



BASIC PRINCIPLES OF EARLY INTERVENTION FOR CHILDREN WITH HEARING LOSS

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Hearing loss is a common birth problem that can affect a baby's ability to develop speech, language and social skills in lack of comprehensive early intervention. Early intervention occurring within the first 6 months has higher effectiveness for hearing impaired children. The introduction of universal newborn hearing screening programs allowed to identify hearing loss in the first months of life. That determines the need of immediate comprehensive early intervention for children identified with hearing loss. The main approaches of such intervention have been described in detail in the literature. However there are not well-developed, evidence-based, well-documented recommendations for family-centred early intervention for children who are deaf or hard of hearing. Similar problems are noted in many countries, that is why in 2012, within the framework of an international conference, specialists and parents of deaf and hard of hearing children developed a document (international consensus statement). The experts arrived at consensus on 10 principles guiding family-centred early intervention. These principles are presented in the article as well as a brief description of their implementation in various countries. The consensus statement has become an important document which is intended to provide a framework for professionals over the world. Knowledge of these principles allows specialists to apply evidence-based approaches working with children who are deaf or hard of hearing.

Keywords: children; hearing loss; early intervention program; principles; consensus.

ОСНОВНЫЕ ПРИНЦИПЫ СИСТЕМЫ РАННЕЙ ПОМОЩИ ДЕТЯМ С НАРУШЕНИЯМИ СЛУХА

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Нарушение слуха – часто встречающаяся проблема у детей раннего возраста. При отсутствии качественной программы помощи данная патология оказывает выраженное негативное влияние на развитие ребенка. При врожденной тугоухости наиболее эффективными являются программы помощи, начатые до возраста 6 мес. Внедрение всеобщего аудиологического скрининга новорожденных позволило выявлять и диагностировать нарушения слуха на первых месяцах жизни. Выявленные нарушения слуха требуют незамедлительного начала всесторонней программы помощи. Основные подходы к оказанию такой программы подробно представлены в отечественной литературе. Однако в настоящий момент отсутствуют единые, хорошо отработанные, задокументированные рекомендации по составлению и реализации программ помощи для детей раннего возраста с проблемами слуха. Сходные трудности отмечаются во многих странах мира, что послужило причиной объединения усилий специалистами из разных стран.

В 2012 г. в рамках международной конференции специалистами и родителями глухих и слабослышащих детей был выработан документ (международный консенсус), регламентирующий основные принципы семейно-центрированной системы ранней помощи детям с нарушениями слуха, соответствующие этим принципам программы и требования к специалистам. В статье представлены данные принципы, а также приведено краткое описание их реализации в различных странах. Данное консенсусное заявление стало важным документом в работе специалистов всего мира. Знание этих принципов позволяет специалистам применять доказательные подходы при работе с глухими и слабослышащими детьми.

Ключевые слова: дети; нарушение слуха; раннее вмешательство; программа помощи; принципы; консенсус.

INTRODUCTION

Sound is very significant in a person's life and perception of the surrounding environment. Each sound carries certain information. During the day, we hear and focus on many everyday sounds, danger signals warn us, music gives great pleasure and enjoyment, but the most critical sound signal for a person is speech, which is the basis of our communication with other people. That is why any hearing impairment can harm a child's development. Especially significant problems can arise with congenital hearing impairment. In the absence of a timely, high-quality program of assistance, the central departments of the auditory system do not receive the necessary acoustic stimulation in the first years of life, which disrupts their formation, leading to irreversible consequences. Hearing impairment is the most common pathology of the sensory systems and, according to the World Health Organization, there are approximately 34 million children with hearing impairment in the world. At the same time, approximately 2–3 children out of 1000 are born with congenital hearing abnormalities, and during the first years of life, another 1–2 babies out of 1000 acquire bradyacusia [11, 16, 19].

Approaches to detecting hearing pathology in children based on the analysis of only risk factors are not highly effective since only approximately 50% of hearing-impaired children are at risk of hearing disorders. That is why in many countries, including Russia, compulsory audiological screening is currently performed, covering all newborns. This enables to suspect bradyacusia very early (in the first weeks of life) and perform the necessary diagnostic procedures already in the first months of life. The methods of screening and diagnostic examinations in children of the first year of life have been studied well, described, and standardized [3, 16]. Such examinations are implemented in most countries in accordance with national recommendations. In the Russian Federation, they are presented in the form of Clinical Recommendations of the Ministry of Health [5]. Undoubtedly, there are still several issues to improve the efficiency of both primary audiological screening

and the diagnostic stage. However, in general, the introduction of the existing hearing screening system in newborns has solved the early detection of congenital bradyacusia. Currently, the average age for diagnosing congenital hearing impairments in Russia is seven months [12, 13].

Identification of hearing impairment requires a comprehensive program of assistance for hearing-impaired and deaf children as soon as the problem is discovered. The main issues of implementing assistance programs in Russia are presented in the literature by various specialists and parents of deaf and hard-of-hearing children [1, 2, 4, 6–9, 14]. However, at the same time, there are no uniform, well-developed programs to help young children with hearing problems. A similar situation is noted in many countries of the world, which was why the pooling of knowledge and efforts of specialists from different countries and parents of children with hearing impairments.

In June 2012, in Bad Ischl, Austria, the first International Family-Centered Early Intervention Conference for Children who are Deaf or Hard of Hearing was held. Later this conference became traditional. During the conference, hearing professionals, program managers, early intervention specialists, and parents of children with hearing impairments discussed the principles of family-centered early care systems and the methods of their implementation in different countries. Based on the discussion results, these principles were clarified, and a consensus was reached in determining the most effective approaches in early assistance to deaf and hard-of-hearing children. A document (international consensus statement) regulating the principles themselves, the programs corresponding to them, and the requirements for specialists were drawn up. The document was signed by representatives from different countries by Professor I.V. Koroleva on the part of the Russian Federation [17]. Since its publication in 2013, this consensus statement has become an essential document for hearing professionals worldwide.

Being aware of these principles, specialists (pediatricians, neurologists, audiologists, teachers of

the deaf and hard of hearing, speech therapists, social workers, special educators, others) can apply comprehensive, evidence-based approaches in working with families with deaf and hard-of-hearing children. The main provisions of the consensus are summarized below, and a brief description of the implementation of its principles in various countries. The full text of the consensus is presented in the publication by M.R. Moeller et al. [17].

INTERNATIONAL CONSENSUS STATEMENT FOR FAMILY-CENTERED EARLY ASSISTANCE FOR DEAF AND HARD-OF-HEARING CHILDREN

Principle 1: Early, timely, and equitable access to services. This regulation prescribes timely audiological screening of newborns and diagnostic examination by qualified personnel in accordance with accepted recommendations; immediate inclusion of the family in the early assistance program when a child's hearing pathology is detected. It provides the family with comprehensive support regardless of the socio-economic status of the family, income, or geographic location. The continuity of the various stages should be monitored, namely the transition from screening to diagnostic procedures, the timely implementation of the assistance program, and other activities.

Principle 2: Collaboration between family and early care professionals. The family-centered early care model aims to develop balanced partnerships between family and professionals. Collaboration between the family and the family service provider must be characterized by interaction, mutual trust, respect, honesty, shared goals, and open communication.

Principle 3: Conscious choice and decision making. It is the right of the family to make decisions. Specialists help the family obtain the necessary information, knowledge, and experience. Families are trained to make informed decisions based on the information obtained. Families need to be aware of the possible outcomes, potential benefits, and challenges of using different approaches.

Principle 4: Social and emotional support for the family. Families can receive the necessary support, knowledge, and experience in official organizations/associations (professional, parental) and public organizations, from friends, relatives, and groups united by religious views and other principles. Professionals should appreciate the importance of family well-being for the child's development, provide social support and encouragement to the family, facilitate obtaining necessary support, and refer to mental health professionals.

Principle 5: Interaction between family and child. The family and professionals cooperate to create the optimal environment for the child's communication and language development. For this purpose, everyday activities, games, and communication with the child are used. Adults provide the child with an action-packed language environment in communication with all family members, adapting their language in accordance with the child's development. The specialists respect and support the communication method chosen by the family (oral approach, kinetic speech).

Principle 6: Use of assistive technology and communications tools. Professionals working with a family with a hearing-impaired child should be aware of current technical devices to help improve the child's hearing (hearing aids, implantable systems, FM systems), provide visual support, and alternative and complementary communication. Professionals should inform families about the existing technical means and technologies used in the educational process (portable microphones, interactive whiteboards, computer and web technologies, others).

Principle 7: Qualification of professionals. Specialists should be well trained, have the necessary qualifications, and specialized knowledge and skills related to working with deaf and hard-of-hearing children of various ages and their families. Families should be able to have access to professionals with specialized knowledge and skills.

Principle 8: Teamwork. An optimally formed family-centered early intervention transdisciplinary team focuses on the family. It includes professionals experienced in supporting early assistance programs for deaf and hard-of-hearing children. The team is formed depending on the needs of the child and family. It might include specialists working in early intervention programs, specialists with knowledge and skills in working with deaf and hard-of-hearing children, including teachers of the deaf and hard of hearing, speech therapists, audiologists, social workers, and psychologists. If necessary, a physical therapist, an occupational therapist, such narrow specialists as a developmental pediatrician, a neurologist, a psychiatrist, a visual impairment specialist, and others can be included. The family is considered an equal rights member of the team.

Principle 9: Tracking the progress of the child's development. Regular monitoring is required to assess the child's individual development, family satisfaction and well-being, and the efficiency of the assistance program. If necessary,

based on the results obtained, the approaches and strategies used are modified.

Principle 10: Control of program functioning. The monitoring of the quality control of all the program elements is required, and monitoring the extent to which specialists adhere to accepted international standards and practices in their work.

EXAMPLES OF IMPLEMENTING THE PRINCIPLES OF EARLY ASSISTANCE FOR DEAF AND HARD-OF-HEARING CHILDREN

There is a wide variety in the planning and implementing family-centered early childhood assistance programs in different countries. This document has been applied both by professionals in countries with well-developed early care services and emerging programs. Examples of implementing this document's recommendations in some countries, namely in Upper Austria* and the United States from 2012 to 2014, are presented below [20]. This information indicates very clearly the difficulties that the colleagues from these countries faced and their solutions.

Implementation of principle 1 on ensuring early, timely, and equitable access to services. Despite the introduction of universal screening for newborn hearing in 1990 in Austria, for 20 years after that, no follow-up system was established for children who had poor screening results or failed to undergo it. In response, Upper Austrian health officials organized meetings. They collected and analyzed data on the age of deaf and hard-of-hearing children at the time of diagnosis establishment and the age of inclusion in early childhood care programs. As a result, a family tracking procedure was developed and implemented in case of an unsatisfactory result of the initial screening in the maternity hospital. If the parents do not attend an appointment, the otorhinolaryngologist contacts them. If the hearing impairment is confirmed by a diagnostic examination, then the information is immediately transmitted to the early assistance service. Finally, the specialist of this service contacts the family within 48 h.

In 2012, in the United States, 96.6% of 3,953,986 newborns were screened for primary hearing. However, 35.9% of these infants did not attend diagnostic audiological examinations, or their documents were lost. Approximately a quarter of children who should have been provided with early assistance programs were not included in them in a timely manner.

*Upper Austria is a federal state of Northern Austria

The UK audiological screening program requires at least 95% of newborns to undergo primary screening in the first month of life (age corrected for premature infants). The diagnostic stage must be completed for at least 90% of children within four weeks after their referral for diagnostics. Data from 4,645,823 children born in the UK from 2004 to 2013 showed a continuous improvement in the quality of implementation of this program. Thus, for children born in 2012–2013, primary hearing screening was performed in the first month of life for 97.5% of newborns. The average age of the diagnostic stage was 30 days; the median age for inclusion of children with hearing impairments in the care program was 50 days nationwide. Primary hearing aid for children with confirmed bilateral bradyacusia was performed on average at 82 days of age. These data demonstrate the high efficiency of conducting initial audiological screening in the UK and follow-up measures up to the initial steps of the assistance program, such as selection and fitting hearing aids [18].

Implementation of principle 2: ensuring a partnership between family and early childhood care providers. Each of the 50 states in the USA has established and operates advisory councils to provide early assistance to deaf and hard-of-hearing children. These advisory councils include parents in most cases. The responsibilities, structure, accountability, and allocation of financial resources of these advisory councils might vary and depend on the laws of the state of their location.

Implementation of principle 3: ensuring informed choices and decision making. The assurance of this principle remains unclear. Interviews with parents and questionnaires of parents did not determine whether this principle is being implemented in any system.

Implementation of principle 4: provision of social and emotional support to the family. This support can be provided in a variety of ways by different professionals. An essential role in supporting families is played by specialists and other parents with deaf and hard-of-hearing children. In Upper Austria, parents who provide professional support to parents and immediate family members have been included in the early assistance program. They attend the initial meeting when the family is included in the program. The seminars-meetings are held, organized by psychologists and experienced parents, where issues such as “living with a child with bradyacusia,” “family communication,” “brothers and sisters,” and others are discussed. Regular meetings provide an opportunity to establish informal communication. Many parents

exchange contacts and visit each other. The assistance program regularly surveys the needs and well-being of parents.

In the USA, many states provide parent-to-parent support. In most cases, this support is provided immediately after the diagnosis establishment, and in some situations, after the initial screening. The Disability Research Distribution Center, as part of the National Early Childhood Assessment Project: Deaf/Hard of Hearing (NECAP), performs assessment and collection of data on the development of deaf and hard-of-hearing young children. Monitoring of the social and emotional well-being of families with deaf and hard-of-hearing young children is implemented in many countries. However, there are no standard approaches to such assessments.

Implementation of principle 5: ensuring interaction between the family and the infant. The early childhood care program helps parents create the optimal language learning environment for their children through everyday family routines. In Upper Austria, early assistance providers were trained to be more aware of the family's living conditions. An automated speech recognition device (Language Environment Analysis, LENA) can assess the quantity and quality of speech that the child hears throughout the day and vocalizations of the child [15]. This is necessary for parents to understand the quality of communication they provide to their children during a typical day. Early assistance specialists have compiled a list of strategies to improve communication. If the family chooses kinetic speech to communicate, then the early assistance professional should be fluent in kinetic speech communication skills. All early assistance professionals are required to complete a two-year kinetic speech course. Together with preschool institutions for deaf and hard-of-hearing children, kinetic speech courses are regularly held, adapted to the needs of parents of young children. In the USA, some states provide a professional who is fluent in kinetic speech and can teach kinetic speech to parents and family relatives who choose to communicate with kinetic speech.

Implementation of principle 6: use of assistive technology and communication tools. In Upper Austria, the child must be provided with devices for adequate hearing correction if the family has chosen spoken language as their primary mode of communication. Hearing aid and implant manufacturers regularly hold seminars for early care specialists on the latest advances in hearing aids. Hearing aids/implants are provided to all children in the USA. Only a small number of young children have access to assistive devices such as FM systems.

Implementation of principle 7: ensuring the qualifications of specialists. Assessment of the qualifications of early care providers is challenging. Some NECAP states in the USA are currently collecting and analyzing data related to the training of early childhood care providers. Some states require all professionals to receive specific training in hearing impairment in young children. However, so far, few states have implemented programs that guarantee the core competencies of professionals.

Implementation of principle 8: ensuring teamwork. The most effective results in the development of deaf and hard-of-hearing children can be achieved only if specialists in health care, education, and the social sphere collaborate. Upper Austria and many states in the USA have a single network of early childhood care professionals, audiologists, otorhinolaryngologists, pediatricians, preschool and school educators, and representatives of parental associations and societies for the deaf.

Implementation of principle 9: Tracking the progress of a child's development. In the USA, the NECAP project monitors developmental outcomes for deaf and hard-of-hearing children in several states. When analyzing the data within the project, it was revealed that the average coefficient of development of deaf and hard-of-hearing children is within the standard values of hearing children, while the data of the three language indicators are below the average values. However, they are within the reference limits. It has been established that the factors such as early inclusion in the assistance program (up to the age of 6 months), milder hearing loss, lack of concomitant impairment in the child, or a family with deaf or hard-of-hearing parents have a positive effect on the results of language development.

Implementation of Principle 10: Maintenance of the program control. This principle is an essential component but not widely adopted in the United States. In some states, such as Colorado, programs are monitored by an early care system using reports and expert supervision.

CONCLUSION

An international consensus statement describing these 10 principles has been translated into many world languages, including Russian [10]. This contributes to its distribution and implementation among specialists around the world. Many factors affect a child's development, including language and speech development, social and communication skills, academic performance, and mental health. Awareness of specialists working with children with hearing impairments with this document and

adherence to the principles set out allows the most effective planning and implementation of a comprehensive assistance program, thereby leveling the possible negative consequences of hearing impairment. In addition, the study of the global situation regarding the implementation of these principles is required. The document provides a framework for program collaboration worldwide to collect and analyze data that will improve the efficiency of early assistance programs for deaf and hard-of-hearing children.

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