

Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

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A diverse panel of experts convened in Bad Ischl, Austria, in June of 2012 for the purpose of coming to consensus on essential principles that guide family-centered early intervention with children who are deaf or hard of hearing (D/HH). The consensus panel included parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers from 10 nations. All participants had expertise in working with families of children who are D/HH, and focus was placed on identifying family-centered practice principles that are specific to partnering with these families. Panel members reported that the implementation of family-centered principles was uneven or inconsistent in their respective nations. During the consensus meeting, they identified 10 agreed-upon foundational principles. Following the conference, they worked to refine the principles and to develop a document that described the principles themselves, related program and provider behaviors, and evidence supporting their use (drawing upon studies from multiple disciplines and nations). The goal of this effort was to promote widespread implementation of validated, evidence-based principles for family-centered early intervention with children who are deaf and hard of hearing and their families.

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Background and Purpose

In June 2012, an international panel of experts in early intervention convened in Bad Ischl, Austria, to come to consensus on best practice principles guiding the implementation of family-centered early interventions (FCEIs). The conference organizers were unified in the belief that family-centered practices optimize outcomes for children and families and that there was a need to clearly articulate agreed-upon tenets of this philosophy. Panel members were invited by Drs. Daniel Holzinger and Johannes Fellinger, and the consensus discussion was facilitated by Dr. Mary Pat Moeller. The panel included parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers from across the world. All participants had expertise in working with families of children who are deaf or hard of hearing (D/HH), and focus was placed on identifying family-centered practice principles that are specific to partnering with these families. Panel members observed that the majority of professionals in their respective countries agree on the major concepts that are foundational to FCEI.

However, the implementation of best practices was judged to be variable and inconsistent at best across the respective nations. This set of agreed-upon guidelines was developed to promote wider implementation of validated, evidence-based principles for FCEI with children who are D/HH and their families. A Call to Action is provided at the end of this document to support this overarching objective.

Several overarching concepts underpin the FCEI process. Fundamentally, interventions must be based on explicit principles, validated practices, and best available research while being respectful of family differences, choices, and ways of doing things. FCEI is viewed as a flexible, holistic process that recognizes families' strengths and natural skills and supports development while promoting the following: (a) joyful, playful communicative interactions and overall enjoyment of parenting roles, (b) family well-being (e.g., enjoyment of the child, stable family relations, emotional availability, optimism about the child's future), (c) engagement (e.g., active participation in program, informed choice, decision making, advocacy for child), and (d) self-efficacy (competent and confident in parenting and promoting the child's development).

Family-professional partnerships are formed and partners collaborate to clarify family values, goals, and aspirations and to respect this input in the intervention process. Interventions are implemented in a manner that is culturally competent, and professionals devote themselves to ongoing continuing education to maintain the highest standards of best practice.

The panel recognized that various nations have different definitions for commonly used terms. An effort was made to avoid terms with varied or controversial interpretations and to adhere to terms with broad, shared understanding. The terms "deaf" and "hard of hearing" (D/HH) are used in this document to represent the entire spectrum of children with varying hearing levels (from mild to profound). The term D/HH is also intended to be inclusive of those from culturally Deaf communities, wherein individuals are considered in the cultural context above and beyond hearing status. Communication development is used broadly to refer to the child's auditory skills, visual skills, receptive and expressive language skills (spoken and/or sign language development), pragmatics, and turn taking.

The panel arrived at consensus on 10 principles guiding FCEI. The first principle deals with the

Best Practice Principle	Provider and/or Program Behaviors
Principle 1: Early, Timely, & Equitable Access to Services Screening and confirmation that a child is D/HH will be effective to the degree that they are linked with immediate, timely, and equitable access to appropriate interventions.	Programs ensure that <ol style="list-style-type: none"> 1. Newborn hearing screening programs are implemented following documented best practices and timelines for follow-up. 2. Follow-up diagnostic services are provided immediately upon referral and are conducted by professionals with pediatric experience. 3. Families are offered comprehensive family support and early intervention programs in a timely manner following newborn hearing screening within a framework of informed choice. 4. Enrollment in early intervention proceeds while audiological follow-up is in progress. 5. Families have access to a coordinated point of entry to early intervention programs. 6. Comprehensive services are offered and available regardless of the family's socioeconomic status, income, or geographic location. 7. Various strategies are used to help families understand the importance of timely follow-up. 8. Transitions from screening or other early identification efforts are timely and consistently monitored to ensure timeliness.

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Best Practice Principle	Provider and/or Program Behaviors
Principle 2: Family/Provider Partnerships A goal of FCEI is the development of balanced partnerships between families and the professionals supporting them. Family-provider partnerships are characterized by reciprocity, mutual trust, respect, honesty, shared tasks, and open communication.	Service providers work in partnership with families to <ol style="list-style-type: none"> 1. Focus on facilitative family-child interactions, rather than child-directed therapies. 2. Focus on family-identified concerns (priorities, hopes, needs, goals, and wishes). 3. Build upon individual family strengths to meet family needs. 4. Recognize and promote the fact that families need to live their typical lives. 5. Work with adults to enhance their confidence and competence in fostering their children's development. 6. Understand ways in which discrimination, oppression, and stereotyping may affect the provision of services. Service providers <ol style="list-style-type: none"> 1. Recognize their own areas of expertise, comfort, and discomfort when working with families from similar or different cultural backgrounds and seek support when needed. 2. Recognize the diversity within cultural groups (i.e., spiritually, views on health and disability, child rearing, help seeking, and family structure). 3. Arrange visits with the families to match family expectations and schedules. 4. Foster family investment and effectiveness, which, in turn, benefits the well-being and development of the child. 5. Implement processes that are flexible, individualized, and responsive to changing needs, preferences, and learning styles of families. 6. Implement participatory help giving, focused on family involvement in achieving desired goals and outcomes. 7. Respond sensitively and empathically in all interactions with families. 8. Provide both informational and emotional support. 9. Recognize the boundaries of their role and expertise and provide referral/access to specialized professionals when needed. 10. Demonstrate both care and concern for families in all interactions. 11. Assume all families as responsible, trustworthy people and treat them as such. 12. Follow through on agreed-upon tasks in a timely manner.

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Best Practice Principle	Provider and/or Program Behaviors
	<ol style="list-style-type: none"> 13. Be a knowledgeable and credible early intervention partner with the family. 14. Listen actively to family members and understand the relationship between their expressed concerns and the real needs that the family is identifying. 15. Support families to feel optimistic about the child's future and to establish and maintain high expectations for the child's development. 16. Support families in ways that match their distinctive nature (e.g., configuration, culture, beliefs, values, emotions, coping skills, and family dynamics).

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Best Practice Principle	Provider and/or Program Behaviors
Principle 3: Informed Choice and Decision Making	Service providers
Professionals promote the process wherein families gain the necessary knowledge, information, and experiences to make fully informed decisions. This includes educating families regarding special education laws and their rights as defined by these laws. Decision making is seen as a fluid, ongoing process. Families may adapt or change decisions in response to the child's and families' changing abilities, needs, progress, and emotional well-being.	<ol style="list-style-type: none"> 1. Recognize that ultimately, decision-making authority rests with the family; collaborate with families to support their abilities to exercise this authority. 2. Adopt open and flexible policies that effectively endorse a range of communication possibilities. 3. Share information and experiences from a variety of sources that are comprehensive, meaningful, relevant, and unbiased to enable informed decision making. 4. Keep in mind that “informed choice” is not synonymous with information that is neutral or functionally descriptive. Rather, evaluative information is essential in that it draws attention to the various risks, benefits, and uncertainties related to particular options. 5. Inform families about expectations for them that are inherent in implementing various approaches, as well as potential benefits and challenges. 6. Actively support the family in processes of decision making and self-determination. 7. Assist families to identify and successfully rely on their abilities and capabilities. 8. Support families to reach decisions in ways that reflect their individual strengths, resources, needs, and experiences. 9. Support families to create a vision and plan for their child's future; assist them in understanding that plans and visions can be altered, if needed. 10. Provide resources and support family members' decisions. 11. Recognize that informed choice is not a one-time decision but an ongoing process. 12. Fully inform families of their rights ensured by law.

Related Resources and Evidence Citations*Guidelines*

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Best Practice Principle	Provider and/or Program Behaviors
Principle 4: Family Social & Emotional Support	Service providers
Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children.	<ol style="list-style-type: none"> 1. Build upon and use both formal (systematic parent–professional partnerships and parent-to-parent support networks) and informal (community organizations, friends, extended family, religious affiliations, play groups) support systems. 2. Understand the ways in which natural networks support the health and well-being of families. 3. Assist families to identify what resources their informal support networks can provide to meet specific needs/concerns. 4. Ensure that families have access to a range of supports so that supports can be individualized to the unique needs of the family. 5. Understand and actively model the practices of reciprocity in order to build networks. 6. Facilitate contacts between families and their communities as a way of strengthening informal capacity. 7. Ensure that all families have access to parent-to-parent support from other families of children who are D/HH. Recognize the key role of parent-to-parent support in promoting social and emotional well-being for families. 8. Support connections between families and adult role models who are D/HH. 9. Provide social and emotional supports to promote the well-being of parents and siblings. Inform parents about and refer them to professional mental health services, if considered appropriate. Recognize the importance of family well-being for child development.

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Best Practice Principle	Provider and/or Program Behaviors
	Early intervention systems
	1. Recognize and actively support parent organizations and networks for direct parent–peer support opportunities.
	2. Incorporate parent leadership into the strategic development and operational function of FCEI systems.

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Best Practice Principle	Provider and/or Program Behaviors
Principle 5: Family Infant Interaction	Service providers support families to
Families and providers work together to create optimal environments for language learning.	1. Use everyday routines, play, and typical interactions to promote the child's communicative development.
	2. Consistently provide the child with language-rich stimulation during natural interactions with all family members (parents, siblings, extended family members).

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Best Practice Principle	Provider and/or Program Behaviors
	<ol style="list-style-type: none"> 3. Respond with sensitivity to the child's communicative attempts and consistently implement techniques known to facilitate language and communicative development. 4. Provide the child numerous opportunities to actively participate in a rich variety of communicative interactions. 5. Ensure that family communication is accessible to the child. 6. Adapt the level of their language input to nurture their child's language skills (i.e., sensitivity to the child's zone of proximal development). 7. Learn a sign language, if this is the family's choice. <p>Service providers</p> <ol style="list-style-type: none"> 1. To the extent possible, have fluency and expertise in the family's languages/culture. 2. Have fluency and expertise using the communication approach selected by the family. 3. Promote linguistic accessibility and home languages. 4. Respect and support families' decisions regarding communication methods. 5. Interact in a manner that is respectful of families' culture, beliefs, and attitudes. 6. Provide functional learning opportunities that are based on child and family routines, interest, and enjoyment. 7. Use adult teaching/mentoring strategies to assist families to learn new strengths and abilities, as well as build upon existing knowledge and skills. 8. Provide a supportive and encouraging context for learning. 9. Credit families for their engagement and provision of positive parent-child interactions. 10. Support families to use language stimulation principles known to promote early development. 11. Adhere to best practice principles in this document and published curricular guides, while flexibly meeting the needs of the child and family.

Related Resources and Evidence Citations

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Best Practice Principle	Provider and/or Program Behaviors
Principle 6: Use of Assistive Technologies and Supporting Means of Communication Providers must be skilled in the tools, assistive devices, and mechanisms necessary to optimally support the child's language and communication development.	Service providers 1. Use technical knowledge and skills to support families in managing all devices that promote children's language and communicative interactions. This includes hearing assistance technology (e.g., hearing aids, cochlear implants, frequency-modulated systems), visual technologies (e.g., texting, alerting devices, video relay), and alternative and augmentative communication. Develop family awareness of educational technology (e.g., interactive blackboard) and computer/web-based technologies that their child may access in the future.

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Best Practice Principle	Provider and/or Program Behaviors
	Early intervention systems
	<ol style="list-style-type: none"> 1. Strive to make all communication approaches accessible to families, which may require engaging in collaborative efforts among programs. 2. Actively support family choices regarding communicative approaches. 3. Use assessments in collaboration with families to determine when there may be a need for a change in or an enhancement to the chosen communication approach(es). 4. Offer communication approaches from providers with the highest level of knowledge and skill. For example: <ol style="list-style-type: none"> a. Indigenous sign languages are made available from native or fluent signers who are able to promote parental use of visual language to support the child's linguistic input and communicative development. b. Listening and spoken language services are made available from providers with high levels of specialized skills and knowledge, supporting the parents' ability to promote the child's auditory, linguistic, and communicative development.

Related Resources and Evidence Citations

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Best Practice Principle	Provider and/or Program Behaviors
Principle 7: Qualified Providers	Early intervention programs
Providers are well trained and have specialized knowledge and skills related to working with children who are D/HH and their families. Providers possess the core competencies to support families in optimizing the child's development and child–family well-being.	<ol style="list-style-type: none"> 1. Identify the core knowledge and skills that are requisite for working with families whose children are D/HH. 2. Develop standards for what constitutes a quality provider and promote both provider assessment and ongoing training to ensure providers' knowledge and skills meet these standards. 3. Ensure that families have access to early intervention providers who have specialized knowledge and skills for working with families of infants and young children who are D/HH.

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Best Practice Principle	Provider and/or Program Behaviors
	<ol style="list-style-type: none"> 4. Provide continuing education for professionals in the form of training and resources needed to maintain currency in core specialized knowledge and skills for FCEI with families of children who are D/HH. 5. Ensure that providers are knowledgeable regarding specific intervention theory and methods and that they implement well-defined interventions based on these theories and methods. 6. Provide supervision, mentoring, and direct observation of practices and provide specific feedback on service-provider performance. 7. Provide access to competent and fluent language models for families who are in the process of learning sign language, which can be accomplished by involving individuals with fluent/native sign language skills and experience in teaching families/parents of infants. 8. Promote professional self-assessment and self-reflection.

Related Resources and Evidence Citations

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Best Practice Principle	Provider and/or Program Behaviors
Principle 8: Collaborative Teamwork	Early intervention teams
An optimal FCEI team focuses on the family and includes professionals with experience in promoting early development of children who are D/HH. Ongoing support is provided to families and children through transdisciplinary teamwork, whereby professionals with the requisite skills are matched to the needs of the child and family.	<ol style="list-style-type: none"> 1. Select members based on the unique needs of each family, regardless of professional discipline, and are transdisciplinary in composition and practice. 2. May include, but are not limited to professionals, parents/caregivers, early intervention providers with specialized knowledge and skills in early childhood, providers with knowledge and skills working with families of children who are D/HH (teachers of the D/HH, speech-language pathologists), otolaryngologists, audiologists, service coordinators, individuals who are D/HH (role models/mentors), sign language tutors, social workers/psychologists, and representatives of a family-to-family support network.

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Best Practice Principle	Provider and/or Program Behaviors
	<ol style="list-style-type: none"> 3. May also include, depending on the needs of the child, a physical therapist, occupational therapist, primary care provider (PCP), medical subspecialty providers (e.g., psychiatrist, neurologist, developmental pediatrician), and/or educator with expertise in deaf/blindness. 4. Offer families opportunities for meaningful interactions with adults who are D/HH. <ol style="list-style-type: none"> a. D/HH adults can serve as role models, consultants, and/or mentors to families, offering information and resources and demonstrate enriching language experiences. b. Involve D/HH community members on the team in culturally and linguistically sensitive ways. <p>Early intervention team members</p> <ol style="list-style-type: none"> 1. Are skilled at working across agencies and across disciplines. 2. Include and consider families as equal team members. 3. Are comfortable with role release and are able to use a variety of consulting techniques. 4. Work as collaborators and clearly understand each agency's resources. <p>Early intervention programs</p> <ol style="list-style-type: none"> 1. Implement transdisciplinary team models and practices. 2. Achieve transdisciplinary teamwork either within their own programs or through effective collaborations with other professionals and programs. 3. Promote good collaboration and communication between providers and agencies/organizations, whether or not there are multiple disciplines involved; seek out the expertise of other providers/agencies if a child is not making optimal progress and/or a program is no longer meeting child/family needs. 4. Strive to provide access to international supports and promote international information sharing.

Related Resources and Evidence Citations

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Best Practice Principle	Provider and/or Program Behaviors
Principle 9: Progress Monitoring	Service providers work in partnership with families to
FCEI is guided by regular monitoring/assessment of child and family outcomes.	<ol style="list-style-type: none"> 1. Routinely and authentically evaluate individual child's development as well as family satisfaction, self-efficacy, and well-being. Rely on reflective practices, appropriate standardized measures, parent-report scales, authentic assessments, and informal procedures. Authentic assessments with emphasis on strength-based perspective are designed to capture real-life competencies in everyday routines and are helpful in documenting incremental improvements in developmental skills for the purpose of intervention planning. 2. Alter approaches or strategies as needed based on assessment information to enable the child to learn. 3. Use continuous assessment to individually design each specific intervention plan of action. 4. Based on assessment data, examine and reflect on practices, apply new skills, and problem solve challenging situations.
	Service providers
	<ol style="list-style-type: none"> 1. Based on a review of assessment data, promote family members' ability to reflect on their actions to determine effectiveness and develop a plan for refinement. 2. Regularly monitor developmental and family outcomes, using appropriate tools; modify interventions if needed to promote optimal outcomes. 3. Encourage families to evaluate the success of all intervention outcomes. 4. Base assessment practices on explicit developmental principles. 5. Are skilled in methods for conveying "sensitive" information to families.

Related Resources and Evidence Citations

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Best Practice Principle	Provider and/or Program Behaviors
Principle 10: Program Monitoring	Early intervention programs
FCEI programs evaluate provider adherence to best practices and include quality assurance monitors for all program elements.	<ol style="list-style-type: none"> 1. Use quality assurance measures to monitor program components. 2. Provide a means for ensuring/measuring that service providers, programs, and systems are aligned with the principles listed in this consensus document. 3. Include program-wide quality assurance measures, documenting child and family outcomes, knowledge and skills of the interventionists, and family benefit from services. 4. Include parent feedback mechanisms beyond satisfaction measures (e.g., convening focus groups, documentation of changes in knowledge and skill, and monitoring involvement and program components that foster it). 5. Use continuous assessment data and validate program practices through continual evaluation.

Related Resources and Evidence Citations

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fundamental need to provide timely and equitable access to early intervention services. Principles 2–6 focus on the content (what we work on) and the processes (how we work with families) involved in implementing FCEI. Principles 7 and 8 describe the qualifications of providers and the critical importance of teamwork in serving children and families. The final two principles (9 and 10) address the need for assessment-driven practices, both to guide intervention with the child and family and to guide FCEI program-wide evolution. Each principle includes program and provider behaviors, along with supporting resources and evidence citations.

Call to Action

With these Principles in mind, this document may be implemented worldwide with this CALL TO ACTION:

1. Write a letter of endorsement from your agency, organization, or personal point of view for the

Principles Statement and send it to appropriate policy makers in the respective countries.

2. Share the Principles document with colleagues and leaders in your field.
3. Recruit parent leaders in your country to take their necessary part in the thought leadership related to FCEI.
4. Support research agendas through collaboration or examination of practices in your own country.
5. Embed these Principles in legislation, guidelines, consensus papers, and position papers regarding early intervention services and models.

Call to Action adapted from: Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPOD) Position Statement and Recommendations for Family Support in the Development of Newborn Hearing Screening Systems and Early Hearing Detection and Intervention Systems Worldwide (<http://www.gpodhh.org>).

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Conflicts of Interest

No conflicts of interest were reported.

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