers and their families within the state of California. The service system should maximally utilize available resources to enhance the ability of families to promote the growth and development of their exceptional infants and toddlers. The system should be able to respond in a timely manner; should reduce duplication and fragmentation; should eliminate gaps in services; should utilize the best available practices; and should enable the infants and toddlers to grow and live within their families and within their communities alongside their non-disabled peers.

The ICC revised the mission statement May 26, 1996 to read:

The mission of the ICC is to promote and enhance a coordinated family service system for infants and toddlers, birth to three years, who have, or are at risk for having a disability, and their families, utilizing and encouraging a family-centered approach, family-professional partnerships, and interagency collaboration.

To the maximum extent possible, these recommendations reflect a conscious effort to

- ▷ coordinate and improve services for children and families
- ▷ enhance family involvement, parent-to-parent support, and parent-professional partnerships
- ▷ take maximum advantage of existing services and providers
- ▷ recommend little or no cost increases

Of particular importance to ICC discussions has been a strong belief in parents and the family as the central focus of the early intervention system. For the purposes of ICC discussions, “parents” includes the biological parents, adoptive parents, primary caregivers, or guardians. This family-focused approach constitutes a shift from a more traditional child-focused delivery system. A family focus has a number of implications for professional practice that include, but are not limited to the following:

- Acting from a belief that the family knows their child best and should take the lead in establishing priorities and pacing for services.
- Acknowledging the family’s concerns, priorities, and resources as the basis for design and implementation of services.
- Acting as a resource to family decision-making by
 - carefully establishing and confirming the family’s concerns, priorities, and resources
 - providing a broad range of information about services available
 - taking specific steps to confirm a family’s understanding of the implications of their choices
- Supporting families’ efforts to develop creative, multiagency service plans.

In broad terms, the ICC believes that families are where children belong and that services should support the child and family’s life in the community. The ICC believes that families need support — the kind of support that enables rather than creates dependencies; supports that encompass the uniqueness of families and the diversity of culture, language, experiences, and values; and the kind of support that reflects a belief in people helping other people.

Taken from the *California Interagency Coordinating Council on Early Intervention Services, State and Local Administration of Early Intervention Services: Expanded Recommendations*, September, 1992.

Appendix B

A Definition of Families

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof, or many. A family can be as temporary as a few weeks, or as permanent as forever. We become a part of a family by birth, adoption, marriage, or from a desire for mutual support ... A family is a culture unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity ... Our families create neighborhoods, communities, states, and nations.

Taken from the *Report of the House Memorial 5 Task Force on Young Children and Families*, New Mexico, 1990.

Family Support Principles

The California Family Support Advisory Committee to the Department of Developmental Services and the State Council on Developmental Disabilities endorses the following vision and principles as the foundation for a comprehensive, statewide system of services to support families.

Vision

All children with disabilities will be given the opportunity to live with a supported and empowered family, fully participating within their community. Every community will be enriched by the inclusion of people with diverse abilities.

Principles

- ▷ Families are the best experts about what they need. The service system can best assist families by supporting them as decision makers instead of making decisions for them.
- ▷ The needs of families change over time, particularly at the transition stages. Services and support should be individualized and flexible to accommodate these unique individual needs.
- ▷ Services and support will best meet the needs of families by focusing on the entire family and building on the family's strengths, respecting cultural preferences, values, and unique lifestyles.
- ▷ Families will benefit from support that promotes the inclusion of people with disabilities in all aspects of community life.
- ▷ Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves, live in typical homes and communities, and exercise their full rights as citizens. When it is not possible for adults with developmental disabilities to live separately from their families, these families should be provided the support services they need. The ongoing contributions many parents and family members make to the support and well-being of their adult children with developmental disabilities should be respected and supported.

The ICC Family Support Services Committee has added the following principle to those listed above:

- ▷ A coordinated statewide system of accessible core services and choices is available for all families.

Performance Self-Rating and Planning Worksheets

The intent of Part C is that early intervention services are family-centered and coordinated. The ICC has developed the *Family Support Guidelines for Effective Practice* to meet this intent. The self-rating process described here is intended as an exercise to measure your FRC/N's performance according to these guidelines.

Performance Self-Rating

To assist you in identifying those aspects of the guidelines that are currently implemented in your FRC/N and those aspects where change may be indicated in your practice, please rate each “bulleted” (☞) item as you read through the applicable section of the *Family Support Guidelines for Effective Practice* booklet.

To rate the item, mark in the booklet margin beside each bullet(☞):

A (Always) U (Usually) S (Seldom) N (Not at all) D (Don't know)

You may notice areas in which the guidelines describe your current practices and other areas where program change may be indicated.

When you have completed the ratings, examine your responses to identify the areas with the greatest concentration of A and U responses and the areas with the largest evidence of S and N or D ratings, and note those areas on the Planning Worksheet.

Planning Worksheets and Input/Feedback Form

Use the Planning Worksheets, wherein essential elements of each component have been summarized to develop specific steps toward fuller implementation of the *Family Support Guidelines for Effective Practice* in your FRC/N. Applications for the planning worksheets are in strategic planning, development of interagency agreements, program development, grant seeking, board retreats, staff training and so on.

Finally, since effective practices are continually evolving, the *Family Support Guidelines for Effective Practices* should evolve as well. Please use the Effective Practices Input/Feedback form to describe the developments of effective practices in your FRC/N, agency, or program.

When completed, please send a copy of the Input/Feedback Form on page 30 to the Interagency Coordinating Council, 1600 Ninth Street, Room 310, Sacramento, CA 95814.

Planning Worksheet for Family Resource Centers/Networks

The recommendation for implementation of the *Family Support Guidelines for Effective Practice* in Family Resource Centers/Networks (FRC/Ns) is as follows:

Each FRC/N receiving Part C funding should develop and implement a plan that addresses:

1. Parent-to-Parent Support

Each FRC/N should have a parent-to-parent support component in which feeling-focused support is provided by parents of children with disabilities or at risk who have been specifically trained in best practices in peer support. Each FRC/N should have a formal system of support and supervision for those providing parent-to-parent support, and a range of support options including one-to-one or group contacts, assistance identifying natural supports and participating in meetings, and facilitation of attendance at trainings and conferences. Support should be available to eligible families who are not currently receiving services.

Two steps my FRC/N can take to strengthen this component are:

a.

b.

2. Information and Referral Support to Families

Each FRC/N should have an information and referral component for both families and professionals that can be accessed free of charge and at regular hours, and that provides basic information in a responsive, culturally competent, and timely manner.

Two steps my FRC/N can take to strengthen this component are:

a.

b.

3. Community Outreach and Awareness

Each FRC/N should have a component that serves as a neutral ground in the community and that promotes the perception of families of children with disabilities as functional and resourceful and encourages their increased participation and acceptance in the community.

Two steps my FRC/N can take to strengthen this component are:

a.

b.

4. Personnel

Each FRC/N should have personnel who embrace collaboration; join with professionals to promote family-centered changes in the service system; are reflective of community diversity; are emotionally available to support families; and have specific training in effective communication, feeling-focused support, decision making and problem solving, family-professional collaboration, enhancing families' empowerment, accessing informational and service resources, and identifying appropriate levels and limits of their involvement with families.

Two steps my FRC/N can take to strengthen this component are:

a.

b.

5. Personnel Development for Families and Professionals

Each FRC/N should have a training component for families and professionals that address topics in response to families' requests and the community's culturally diverse needs. The training should include best practices in peer support, cultural competence, relationship building, collaboration and partnerships, problem solving and negotiation, and should be regularly evaluated for quality and impact on personnel and program effectiveness. Personnel development may also include creating a pool of parent-professional co-trainers and shared training and networking with other FRC/Ns.

Two steps my FRC/N can take to strengthen this component are:

a.

b.

26

6. Organizational Structure

Each FRC/N should have an organizational structure characterized by a board or advisory group that includes parents, community members and early intervention service providers, and management directed by parents or parent-professional partners. The statement of mission, purpose, or goals should be consistent with ICC values and these guidelines. Each FRC/N should promote the valuing of family participation in multiagency team processes. Each FRC/N should have a role in decision making about distribution of funds for family support services and a mechanism for contracting for funds. Personnel should be selected from among those who are parents of children with disabilities or at risk and those who are culturally consistent with the community served. There should be written personnel policies and job descriptions for all staff, and systems for staff support and supervision, data collection, and fiscal accountability (which includes methods for identifying and tracking all funds as well as volunteer and in-kind contributions).

Two steps my FRC/N can take to strengthen this component are:

a.

b.

Date completed: _____

Planning Worksheet for Agencies or Early Intervention Programs

The recommendation for implementation of the *Family Support Guidelines for Effective Practice* in early intervention programs is as follows:

Each public and private nonprofit agency, including regional centers and local education agencies, involved in the provision of early intervention services should develop and implement a plan that promotes family-centered service delivery in the following areas:

1. Procedural Guidelines for Family Support

Each agency or program should provide information about family support services, including Family Resource Centers/Networks (FRC/Ns), to families as part of the intake process. Each agency or program should assure access to family support services by incorporating a family-centered service model into all interactions with families, by including all appropriate family members, and by providing or assuring availability of direct services such as counseling, home visits, support groups, and parent training as needed. Each agency or program should take demonstrable steps toward achieving culturally-sensitive and consistent family support services.

Two steps my agency or program can take to strengthen this component are:

- a.

- b.

2. Personnel Qualifications and Personnel Development

Each agency or program should assure that all agency staff receive ongoing training and supervision in family-centered service delivery and parent-professional collaboration strategies. This can be accomplished by means of co-training by parents; technical assistance from FRC/Ns, California Early Intervention Technical Assistance Network, etc.; and review of all personnel development plans and materials for family-centered orientation and content. Each agency or program should assure personnel providing family support services are appropriately qualified by seeing that professionals meet early intervention personnel requirements, and that parents in peer support roles have training and ongoing supervision and support as defined under FRC/N Personnel (see FRC/N Planning Worksheet).

Two steps my agency or program can take to strengthen this component are:

a.

b.

3. Family Support Service Settings and Environments

Each agency or program should provide family support services in a variety of settings that are comfortable and accessible for families. These may include home, community, neighborhood, service delivery site, and FRC/Ns.

Two steps my agency or program can take to strengthen this component are:

a.

b.

4. Family Empowerment Strategies

Each agency and program should provide family support that enhances families' skills and confidence in utilizing and developing their own support systems by listening to parents, building relationships on families' strengths and resources, and respecting families' decisions. Family-professional collaboration should be in evidence in each agency or program through families and professionals working together to develop, refine, and monitor family support and other early intervention services, and through mechanisms for parent-professional joint problem solving in cases of individual service delivery problems and in the overall service system.

Two steps my agency or program can take to strengthen this component are:

a.

b.

5. Family Support in the IFSP Process

Each agency and program should assure that the Individualized Family Service Plan (IFSP) is family-centered through building collaborative relationships with families, respecting family choices, and assuring that intended IFSP outcomes are family-generated and incorporated in the written IFSP document.

Two steps my agency or program can take to strengthen this component are:

a.

b.

Date completed _____

Family Support Guidelines for Effective Practice Input/Feedback Form

If your involvement is with an FRC/N:

Please describe emerging effective practices in your FRC/N.

In what ways have you developed innovative or effective practices in providing family-centered family support services that build on the practices described in the ICC's *Family Support Guidelines for Effective Practice*?

What changes or additions would you suggest in future editions of the guidelines?

If your involvement is with an agency or program:

Please describe emerging effective practices in your agency or program.

In what ways have you developed innovative or effective practices in providing family-centered family support services that build on the practices described in the ICC's *Family Support Guidelines for Effective Practice*?

What changes or additions would you suggest for future editions of the guidelines?