

INTERNATIONAL CONSENSUS ON BEST PRACTICE IN FAMILY-CENTRED EARLY INTERVENTION: FROM PHILOSOPHY TO REALITY

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Abstract

In 2012 an international panel of experts in early intervention for children who are deaf or hard-of-hearing convened in Austria to come to consensus on best practice principles guiding implementation of family-centred early interventions. The panel included parent representatives, early intervention program leaders, multi-professional early intervention specialists, deaf and hard of hearing representatives and researchers from 10 nations across the world. The consensus was published in 2013 in *Deaf Studies and Deaf Education*. Principles were revisited at the 2nd International Family-Centred Early Intervention Conference (Moeller et al 2013).

Purpose:

The purpose is to review progress of countries in responding to the 10 best practice principles.

Method:

Country responses to how they have used the Best Practice document to improve services in their country or to influence the development of strategy or policy will be presented.

Results:

We will give examples of individual country initiatives and responses to a number of the 10 principles. And these will be described and discussed in the context of the Best Practices framework.

Conclusion:

There is great diversity among countries in the development of family-centred early intervention programs. The document has been able to be utilized by countries with well-developing and beginning programs. It is being used in a number of cultural contexts and has been adapted to the wide range of diverse political and systemic characteristics.

Background

There is a multitude of factors that influence academic outcomes and mental health of people who are deaf or hard of hearing (d/hh). Regarded from a life time perspective healthy development begins with the well being and interactions of the families children who are d/hh are born into and in which they grow up. The strong correlation between family variables and child development has numerous implications for how we conceptualize, organize and implement early intervention services.

In 2012 the First International Congress on Family Centred Early Intervention for Children who are D/HH was organized in Austria (www.fcei.at). After the main conference an international panel of experts met for a consensus conference on evidence based best practice in early intervention for children who are d/hh. The group of about 30 people from 10 nations was composed of parent representatives, d/hh professionals, early intervention program leaders and interventionists, researchers and clinicians from the fields of medicine, psychology, audiology and speech language pathology.

Evidence base

For the formulation of best practice guidelines best available research evidence is required. There are limitations and complications of conducting research with children who are d/hh such as small sample sizes, often composed of children with very different degrees, histories and types of hearing loss, few representative and longitudinal studies, varied measurement strategies and lots of variables that influence child outcomes, whether additional educationally relevant handicaps or family and intervention factors. Furthermore, there is a lack of research on comparisons of different intervention approaches, which is complicated by the fact, that many approaches are not curriculum based and in those that follow a curriculum fidelity of implementation is rarely monitored.

Due to the limitations of research outcomes professional experience is necessary as another source for the development of best practice guidelines. Professional experience refers to craft knowledge many people in the field have accumulated over the years. Finally, we essentially need to include parent experience as well as the experience of d/hh representatives.

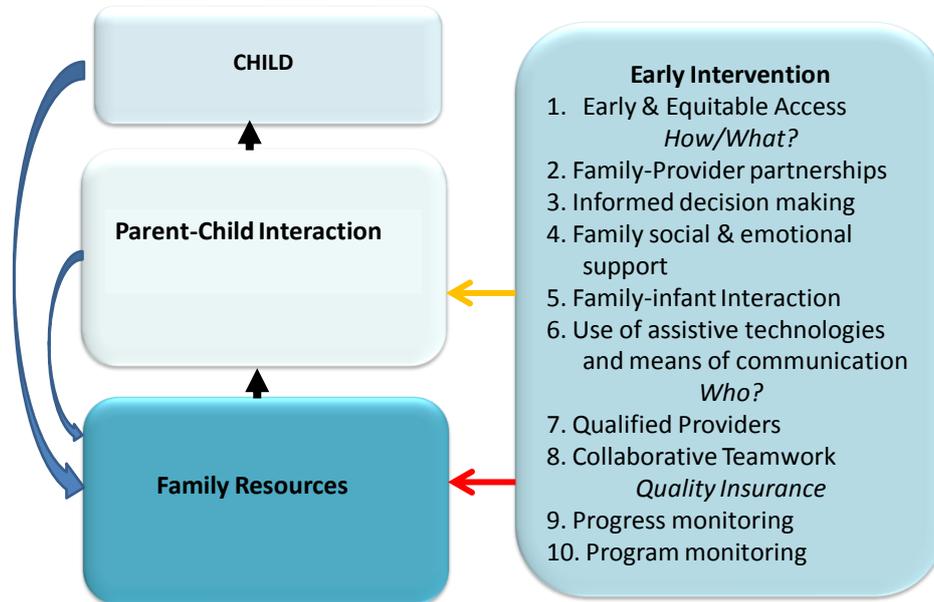
Model orientation

Guralnick (2011) proposed the developmental systems approach to better understand the mechanisms that are involved in promoting a child's development in the context of early intervention. Children utilize their developmental resources (such as cognition, language, motor, or social-emotional) and organizational processes (executive function, social cognition, or emotion regulation) to expand their social and cognitive competence throughout their childhood. In addition there are environmental influences that support children's development governed by a family's pattern of interactions involving their child. This pattern of interactions depends on many factors including adjustments to accommodate to their child's specific needs. Third, and essentially family resources determine and are available to support optimal family patterns of interactions and as a consequence child development. Family resources include the parents' mental and physical health as well as intellectual ability, but also parents' attitudes towards child rearing and their preparedness to rearing a child. In addition, material resources as well as networks of social support can serve as a highly valuable resource to optimize family patterns of interaction.

The findings of Trivette and colleagues (2010) empirically support Guralnick's model. They investigated the influences of family systems intervention and capacity building practices on child development in a meta analysis including about 900 children in early childhood intervention programs by means of structural equation modelling. Results showed that parental resources such as self-efficacy and parental well-being had direct or indirect influence on child development.

Following Guralnick's model best practice in early intervention services needs to activate, strengthen and support family resources as indicated by the horizontal arrows in diagram 1. In addition early intervention aims to provide specific support in parent-child interaction that is vulnerable not only due to the parents' emotional reaction to having a deaf child but also as a consequence of the specific communicative needs of their child. Most parents are not prepared for. The presence of a child who is deaf may stress or perturb family patterns of interaction with their child as well as family resources.

Diagram 1: Model of Family Centred Early Intervention



Principle 1 is about early and equitable access not only to diagnosis but to intervention services. In addition to sensitive periods for auditory maturation and language development an early start of intervention seems to facilitate adaptation mechanisms of families. Principles 2 to 4 directly pertain to family support; balanced partnerships between families and providers, informed choice and decision making as well as social and emotional support of families. Principle 5 relates to practices that more directly support parental interaction with their d/hh child, principle 6 states the importance of assistive technologies as well as a broad range of means of communication to make communication accessible to each individual child. Principle 6 relates to the skills of interventionists, principle 7 to the necessity to provide of collaborative teamwork as part of a support network. Principles 9 and 10 are about quality insurance; progress monitoring and adaptation of intervention related to each child, that is regular assessments with strong family participation as well as program monitoring. For every principle the consensus group formulated a list of provider behaviors going along with it. In addition sources of evidence and helpful resources are quoted.

National initiatives

In the following Upper Austrian and/or U.S. American initiatives as response to FCEI principles are described. Upper Austria is a federal state of Austria.

Principle 1: Early, timely, and equitable access to services

Despite introduction of universal newborn hearing screening (NHS) in 1990 in Austria no tracking system after failing NHS has been established so far. As reaction to FCEI principle 1 meetings with health authorities and representatives of ENT physicians and gynaecologists in Upper Austria were initiated. Data on age at diagnosis and entry to the early intervention program were collected. As a result a tracking procedure was agreed upon including scheduling of a diagnostic ENT appointment after failing NHS before leaving the birth clinic. In case parents do not keep the appointment they will be reminded by the ENT department by telephone. If hearing loss is confirmed the intervention program will be informed directly

and will contact the family within 48 hours. Trainings for screeners with focus on high quality in the execution of the screening but also on communication with the families are planned for 2015. A system of collection of key data in the assessment procedure is still under discussion.

In the United States, in 2012, 96.6% of the 3,953,986 infants born in the United States were screened for hearing. 35.9% were lost to follow-up or to documentation. Of the 5,475 children diagnosed with hearing loss, 4,136 children were eligible for early intervention services, 14.04 or 24.6% of these children were lost to follow-up or documentation. About ¼ of the children eligible for early intervention services are not being enrolled in a timely manner. Of the 50 states, individual states have significantly better statistics of enrolling infants into early intervention than others.

Principle 2: Family-Provider Partnerships

Early hearing detection and intervention advisory boards have been formed in each of the individual 50 states in the United States. Representation from parents is required on the vast majority of these advisory boards. The roles and responsibilities of the advisory boards/committees differs by state and may include recommendations related to accountability, system design, and funding allocations

Principle 3: Informed Choice and Decision Making

Evidence that informed choice and decision making is assured is challenging. In the literature, parent interviews, focus groups and parent questionnaires have been used to try to obtain data on whether or not this principle is implemented in any system.

Principle 4: Family Social & Emotional Support

Family social and emotional support can be provided in a number of different ways and through a number of different professionals. Interventions need to ensure that all families have access to parent to parent support from other families with children who are deaf recognizing the key role of parent to parent support in the promotion of social and emotional well being.

In Upper Austria two parents were employed the intervention program for professional parental peer support. They are present at the first appointment when families are admitted to the program. Many of the families have used their offer of telephone contacts and home visits so far.

A parent workshop with a focus on family well being was organized by a team of a psychologist/psychiatrist and a professional parent. Guided by specific interests of the participating families topics such as "living with the diagnosis of your child's hearing loss", "family communication", or "siblings" were discussed and helpful strategies were developed by the group.

As part of the program's curriculum parental needs and well being are enquired regularly. Families are supported to identify and to activate informal support networks. Regular family meetings are offered to provide opportunities to make informal contacts.

In the United States, family-provider partnerships that are institutionalized within the health services provided after universal newborn hearing screening are Guide By Your Side programs. These programs are established in 22 of the 50 states and in 1 province in Canada. The Guide By Your Side program conducted a parent satisfaction survey in 2013. The programs provide parents with parent-to-parent support and differ by state when this support occurs. It may occur at the time of screening, though most programs begin after the diagnosis of the hearing loss. Professionals play a large role in providing family social and emotional support. Programs throughout the United States vary according to the level of

training that is provided to early intervention providers in social and emotional support. Fifteen of the US states are participating in a national assessment project. The primary goal of the project is to establish state/territory-wide data collection systems of developmental outcomes of young children identified in the birth through 3 year period. This NECAP (National Early Childhood Assessment Project: Deaf/Hard of Hearing) project is funded through the DRDC (Disability Research Dissemination Center) of the Centers for Disease Control National Center for Birth Defects and other Developmental Disabilities. Many, but not all states are collecting child developmental outcomes in social development. Monitoring of parent social and emotional well-being in infant stages throughout the world and is not standardly monitored.

Principle 5: Family-Infant Interaction

Early intervention helps parents to create optimal environments for their children's language learning by use of everyday family routines. In Upper Austria interventionists have been trained to be more aware of existing family routines. Automatic speech recognition devices (Language Environment Analysis (LENA)) have been used to give parents feedback on the amount and quality of language input they provide for their child within a regular day. In addition video taped parent-child interactions are analyzed by students of speech-language pathology to make parents aware of already existing successful communication strategies. A list of facilitative strategies to enhance communication was formulated..

Across the United States, systematic collection of family-infant interaction is rarely done. The state of Colorado has collected, analyzed and reported the parent-infant interactions from half hour video-taped parent-child interactions across their population since the 1980s. Auditory spoken language interactions have been recorded with the LENA technology providing information about parent-child conversational turn-taking in spoken language and also analyzes the child's vocalizations in an average day.

Principle 6: Use of Assistive Technologies and Supporting Means of Communication

Children need to be provided with appropriate amplification, if the family chooses spoken language as one of the goals. In addition, if the family chooses sign language for communication, the family needs to be assured that the provider has fluent and/or native skills in sign language communication. In Austria, a native signer has been employed to provide sign language in the homes. A sign language course adapted to the needs of parents of young children is organized in cooperation with a preschool for children who are deaf or hard of hearing. All the interventionists are required to attend a two year sign language course. Hearing Aid and Cochlear Implant companies are invited regularly to keep staff at the latest state of knowledge.

Across the United States, there are a number of states who provide parents with appropriate amplification, typically personal hearing aids and/or cochlear implants. Only a minority of young children have access to assistive devices, such as FM technology. With regard to sign language access, a minority of states provide some of the children, but not all children access to a native and/or fluent signer who can teach the parents/families sign language. A national survey has not been taken in the United States, so it is not currently known how many families have access to these services.

Principle 7: Qualified Providers

Measurement of qualifications of providers is also a challenging goal. Data related to the professional training of the early intervention provider is being collected across the 15 states participating in the United States NECAP program. A self-assessment of skills and areas in need of professional development is being developed by the NECAP program but has not yet been implemented. Some programs require all early intervention providers who are hired by

the program to have specialized training in early childhood deafness and hearing loss. However, very few states have implemented this type of program that would assure at least basic competencies.

Principle 8: Collaborative Teamwork

Children who are deaf or hard of hearing can only attain optimal developmental outcomes when professionals and programs work together across health, education, with families and deaf and hard of hearing individuals. To our knowledge, monitoring tools to determine the extent and nature of collaborative teamwork and how it impacts the lives of children who are deaf or hard of hearing and their families have not yet been developed. In Upper Austria and many states of the USA collaborative networks of interventionists, diagnostician, ENT-physicians, therapists, teachers in pre-schools and kindergartens as well as parent associations and representatives of the deaf community has been established.

Principle 9: Progress Monitoring

In the United States, the NECAP project monitors developmental outcomes across 15 states. In an analysis of over 1000 assessments, children who are deaf or hard of hearing across these 15 states have a median developmental quotient within the average range, though low average range on three language assessments (Developmental quotients 92, 84, 81). Productive vocabulary is the most difficult area of development on the 3 assessments. Not all states had a median quotient in the average range across all three language assessments. Several variables were found to positively impact language outcomes: earlier enrollment in early intervention (by 6 months), milder hearing loss, children without additional disabilities, and children with deaf or hard of hearing parents.

Principle 10: Program Monitoring

Program monitoring is an important aspect that has not been widely implemented across the United States. In the state of Colorado, program monitoring is attempted through early intervention provider self-reports, through mentorship from specialists in social-emotional variables and in spoken language. Sign language instruction has been monitored through the training and implementation of a teaching curriculum. Early intervention providers are monitored by the Colorado Hearing Coordinators, through visitations and observations. However, no systematic data is collected at this time.

Future Prospects

At present the dissemination of the consensus document is supported by translations into spoken and signed languages. A survey to describe the global status quo concerning the implementation of FCEI principles has been started this year. The FCEI consensus document is used internationally as a guideline in setting up or redesigning early intervention services.

Research on early intervention outcomes including child and family mental health as related to intervention variables is undertaken in the US, UK, Austria and Australia.

Summary

Accountability and data collection for these principles is just beginning or has not yet begun in many parts of the world. The document is intended to provide a framework for the collaboration of programs across the world and for the collection of data that will inform practice.

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