# Effective Practice in Providing Family Support

Making It Real for Families of Infants and Toddlers with Disabilities





#### **Publishing Information**

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# Preface

Effective Practice in Providing Family Support: Making It Real for Families of Infants and Toddlers with Disabilities, formerly called Family Support Guidelines for Effective Practice, was originally developed in 1994 by the Family Support Services Committee of the California Interagency Coordinating Council on Early Intervention (ICC). The ICC provides advice and assistance to the Department of Developmental Services, lead agency for Part C of the Individuals with Disabilities Education Act (IDEA), which defines early intervention service provision for infants and toddlers with disabilities, birth to age three. These guidelines reflect the ICC mission and were designed specifically for public and private agencies that are early intervention service providers under IDEA, Part C in California.

The revised guidelines distinguish the following three core concepts that are discussed at length:

- Family-Centered Care: a philosophy and approach to service delivery
- Family Support Services: specific services for families that enhance their child's development

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 of having a disability, and their families, utilizing and encouraging a family-centered approach, family-professional partnerships, and interagency collaboration.

#### Family Empowerment:

the concept that families are supported and prepared and are offered the opportunity to participate as full partners

These concepts are critical to understanding how best to serve young children and their families. The intent of these guidelines is to ensure that the concepts are operationalized in daily practice to provide more effective early intervention services to infants and toddlers and their families.

When applied appropriately and consistently, this information can create effective change in the way services are provided throughout California, resulting in more positive outcomes for children and families.

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Family is the single most important influence on the growth and development of a young child. Early childhood intervention recognizes the centrality of the family and supports the child's relationships with parents and other primary caregivers.

— One of nine Core Messages developed by the California Training and Technical Assistance Collaborative (TTAC), an interagency partnership dedicated to delivering quality professional development activities for personnel who serve children birth to 5 with disabilities and other special needs and their families.

# **Overview of Early Intervention**

In 1993, the Individuals with Disabilities Education Act (IDEA) Early Intervention Program for Infants and Toddlers with Disabilities went into full implementation across the nation to address the needs of children, birth to age three, who may have a developmental delay or disability. Current federal legislation, IDEA 2004, upholds this provision.

It is the intent of IDEA that the early intervention system is family centered and includes such services as family support, family training, counseling, and home visits to assist the family in understanding the special needs of their child and to enhance their child's

development. Implementation of this statute means that states are to develop comprehensive early intervention service systems for all eligible infants and toddlers with disabilities and their families. Family support that enhances a child's development is at the core of these systems. Additionally, parent support is identified as an early intervention service under IDEA, Part C.

This federal law-IDEA, Part C—also requires "to the maximum extent appropriate, early intervention services are provided in natural environments; and the provision of early intervention services for any infant or toddler with a disability occurs in a setting other than a natural environment that is most appropriate, as determined by the parent and the individualized family service plan team, only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment" (20 USC 1435 section 635 [16][A][B], emphasis added). The child's natural environment is defined in federal regulations as "settings that are natural or normal for the child's age peers who have no disabilities" (34 CFR Part 303.26). In practice, it means providing services within the child's everyday routines, relationships, activities, and places in partnership with service agencies and the family's community.

IDEA, Part C Requirements<sup>1</sup>

Congress finds that there is an urgent and substantial need to—

- Enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
- (2) Reduce the educational costs to our society, including our nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
- (3) Maximize the potential for individuals with disabilities to live independently in society;
- (4) Enhance the capacity of families, particularly minority, low-income, inner city, and rural families and those with infants and toddlers in foster care, to meet the special needs of their infants and toddlers with disabilities; and
- (5) Enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.
- 1. Public Law 105-17, IDEA, 20 United States Code 1431 (1-5).

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California's legislature, through the California Early Intervention Services Act (CEISA), established California Early Start, a comprehensive early intervention service system for all eligible infants and toddlers with disabilities and their families. Infants and toddlers, birth to age three, may be eligible for early intervention services if, through documented evaluation and assessment, they meet the criteria of having a developmental delay in either cognitive, communication, social or emotional, adaptive, or physical and motor development, including vision and hearing or an established risk condition.

Multiagency and multidisciplinary service providers play a fundamental role in early intervention service provision. Throughout this document, the term "early intervention agency" is intended to be inclusive of early intervention organizations, centers, and programs, or any person or entity that serves the birth-to-three population under IDEA Part C and CEISA. Early identification of children who may have a developmental delay or disability is a shared responsibility in the service system. For some, this means disseminating information throughout local communities; for example, Early Start family resource centers are required to implement public awareness and outreach activities. For others, this refers to educating families and others who work with young children about the referral processes. It is through these collaborative relationships and activities that children and families are best served.

Early intervention services under IDEA, Part C, include:

- Family training, counseling, and home visits
- Special instruction
- Speech-language pathology, audiology, sign language, and cued-language services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Medical services only for diagnostic or evaluation purposes
- Health services necessary to enable the infant or toddler to benefit from the other early intervention services
- Respite that allows parents to participate in early intervention services
- Social work services
- Assistive technology devices and assistive technology services
- Transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to benefit from services in the individualized family service plan

Early intervention functions under Early Start include:

- Child find
- Evaluation
- Assessment
- Service coordination

# Supporting Families

# The Need to Support Families

The purpose of the early intervention program for infants and toddlers with disabilities is to maintain and implement a statewide, comprehensive, coordinated, and multidisciplinary, interagency system of early intervention services for infants and toddlers

with disabilities and their families.<sup>2</sup> This early intervention service system interacts with families soon after they have learned that their child has a developmental delay or disability.

The intent of the Individuals with Disabilities Education Act (IDEA), Part C is that early intervention is **family centered**, and **supportive services are available for families** at all levels of planning, decision making, implementation, and evaluation of services. Understanding this concept is vital to providing appropriate early intervention services to families. In this document the following concepts are broken down in order to present a better Family is the single most important influence on the growth and development of the young child.<sup>3</sup>

understanding of each; however, in order to best serve the whole family comprehensively, early intervention encompasses all three:

- Family-Centered Care: a philosophy and approach to service delivery
- **Family Support Services:** specific services for families that enhance their child's development
- **Family Empowerment:** the concept that families are supported and prepared and are offered the opportunity to participate as full partners

### FAMILY-CENTERED CARE—AN APPROACH

### Overview

Family-centered care is a **philosophy and approach to service delivery** and was first defined in 1987 as part of former Surgeon General C. Everett Koop's initiative for family-centered, community-based, coordinated care for children with special health care needs and their families. It recognizes that the *way* care is provided is important, if not more important, than the actual provision of care and that it also leads to better child and family outcomes and wiser allocation of resources.<sup>4</sup> In addition, family-centered care **enhances success** and satisfaction for families and professionals.

<sup>2. 34</sup> California Code of Regulations Part 303.1(a).

<sup>3.</sup> California Training and Technical Assistance Collaborative Core Message.

<sup>4.</sup> For more information, visit Community Gateway at http://www.communitygateway.org/faq.fcc.htm.

### **Defining Family-Centered Care**

- The Maternal and Child Health Bureau defines family-centered care as a philosophy and approach to service delivery that shapes policies, programs, and practices. Information sharing and collaboration between families and providers are cornerstones of family-centered care. Family-centered care recognizes the vital role that all families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. It acknowledges that emotional, social, and developmental supports are integral components of health care.<sup>5</sup>
- In addition, family-centered care:
  - → Supports family caregiving and decision-making; respects family choices; builds on family strengths; and involves families in all aspects of the planning, decision making, implementation, and evaluation of services.
  - → Assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship.<sup>6</sup>
  - + Is the standard of practice that results in high quality services.
  - → Is a set of beliefs and an approach to strengthening and empowering families and communities so that they can foster the optimal development of children, youth, and adult family members.
  - → Is a type of grassroots, community-based model to strengthen parent-child relationships and provide whatever parents need to nurture their children to the best of their ability and to be successful providers.
  - → Is a shift in human services delivery that encourages public and private agencies to work together and to become more preventive, responsive, flexible, family focused, strength-based, and holistic, and thus more effective.
  - → Is a way for families to be a resource for their own members, for other families, for programs, and for the community.
  - + Is a system where services are fair, responsive, and accountable to the families served.
  - Means having staff that work with families, based on equality and respect, to mobilize formal and informal resources to support family development.
  - + Includes principles that are modeled in all program activities, including planning, governance, and administration.

5. Adapted from Egg Harbor Family Summit, 1996.

<sup>6.</sup> Maternal and Child Health Bureau, 2005.

# Key Indicators of Effective Family-Centered Care<sup>7</sup>

Agencies and programs:

- Recognize that the family is the constant in the child's life, whereas the service systems and personnel within those systems fluctuate.
- Share unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner while honoring the racial, ethnic, cultural, and socioeconomic diversity of families.
- Recognize family strengths and individuality and respect different methods of coping.
- Encourage and facilitate parent-to-parent support.
- Facilitate parent-professional collaboration at all levels, including:
  - + Service delivery
  - + Program development, implementation, and evaluation
  - + Policy
  - + Systems
- Provide written information in easy-to-understand language; ensure rights and benefits are explained; and offer interpreters and translators.
- Provide services and supports that are responsive to the needs of families, for example, provided in the family's home or community during flexible hours, including evenings and weekends.
- Train staff to have knowledge of family-centered care principles and to share information about community resource options with families, such as special education, family resource centers, respite care, community agencies, and other programs and services.
- Hire staff who reflect the diversity of the community.
- Ensure that decisions regarding early intervention services include the family receiving information in order to make informed choices, consider multidisciplinary team input, and incorporate the developmental needs of infants and their families into the family's service plan.
- Consider family satisfaction as a major priority and ensure that an integral part of the relationship is trust and negotiation, and that the relationship includes a mechanism for consumer feedback.
- 7. Adapted from Egg Harbor Family Summit, 1996; National Center for Family-Centered Care, 1990; and Community Gateway.

### FAMILY SUPPORT SERVICES—A SET OF SERVICES Overview

Family support is the **implementation of family-centered care**. Family support services are most effective when they are culturally sensitive; respectful of different child-

rearing practices; available in different formats (such as written, auditory, or electronic); and provided in a manner and place that is beneficial to the family. Research shows that parent-to-parent support is vital to the success of families that are caring for children with special needs.<sup>8</sup>

### **Defining Family Support Services**

Family support services are specific services for families that:

- Build their capacity to enhance their child's development more effectively.
- Assist them in identifying and understanding their individual needs and talents as well as their concerns, priorities, and resources.
- Help them communicate with professionals.
- Result in understanding systems and services.
- Assist with advocating effectively for their child.

Parents have dreams for their children. When a disability is identified, families may grieve the loss of those dreams. Often families are facing a confusing array of services. Family support can establish relationships that provide the foundation for emotional support and the development of new skills and resources that can have a lasting impact throughout 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 often may come from other parents.

Effective practices enhance the delivery of family support services that may be provided in addition to early intervention services either directly or through referral to public or private agencies. These include, but are not limited to, the following:

- Attendant care
- Child care
- Specialized dental services
- Diet and nutritional assistance
- Disability specific information
- Early childhood mental health
- Family-child activities (for example, Mommy and Me)
- Financial assistance (due to the impact of the family member who has a disability)
- Health insurance
- Home modifications
- Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (2000). Statewide parent to parent programs: Partners in early intervention. *Infants and Young Children, (13)* 1, 74-88 and Turnbull, A., Turnbull, R., Wehmeyer, M. L., & Shogren, K. (2013). *Exceptional Lives: Special Education in Today's Schools* (7th ed.). Columbus, OH: Merrill.

- In-home support services
- Information, resources, and referral
- Instructional guidance to blogging
- Multimedia libraries
- Parenting and education classes/workshops
- Parent-to-parent, peer-to-peer, and/or family-to-family support
- Recreation
- Respite
- Socialization
- Specialized clothing
- Support groups
- Vehicle modifications

Families who are eligible for early intervention services also may need assistance to secure access to other services that any family might need (for example, faith groups, community activities, 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, or probation).

# Key Indicators of Effective Family Support Services<sup>9</sup>

- Personnel support the concerns, priorities, and resources of the family.
- Families are included in planning, developing, implementing, and evaluating support and resources.
- Families decide and identify how family support services are delivered.
- Peer support is offered and can include family-to-family, parent-to-parent, peer-to-peer, and sibling-to-sibling support.
- Support, information, and education services are responsive and flexible and are provided in a variety of ways depending on the needs of the families in the community, such as the following:
  - + Materials and trainings provided in different languages.
  - + Staff who represent the cultures in the communities.
  - + Issues that are presented from different perspectives.
  - + Support that is provided individually and/or through groups.
  - + Services that are available in natural environments within the family's everyday routines, activities, and relationships.
  - + Information is provided in formats that are relevant for the family.
- Family support services may be provided even if the family chooses not to accept other early intervention services.
- 9. Adapted from Family Support America.

### FAMILY INVOLVEMENT—SUPPORTING AND PREPARING FAMILIES FOR FULL PARTICIPATION Overview

In addition to providing family support services and family-centered care, families need to be involved at every level. Families are the 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 transition from early intervention to preschool services.

### Key Indicators of Effective Family Involvement<sup>10</sup>

Family members and professionals work together to ensure the best services for children and their families.

Defining Family Involvement<sup>11</sup> Family involvement means that families receiving services are supported, prepared, encouraged, and offered the opportunity to participate as full partners at all levels, especially in planning, implementation, and evaluation of programs, services, and their related policies and practices.

- Families are recognized and respected for the knowledge, skills, and experience they bring to the planning, implementation, and evaluation of programs and services.
- Information is shared so that all partners have access to the same information, and open communication is encouraged so that families and professionals feel free to express themselves.
- Professionals are ready to hear what families say; encourage and support family members to find their voice; and always consider an individual parent's story as being valid.
- A variety of strategies are used to engage families (for example, chat rooms, agency events, or community events).

<sup>10.</sup> Florida Institute for Family Involvement.

Families are provided—in writing—complete, appropriate, and necessary information prior to meetings, such as results of evaluations and assessments. Culture, language, and value differences among families are respected.<sup>12</sup>

- Families are represented at all levels: individual, program, policy, and statewide system (such as by the California Interagency Coordinating Council on Early Intervention).<sup>13</sup>
- Family-to-family support and networking is encouraged and facilitated by referring families to local Early Start family resource centers. <sup>14</sup>
- Parents participate in providing technical assistance, leadership mentoring, training, and other parent leadership activities.
- Parents are compensated for their time, expertise, and expenses.

Services and support best meet the needs of families by focusing on the entire family and building on the family's strengths and respecting cultural preferences, values, and unique lifestyles. Families benefit from support that promotes the inclusion of people with disabilities in all aspects of community life.

12. A core message of the California Training and Technical Assistance Collaborative.

- 13. Information on the California Interagency Coordinating Council on Early Intervention is available at http://www.dds.ca.gov/EarlyStart.
- 14. Information on Early Start family resource centers is available at http://www.dds.ca.gov/EarlyStart.

# *Effective Practice Guidelines for Engaging Families in Early Intervention Services*

Developing and implementing a plan that promotes family-centered service delivery in the areas that follow is critical for each public and private non-profit agency involved in the provision of early intervention services, including regional centers and local education agencies (LEAs).

# Parent-to-Parent Support

Kurt Vonnegut, Jr., 20<sup>th</sup> century American writer and humanist, is credited with saying, "You are not alone."

As true as that is, for a family dealing with a serious medical diagnosis, nothing feels further from the truth. Parent-to-parent support could be the one mobilizing force in integrating a family with a child with special needs back into society. As studies have shown, parent-to-parent support often leads to fewer feelings of isolation and can help families cope in times of need.

Engaging families with other families with children with special needs offers a sense of community and belonging. Networking through support groups, family resource centers (FRCs), and other community resources is a powerful tool.

Many families are willing to share their experiences and expertise with other families. Not only do these relationships promote emotional support, they help families gather information, find solutions to problems, and, ultimately, advocate for their child's needs.

Referrals from early intervention agencies to the local Early Start FRC serve to initiate contact that fosters a parent-to-parent relationship. The FRC matches the family of a child with a disability to another parent who has specific training in best practices in peer support representing the ethnic, cultural, linguistic, or socioeconomic diversity of the family as identified by the family.

Even if the family chooses not to accept other early intervention services, access to family support services may be provided.

### Essentials of Parent-to-Parent Support

- The support promotes opportunities for families to interact with each other for emotional support.
- Parent-to-parent support services include, but are not limited to, individualized and group support models; community parent-child programs, such as Mommy and Me classes; informal face-to-face introductions; and communication by email or telephone.

- Parent-to-parent support staff receive training in effective practices for peer support.
- Parent feedback is used to evaluate effectiveness of parent-to-parent support activities.

# **Parent Education and Training**

Children are not born with instruction manuals. The pressure of child rearing is further compounded by the diagnosis of a disability. For families raising a child with special needs, the paperwork alone can, at times, feel unbearable. At first diagnosis, a family raising a child with a disability may be simply trying to make it through one more day, one more sleepless night.

With the family-centered guidance of a professional and parent education and training, these families can make significant strides toward regaining a sense of stability. The benefits of parent education and training have been proven to help a family gain confidence and competence in supporting the development of their child. Offering training in areas on which the individualized family service plan (IFSP) focuses, parentprofessional partnerships, peer support, communication, therapies, transitions, and other components of the Early Start system can support families raising a child with a disability.

The early intervention system can be complicated. Fostering leadership through skill-building opportunities and mentor support can help to ease the family into an advocacy role so they can learn ways to meet their needs and the needs of their child. Likewise, staying abreast of current research and best practices will help parents and professionals alike as they partner to support the development of each eligible child.

### Essentials of Parent-to-Parent Education and Training

- Conferences, workshops, and trainings for families are encouraged and supported by early intervention agencies.
- Families and professionals plan and conduct trainings to model parent-professional partnerships.
- Parent education and training activities are provided in community-based settings frequented by families.
- Support (for example, child care, interpreters, peer support, and transportation vouchers) is provided so parents may participate in education and training activities.
- Trainings are culturally and linguistically appropriate.
- Trainings include how systems work and how families can participate as full partners and take on a leadership role.
- Current training topics include IFSPs, parent-professional partnerships, transition, individualized education plans (IEPs), methodologies, therapies, and other components of the Early Start system.

# Information, Resources, and Referral

As mentioned earlier, staff and service providers play a fundamental role in service provision. In the IDEA, Part C, Congress found there is an urgent and substantial need "to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities."

Families make informed decisions when they have access to current, unbiased, varied, and accurate information and resources. Ensuring access to complete, objective information from early intervention agencies involved in Early Start service provision is critical. The Early Start FRC is a key resource for local, regional, statewide, and national information gathering. It is every agency's responsibility to ensure information is readily available in a variety of media accessible to families.

Families are best reached when information is delivered in a timely manner and in a variety of modalities. Information includes topics such as assessment, various disabilities, education, recreation, social events, therapies, transitions, advocacy, and respite. Information is culturally competent and responsive to the needs of the community.

To be prepared and informed, families must feel comfortable asking questions when seeking early intervention services. It is important to remember that there is never a "dumb" question. The family's first point of contact at intake, registration, and reception is with someone knowledgeable about early intervention services who is welcoming to families. Ultimately, families will use the knowledge provided to make informed decisions for their child.

# Essentials of Information, Resources, and Referral

- A knowledgeable, caring, and responsive person is the family's first point of contact.
- Families have access to information in a variety of modalities (for example, print, audio, and video and in the language preferred by the family).
- Information includes topics such as assessment, various disabilities, education, recreation, social events, trainings, support groups, therapies, transition, advocacy, and respite.
- Information is available by telephone, email, Internet, and/or fax.
- Information is available during flexible hours, based on family needs.
- Information is available throughout the community.
- Parents are given opportunities to discuss and process information with someone who is knowledgeable about early intervention services and IDEA Part C.
- Parents' rights and responsibilities are provided and reviewed with families on a regular basis.

### **Community Outreach and Awareness**

Community outreach that is accessible and culturally responsive to the families served is vital, and getting families involved is key to the success of early intervention. Public awareness and child-find activities to locate, identify, and refer infants and toddlers who may be in need of services have a direct relationship to the success of early intervention. And, as identified through research, early intervention increases the number of successful outcomes for children with a disability.

To help provide parent support, outreach and informational materials are available in a multitude of languages and in places where families gather. Early intervention agencies may serve as a resource to promote families of children with disabilities as healthy, functional, and resourceful community members.

Local coordinated public awareness efforts include a referral system for service providers from a variety of disciplines—family support, health, and social services ensuring early identification of infants and toddlers and a mechanism for disseminating materials that inform the public about the availability of early intervention services. It is every agency's responsibility to ensure that information is readily available.

### Essentials of Community Outreach and Awareness

- Outreach and informational materials are available in languages accessible to the cultures of the families served.
- The early intervention agency provides referral sources in the community with program and contact information that facilitates appropriate referrals to early intervention and family support services.
- Outreach and awareness materials are developed with input from families.
- Agency teams implementing outreach activities include parents and family members.
- Child-find activities are implemented in a way that supports families.
- Information is available where families gather.

# **Professional Development and Training**

To ensure professionals are informed and appropriately trained, agencies provide continuous staff development opportunities, which include strategies that support familycentered services and supports. Family input is recognized as a valuable resource to identify areas where additional training is needed. Mentor support, fostering leadership, and skill-building exercises reflect a belief that professionals providing family support benefit from ongoing training and technical assistance opportunities. Promoting the family-centered service model while building on concepts such as cultural competence and parent-professional collaboration creates a cohesive approach to early intervention for both public and private non-profit agencies.

# Essentials of Effective Personnel Development and Training

- Family input is used to identify knowledge and skill areas for personnel development and training.
- Staff participates in training using a family-centered approach to services.
- Personnel development activities reflect cultural competence.
- Personnel development activities model parent-professional collaboration.
- Early intervention staff and professionals see families of children with disabilities as healthy, functional, and resourceful community members.
- Opportunities are provided for personnel to share their learning with peers and colleagues.
- Families provide feedback on the integration of new knowledge into practice after training occurs.

# **Early Intervention Service Settings**

According to Part C of the IDEA, early intervention services must be provided in natural environments, including home and community settings where children without disabilities participate. Similarly, providing early intervention in natural environments reflects the belief that every community is enriched by the inclusion of people with diverse abilities.

Providing intervention within the family's natural environment of everyday routines, relationships, activities, places, and partnerships increases the availability of learning opportunities that enhance the parents' ability to support their child's development and promotes parent confidence and competence. It also empowers the child-parent relationship, the most significant factor in the child's overall development.

Providing early intervention service in natural settings promotes the vision that all children with disabilities are given the opportunity to live with a supported and empowered family, fully participating within their community.

# Essentials of Early Intervention Service Settings

- Early intervention services, including family support services, are offered in environments that are accessible for families and where families feel comfortable.
- The natural environments for service delivery for an individual family are determined with input from the family (questionnaire, parent interview, etc.) and not by the agency's service delivery model.

- Families are provided services and supports that promote participation in a range of environments that allow parents to interact with parents of children with and without disabilities.
- Families are provided opportunities to identify support needs that will enable them to participate in community activities with families with typically developing children.
- Staff plan with service providers across agencies to coordinate the delivery of services within a family's natural environments.

# **Family Empowerment**

Family is the cornerstone in a child's life. A family-centered approach builds family confidence and the capacity to participate in all stages of their child's care, from evaluation and implementation to transitions to other service systems. Ensuring a family has access to resources and leadership-building activities means the family has the tools they need for success in supporting the development of a child with a disability. Equally vital is educating families on the service system processes that support positive outcomes for the child and family.

Empowering families and supporting them in building competence and confidence to meet the needs of their child are primary goals of the professionals involved with the family. Informing families of their rights, facilitating their participation in the decision-making process, and supporting active participation in the delivery of early intervention services empower families to be active in enhancing their child's development.

When decisions are made, it is critical to listen to input from the families. A family is empowered when its voice is heard and acknowledged in the decision-making process at all phases, from entry to transition from Early Start. The multidisciplinary IFSP team meeting, where family input is recorded and service options negotiated, is a place where the empowered family can participate as an active member. Empowered families are able to communicate their child's needs at all levels of implementation, including IFSP meetings, service delivery, and trainings.

Furthermore, when parents are approached as the primary agent of change in their child's life, the dynamic is changed from the professional "fixing" the child to the parents' ability to anticipate and meet the needs of their child. This change strengthens both self-esteem and resilience.

### Essentials of Effective Family Empowerment

- Families are aware of, and understand, their rights under Early Start.
- Parents participate in education and training activities that provide information about the service system processes and caring for their child.

- Professionals make a record of the family's input in (multidisciplinary) team meetings.
- Families effectively communicate their child's needs.
- Family input about satisfaction with services is used to improve service delivery.
- Opportunities exist for a family's voice to be heard and for service options to be negotiated.
- Decisions about services are based on information provided by members of the multidisciplinary team, including the family.
- Programs are respectful and responsive to the diversity of families and to the individual needs of each child and family.
- Services and supports build on the family's strengths and resources.
- Families receive assistance in identifying and accessing early intervention and support systems.

# **Parent-Professional Collaboration**

Increasingly, early intervention professionals acknowledge they no longer can see themselves as the "experts" about the child; rather, they must take on the role of a listener and partner with par"Providers can feel competent in their own work, when parents feel competent," is the phrase Dr. Victor Bernstein of the University of Chicago uses to explain "mutual competence." One way to cultivate this mutual competence is to train parents and professionals together so they have access to the same information that is provided by parent-professional presenters. This way, parents and professionals work together to deliver family-centered personnel development.

ents in services. To have successful parent-professional collaboration, professionals must shift their thinking in this direction. Instead of having a preconceived notion of what a child or family needs, it is important to listen to what the parents say they need and want.

The relationship between the child and family is the most important and influential relationship in the child's life. To have a partnership, families and professionals must value the contributions each brings to the process. A family-centered approach ensures families are involved every step of the way, from goal setting and evaluation to policy development. The parent plays a vital role. Encouraging open and frequent communication can foster successful parent-professional collaboration in support of the child's development.

Trust and open communication help lay the foundation for a successful collaboration. The more clearly and safely parents can express their needs, the better equipped the professional can be at assisting the family. Just as parents can bring to the table an intimate understanding of their child, the professional can bring a body of knowledge and strategies specific to the field of early intervention, as well as additional resources and options that further expand the parent-professional collaboration.

# Essentials of Parent-Professional Collaboration

- Parents are proactively supported for their involvement.
- Families are involved in decision making at all levels including joint planning, goal setting, policy development, and evaluation.
- The knowledge, skills, and experience families and professionals bring to the relationship is recognized and respected by both sides.
- Trust and open communication are integral to parent-professional collaboration.
- At all levels of parent-professional collaboration, the family's perspective is represented.<sup>15</sup>
- Parents and staff have access to the same information.
- Parents and professionals work together to deliver personnel development.

# **Cultural Competence**

The concept of "culture" is broader than that of "race" or "ethnicity." Language, class, gender, sexual orientation, geography, ancestry, physical and sensory abilities, occupation, family composition, and affiliation all reflect the complex realities of identity. A person may belong to one culture or several cultures. Whether ethnic or geographic, everyone has a culture. These predominant affiliations shape beliefs, behaviors, values, and attitudes of both providers and the families they serve.

Unlike previous trends, cultural proficiency is not about integration, assimilation, tolerance, or superficial multiculturalism focused on learning about holidays or food. Cultural proficiency is a concept and a framework for expanding the notion of diversity. It is about learning to see differently through a cultural proficiency lens, seeing culture and its influence as an asset and great source of strength for everyone.<sup>16</sup>

Identifying and establishing a plan that integrates a family's culture promote a family-centered approach to service. For staff members, the goal is to work effectively cross-culturally. Materials are available in variety of languages and formats.

Exploring with the family their cultural strengths and resources is an invaluable source of support. Identifying resources and tools increase a family's capacity to meet their child's needs. At a time of crisis, families dealing with a serious medical diagnosis or challenging behaviors might need assistance in identifying—and accessing—these resources.

Early intervention staff using self-assessment to examine attitudes and values related to cultural competence is an important tool for delivering insightful, compassionate, knowledgeable family-centered services. To help with the wide range of cultural diversity

15. University of Vermont.

16. The Data Coaches Guide to Improving Learning for All Students, Love, Stiles, Mundry, and DiRanna, 2008.

within a community, agencies train their staff using effective self-assessment strategies. These assessments help staff identify and enrich their own attitudes about working with families representing different cultural backgrounds.

In addition to self-assessment training, staff providing family support services receive written policies and procedures describing professional expectations for working within a culturally diverse community. With continued education, staff have the capacity to value diversity, manage the dynamics of difference, acquire and institutionalize cultural knowledge, and adapt to the diversity and cultures of the communities they serve.

# **Essentials of Cultural Competence**

- Staff work effectively cross-culturally.
- Staff integrate services into activities familiar to the family's culture.
- Diversity in families, personnel, and communities is valued.
- Hiring practices reflect the cultural diversity of families served.
- Agencies incorporate cultural diversity into policymaking, administration, and practice and service delivery, and systematically involve consumers, key stakeholder, and communities.<sup>17</sup>
- Self-assessments are a tool used to promote cultural proficiency.
- Materials are available in a variety of languages.
- Written policies and procedures describe professional expectations for staff working within a culturally diverse community.

# **Individualized Family Service Plan Development**

The development of a family-centered IFSP drives service delivery for children and families. It is an opportunity for professionals and families to collaborate to identify and implement a strategic plan that best meets the needs of the child and family. With this partnership between the family and the early intervention team, a child is more likely to achieve the desired outcomes.

The family-centered IFSP offers benefits to the professional. The IFSP engages family members as colleagues, accesses the family knowledge about the child's strengths and needs, shares expertise with the family and each other, and prioritizes efforts.

17. http://www11.Georgetown.edu/research/gucchd/nccc/foundations/frameworks.html (bullets 1-3).

### **Essentials of IFSP Development**

- Part C requirements are followed.
- Parent-to-parent support is offered to all families.
- Team decisions regarding services and supports for an individual child and family include the input of the family—such as their concerns, priorities, and resources—as an active member of the IFSP team.
- Families are provided access to information prior to meetings.
- Family choices are respected.
- Family outcomes, as identified by families, are included in the IFSP.

### **Transition**

By a child's third birthday, families receive timely planning support for their child's transition to preschool or other appropriate community services. Effective transitions for children and their families ensure timely access to appropriate services as they leave early intervention services. State and local policies, interagency agreements, personnel development processes, and other mechanisms are in place to support the transition process.<sup>18</sup>

Maintaining family-centered practices, families remain active partners in the transition process. They are informed and educated about their child's potential eligibility beyond three years of age. They are active in the planning and exploration of options and are provided sufficient time to prepare for the transition experience. This preparation includes necessary resources, including training, to make informed decisions in the transition process.

Effective transition practices are designed for all children eligible for services under the Lanterman Developmental Disabilities Services Act through regional centers and/or those potentially eligible for IDEA, Part B preschool services through local education agencies. This includes children exiting Early Start to the community at age three. Children who transition to appropriate services retain and maintain developmental gains achieved during Early Start enrollment.

Family support is critical during all types of transitions and may be achieved more effectively in collaboration with family resource centers, parent training and information centers, family empowerment centers, disability-specific support, and other parent-to-parent support organizations.

18. http://www.nectac.org/topics/transition/transition.asp.

# **Essentials of Transition**

- Upon entering the Early Start system, families receive written information about the transition process that will occur when their child turns three years of age.
- Families are informed and educated about their child's potential eligibility for other services prior to exiting Early Start, and steps to prepare for change in services are introduced.
- Training is provided for parents on the transition planning process from Part C to Part B services and/or to other community resources.
- Staff begin to discuss service options with families early in the transition planning process.
- Strategies for effective communication are provided to families, supporting them to articulate their child's strengths and needs.
- Families are encouraged and supported in their role as an IEP and individual program plan (IPP) member.
- For children who are exiting the Early Start system and **are not eligible for Part B**, reasonable effort is made during the transition conference to provide families the necessary resources and information to make informed decisions about the options available to their child, whether the child is entering preschool or other community-based services.

# **Recommendations for Implementation**

These guidelines have application to three major target groups: state agencies, local agencies, and Early Start family resource centers (FRCs). The recommendations for implementation of the guidelines follow.

### **State Agencies**

It is recommended that state agency partners that are involved in services to infants and toddlers and their families assist local agencies with implementation and evaluation of family support guidelines as part of their early intervention administration and monitoring responsibilities. These agency partners include the California Department of Developmental Services, California Department of Education, and other state agencies.

### **Local Agencies**

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

- Procedural guidelines for family support
- Personnel development activities that include effective family support strategies and cultural competence
- Early intervention services including family supports provided in the family's natural environments
- Family empowerment strategies
- Family support in the individualized family service plan (IFSP) process, including transition
- Cultural competence and linguistic diversity

# **Early Start Family Resource Centers**

It is recommended that all Early Start FRCs develop and implement a plan that addresses how family support services will be delivered in the following areas:

- Parent-to-parent support
- Parent education and training
- Information, resources, and referral
- Community outreach and public awareness
- Personnel development and training
- Early intervention service settings
- Family empowerment
- Parent-professional collaboration
- Cultural competence
- IFSP development
- Transition

### Agency Assessment and Planning

*Effective Practice in Providing Family Support* distinguishes three core concepts that have been described throughout this document. The following concepts are critical to understanding how to best serve young children and their families:

- **Family-Centered Care:** a philosophy and approach to service delivery
- **Family Support Services:** specific services for families that enhance their child's development
- **Family Empowerment:** the concept that families are supported and prepared and are offered the opportunity to participate as full partners

To ensure that these concepts are operationalized in daily practice when providing services to infants and toddlers and their families, it is recommended that agencies use the Self-Assessment and Planning Guide provided in the next section for program planning purposes and to identify training needs, guide and enhance services, and design personnel development opportunities.

# Self-Assessment and Planning Guide

# **Effective Practice Self-Assessment Tool**

Agencies may use the following self-assessment tool to rate the extent to which they have implemented the practices described in this document in their daily work with young children and families.

This self-assessment tool uses a frequency rating scale of 1 to 5 (1=Never, 2=Rarely, 3=Sometimes, 4=Often, and 5=Always). Enter a numerical rating in the box before each statement, as appropriate. If a statement does not apply to your agency, mark "N/A."

Once you have rated each item, determine the subtotal for the each effective practice domain by adding your ratings of the items for that domain. Once you have subtotaled all of the domains, add a total score and refer to the scoring guide for an idea of how frequently you implement effective practices in each area.

# RATING EFFECTIVE PRACTICE

### **1. PARENT-TO-PARENT SUPPORT**

Parents have opportunities to interact with other parents of children with disabilities for emotional support.
Parent-to-parent support is delivered in a variety of ways, including both individualized and group support models, to meet the needs of the families served.
Parent-to-parent support staff receive training in best practices in peer support.
Parent feedback is used to evaluate effectiveness of parent-to-parent support activities.
 Subtotal for Parent-to-Parent Support

# 2. PARENT EDUCATION AND TRAINING

	Current information about parent education and training is provided to families.
	Parent education and training content and materials reflect positive models for parent-professional interactions.
	Parent education and training activities are provided in community-based settings frequented by families.
	Support (such as child care, interpreters, peer support, transportation vouchers, or assistance) is provided for parents to participate in education and training activities.
	Subtotal for Parent Education and Training
3. INFORMATION, RESOURCES, AND REFERRAL	
	The family's first point of contact (intake, registration, reception) is a person knowledgeable about early intervention services.
	Information and resources are available in a variety of media accessible to families.
	Information and resources are disseminated throughout the community in places frequented by families.
	Staff answer questions from parents to assist their understanding of information and resources provided.
	Subtotal for Information, Resources, and Referral

# **RATING EFFECTIVE PRACTICE**

4. COMMUNITY OUTREACH AND AWARENESS	
	Outreach and informational materials are available in languages accessible to the cultures of the families served.
	Agency provides referral sources in the community with program and contact information for family support services.
	Outreach and awareness materials are developed with input from families.
	Agency teams implementing outreach activities include parents and family members.
	Subtotal for Community Outreach and Awareness
5. PERS	ONNEL DEVELOPMENT AND TRAINING
	Family input is used to identify knowledge and skill areas for personnel development and training.
	Personnel development content represents families of children with disabilities as capable community members.
	Staff participate in training using a family-centered approach to services.
	Families provide feedback on the integration of new knowledge into practice after training occurs.
	Subtotal for Personnel Development and Training
6. EARL	Y INTERVENTION SERVICE SETTINGS
	Early intervention services, including family support services, are offered in environments natural for families.
	The natural environments for service delivery for an individual family are determined with input from the family.
	Staff plan with service providers across agencies to coordinate the delivery of services within a family's natural environments.
	Families are provided services and supports in a range of environments that allow parents to interact with parents of children with and without disabilities.

### **RATING EFFECTIVE PRACTICE**

### 7. FAMILY EMPOWERMENT

Professionals explain parents' rights documents when they are disseminated to parents.
Parents participate in education and training activities that provide information on the service system processes.
Professionals make a record of the family's input in (multidisciplinary) team meetings.
Family satisfaction is a priority.
Subtotal for Family Empowerment

### 8. PARENT-PROFESSIONAL COLLABORATION

Parents and staff receive training together, so families and professionals hear the same messages.
Family members represent the family perspective on agency groups and committees.
Parents and professionals work together to deliver personnel development.

Support is provided for parent involvement in program implementation activities.

Subtotal for Parent-Professional Collaboration

# 9. CULTURAL COMPETENCE

 Subtotal for Cultural Competence
 Staff integrate services into activities familiar to the family's culture.
 Staff receive training to conduct a self-assessment of their own attitudes about working with families representing cultural backgrounds different from their own.
 Written policies and procedures describe professional expectations for staff working within a culturally diverse community.
 Staff composition is representative of the cultural demographics and primary languages of the families served.

# **RATING EFFECTIVE PRACTICE**

10. INDI	VIDUALIZED FAMILY SERVICE PLAN DEVELOPMENT
	Parent-to-parent support is offered to all families.
	Families are provided a list of early intervention service delivery options available in their community.
	Team decisions regarding services and supports for an individual child and family include the family's input.
	Family outcomes, as identified by families, are included in the IFSP.
	Subtotal for Individualized Family Service Plan Development
11. TRAI	NSITION
	Upon entering the Early Start system, families receive written information about the transition process.
	Agency provides training for parents on the transition (from Part C to Part B) planning process.
	Staff begin to discuss service options with families before transition planning begins.
	All families approaching transition planning are provided contact information for an Early Start family resource center to access transition support.
	Subtotal for Transition

# **Effective Practice Planning Guide**

After completing the self-assessment, examine your scores by domain area.

### **SCORING GUIDE:**

**0-7 points:** Program change may be indicated. By taking this assessment, you have begun to identify the need for further examination and identification of specific steps toward strengthening the implementation of these guidelines, leading to improved outcomes for children and families.

**8-14 points:** You have taken steps to ensure that this area of your program is improving. It might benefit you to examine individual items in this domain to determine where you can further strengthen your program.

**15-20 points:** You have shown commitment to this domain in your program. Continuing to focus on this as well as raising the scores in other domains will assist in promoting effective practices and result in more positive outcomes for children and families.

Transfer your scores for each domain into the white circles next to each domain name on the following pages. Think about your agency's strengths and areas for improvement in each domain.

SUBTOTAL FOR PARENT-TO-PARENT SUPPORT

Our greatest strength in providing parent-to-parent support is:

Two things our agency could do to strengthen parent-to-parent support are:

### SUBTOTAL FOR PARENT EDUCATION AND TRAINING

Our greatest strength in providing parent education and training is:

Two things our agency could do to strengthen parent education and training are:

### SUBTOTAL FOR INFORMATION, RESOURCES, AND REFERRAL

Our greatest strength in information, resources, and referral activities is:

Two things our agency could do to strengthen information, resources, and referral are:

#### SUBTOTAL FOR COMMUNITY OUTREACH AND AWARENESS

Our greatest strength in community outreach and awareness activities is:

Two things our agency could do to strengthen community outreach and awareness activities are:

### SUBTOTAL FOR PERSONNEL DEVELOPMENT AND TRAINING

Our greatest strength in providing personnel development and training is:

Two things our agency could do to strengthen personnel development and training are:

#### SUBTOTAL FOR EARLY INTERVENTION SERVICE SETTINGS

Our greatest strength in providing services in early intervention service settings is:

Two things our agency could do to strengthen the provision of services in early intervention service settings are:

#### SUBTOTAL FOR FAMILY EMPOWERMENT

Our greatest strength in empowering families is:

Two things our agency could do to strengthen family empowerment are:

#### SUBTOTAL FOR PARENT-PROFESSIONAL COLLABORATION

Our greatest strength in parent-professional collaboration is:

Two things our agency could do to strengthen parent-professional collaboration are:

### SUBTOTAL FOR CULTURAL COMPETENCE

Our greatest strength in demonstrating cultural competence is:

Two things our agency could do to strengthen cultural competence are:

### SUBTOTAL FOR INDIVIDUALIZED FAMILY SERVICE PLAN DEVELOPMENT

Our greatest strength in the development of individualized family service plans is:

Two things our agency could do to strengthen the development of individualized family service plans are:

### SUBTOTAL FOR TRANSITION

Our greatest strength in supporting children and families through transition is:

Two things our agency could do to strengthen our support of children and families during transition are:

# Appendix A

# Training and Technical Assistance Collaborative Core Messages

The California Training and Technical Assistance Collaborative (TTAC) is an interagency partnership dedicated to delivering quality professional development activities for personnel who serve children birth to 5 with disabilities and other special needs and their families. TTAC believes early childhood intervention training and technical assistance activities that are guided by the following messages promote positive outcomes for young children and their families.

**Early childhood from birth to age 5 is a dynamic period of development.** Early childhood intervention contributes to positive outcomes for children and families.

**F**amily is the single most important influence on the growth and development of a young child. Early childhood intervention recognizes the centrality of the family and supports the child's relationships with parents and other primary caregivers.

**F**amily and professional partnerships contribute to quality service delivery systems. Effective partnerships are based on mutual trust; are developed over time; and support families as active participants and decision-makers for their children.

**Every young child with disabilities or other special needs and every family has strengths.** Early childhood intervention teams identify the strengths of the child and family and help to enrich existing formal and informal resources and supports.

**Culture, language, and value differences among families are respected.** Early childhood intervention services are individualized, flexible, respectful, and responsive.

**Teachable moments occur in everyday activities and in a variety of settings.** Early childhood intervention promotes practices that appropriately include young children with disabilities and their families in family activities and settings where young children without disabilities and their families come together.

**Interagency and interdisciplinary partnerships improve the experiences of children and families.** Coordination among agencies, providers, and disciplines creates early childhood intervention systems that are cost-effective, comprehensive, cohesive, and easily accessed.

**Validated, evidence-based research guides practice.** Quality early childhood intervention services are based on research and outcome-driven practices.

Effective systems of personnel development provide opportunities for building Skills, supporting mentors, and fostering leadership.