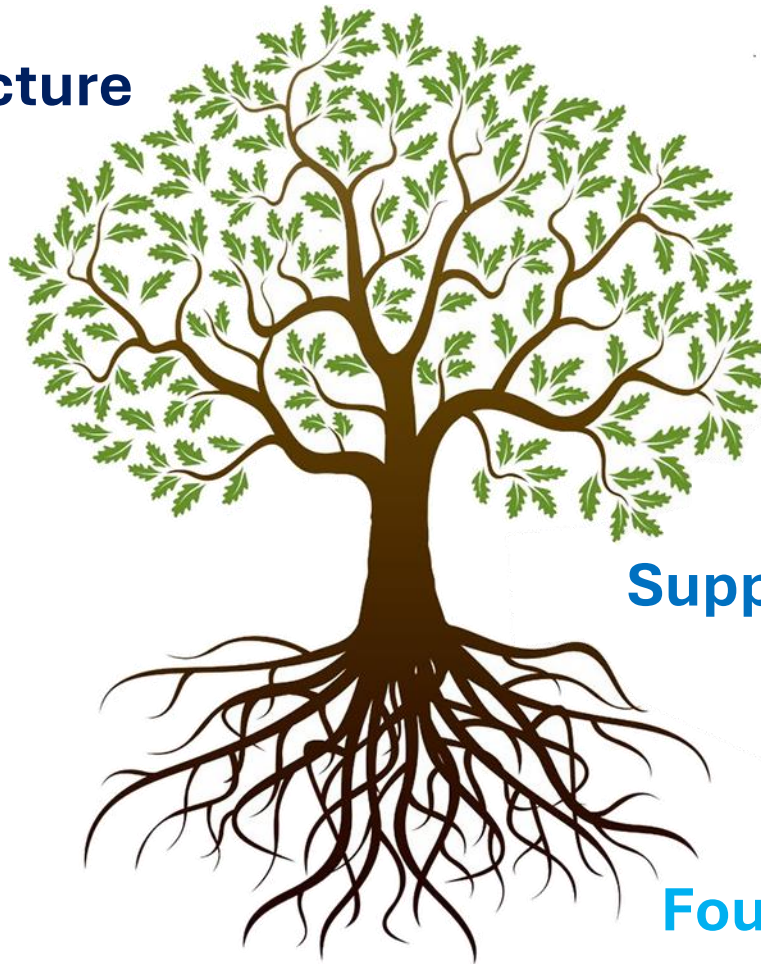The User-Friendly Guide

The Family Centered Early Intervention Deaf/Hard of Hearing Principles

A guide for early intervention providers, programs, and families

Structure

Support

Foundation

FCEI
international

About this Guide:

This guide is a summary of the special issue on Family-Centered Early Intervention (FCEI) for children who are deaf or hard of hearing (DHH) published in the Journal of Deaf Studies and Deaf Education, 2024, 29, SI53–SI63. https://academic.oup.com/jdsde/issue/29/SI

This guide was developed by an FCEI-DHH Advisory Sub-Committee of the FCEI Executive Committee. Committee members include James Anderson-Pole, Julia Carneiro, Gwen Carr, Janet DesGeorges, Elaine Gale, Daniel Holzinger, Josip Ladic, Trudy Smith, and Amy Szarkowski.

More information about FCEI can be found here: https://www.fcei.at/unit/fcei/home

Introduction:

Across the globe, parents of children who are DHH, early intervention providers, and the programs they work with have relied on the evidenced-based FCEI-DHH Early Intervention Principles first published in 2013. (Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013).)

This document is a user-friendly summary of the Principles updated and revised in 2024   It is not intended to replace or add to the published Principles, but to support the ease of understanding for audiences that include families of children who are DHH, readers whose first language may not be English, and others who may be allies to the programs that serve children who are DHH but may not have explicit expertise in this area. The purpose of this user-friendly guide is to use the FCEI-DHH Principles to support effective communication between families and providers, and to develop a shared understanding of Principles with a diverse range of audiences. We encourage all users of this guide to also read the original documents for full information and further clarity and to share the Principles with others who may not have access to or take the time to read the full version of the Principles.

Where the information for this Guide comes from:

The Principles were developed and built upon research and evidence-based information. While most of the citations are not included in this document, please find the citations in the original publication. Definition of terms can also be found in in the original version. https://academic.oup.com/jdsde/issue/29/SI

This Guide can:

- Help you understand the FCEI-DHH Principles in a simplified format.

- Help you assess services based on the Principles recommended by an expert consensus group.

- Empower families to advocate for appropriate services.

- Improve partnerships between the intended audiences.

Below are the ten Principles that are grouped into three areas: Foundation, Support, and Structure.

FAMILY-CENTERED EARLY INTERVENTION DEAF/HARD OF HEARING (FCEI – DHH)

PRINCIPLES

Foundation

Principle 1:
Early intervention following identification

Principle 2:
Family-EI Provider relationships

Support

Principle 3:
Family support

Principle 4:
Child well-being

Principle 5:
Language and communication

Principle 6:
Family decisions

Structure

Principle 7:
Trained FCEI-DHH Providers

Principle 8:
Teamwork among professionals

Principle 9:
Developmental assessment

Principle 10:
Progress monitoring

FCEI international

THE PRINCIPLES, WHAT THEY MEAN AND NEXT STEPS

What follows is a look at each Principle in the recommendations to see what it means for EI providers and families.

For each of the ten Principles there is:

Principle:

Short description of the Principle

What this means:

Brief description of what the Principle means to families, professional providers, and systems implementers.

The published guidelines additionally include EI Provider actions, family activities and outcomes, and program/service and system processes that can be used to implement the Principles.

FOUNDATION

1. Early intervention following identification

Principle

Early identification that an infant or child is DHH should be linked to provision of **early, timely, and equitable** access to supports and interventions as soon as possible in the child's life.

What this means

Early
Babies' first experiences are very important for their growth. Checking a newborn's hearing early helps find any issues. The World Health Organization supports this and says it is important to help babies early. Family-Centered Early Intervention for Deaf or Hard of Hearing (FCEI-DHH) should start when a child is identified as having hearing concerns, even before we know all the details about their hearing. It is important to help children early in life for their language, thinking, and emotions. Getting enough language exposure is key. FCEI-DHH helps prevent problems with language, learning and social-emotional development. FCEI-DHH also helps families accept having a child who is DHH and guides them from the beginning.

Timely
It is important to quickly identify and address hearing issues in children. The recommended plan is to screen by 1 month, do diagnostic hearing assessment by 3 months, and start early intervention by 6 months. This supports families in understanding and adjusting to the child's hearing condition. It is

important to make it easy for families to access DHH support services. If possible, there should be one entry point staffed by knowledgeable people. When that's not possible, coordination is crucial. Well-trained providers should help families transition from identification to intervention, providing consistent support during emotional times.

Equitable

Equity means giving everyone equal chances by removing barriers. Equity involves recognizing inequalities, coordinating support efforts, and advocating for more types of support. Flexibility is key. While home-based services are common, some families prefer support in other places. Regardless of the location, support varies based on the child and family's needs. Achieving equity involves not just where and how support is provided but also building strong relationships between providers and families.

2. Family-Early Intervention Provider relationships

Principle

Family-early intervention (EI) provider partnerships are important for empowering families to support their child and improving EI Providers' ability to assist families effectively. In FCEI-DHH, EI Providers aim to collaborate with families, where both sides bring knowledge and expertise.

What This Mean

Partnerships

It is important to have effective partnerships where families and EI Providers work with each other, share information, and learn from each other. It is important for EI Providers to respect family decisions about the level of partnership they want. Recognizing the strengths of both families and EI Providers improves relationship-building and improves outcomes. Trust, respect, and clear communication are important to these partnerships. Both relational (respect, empathy) and participatory (family engagement, informed decision-making) practices are valued. Partnerships vary and EI Providers may need to collaborate more with families rather than be the expert for families. It is important to find a balance between EI Providers and families, with both contributing to decision-making.

Engagement

Family involvement varies over time and across family members. EI Providers engage with each family member based on their preferences. Cultural norms may influence engagement styles. Cultural competence and humility are important for understanding and respecting diverse perspectives.

Capacity-Building

FCEI-DHH focuses on building families' confidence and skills to support their child's development. This includes improving the parents' confidence and providing knowledge and support specific to the child's needs. Collaboration between families and EI Providers helps to improve family-child interactions and advocacy skills.

Reflection For both families and EI Providers, reflection is important for evaluating their partnership and making improvements. It helps in understanding biases, improving cultural responsiveness, and improving interventions to benefit the child and family.

3. Family support

Principle

Family support is essential to families with DHH children. It is important to recognize their strengths, concerns, and needs. Every family is different, so support should be adjusted to fit each family's situation. This support includes both formal help and informal connections that offer guidance and encouragement.

What This Means

Basic Needs
Children must be safe and secure, free from harm and danger. Early Intervention (EI) Providers need to make sure children are safe. Families also need access to healthcare, food, and stable living conditions. These basic needs are important for children's development and well-being. Access to language is also very important for children who are DHH. EI Providers can help families find resources to meet these needs.

Family Strengths/Challenges
Every family has strengths and challenges. It is important for EI Providers to understand each family's unique situation and provide support accordingly. Families may struggle with accepting their child's DHH status, so they need empathy and understanding. Support from professionals and other families can make a big difference. Building strong relationships within the family and with professionals is key to positive outcomes for children.

Connections
Families benefit from connecting with other families and DHH adults. These connections provide support and understanding. Families also find support from neighbors, friends, and community groups. These connections help families feel less isolated and more optimistic about their situation.

4. Child well-being

Principle

Child well-being can be accomplished when early intervention focuses on the whole child: Infant/child development, positive social-emotional functioning, child welfare, and safeguarding.

What This Means

DHH children deserve to grow, learn, and thrive in safe and supportive environments, with respect for their dignity. It is important to think about the overall development of DHH children, including their social-emotional, physical, and cognitive skills.

Infant/child development

FCEI-DHH supports the growth of the whole child by providing interventions guided by the strengths, challenges, and goals of each family and child. Play is recognized as an important aspect of children's development, fostering bonds between children and caregivers, and influencing their social interactions and identity formation.

Positive social-emotional functioning

Children who are DHH need affectionate touch, responsive interactions between caregivers and children, and early access to social exchanges. The role of families in promoting emotional understanding and regulation in children who are DHH is important, while considering the influence of cultural differences on emotional cues.

Child welfare

It is important to look after the overall well-being of children, considering factors such as nutrition, caregiving consistency, safety, and access to healthcare. It emphasizes the need for early intervention providers to be aware of mental health and child welfare issues, even if they may not directly address them, and to provide families with information about relevant resources and support services.

Safeguarding

It is important to safeguard children who are DHH, who are at increased risk of abuse due to factors such as communication barriers, reduced expectations, isolation, and lack of appropriate services. Children need to be protected from unsafe environments. Resources for promoting child safety should be provided.

5. Language and communication

Principle

Families should be supported to promote their children's language and communication development in natural, daily interactions. Early access to language, whether signed, spoken, or combined, is important.

What This Means

Early and consistent access

It is important that all children are exposed to language that is accessible to them from infancy. Early and consistent access to language is critical for the development of learning, cognitive and social-emotional development, self-advocacy, and empowerment.

Approaches and opportunities

Implementing FCEI-DHH should not wait until a child is expressively communicating. Lots of things can support the child's early development of building of skills, relationships and understanding. EI Providers support families to make decisions about the communication approaches used with their child. To help guide families in learning how to use communication approaches, the EI Providers share accurate, comprehensive, balanced, and objective information.

Language-rich environment

To create a language-rich environment for children who are DHH, they need regular and consistent language exposure, interaction, and development. EI Providers support families in using strategies during daily routines. This is proven to promote language development in young children.

Language-rich environments need to be accessible to children who are DHH:

- Visual language(s) and communication – for families communicating through sign language or bilingually (in signed and spoken language(s)).

- Auditory access and spoken communication – for children learning spoken language(s). This can be facilitated by consistent wearing of well-fitted hearing devices, such as cochlear implants, hearing aids or bone anchored devices. It is important to note that access to hearing technologies varies around the world, nor will all families want to use them, but they are important for improving spoken language.

- Visual and/or spoken language – children benefit from having multiple communication partners regardless of communication and language approach.

High quality family-child interactions that improve language include:

a). Waiting for or getting the child's attention

b). Sharing and maintaining a mutual focus with the child

c). Eliminating "visual noise" or background noise

d). Improving lighting

e). Encouraging the child to take turns in conversation

f). Consistently repeating and expanding on what the child is communicating

6. Family decisions

Principle

Families have different structures and relationships. It is important to understand the family structure in order to involve the most appropriate family members in the intervention process. FCEI-DHH provides support, information, and experiences that strengthen families to make competent decisions for themselves and their children.

What This Means

Decision-makers
To support families to be informed decision-makers, EI Providers should respect families and provide them with comprehensive, accurate, and impartial information.

Culture and context
FCEI-DHH describes culture as groups of people who share (a) basic assumptions, (b) values, and (c) artifacts and creations. Providers should be transparent with families, and they should reflect on their own culture(s) and political biases to avoid biased guidance.

Information
There are three examples of family decision-making:

1) Informed Choice –the ability of families to make knowledgeable decisions through access to comprehensive, objective, balanced, relevant, and evidence-informed information on the full range of options.

2) Shared Decision-Making –families can make decisions through their interactions with EI Providers and maybe other professionals.

3) Collaborative Consideration of Choices – includes three components: "choices talk" (talk about options), "options talk" (discussing benefits and risks) and lastly the "decisions talk" (where families are supported to make a decision).

Decision-making is a step-by-step process which is flexible, adaptive, and responsive to the changing needs of the family and child. During EI, the child's progress is monitored and if necessary, support is adjusted to continuously adapt with the child and family's needs.

STRUCTURE

7. Trained FCEI-DHH Providers

Principle

EI Providers need to have certain qualities so they can connect with and build relationships with families and other providers. They also need competency in their own area of expertise, in general early intervention, and when providing specific support to children who are DHH. Trained EI Providers offer effective, professional, equitable, and inclusive FCEI-DHH supports to promote children and family outcomes.

What This Means

Dispositions

There are a range of characteristics that an EI Provider should have to be effective. It is important for EI Providers to demonstrate integrity, allowing them to interact respectfully with families and be attentive to their needs. EI Providers are encouraged to regularly reflect on their work and their personal approach, while following the Principles of FCEI. EI Providers actively involve family members as important partners in delivering services to their children. This involves using practical wisdom such as empathy, emotional insight, and resilience to collaborate with and support families.

Competencies

Skilled EI providers need three competencies to help families and their children. First, they need to have discipline- specific knowledge and training related to their field. They might also have qualifications or licenses allowing them to work with families in their role.

Secondly, EI Providers need to have expertise that is specific to early intervention. This means knowing how young children develop and being able to work effectively with families from different backgrounds. EI providers design and implement family-centered programs that use a family's strengths and needs to support early development for young children.

Lastly, EI Providers need competencies related to working with children who are DHH. This includes understanding deaf culture and community and knowing how to help DHH children develop language skills. EI Providers are often the first people families meet after a hearing diagnosis, so they need to be able to explain test results and advise on communication technologies to parents and caregivers.

All EI Providers need to take part in regular training programs and other learning opportunities to stay updated.

Competencies offered by individuals who are DHH

People who are DHH can be very helpful to families in different ways. They might work directly with families as an EI Provider, or they might be mentors who support family learning and wellbeing. However, just being DHH does not automatically mean someone has all the skills needed to be a good EI Provider. People who are trained and also happen to be DHH bring their personal experiences and knowledge, which can be really helpful to families and other colleagues, whether they can hear or not. It is important to include trained people who are DHH in early intervention programs and services.

Competency offered by family members of children who are DHH

Sometimes, a family member of a child who is DHH might decide to learn the skills and knowledge needed to become an EI provider. Other times, they might join family-to-family support programs, which are really important for teams focused on FCEI-DHH. They can join as a regular participant or learn leadership skills to become a strong "parent voice" that helps shape the EI system they are involved in. Family members who want to be leaders are encouraged to be part of creating the plan and putting it into action for FCEI-DHH systems.

8. Teamwork among professionals

Principle

Teamwork among professionals is important in FCEI-DHH services. Teams consist of various skilled EI Providers and other experts who collaborate to support positive outcomes for children and families.

What This Means

Key points of teamwork among professionals include:

Composition of Teams

Family members are important members of the team. Their needs and values guide the selection of supports. Different professionals bring specialized expertise, such as:

- Teachers of the Deaf and Hard of Hearing
- Speech-language pathologists
- Individuals who are DHH
- Family members and leaders
- Case managers and service coordinators
- Pediatric audiologists
- Otolaryngologists

Additional Specialists

Depending on the child and family's needs, other specialists may be included, such as sign language specialists, therapists, mental health professionals, developmental professionals, community health workers, and medical specialists.

Roles of Community Health Workers, Interpreters, and Patient Navigators

These professionals have an important role in connecting families and services, especially in culturally diverse contexts. They make sure the service is accessible and culturally sensitive.

Collaboration Approaches and Models

Collaborative models like coproduction, medical home, and case coordination facilitate teamwork. They involve multidisciplinary, interdisciplinary, transdisciplinary, and interprofessional approaches to optimize support delivery.

Responsibilities of Teams

Effective communication, skill development, and mutual respect among team members are essential. Teams must ensure high-quality, accessible, and culturally responsive supports, focusing on individual family needs.

Recommended Collaborative Practices

These include effective communication, sharing of information and skills, joint planning, compromise, modeling, acknowledgment, and establishing mechanisms to support teamwork.

9. Developmental assessment

Principle

Meaningful continuous assessment for children and their families is important in FCEI-DHH. Professionals need skills to do assessments, manage language(s), and interpret results for planning interventions.

What This Means

Purpose of assessment

The purpose of assessments is to track a child's growth in different areas over time and set goals. Tracking growth helps families and professionals see areas of strength and needs. For children who are DHH it is very important to track language and communication development. When setting goals, they should be clear and meaningful for the child and family members. Goals can change over time based on assessment results and needs. Assessments should take place where the child and family feel comfortable. Family members should be included in setting goals and making sure supports are provided to meet goals.

Approaches to assessment

There are many types of assessments. Examples of assessment types include checklists or questionnaires, and interviews. A team-based assessment approach means a group of professionals from different areas collaborate with the family to ensure the best supports. An authentic approach means to observe the child and family in their natural environment. A Family assessment approach means to learn and understand family values, priorities, strengths, and needs.

Skilled assessors

Professionals assessing DHH children and families should have a range of assessment tools and understand developmental domains and limitations in interpreting assessments. For language assessments, assessors should be fluent in the language(s) being assessed.

Interventions

Continuous assessments help families by adjusting goals and strategies based on developmental milestones, strengths, and needs over time.

10. Progress monitoring

Principle

Progress monitoring is an important part of making sure the support provided to families is effective across families and across FCEI-DHH programs / services and systems.

What This Means

Progress monitoring is not just for individual children and families. Programs or services also need to track and monitor outcomes across the whole system. To do this they need to develop and use measures which check how effective and successful the system is in meeting the needs of all the families they serve. This includes getting feedback from families themselves and following up with their feedback. Providers should also be trained in effective monitoring practices.

Relevance
In different places around the world, and even within individual countries, there are many different cultures and different ways of organizing services. FCEI-DHH programs need to develop and deliver support which respects and is inclusive of the cultures of the setting they are in, whether that is local, regional, or national. The way progress is measured will differ according to those cultures and settings. Monitoring relevant services is an important part of overall progress monitoring in FCEI-DHH.

Effectiveness
Another essential part of supporting positive outcomes for children and families at a systems level is the development and /or use of measures which assess the effectiveness of access to services and the quality of the early intervention provided for children and families. Assessing effectiveness is important for programs/services and systems to understand what is needed to grow and improve in quality.

Evaluations of how effective the support is must also think about the different needs of children and families. These may relate to their communication preferences and home languages, their cultures, their social circumstances, or the needs of subgroups of DHH children, such as those with different levels of hearing difference, those with one sided hearing difference or those with disabilities. This is important so that a program/service can check that its support is effective in meeting a range of needs rather than having a 'one-size-fits-all' approach.

Tracking
Programs need to ensure that they document, track, and monitor the outcomes of their program/service and system. They should use published evidence, guidance, and benchmarks to help them do this, and families should be aware of the benchmarks being used. Monitoring can be at different levels, according to whether a program / service or system is local, regional or national, and different monitoring tasks may be undertaken by different parts of the system. For example, programs/services need to adopt practice standards for outcome tracking so that they understand what is and what is not working – both in the interventions they offer and in the ways their services are organized.

Systems, on the other hand, need to develop a framework for effective monitoring at a strategic level. This will involve deciding on such things as how often to undertake the monitoring, what measures to use, how accountability will be decided and how feedback from families and other professionals will be included. There also needs to be a strong process for data collection and the data should be used to help develop the program and system so that they can keep on improving.

Call to Action

The eighth and final article in the special issue of Family-Centered Early Intervention (FCEI) for children who are deaf or hard of hearing and their families is the Call to Action. The call to action urges:

1) Incorporate the 10 Principles of FCEI-DHH into programs/services and systems.

2) Provide relevant support for families with DHH children, implemented step-by-step for maximum impact.

3) Include diverse stakeholders in developing, implementing, and monitoring FCEI-DHH programs.

4) Educate policymakers about FCEI-DHH and its effects on DHH families and communities.

5) Recognize and involve family and DHH leaders in FCEI-DHH, encouraging diverse perspectives.

6) Train and supervise EI Providers and professionals for effective family-centered support.

7) Collaborate regionally and nationally to assess training needs and set standards for EI providers.

8) Enhance EI Providers' skills through supervision and mentoring.

9) Investigate factors influencing the effectiveness and outcomes of FCEI-DHH.

10) Advance research on FCEI-DHH to improve child and family well-being.

11) Study what makes FCEI-DHH interventions effective and how diverse families benefit.

12) Support global collaborative research to promote family well-being through FCEI-DHH.