



HAUTE AUTORITÉ DE SANTÉ

CLINICAL PRACTICE GUIDELINE

**Deaf children: family support and
follow-up of children aged 0 to 6 years
- Provision made within schools excluded -**

GUIDELINE

December 2009

The quick reference guide and full evidence report (in French) can be downloaded from
www.has-sante.fr

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Abbreviations and acronyms

To facilitate reading of the text, the abbreviations and acronyms used are explained below.

AHRQ	<i>(American) Agency for healthcare research and quality</i>
CAMSP	Centre for early socio-medical intervention
dB HL	<i>Decibel Hearing Level</i>
DGS	Directorate general for health
HAS	HAS Board
INSERM	French National Institute for Health and Medical Research
IQWiG	<i>(German) Institute for Quality and Efficiency in Health Care</i>
LPC	French cued speech
LPPR	List of reimbursable products and services
LSF	French sign language
MDPH	Regional homes for the disabled
ORL	Otorhinolaryngology (ENT - Ear, Nose and Throat)
PPS	Personalised education plan
RPC	Recommendations for clinical practice
SAFEP	Family support and early education department
SESSAD	Special education and home care department
SSEFIS	Department for the support of family education and integration at school

Definitions used

Language (ability to talk: ["langage" in French])	Capacity, observed in all human beings, to express their thoughts and to communicate by means of a system of linguistic signs. This human faculty is implemented by means of a particular tongue [langue in French].
Language, oral and written (particular tongue: ["langue" in French])	System of linguistic, vocal, signed or written signs, specific to a community of individuals, who use them to express and communicate between themselves. For example: French, English, French sign language (LSF). The languages are divided into one or two modalities: oral (e.g. expressing oneself in face-to-face discussion while speaking French or while signing in LSF) and written (e.g. reading or writing in French).
Oral language	This expression was not used in this document because it is a source of confusion. Indeed, according to those involved it can be understood as «spoken language», the understanding commonly widespread among the general public, or «oral modality of a language, this one being able to be a spoken language or sign language», the understanding classically used by linguists and often used by people expressing themselves in sign language.
Spoken language	Language whose oral modality uses the audiophonic route of communication; the term «vocal language» is also used. There are many country-specific spoken languages (French, English etc.).
Sign language	Language whose oral modality uses the visuo-gestural route of communication. There are many country-specific sign languages (French, English, American sign language etc.).
French language	In France, «the language of the Republic is French» (Article 2 of the Constitution). Among the languages of France, «French sign language is recognised as a language in its own right.» (Article L. 312-9-1 of the Education Code). «French sign language» and the «French language» are two languages considered «within the framework of an education or schooling with bilingual communication» (Article L. 112-2-2 of the Education Code). In this guideline, each time reference is made to the statutory texts, the wording used in these texts must be adhered to. «The French language» should therefore be understood as «French».
Bilingualism	The ability to express oneself and think without difficulty in everyday life: for example, using one language at home and one at school. Bilingualism can refer to phenomena concerning an individual who makes use of two languages, or to a community where two languages are employed. The level of precision in each language, as well as the fields of expertise, can be different: e.g. mastery of spoken and written French and of written English only. Perfectly-balanced bilingualism (same level of language in all the modalities of 2 languages) is rare.
Bilingual person	A bilingual person, in the broadest sense of the definition, is one who can communicate in two languages at least, in his/her everyday life, in an active (through words, sign language, writing) or passive way (listening and reading). The bilingual person has specific traits, in particular: in-depth knowledge of two cultures, strategies of compensation between the two languages, cognitive flexibility.
Bilingual education	A bilingual education is an education during which two languages are used alternately in the child's day. There is no consensus in France in 2009 on the means for implementing a bilingual education in the young deaf child, especially before 3 years of age.
Communication	Communication is when there is an interaction between two or several people. This communication can be verbal (using a language: French, LSF) or non-verbal (using means of communication other than language: gestures, conventional or not, facial expressions, visual interactions, physical contacts, vibrations, etc.). Real communication frequently uses verbal and non-verbal communication at the same time.

Guideline

1 Introduction

► Guideline development context

This guideline was drawn up by the French National Authority for Health (HAS)¹ at the request of the Ministry for health. This topic lies within the scope of law no. 2004-806 of 9 August 2004 relating to public health policy, one of the objectives of which is to «ensure early screening and management of all sensory disorders in a child». Whereas law no. 91-73 of 18 January 1991 reintroduced, after a 100 year ban on sign language teaching, free choice in the education of young deaf people «between bilingual communication – sign language and French – and oral communication», there is still lively debate in France around screening for deafness and the concept of «bilingual education». This was demonstrated in 2008 by the referral to the National Ethics Advisory Committee² following publication of the HAS economic and public health evaluation relating to neonatal screening for deafness. In this context, HAS formed a working group including deaf or non-deaf professionals, health professionals, psychologists and teachers, and representatives of the users, deaf people and parents of deaf children (see appendix 1). HAS also extended the reading of the preliminary version of the guideline to individuals not preselected by HAS, by organising a public consultation in parallel with the usual peer review group (see document in appendix 3). The working group, conscious of the the social representations' diversity of deafness in France and the ethical questions that these situations raise, paid a huge attention to consider the various educational approaches possible so they could propose pragmatic recommendations in order to better support families and children.

► Children and families concerned; objectives and limits of the guideline

The follow-up of children aged between 0 and 6 years of age who present with permanent bilateral deafness and a hearing threshold > 40 dB HL⁴ and the support of their family has the objective of enabling a deaf child⁵ (appendix 2), like any other child, to acquire within his/her family and the society in which he/she develops, a state of physical, mental and social well-being. This objective largely exceeds the objectives of this document, but it was taken into consideration throughout its preparation.

The main objective⁶ of this guideline is to encourage language development in the deaf child within the family, whichever language(s) is/are used, French⁷ or French sign language (LSF). «During the education and schooling of deaf children, freedom of choice between a bilingual communication, sign language and French language, and communication in the French language, is a right⁸.» This choice, exercised by the parents, can change over time, taking into account the overall development of the child in particular. Educational projects aiming to encourage the development of the deaf child, especially the development of language will partly depend on the ability of this child to grasp the language used by those around him. Within the framework of the families whose main language is a spoken language, the educational programmes will be adapted specially to the deaf child's ability to

¹ In French: Haute Autorité de Santé (HAS)

² In French: Comité consultatif national d'éthique (CCNE)

³ Refer to the document in the appendix «Deaf children: public consultation and review group – Results relating to the preliminary project recommendations» [in French], downloadable from www.has-sante.fr

⁴ dB HL: unit of measurement with reference to the auditory sensitivity of a normal subject (*Decibel Hearing Level*)

⁵ See appendix 2 for precise definitions relating to the varied and heterogeneous clinical situations envisaged.

⁶ See the summary data sheet p.44 if you wish to know the clinical questions which these guidelines address.

⁷ Other languages can be used within the family, especially if the native tongue is different. Nevertheless, the services proposed for deaf children aim to help the child to acquire French or French sign language.

⁸ Law no. 2005-102 of 11 February 2005 on equal rights and opportunities, participation and citizenship of handicapped people

audibly detect the words of those around him, whether or not the child has a device fitted. At today's current state of knowledge, a vast majority of deaf children with a hearing threshold < 70 dBHL, use a spoken language exclusively. On the other hand, deaf children with a hearing threshold > 70 dB HL use either a spoken language exclusively, or, for the majority of them, a spoken language and sign language, or sign exclusively. The three prognostic factors for the use and level of acquisition of a spoken language, sign language or both, depend mainly on the hearing threshold, the language used at home and the presence of associated disorders. Given the heterogeneity of the profile of deaf children (linguistic environment, hearing threshold, fluctuations or not of the latter, amplification gain, isolated deafness or deafness associated with other disorders), it is not possible based on hearing threshold alone to define a follow-up and support strategy for the deaf child and his/her family. Nevertheless, the problems associated with acquiring a spoken language are very different according to whether the hearing threshold is > 70 dB HL or < 70 dB HL.

This guideline does not consider the questions relating to screening, the diagnosis of deafness and the investigation into its causes, or the health-economic or organisational aspects. This does not diminish the importance of these questions within the framework of implementation of social, education or health policy for deaf children.

Support at school is also no longer dealt with directly in this guideline. Nevertheless, the modalities of organisation of the child's schooling and training are closely related to language acquisition in one or the other language. Decree no. 2009-378 of 2 April 2009 relating to the schooling of children, adolescents and young handicapped adults and to the cooperation between establishments specifies the links between the individualised service plan implemented following decision from the commission of rights and autonomy for disabled people within the Regional Homes for the Disabled (MDPH9), the personalised schooling plan (PPS10) linked to the referent teacher and the use of specialist techniques for medical monitoring, training in communication methods and materials, acquisition of knowledge at school, professional training and access to social autonomy. Between 3 and 6 years of age links between early interventions and school support are essential.

► **Professionals concerned**

Follow-up and support of the deaf child and his/her family are carried out by numerous professionals whose practice methods and structures are very varied and go well beyond the scope of a mere health professional. The importance of social networks and the family circle must also be underlined in this support process. This guideline, which is primarily intended for health professionals, may be of interest to any person who is in regular contact with a deaf child.

► **Grading of the recommendations**

The guideline were drawn up according to the method presented in appendix 1. The method relies, on the one hand, on analysis and critical synthesis of the available scientific literature, and on the other hand on the opinion of a multidisciplinary group of professionals. The texts on which this guideline is based are mainly: (1) French statutory texts, in particular the law of February 2005; (2) guides published by national organisations such as the French National Health Prevention and Education Institute¹¹, the British National Deaf Children's Society, or the International Bureau for Audiophonology; (3) finally, international clinical practice guidelines and scientific publications (social sciences and medical literature) published since 2000 using the methodological criteria selected (see evidence report [Argumentaire, in French] – method part § 4, downloaded to www.has-sante.fr).

⁹ In French: Maisons départementales des personnes handicapées

¹⁰ In French: Projet personnalisé de scolarisation (PPS)

¹¹ In French: Institut national de prévention et d'éducation pour la santé (INPES)

The proposed recommendations have been rated as grade A, B or C according to the following criteria:

- a grade A recommendation is based on scientific proof established by studies with a high level of evidence, such as powerful comparative randomised trials free of major bias, meta-analysis of randomised comparative trials, or analysis of decisions based on well-conducted studies (level of evidence 1);
- a grade B recommendation is based on scientific presumption obtained from studies with a moderate level of evidence, such as less powerful comparative randomised trials, well-conducted non-randomised comparative studies, and cohort studies (level of evidence 2);
- a grade C recommendation is based on studies with a lower level of evidence, such as case-control studies (level of evidence 3), retrospective studies, case series or comparative studies with considerable bias (level of evidence 4).

In absence of evidence, recommendations are based on professional agreement among members of the working group, after analyse of the peer reviewers' comments. The absence of any level of evidence does not mean that the recommendations are not relevant or useful. It should, however, encourage investigators to conduct additional studies. Some proposals are shown in Appendix 1. The results of these studies will enable the guideline to be updated in 3 to 4 years' time.

2 Developing communication and language and following their progress

2.1 Early intervention: before 1 year of age

An early intervention programme should be recommended for any deaf child¹² and his/her family, before one year of age (grade B), adapted to his/her particular needs and the educational project chosen by his/her parents.

Early intervention programmes aim to:

- clarify levels of hearing;
- reinforce correct skills within the family;
- ensure and reinforce the skills and personal development of the child with special needs;
- promote inclusion of the child and his/her family in society and facilitate access of the child to the education system.

Professionals are advised to systematically give a place to parents in the early intervention programmes and to pay special attention to brothers and sisters, for whom specific support should be suggested if necessary.

Early intervention programmes include activities centred around the child (see § 2.2) and activities centred on the family (parents, siblings) (see § 3). Activities centred around the child aim to address all his/her particular needs, especially but not exclusively his/her needs relating to development of communication and language. Only the activities centred on the development of communication and language are detailed hereafter, in accordance with the main objective of this guideline; the more general recommendations agreed to during the elaboration of this guideline, are developed in appendix 4. They should be adapted to the particular situation of each child, especially if there are disorders associated with the deafness.

¹² Child with permanent bilateral deafness with hearing threshold > 40 dB HL, whatever the aetiology (see appendix 2).

2.2 Early intervention: various possible approaches for acquisition by the deaf child of one or several languages

The social representations of deafness are extremely diverse in France because of complex social, historical, ethical, political and statutory factors. In order to act in the best interests of the child, this means that everyone must consider their own representation and that of their interlocutors in order to ensure quality interactions with other participants.

Whereas each of these representations is legitimate, there is still strong opposition¹³ between the supporters of a primary education in French and the defenders of a primary education in LSF. Since these arguments regarding deaf children less than three years of age appear to be both endless and futile, a more pragmatic distinction between the two approaches is suggested. **These are summarised in sequence, though their order of appearance does not reflect any value judgement.**

► Audiophonic approach

The first approach, itself divided into two, has as an essential principle the will to stimulate auditory function and thereby enable the deaf child to develop a socially useful spoken language. It is proposed that this approach be called *audiophonic*, aiming to stimulate hearing early in order to encourage the development of spoken language (comprehension then expression).

Practical implementation of this first approach is based on data from auditory assessments, which must be obtained whatever age the child is. According to the level of hearing, auditory aids, then, if indicated, cochlear implants are used to stimulate the auditory pathways of the deaf child. During the last decade, significant technological progress has been made in stimulation methods. The educational environment proposed to parents to take advantage of auditory stimulation, and to promote the development of spoken language in the deaf child uses two methods from early intervention programme implementation:

- either a programme of the type «audiophonic approach in French» which lies within the scope of an education project with «*communication in French*». Before 3 years of age, this programme aims to promote the development of language via the intermediary of spoken French¹⁴, the child's first language;
- or a programme of the type «audiophonic approach in French, with LSF» which lies within the scope of an education project with «*bilingual communication, French sign language and French*». Before 3 years of age, this programme aims to promote the development of language via LSF and spoken French¹⁵, without prejudging the first language to be used by the child.

Even if these two methods for implementation of early intervention have particular characteristics and should not be confused (cf. § 2.3), three reasons encourage us to group them under the same approach: (a) these two early intervention programmes have a common objective: to promote the development of spoken language in the deaf child (b) studies that describe the audiophonic results of «early intervention» often reveal two means of communication, spoken and signed, especially in the implanted, profoundly deaf child; (c) the only cohort study on the benefits of early education which have been judged of good methodological quality by HAS, the German agency IQWIG and the American agency AHRQ, uses as their main criterion the level of language developed by the deaf child at the age of 8 years, the various aspects of comprehension and of expression (spoken words, but also gestures and facial expressions).

¹³ Refer to the joined document « Deaf children: public consultation and review group – Results relating to the preliminary project recommendations », downloadable from www.has-sante.fr

¹⁴ Spoken French or any other language spoken within the family if the native language is not French.

¹⁵ As above.

► Visuo-gestural approach

The second approach is very different. It relates more to the cultural model which the French Deaf community has. The main principle of this approach is to stimulate the naturally active sensory functions, especially visual and motor functions. Auditory function is not stimulated simultaneously. This approach aids communication by using visuo-gestural channels which enable the child to exploit his/her abilities in an optimal manner. This is why it has been suggested that the approach be called *visuo-gestural*. Indeed, in this approach, priority is given to the visual learning of a language, LSF. This learning is done starting with codified *signs*, or symbolic gestures, which have the same meaning for all those practising this language. The visuo-gestural approach aims to promote the early development of language using French sign language, adapted for the deaf child, and not spoken French, which it considers to be difficult for the child to access and may accentuate the child's handicapped situation. Since amplification of residual hearing does not form part of the objectives, it is logical that this approach does not consider the precise hearing level of the child.

Within the scope of an early intervention programme using the visuo-gestural approach, LSF constitutes the first language of the child. This approach will be secondarily combined with the progressive introduction then learning of written French, to become an education project «with bilingual communication» in which French, mainly written, becomes the second language of the child.

► Choosing one approach or another

The two approaches have common objectives to achieve before the child is 3 years old (appendix 5):

- maintaining and developing all forms of communication, verbal or non-verbal, between the child and those around him;
- promoting the development of at least one language, French and/or LSF. Indeed, because of the concept of 'critical period of language acquisition', whichever language is first suggested, studies have shown that the level of language acquired is superior when a language is grasped early by the child.

Training in LSF can be considered within the scope of the two approaches.

On the other hand, before the child is 3 years of age, the audiophonic and visuo-gestural approaches are basically distinguished by the principle of stimulating, or not stimulating, the auditory pathways as early as possible, the objective of the stimulation being to promote the development of spoken French.

In the sensitive context of early education, the great difficulty in recommending one approach or another to the parents of a young deaf child is that they are in practice irreconcilable at a given moment in the child's life.

The incompatibility lies not in the introduction or not of LSF early into the linguistic environment of the child, but in the decision to stimulate, or not, the auditory pathways sufficiently early, namely during the first year of life in congenitally deaf children, and probably even in their first 6 or 8 months.

From the current state of scientific knowledge, it has not been possible to gather a consensus between the different participants in order to be able to recommend one approach rather than another (audiophonic approach or visuo-gestural approach).

Nevertheless, it is recommended that parents be informed specifically about the following points:

- The prejudice according to which early acquisition of sign language delays acquisition of a spoken language is not scientifically validated (absence of controlled studies);
- The level of language obtained in spoken language or sign language mainly depends on the 3 following factors: the language used at home with the child according to the parent's education project, the child's hearing threshold (for spoken language) and the presence or the absence of associated disorders (level of evidence 2);

- The initial education project chosen, using a visuo-gestural approach or an audiophonic approach in French or in French with LSF can be changed or modified secondarily, especially with regard to the acquisition of the proposed language observed, the child's overall developmental progress, and possible associated disorders diagnosed initially or secondarily. In the event of significant developmental delay in language, introduction of a new language¹⁶ cannot in itself guarantee that the development of language will be more significant or more rapid in this new language; however, it is highly advisable to give consideration, as far as possible, to deadlines related to the critical period of language development, which exist whatever language is provided; clinical studies have shown that:
 - ▶ auditory stimulation and education before 2 years of age in the child, make it possible to reach a level of spoken language superior to that obtained by children who have not benefited from auditory stimulation and education before this age (level of evidence 4);
 - ▶ the linguistic environment in sign language proposed before the age of 5 years makes it possible to reach a level in written language and a level in sign language superior to that obtained by children without associated disorders when they didn't acquire spoken language (level of evidence 3).

2.3 Audiophonic approach: implementation

▶ Objectives

Before the age of 3 years, the objectives for development of communication and language are:

- to maintain and develop all forms of communication, verbal or non-verbal, between the child and those around him;
- to improve auditory perception;
- to develop the child's abilities in the comprehension and expression of spoken French;
- as with any child, to gradually introduce French writing, in particular starting with everyday situations (reading stories, hand-writing, etc.).

When the parents choose a bilingual communication form of education, an additional objective is added to those preceding:

- to develop the child's abilities in the comprehension and expression of LSF.

▶ Recommendations common to all the programmes for implementing an audiophonic approach

It is recommended that the maintenance and development of all forms of communication (multimodal communication) starts with the different sensory afferents, visual, tactile, proprioceptive and auditory during encounters with the child and his/her family within the scope of early intervention. It is a question of supporting, as early as possible, a craving for communication and relationships by giving the deaf child an early means of communication enabling him to express all of his/her needs, feelings and desires.

It is recommended that arbitrary or iconic gestures are used in support of the oral in accordance with the needs of the child, the wishes and abilities of the family: signs borrowed from sign language (LSF), intrafamilial gestural codes, keys from French cued speech.

Acquisition of the French language in its two modalities (spoken and written language) requires:

¹⁶ The secondary introduction of LSF within the scope of the early intervention audiophonic programme with the initial education programme «in the French language» or secondary introduction of spoken language during the initial education programme in accordance with early intervention visuo-gestural programme

- stimulation of auditory function by conventional amplification devices then, if indicated, cochlear implants (appendix 6);
- daily exposure to language in the environment;
- specific training with orthophonic rehabilitation several times a week, centred on word training, lip reading, and on vocabulary and syntax acquisition in this language. This training does not exclude acquisition of sign language whose lexicon (vocabulary) and grammatical structure are different.

Equipping with conventional amplification devices is recommended during the 3 months following the diagnosis, for all children with permanent bilateral deafness whose auditory threshold is greater than 40 dB HL. This period can however be lengthened to 6 months from when the diagnosis was made if the diagnosis was made before 6 months of age, especially if there is only moderate deafness. The device is binaural and stereophonic except where clinically contraindicated. Regular wearing of hearing aids is recommended to reinforce the effectiveness of the equipment in this period of great brain and developmental plasticity.

When assuming responsibility for the hearing correction devices, the parents must be clearly informed about the need for the equipment and the benefits the child will derive as well as the restrictions when wearing the device. This information reinforces and supplements the preliminary information given by ENT when the diagnosis is pronounced.

It is recommended that particular attention be paid to supporting parents during the process of acceptance of the equipment, and when the equipment is fitted. Interaction with the family should in addition consider their worries in encountering difficulties of acceptance within the family or social circle, because hearing aids make deafness visible when it was not previously so.

Equipment fitting by an audioprosthologist should not be limited to placement of a device, but include the choosing and adaptation, immediate and on-going effective monitoring, as well as prosthetic education. This prosthetic education relates to the various practical installation and maintenance demonstrations for the hearing aids, discussions and instructions concerning their use, checking their effectiveness and explaining possible adjustments.

This prosthetic education must progress over time in order to adapt to the child's reactions and to the progression in development of spoken language noted during the ongoing monitoring at follow-up. This follow-up is integrated into the interdisciplinary management framework in close and permanent cooperation with the family.

Within the scope of congenital deafness, or deafness acquired before the development of spoken language, when the child presents with criteria indicating the need for a cochlear implant¹⁷, it is recommended that the parents are informed before the child is 18 months old, and as early as possible if the child is older, about the possibilities offered by cochlear implants of stimulating hearing function: expected results, compatibility of this programme within the scope of bilingual education and of its constraints: the risk of complications or repeat interventions, the requirement for orthophonic rehabilitation over the following years, the financial impact (see evidence review § 6.4.7). It is recommended that parents are informed that expected results of auditory perception and language development will be better if implantation takes place before the child is 2 years of age (grade C).

It is recommended that an auditory education be regularly provided by a specialised professional to develop interest in and then knowledge of the world of sound (daily noises and word recognition). The many adapted tools and musical toys at the disposal of professionals encourage the child's participation in activities of discovery in the world of sound and vocals. This auditory education requires that the equipment is fitted and that activities are practised in a playful manner.

It is recommended that the child's ability to express itself is developed by working specifically on breathing and voice control and by encouraging the child's expression in spoken French during everyday activities.

¹⁷ Indications for cochlear implants are defined, except in special cases, by an HAS opinion published in 2007 (see appendix 4).

The recommendation is two weekly sessions for cases of moderate deafness, 3 to 4 weekly sessions for severe and profound deafness.

► **Audiophonic approach and education programme**

Early intervention programmes that propose an audiophonic approach are based on the principle of stimulating the auditory pathways in order to develop spoken language (comprehension and expression). They can be included within the scope of education programmes with «communication in French» or education programmes with «bilingual communication, French sign language and French».

Within the scope of education programmes with «communication in French», spoken French¹⁸ constitutes the child's first language. Before 3 years of age, two types of early intervention audiophonic programme in French are classically described according to the main means of verbal communication used by the deaf child:

- communication in LCP (French cued speech); the language used is French¹⁹; LCP facilitates comprehension and interaction in situations in which spoken French is difficult for the child to grasp; the message transmitted in French by the person talking to him is supplemented simultaneously by a gestural code which enables ambiguities of lip reading to be removed, while respecting French vocabulary and grammar; when he/she speaks the deaf child does not need this code, except if he/she interacts with another deaf child using LCP; in this type of programme it is recommended that parents should learn and use the keys to French cued speech at home, if possible before the child goes to school (grade C);
- or communication in 'signed French', which is equally commonly called «total communication»; the language used is French; comprehension or expression by the deaf child of the message expressed in spoken French is supported by the simultaneous use of signs isolated from LSF, employed in the word order of the French sentence. This word order is different to that used in LSF to express the same idea, as the grammar of LSF is different to that of French.

From the current state of scientific knowledge, it has not been possible to gather a consensus between the different participants in order to be able to recommend one or other of these early intervention French audiophonic programmes (see evidence review § 6.4.1). On the other hand, a consensus is clearly emerging that early intervention programmes exclusively in spoken French should no longer be proposed for deaf children without additional gestural support.

Within the scope of an education programme with «bilingual communication», the audiophonic approach enables an early intervention programme to provide spoken French alternately with LSF, without prejudging the first language which will be used by the child to express itself. Everyday communication and interactions can take place in one language or the other. LSF facilitates comprehension and interactions during situations in which the child has difficulty grasping spoken French. The use of two languages enables the child to develop the particularities of all bilingual people: immersion in two cultures, compensation strategies between the two languages, cognitive flexibility. The implementation of an audiophonic intervention programme in French, with LSF, must observe both the conditions required for all audiophonic approaches and those required for the visuo-gestural approach.

In order to ensure their education programme conforms with the law²⁰, from the moment parents express a wish for their deaf child to have an education with «bilingual communication» to develop French in its two modalities (spoken French and written French),

¹⁸ Between 0 and 3 years, when the native language is another spoken language, the first language of the child can be a spoken language other than French.

¹⁹ The LCP code also exists for languages other than French.

²⁰ Law no. 2005-102 of 11 February 2005 on equal rights and opportunities, participation and citizenship of handicapped people.

it is recommended that an audiophonic approach is provided to the child and his/her parents as soon as possible, associated with an environment that will enable them to acquire LSF and not signed French, as the latter only aims to teach «communication in French».

2.4 Visuo-gestural approach: implementation

► Objective: to develop communication and language

Before 3 years of age, the objectives for developing communication and language are:

- to maintain and develop all forms of communication, verbal or non-verbal, between the child and those around him;
- to develop the child's ability to understand and express himself in LSF;
- to gradually introduce, as with all children, the written modality in French, starting from everyday situations in particular (reading stories, hand-writing, etc.).

► Recommendations for implementation of a visuo-gestural approach

Within the framework of early intervention, during meetings with the child and his/her family, it is recommended that all forms of communication are maintained and developed, starting with different sensory afferents remaining active. It is a question of supporting, as early as possible, a craving for communication and relationships by giving the deaf child an early means of communication enabling him to express all of his/her needs, feelings and desires.

It is proposed that communication be given priority, starting from the functional abilities of the child, particularly visual and motor abilities, and not the deficient afferents.

Sign language is a language that allows one to express oneself using the same capacities of abstraction, subtlety and register of language as any spoken language. Language acquisition in sign language follows the same process and the same chronology as that of an ordinary child with spoken language, provided the deaf child is placed in equivalent conditions of stimulation, transmission and communication.

It is recommended that the early intervention visuo-gestural programmes propose that in the child's reception area there is a space for play, activities and encounters where LSF is used, if possible by many interlocutors, deaf or hearing, for a minimum of 5 hours per week.

It is recommended that qualified deaf professionals trained in teaching the language and in relationship and educational aspects, form part of the reception teams.

So that conditions of stimulation, transmission and communication in any language are observed, and that this language can make it possible for the deaf child to participate fully in everyday life, it is necessary that the child's interlocutors, particularly his/her parents, brothers and sisters or daily carers, know or learn this language. It is advisable to check whether the family should be given assistance in acquiring this language, and in particular to find out whether the family uses signed French or LSF, and to implement specific methods for families not mastering this language. Depending on the time and as a function of the needs identified, linguistic immersion can take the form of courses in LSF, or support with communication in real situations in the child's normal environments.

► Visuo-gestural approach and education programme

Within the scope of an early intervention programme by the visuo-gestural approach, LSF constitutes the child's first language. This approach will be secondarily combined with the gradual introduction of, then training in, written French to become an education programme «with bilingual communication».

2.5 Regular evaluation of progress in the development of communication and language(s) used

It is recommended that the deaf child's communication and language be regularly evaluated (every 6 months up until 3 years of age, then every year) by means of standardised tests adapted to the child's development, if these exist²¹:

- to allow follow-up of the child's ability to communicate and acquire each of the languages proposed, in order to ensure these are developing steadily and well;
- to identify any delay relative to children of the same age, and as best as possible to adapt implementation methods to respond to the particular needs of the child, especially at the time of school entry.

It is recommended that an evaluation be made in each of the languages proposed to the child²². One should make sure that follow-up at least enables progress to be assessed in the following areas:

- ability to communicate during everyday activities;
- ability to understand words and syllables, signs, phrases and stories;
- ability to express words and syllables, signs, phrases and stories.

During the follow-up of an audiophonic approach, it is recommended that the family be told of the possible delay in acquisition of spoken French compared to the norm in hearing children, and that they be alerted if this shift increases during the course of the follow-up. It is then necessary to suggest additional assessments in consultation with teams specialised in developmental disorders, and to consider if an adaptation and/or change of linguistic programme is necessary.

It is recommended that the evaluation of communication and language in the deaf child is recorded within the framework of a more general paediatric evaluation taking into account the following multidisciplinary aspects:

- an evaluation of auditory function with and without a device;
- an evaluation of visual function;
- a psycho-affective evaluation;
- a psychomotor evaluation;
- an evaluation of cognitive development.

3 Informing and supporting the parents

There have been no studies evaluating the effectiveness of specific information or support programmes for parents or the family. The following guidelines are based on agreement within the working group, after considering qualitative studies and investigations carried out with the parents and of testimonies and comments received during the review phase. No studies or investigations have been carried out with brothers and sisters.

To welcome a deaf child into one's family is above all to welcome a child. In order not to overshadow all that is usually done by and given to the parents when the child is accommodated²³, it is recommended that the information given to, and the support of families,

²¹ Refer to the evidence review (§ 5) to find out about the tests suggested for childhood deafness. In the absence of standardised tests for deaf children, the international classification of function, disability and health (child and adolescent version) and state education reference documents on language learning in schools make it possible to structure an evaluation of the development and communication and language/languages used in accordance with the linguistic programme (education with communication in French language or with bilingual communication).

²² Within the scope of early interventions, not including school evaluations, the evaluation of acquisition of the French language is generally carried out by speech therapists; the evaluation of acquisition of sign language requires the presence of professionals with a command of this language who are aware of how it is transmitted to young children.

²³ For more details, refer to clinical practice guidelines published in 2006 by HAS «Preparation for birth and parenting».

should not be centred solely on specific aspects due to the child's deafness, but primarily take into account the requirement for information about the overall development of the child, such as is proposed for any child.

3.1 Informing the parents

► General principles and variety of information available

Informing the child and his/her family is a continuous process throughout the follow-up of the child. Specific recommendations at certain times during the follow-up are suggested in the appendix: information before diagnosis (appendix 7) and when the diagnosis is announced (appendix 8).

When a professional informs a deaf person (child or parent), it is recommended:

- that he addresses himself as far as possible in the language used by the person to whom he is giving the information: it may be necessary to use an interpreter if required²⁴;
- that he observes favourable conditions for quality communication with a deaf person²⁵.

In accordance with the law²⁶, any health professional has a duty to inform a person coming to him within the scope of his/her abilities, and in compliance with professional regulations which apply. Together with the health professional, the person makes decisions concerning their health, or the health of the person for whom they have legal responsibility, taking into account the information and recommendations provided by the health professional. Professionals must respect the will of the person after having informed him of the consequences of his/her choices. No medical procedure or treatment can be carried out without the free and informed consent of the person and this consent may be withdrawn at any time.

It is recommended that the information given to the parents is supplemented by suitable information given to the child, according to his/her age and cognitive development. Particular attention should be paid to siblings and specific information can be given to them.

In order to ensure a variety of types of information are provided that reflect the different social representations of deafness and the heterogeneous clinical situations of deafness in children, it is recommended that the health professionals and all people engaged in informing families tell them that there are different educational approaches available to the deaf child, especially if the hearing threshold of the child is > 70 dB HL. Health professionals, associations of parents of deaf children, associations of the deaf, information centres on deafness are able to provide parents with additional information before they commit to one educational approach or another. Even though all participants questioned in the drafting of these guidelines would like there to be a single neutral place where parents could receive all information about their child's deafness, whatever the clinical and educational differences, there is no consensus in France in 2009 which would make it possible to define the function of such a place, in particular the relevance of identifying a coordinator for the family.

It is recommended that the internet sites and information providers develop information about moderate deafness, the most common clinical condition and the least well documented;

²⁴ In compliance with law no. 2005-102 of 11 February 2005 on equal rights and opportunities, participation and citizenship of handicapped people, «persons who are hard of hearing should be given, at their request, a simultaneous written or visual translation of any oral or hearing information concerning them within the context of their relationships with public services, whether this information be administered by the state, regional authorities or a body representing them, as well as by private persons charged with a public service.»

²⁵ See: Barnett S. *Communication with deaf and hard-of-hearing people: a guide for medical education*. Acad Med 2002; 77(7): 694-700

²⁶ Law no. 2002-303 of 4 March 2002 relating to the rights of patients and the quality of the healthcare system.

when information is provided via an internet site, it is recommended that the quality standards of health sites are adhered to.

► Information content

It is recommended that information provided be classified based on:

- the multiple competences that the deaf child has and uses to communicate and the practical consequences related to the child's need to understand the world which surrounds it with visual information:
 - ▶ pursue communication in all its forms, visual, oral, tactile, etc.
 - ▶ place the child in an open space, place yourself in its field of view, etc.
 - ▶ adopt new strategies (e.g. do not call the child from a distance by shouting);
 - the particular needs of the child to learn a language, in particular one related to its hearing threshold, when the approach desired by the parents is an audiophonic approach;
 - the needs expressed by the families, generally and specifically (see evidence review § 2);
 - the possibility of and interest in an aetiological medical assessment;
 - the different education programmes possible; giving time to parents before involving them in future decisions is recommended, especially if the diagnosis is made during the first year of life; the consultation when the diagnosis is pronounced is not the time to make decisions about the education programme;
 - the expected results, especially those concerning the acquisition and use of French (spoken or written) or LSF, in accordance with audiophonic or visuo-gestural approaches, the hearing threshold of the child and possible associated disorders (see scientific evidence § 2 and § 6);
 - the importance of a social network and association network; several investigations show that social and association networks help parents to get involved or are associated with lower levels of parental stress. Informing parents early on about the existence of such associations and of the support they can find there, is recommended; it is best to leave the time that they do this to the families as no scientific argument or consensus makes it possible to generally define the opportune moment for such an encounter;
 - local availability of services enabling support of the parents and follow-up of the child (appendix 9).

3.2 Supporting the families

Supporting the families requires the intervention of many professionals and civilians (the parents' social network, associations). This support can be carried out within the scope of early interventions, by multi-disciplinary teams possibly as a formal or informal network (see section 2). For children of less than one year, a weekly link-up with the families is recommended (meeting with a professional, telephone contact, e-mail, etc). Gradually, this family support is supplemented by interventions centred on the child, and the frequency of parents' meetings will be adapted to the needs expressed.

It is recommended that family support be adapted on a case-by-case basis, taking into account factors related to the child and his/her particular needs, and also environmental factors. Support of the families includes:

- support for the parents themselves, and if necessary, for the siblings; when they wish to acquire LSF or the hand-shapes for LPC, support is provided for all the family;
- and support in the presence of the child, individually or as a group.

The proposed support must be able to:

- provide a positive vision of the deaf child's competences and his/her future;

- reassure the parents that what they will have to know and do is within the normal competences of all parents;
- encourage parents to share their experiences and ask questions, in order to enable partnerships between parents and professionals and not dependencies;
- inform parents of the choices possible depending on the particular needs of the child (audiophonic or visuo-gestural approach, methods of schooling possible, etc);
- help parents to develop specific parental competences necessary for the deaf child;
- help parents in their approach by explaining the different roles and training of the professionals or the institutions to the parents;
- respect that there are many ways to be a parent, and this requires that actions provided be adapted to each family's individual situation;
- support the parents in their choice and to give them the means to adapt their training programme by regularly informing them about the overall development of the child and the specific development of acquisition of the language(s) proposed (appendix 10).

4 Prevention of future psychological and relationship difficulties in the child

4.1 Identifying problems

In itself, deafness is not a factor in mental health disorders. However it leads to communication difficulties between the child and the environment in which he/she lives, which is likely to cause relationship difficulties or reactional behavioural problems. In spite of the absence of specific studies in deaf children from 0 to 6 years old, the clinical experience of the professionals and the epidemiological studies carried out in children older than 8 years confirm the existence of more frequent behavioural problems in deaf children than in hearing children of the same age (see scientific evidence § 4.2).

It is recommended that health professionals remain vigilant in order to detect as early as possible the appearance or presence of behavioural problems or mental disorder in deaf children, whatever their hearing threshold.

Amongst the signs which might alert professionals are found: problems with gaze (fleeting or too persistent, deterioration in psychomotor development, sleep problems (difficulties falling asleep) or appetite disorders, delay in achieving cleanliness, disorders of attention, withdrawal, sadness or agitation, separation anxiety which continues in excess of the normal period, a persistent delay in language acquisition, frequent unexplained tears, a sudden or progressive change in behaviour, relationship difficulties with children of the same age.

These non-specific signs can reveal difficulties, even psychological suffering.

In the presence of recently observed behavioural or mental health disorders, it is recommended to first of all monitor hearing and adaptation in the child (change in the hearing threshold, adaptation and functioning of equipment, school adaptation, especially with inclusion etc). Then, depending on the problems seen, the child and his/her parents should be directed towards a psychologist or psychiatrist, if possible one who knows deafness specificity. When the main language used by the child is sign language, recourse to a team using this language is recommended.

4.2 Adopting preventative measures

A common means of communication, oral or signed, between deaf children and parents, hearing or deaf, is associated with better psychological development of the child (scientific evidence § 4.2.2).

To allow harmonious psychological development of the child, it is recommended that all the means to enable a common means of communication between parents and children are implemented as early as possible. The acquisition of a common language must be set up as soon as possible, before 4 years of age is best, and in any event before 5 years of age (grade C).

If despite these measures, the development of language is significantly delayed in the 4th year, it is recommended to provide to the child and the parents an environment that will enhance the child's ability to learn a language.

In addition, in view of the clinical experience of the professionals, deaf people and parents questioned by HAS, in order to prevent psychological problems in the deaf child, it seems appropriate:

- to inform the parents and the people dealing with the child about:
 - ▶ the methods of communication adapted to him,
 - ▶ the characteristics of attention specific to deaf children,
 - ▶ the importance of using a language register that is adapted to the specific sensory abilities of the child and his/her level of language;
- to respect the rate of development of the child and his/her family's acceptance and to take account, in particular, of the appropriateness between the real possibilities of the child and the performance and requirements of the family and social circles. It is important to take care not to overload the attention capacities of the child and thus prevent excessive stimulation;
- to ensure good adaptation to and tolerance of the equipment provided for the child ; refusal by the child to wear his/her devices should not be trivialised, moreso if it is accompanied by unusual behaviour and/or the warning signs discussed previously. Persistent refusal to wear the equipment, whatever it is, can be an indicator, amongst other things, of the inappropriateness of the programme proposed for the child;
- to regularly ensure the quality of the interactions, of communication, and of the steady development of the child's language (see § 2.5);
- to regularly assess the relevance of the interventions implemented, such as the schooling method provided, in the light of the child's overall development;
- to propose psychological support for the parents with persistent anxiety states or signs of depression;
- to train professionals from the socio-medical sector (teachers, speech therapists, etc) in prevention of psychological and relationship problems in deaf children.

5 Identifying the meeting places for family support and follow-up of deaf children

Various institutions and services are necessary to enable adaptation of support and follow-up:

- for the specific needs of deaf children, who constitute a heterogeneous population, especially in responding to the very diverse needs of children with disorders associated with deafness. When the child followed-up in a specific institution has an additional disorder, a close partnership with an institution specialised in the follow-up of deaf children is necessary to better adapt the follow-up related to deafness;
- for the training programme of the family (training with communication in the French or training with bilingual communication).

The geographical spread of the institutions can limit this adaptation in many areas, especially in the very young child: one department (region) in two does not have a specialised early intervention institution (CAMSP deafness specialist, SAFEP, SESSAD, SSEFIS) and the methods implemented are different between general-purpose institutions and specialised ones. In order to develop early intervention strategies within the family, in particular with the spread of specialised institutions, follow-up by a specialised institution within the network with independent professionals, or general-purpose institutions is necessary.

It is recommended that each institution clearly identifies the provided approaches, audiophonic and/or visuo-gestural approaches (see §2), and the specific methods available to the children or the families (e.g.: time of intervention with LPC, LSF, etc). In order to facilitate the flow of information to the families and professionals, a local and national register of the institutions specifying the approaches provided is necessary.

Professionals taking part in an early intervention programme which is within an institution or practising independently in an informal network, must forge the links with the child's home and place of schooling in order to ensure continuity of communication methods placed at their disposal.

The places of reception, support and follow-up, proposing a training programme with bilingual communication, using a visuo-gestural or an audiophonic approach in French and LSF, must be clearly posted. They must be able to propose immersion in LSF to the children and the families, within social (nurseries, day care centres, etc), socio-medical institutions (CAMSP, SAFEP, SESSAD, and SSEFIS) or schools possibly working in a network.

Although since 2005²⁷ freedom of choice in French or bilingual(French sign language and French) education and schooling is a right, the access of children to an early intervention bilingual communication training is very varied across regions (French 'départements'). It is the same with access to certain specific methods such as training in LPC. From these recommendations, it follows on the one hand, that access to various early intervention programmes needs to be developed in France within each health region, and on the other hand, that the services should work with professionals trained in the different approaches outlined above (see § 2).

²⁷ Law no. 2005-102 of 11 February 2005 on equal rights and opportunities, participation and citizenship of handicapped people

Appendices

Appendix 1. The Clinical Practice Guideline Method

Clinical practice guidelines (CPG) have been defined as proposals developed by an explicit method to help the practitioner and the patient to find the most appropriate care in a given clinical situation.

The clinical practice guidelines method is one of the methods used by the Haute Autorité de Santé (HAS -French National Authority for Health) to produce clinical guidelines. It is based on critical analysis and review of the available medical and scientific literature as well as on the opinion of a multidisciplinary group of professionals and users representatives involved in the subject area of the guidelines.

► Choice of topic area

The HAS Board chooses the topics for clinical guidelines. For this purpose the Board takes into account public health priorities and any requests from Ministry for health and national health insurance. The HAS Board may also consider topics proposed by learned societies, the French national cancer institute, the French Association of National Health insurance, the French national union of health professionals, organisations representing health care professionals or establishments, or registered user groups.

For each chosen topic, the working method follows the next steps. A HAS project manager coordinates the work as a whole and ensures that it conforms to HAS' methodological principles.

► Steering committee

HAS sets up a steering committee composed of representatives of the learned societies, professional or user organisations and, if need be, of the relevant health agencies and institutions. The steering committee specifies the exact subject area of the guidelines, the issues to be dealt with, the patient populations and the professionals for whom the guidelines are intended. It draws attention to relevant publications, notably guidelines. It proposes suitable professionals to take part in working and peer review groups. Finally it takes part in the peer review.

► Working group

HAS sets up a multidisciplinary and multiprofessional working group composed of healthcare professionals in public or private practice, from various geographical areas or schools of thought, and, if appropriate, of other professionals involved in the area and representatives from patient and user groups. HAS appoints a working group chair to coordinate the group's work in collaboration with the HAS project manager. A report author is also designated by HAS to select, analyse and summarise the relevant medical and scientific literature. The report author drafts the evidence report and specifies the level of evidence of the studies considered, under the supervision of the HAS project manager and the working group chair. The evidence is regularly updated until the end of the project.

Within the particular framework of this study, the working group was able to integrate deaf people into it (representatives of deaf people and deaf professionals), people expressing themselves in French, sign language or in the two languages. Among the people expressing themselves in French, were included in the group people using French cued speech, and people using signed French. Simultaneous translation into sign language by interpreters and the provision of a magnetic loop were ensured for all meetings.

Sources for drafting the evidence report

(see details in scientific report (in French))

- Medical and scientific databases searched systematically over an appropriate time period for the subject (languages: French, English). In particular, search for clinical practice guidelines, consensus conferences, medical decision-aid articles, systematic reviews, meta-analyses and other assessments.
- If appropriate, more specific databases (e.g. Educational database)
- All useful internet sites (government agencies, learned societies, etc.)
- Grey literature (documents which cannot be accessed through conventional channels)
- Legislative and regulatory texts which could be related to the subject
- Cited references in the articles retrieved (manual search)
- Articles provided by the members of the working group and by peer reviewers.

Within the scope of this study, the specific sources questioned explored the fields of education, psychology and sociology in addition to the medical and scientific sources usually consulted.

► First version of the guideline

A first version of the guideline is drafted by the working group based on the evidence report and the opinions expressed during the working group meetings. Recommendations are graded based on the scientific evidence level (table 1).

This first draft guideline is then submitted to the peer reviewers.

Within the framework of this study, this first version of guidelines was also subjected to a public consultation via the HAS site (results of the opinions formalized in the appendix to the scientific evidence).

Table1. Grading of guidelines

Grade	Scientific evidence level
A	trials of a high level of evidence (level of evidence 1), e.g. high-power randomised controlled trials (RCTs) free of major bias and/or meta-analyses of RCTs or decision analyses based on level 1 trials.
B	studies of an intermediate level of evidence (level of evidence 2), e.g. RCTs with some bias, meta-analyses based on questionable methodology, well-conducted non-randomised controlled trials or cohort studies;
C	studies of a lower level of evidence, e.g. case control studies (level of evidence 3) or case series (level of evidence 4).

In the absence of reliable publications, the guidelines are based on professional agreement among members of the working group, after taking into account comments from peer reviewers and public consultation.

► Peer review group

HAS appoints the peer reviewers using the same criteria as for working group members. The peer reviewers are consulted by e-mail and give an opinion on the content and structure of the evidence report and guideline, in particular on guideline's legibility and applicability.

► Public consultation

At the request of the HAS Board, a public consultation was organized in order to gather the collective opinion of all organisations, associations or institutions²⁸ involved in the follow-up of deaf children from 0 to 6 years of age, and in the support of their families, without them having been previously identified and selected by HAS.

In order to disseminate information as widely as possible on the remit of this consultation, a press release was addressed to the main groups potentially interested in the subject, such as sign language groups, and a letter invited the principal parties identified by the working and task group "Relationships with patient and user associations", to inform their members and their various networks, if they considered it useful.

A pre-registration system open to all was set up on the HAS site six weeks before the beginning of the public consultation and until the end of it, in order to make sure that only one collective opinion by association, institution or organization would be gathered.

The scientific evidence and the preliminary version of the guidelines were made available via the HAS site for 45 days, in order to allow a debate within the various organisations, associations, or institutions. The opinion of the recipients was collected using an on-line questionnaire (see document in appendix²⁹). The questionnaire consisted of 37 questions, open and closed, in order to collect a formalised opinion and free comments relating to the overall document, then chapter by chapter.

Within the framework of this study, an additional document relating to the results of the public consultation and review group is appended [in French].

► Final version of the guideline

The working group analyses the peer reviewers' comments, amends the evidence report if necessary, and drafts the final version of the guideline and a quick reference guide (QRG), during a working session.

The final version of the evidence report and guideline and the development process are discussed by the *Committee of guidelines approval*. At its request, the evidence report and the guideline may be amended by the working group. The committee submits its opinion to the HAS Board.

► Validation by the HAS Board

Acting on the proposal from the *Committee of guidelines approval*, the HAS Board validates the final documents and authorises their publication.

► Publication

HAS makes available on its website (www.has-sante.fr), free of charge, the evidence report, the guideline and the Quick Reference Guide (QRG).

For further details on the method used to develop clinical practice guidelines, see the guide published by ANAES in 1999: *Recommandations pour la pratique clinique – Base méthodologique pour leur*

²⁸ Associations representing deaf children, professional associations, health establishments, socio-medical establishments, learned societies, public institutions, health agencies, unions, manufacturers etc.

²⁹ Document in appendix «Deafness in the child: public consultation and review group – Results relating to the initial programme of recommendations», downloadable from www.has-sante.fr

réalisation en France [Clinical Practice Guidelines – Methodological basis for their production in France]. This guide may be downloaded from the HAS website: www.has-sante.fr

Appendix 2. Defined clinical situations

These recommendations concern:

- children aged 0 to 6 years with³⁰:
 - ▶ permanent bilateral deafness, isolated or not, congenital or not;
 - ▶ a hearing threshold of > 40 dB HL, calculated according to the recommendations of the International bureau for audiophonology;
- and their families; deaf children are mostly raised within hearing families. The largest public survey, carried out with 30 000 deaf children by the Gallaudet Research Institute in the United States, showed that 91.7% of deaf children are born to parents, both hearing. In France in 1998-1999, an estimate of the number of people using sign language was 119 000 of whom 44 000 were deaf (i.e. 8% of the people having a profound or total hearing loss).

Deafness cannot be defined in an absolute way because in France there are extremely diverse social representations of deafness because of complex historical, ethical, political and regulatory factors (see scientific evidence §1.2.2).

However, in order to define the population of children to whom these recommendations are addressed, the audiophonological criteria were selected because of the effect of hearing threshold on speech perception:

- between 41 and 70 dB HL, words are perceived if the voice is raised; the subject understands better while looking at the speaker; some familiar noises are still perceived; these criteria correspond to what many publications define as “moderate” deafness³¹
- between 71 to 90 dB HL, words are perceived with a loud voice close to the ear; loud noises are perceived; these criteria correspond to what many publications define as “severe” deafness.
- 91 dB HL, words are not perceived; only very powerful noises are; these criteria correspond to what many publications define as “profound to total deafness”.

In the absence of specific actions or environment making it possible to meet the particular needs of these children, the latter develop language delay (see scientific evidence § 2.1.2). The last French survey (Handicap-Incapacity-Dependence 1998-1999) showed that 14% of cases of mild to moderate deafness, 21% of cases with moderate to severe deafness, and 56% of cases with profound to total deafness had language or speech disorders. Deafness has repercussions on learning at school and access to employment (41% of deaf children from 6 to 11 years know how to read, write, count without difficulty compared to 81% in the general population; 10% of deaf people obtain post-baccalaureate education, compared to 29% in the general population; 34% of people from 20 to 59 years of age with a profound or severe hearing deficit have a job, compared to 73% in the general population).

In addition, the clinical situations that cover the expression “deafness in children” or “deaf child” are extremely many and heterogeneous (see scientific evidence § 2):

- The incidence of permanent bilateral deafness in children is between 1 and 2 children in 1000; that is, in 2009, about 800 to 1600 new children affected per year in France;
- Moderate to profound deafness at birth is subdivided into 53% moderate deafness, 21% severe deafness, 25% profound deafness;

³⁰ Throughout the document these children are referred to as “deaf children”. The public consultation expressed the fact that a hearing threshold of between 41 and 70 dB HL cannot be considered as “deaf” as they have partial hearing. That is why they are sometimes described as “hard of hearing”. This term was not used in this document because it tends to stigmatise the person with a negative description. For partially hearing people, the term “auditory deficient” is also sometimes used.

³¹ The idea of deafness as “mild, moderate, severe or profound” correspond to audiophonological criteria based on the threshold for sound perception. They do not have any characteristics of value judgement for professionals, who use them, but are sometimes perceived as such by certain deaf people, which was confirmed at the public consultation.

- The aetiologies of deafness are many; 32.4% of bilateral perception deafness in the child is genetic in origin, 37.7% is of unknown origin and 29.8% are of prenatal, perinatal or post-natal origin, identified as non-genetic (infections, prematurity etc.);
- Deafness can be associated with other health problems, within the scope of polymorphic disorders or multiple pathologies, themselves extremely varied but little differentiated in the studies identified, which is why they are generally called “associated disorders”. This association is more common in children with moderate deafness. In 8-year-old children in the Rhone-Alpes region deafness with a hearing threshold ≥ 70 dB was identified alone in 91% of patients, whereas at less than 20 years of age, all mixed hearing thresholds, 42% of the deaf people reported other health problems.

This heterogeneous nature of the deaf population requires that the health professional adapts the evaluation and follow-up to the particular needs of each child within his/her family.

Appendix 3. Future actions or research

Analysis of the literature provided information on many areas in which clinical studies were unable to answer questions posed by parents and professionals concerning the future of deaf children.

The following actions or research will enable this knowledge to be improved and make it possible to improve practice:

- Engage epidemiological studies to describe the development of deaf children and the results obtained in common areas to the different approaches (quality of life of the child and his/her family, level of acquisition of the written language at 8 years of age, prevalence of psychopathological signs, cognitive development);
- Engage studies that will enable us to work out how parents have chosen a specific education programme, in particular specifying the real time delay between the time of diagnosis and entry into a given education programme and the reasons for selecting this programme (is it an enlightened choice or one by default, due to lack of information or availability of services);
- Developing then validating the specific evaluation methods for development of language in LSF;
- Developing the means for remote learning (internet platform) enabling families to acquire LSF or the hand-shapes for LPC;
- To carry out practical surveys in order to:
 - ▶ Evaluate the number of families with access to education approaches of their choice (audiophonic programme in French (with LPC or signed French); audiophonic programme in French and LSF; programme with visuo-gestural approach);
 - ▶ Evaluate the number of deaf children benefiting from a follow-up which observes the recommended conditions for implementation of the chosen education approach;
 - ▶ Understand the methods for evaluating the hearing of young children within the framework of individual tracking by independent professionals (general practitioners, paediatricians) or professionals in the mother and child welfare service and school medicine.

The relevance of updating these recommendations will have to be studied in 3-4 years ' time in the light of results from the studies performed.

Appendix 4. Early intervention³²

Early intervention is defined by the European agency for the development of education for people with special needs as “all the actions and measures (social, medical, psychological and educational) which it is necessary to undertake with children and their families in order to address the different needs of children at risk of delay or severe delay in their development [...]. Early intervention concerns the early years (generally 0 to 3 years), it must not be confused with the education of young children”. According to the different sources analysed, support is given to a child and his/her family until he is integrated into the school system, i.e. from birth until 6 years at the latest.

It is recommended that the teams proposing the early intervention programmes support the families with a multi-disciplinary team from the time of the pronouncement of the diagnosis.

In accordance with European recommendations:

- early intervention is provided at the request of the family; to satisfy the particular needs of the child and of his/her family “implying that early intervention cannot be imposed on the families, but it must guarantee the right of the child to be protected. The rights of the children and the families must converge”;
- early interventions, whether carried out in a specialized centre or within an independent framework, must be formalized in a follow-up program personalized for the child and his/her family and discussed and written by the professionals with the parents. This should comprise the objectives, the actions provided and the evaluation procedures. This personalised program takes account of the parents’ training programme. This latter can evolve over time (training with “communication in French”, possibly with the assistance of LPC or training with “bilingual communication, French sign language and French”);
- Early intervention programmes must be made available to families free of charge.

In France, this free access can be proposed by dedicated institutions (e.g. CAMSP, SAFEP, SEFISS, etc) or via the disabled compensation service delivered by the MDPH (e.g. training in LPC or sign language for the families).

In the international publications relating to the early interventions provided to deaf children, all the teams detailing the content of their interventions, except one, make available to the families interventions in spoken language and sign language (see scientific evidence § 6.1). The choice of language, spoken language of the country and/or sign language is a parental decision. The activities suggested are usually weekly.

³² The recommendations presented in this appendix obtained 85% - 95% favourable opinions during the review phase and were modified after taking into account the remarks from the review phase and the public consultation, to form a consensus within the working group.

Appendix 5. Different possible approaches for early intervention programmes in deaf children.

Education project	«Communication in French» education		«Bilingual communication, LSF and French » education	
Objective	Acquisition of French		Acquisition of 2 languages: LSF and French ¹	
First language(s) provided prior to 3 years of age	Spoken French		Spoken French and LSF	LSF
Principal means of verbal communication used before 3 years of age	Interactions in spoken French ± LPC code ²	Interactions in signed French ³	Interactions in spoken French and LSF alternately	Interactions in LSF
Types of early intervention programmes	Programme with LPC	Programme in signed French	Audiophonic programme with LSF	Visuo-gestural programme
	Audiophonic approach			Visuo-gestural approach
Implementation principle	To stimulate the auditory pathways			To stimulate the visual pathways

¹ French is provided with the two modalities (spoken and written) within the framework of an audiophonic approach, whereas in a visuo-gestural approach French is addressed mainly by written French.

² LPC: French cued speech

³ Signed French: spoken French simultaneously accompanied by isolated signs from LSF (equivalent to Signed English)

Table 2. Objectives of early intervention programmes depending on the approach chosen, audiophonic or visuo-gestural

Types of early intervention programme		Recommendations			Visuo-gestural approach
		Audiophonic approach			
		Programme with LPC	Programme in signed French	Audiophonic programme with LSF	
OBJECTIVES BEFORE 3 YEARS OLD	A. To encourage situations of communication	Multi-modal communication: to maintain and develop all forms of verbal or non-verbal communication from the different sensory afferents (visual, tactile, proprioceptive and auditory)			Multi-modal communication and use of LSF in all everyday situations
	B. To encourage the understanding of spoken language	<ul style="list-style-type: none"> - Hearing aids: recommended in the 3 months following diagnosis in all children with a hearing threshold > 40 dB HL. This time period can be extended to 6 months if the diagnosis is made before the age of 6 months, especially if deafness is moderate (threshold between 40 and 70 dB HL). - Cochlear implants: within the framework of congenital or acquired deafness, before the development of spoken language, information about the possible indications, results and complications of a cochlear implant (see appendix 6) is recommended before the child is 18 months old and as early as possible if the child is older, because the results will be better if implantation takes place before 2 years old (grade C). - Hearing training: 2 to 4 weekly sessions by a specialised professional are recommended depending on the hearing threshold. 			Is not one of the objectives
	1. To stimulate the development of auditory function depending on the hearing assessment				
	2. To develop lip reading	Sense decoded thanks to simultaneous codes from French cued speech (LPC) (French vocabulary and syntax)	Sense supported by simultaneous signs borrowed from LSF (LSF vocabulary, French syntax)	Sense supported by a delayed explanation in LSF (LSF vocabulary and syntax)	

Table 2. Objectives of early intervention programmes depending on the approach chosen, audiophonic or visuo-gestural (continued)

		Objectives			
Types of early intervention programme		Audiophonic approach			Visuo-gestural approach
		Programme with LPC	Programme in signed French	Audiophonic French with LSF	Visuo-gestural programme
OBJECTIVES BEFORE 3 YEARS OLD	C. To encourage expression in spoken language	Orthophonic retraining sessions several times a week centred on the word and lexical and syntactical acquisition of the French language			Is not one of the objectives
	D. To encourage the understanding of sign language	Is not one of the objectives		<ul style="list-style-type: none"> - To propose to the child a playing and meeting space where activities in sign language take place individually and in groups for at least 5 hours per week, by deaf or hearing interlocutors qualified in this language and if possible, with experience of teaching this language to young children - To integrate within the reception teams qualified deaf professionals, trained in teaching language and in the relationship and educational aspects - to propose to the parents and siblings courses in LSF or support in communication in real situations in the child's normal environments 	
	E. To encourage expression in sign language				
	F. To encourage the gradual learning of written language	As with all children, to gradually introduce writing in the French language depending on age through everyday situations (reading stories, hand-writing, etc.)			

Appendix 6. Indications for cochlear implants

This appendix presents the indications for cochlear implants such as defined in 2007 by HAS within the framework of an evaluation of the expected benefit of these professional procedures and medical devices. This evaluation was carried out in order to deliver a notice relating to the registration of these activities under the Classification Commune des Actes Medicaux (CCAM), the list of reimbursable medical procedures and the list of reimbursable products and services (LPPR). Extracts from this evaluation of medical technologies concerning children, are reproduced below³³. "Cochlear implants are indicated in the event of severe to profound bilateral neurosensory deafness. These indications are defined by precise audiometric characteristics. Implantation is unilateral, except in particular pre-defined cases.

Installation of an auditory implant is systematically preceded by a test of the prosthesis carried out under the best conditions. A decision on whether or not to install a cochlear implant can be based on the results of this test and if audiophonic rehabilitation is chosen [...].

Indications in the child

- Age of implantation
 - ▶ In prelingual deaf children, implantation must take place as early as possible. Early implantation gives better results in understanding and production of the language, which is faster than if implantation is delayed.
 - ▶ Above 5 years of age, in cases of non-evolving profound or total congenital deafness, there is no indication (except in particular cases) except if the child develops a desire for oral communication.
 - ▶ If the child is entered onto an oral communication (programme), he can benefit from an implantation whatever his/her age. [...]
- Audiometric indications for implantation
 - ▶ In cases of profound deafness, cochlear implantation is indicated when the gain from the prosthesis does not allow language to develop.
 - ▶ In cases of severe deafness, cochlear implantation is indicated when discrimination is less than or equal to 50 % when vocal audiometry tests appropriate for the child's age are carried out. The tests must be carried out at 60 dB, in an open space, with well-adapted prostheses.
 - ▶ If there are fluctuations, a cochlear implant is indicated when the criteria cited above are present many times per month and/or when fluctuations impact language development in the child.
- Indications for bilateral implantation
 - ▶ Causes of deafness which risk being accompanied in the short term by bilateral cochlear ossification, especially bacterial meningitis or bilateral petrous bone fracture. Intervention must occur before the ossification becomes too advanced.
 - ▶ Usher's syndrome (autosomal recessive hereditary disorder associated with ocular and auditory problems) in children.

Results

- Efficacy

In children, an improvement in hearing is recorded in auditory capacities, linguistic capacities and spoken communication. Progress based on these criteria is significant during the months following implantation and is long-lasting.

- Safety

Analysed in over 2000 patients, the rate of complications is low (less than 5 %). The most serious complication reported is bacterial meningitis, for which prophylactic measures have been put in place (pre-operative anti-meningococcal vaccination). The other complications are less serious (problems with the skin flap, migration of the electrodes, paralysis of the facial nerve...).

- Results of reimplantations

Re-implantation may be indicated in cases of implant dysfunction. It does not expose the patient to more complications than the primary implantation. Performances obtained at the time of the primary implantation are maintained.

Extension of indications

Well-conducted comparative studies are still necessary to evaluate provision of implants to patients with less serious deafness, as well as (to evaluate) the interest of bilateral implantation in other circumstances to those recommended.»

³³ The entire best practice guide, as well as the complete evaluation report and its summary are downloadable from http://www.has-sante.fr/portail/jcms/c_559051/traitement-de-la-surdite-par-pose-dimplants-cochleaires-ou-dimplants-du-tronc-cerebral

Appendix 7. Information before diagnosis³⁴

Before pronouncing a diagnosis of deafness, health professionals should clearly distinguish between two situations:

- The situation in which the professionals suggest to the parents a screening test for deafness in their child (situation where the parents have not considered the possibility that their child does not hear well);
- The situation in which the parents wish to know if their child can hear well, because his/her behaviour appears to them to be unusual (e.g. parental request to a doctor).

► Information within the context of screening

It is recommended that information delivered within the framework of screening is given by a health professional with specific training, taking into account relationship and psychological aspects and not just techniques of the screening procedure.

➤ Before birth (8-month visit)

It is recommended that pregnant mothers are informed about the different screening methods carried out in maternity on all newborns. The aim of neonatal screening for deafness is to provide reassurance that the newborn hears well.³⁵

➤ On the maternity ward

Before carrying out the test, it is recommended:

- ▶ to inform one, and if possible both parents about the existence of screening to investigate auditory function: «I suggest that we check that your child has good hearing like we do for all newborns»,
- ▶ to give them an information pamphlet,
- ▶ to explain how the test is done “ the test does not hurt; it is carried out when your child is sleeping or calm (after a bath or feeding); a probe is placed in the ear or electrodes are placed on the skin; in a few minutes, the apparatus automatically registers the responses of the ears”,
- ▶ to invite the parents to help at the test “ If you wish, you can assist during the test”,
- ▶ to inform the parents that they will receive the test results from the ward doctor before discharge. “The doctor will confirm before discharge if the test is conclusive, that is, if it confirms that your child’s hearing is good, or if the test is not conclusive, that is, that it does not currently permit a conclusion that your child’s hearing is good”.
- ▶ to inform the parents of the possibility of a second test before discharge from the maternity ward if the 1st test is inconclusive: “In the situation where the first screening test is not conclusive, which can happen as the equipment is sensitive, if the child moves or wakes, or if there are secretions in the ear, a second similar test will be carried out before discharge”
- ▶ to ask the doctor to meet the family if they have additional questions
- ▶ to inform (the parents) that the test is not compulsory
- ▶ to obtain oral consent from one and if possible both parents, before proceeding with the test and to record possible refusal by the parents “Do you agree for me to check that your child’s hearing is good?”.

³⁴ The recommendations presented in this appendix obtained 69 % - 96 % favourable opinions during the review phase and were modified after considering the comments from the review phase and the public consultation forming consensus within the working group.

³⁵ The objective of these recommendations is not to determine the relevance of neonatal screening for deafness, but to propose recommendations about delivery of information when screening has been proposed (e.g. neonatal screening experiments, screening targeted during risk situations for the child, etc.)

It is recommended that the maternity ward doctor automatically gives the screening test results to the parents before the newborn is discharged, as well as to the child's general practitioner.

As soon as the neonatal screening test results are announced:

- 1st situation: the test confirms the newborn's hearing is good (conclusive test). It is recommended to the doctor giving this result to carefully alert the parents to the fact that hearing problems can arise secondarily. « Your child's hearing is good, however, remain vigilant throughout his/her childhood as hearing can change over time. Do not hesitate to ask if in doubt.»
- 2nd situation: the test does not enable a conclusion to be made straight away that the newborn's hearing is good (non-conclusive test).
- After having carried out a monitoring test before discharge from the maternity ward, it is recommended that the doctor delivers this result :
 - ▶ to reassure the parents: « The test did not enable us to clarify the quality of your child's hearing. This type of situation is common as the test is very sensitive to the child's movement, external noises, the presence of secretions behind the tympanic membrane.»
 - ▶ to suggest a meeting in infant audiology in order to carry out an in-depth hearing test on the newborn,
 - ▶ to respond objectively to questions posed by the parents, as some parents will raise the possibility of deafness ;
 - ▶ to give contact details of a professional who can be contacted if the parents wish to obtain additional information after discharge from the maternity ward,
 - ▶ to inform the parents about the methods for the in-depth assessment (clinical examination, diagnostic evoked auditory potential, behavioural audiometry). Certain examinations require that the child is asleep, it is therefore useful to make provision for time (2 to 3 hours), bottles and changes.

▶ **Information in the event of a parental request to see a doctor**

If the parents have any doubt about the hearing of their child, a complete hearing assessment by a doctor with expertise in infantile audiology is recommended. A neonatal screening test concluding that hearing is normal should not delay a rigorous secondary clinical hearing examination; this should take into consideration possibilities of visual or proprioceptive compensation already acquired by the child.

Appendix 8. Pronouncement of the diagnosis³⁶

Whatever the process which concludes with establishment of the diagnosis, and whatever the hearing threshold of the child, the pronouncement of the diagnosis of deafness is an event, whose effect is often traumatic and lasting in all the parents. Even if it is news which is easily accepted by some deaf families, it is more often a difficult news for the vast majority of parents to receive and difficult for many professionals to pronounce. The pronouncement must therefore obey precise rules.

It is recommended that:

- The diagnosis of deafness should be pronounced by the doctor who carried out the diagnostic test; this doctor must have also trained both in relationship and technical aspects, in particular how to deliver a positive message about the competences of the child and his/her family to communicate, and about experience with deafness;
- The pronouncement should be carried out in a favourable environment, considering the following general principles:
 - ▶ Ensure confidentiality, and sufficient time and means not to be disturbed;
 - ▶ Announce the diagnosis during a one-to-one discussion, as far as possible in the presence of both parents,
 - ▶ Announce the diagnosis in a simple and precise way: «As you know, we have tested your child's hearing and the results indicate deafness»;
 - ▶ Listen to the parents and answer their questions without seeking to give additional detail initially, just the means of supporting the parents in a way that is appropriate to their particular needs: «I will have a lot of information to give you but for now what questions would you like to ask me?»,
 - ▶ Encourage the parents to express their feelings, now or later,
 - ▶ Answer with warmth and empathy, but do not seek to diminish the information, as each parent will have to make their own emotional adjustment to the situation,
 - ▶ Address the child as well and observe him with his/her parents to promote his/her relationship abilities and to help his/her parents to assume their role as parents, « Your deaf child is above all a child, he needs you like any child; your child has not changed, continue to communicate with him through words, looks and touch»,
 - ▶ Suggest a second meeting soon (i.e. in a few days or even one or two weeks later), if possible in the presence of both parents, during which additional information can be provided.

The pronouncement of the diagnosis is not the time where decisions about the training programme should be taken: it is recommended that the parents are given time before committing to decisions of the future, in particular if the diagnosis is made during the first year of life.

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The recommendations presented in this appendix obtained 83 % - 89 % favourable opinions during the review phase and were modified after considering the comments from the review phase and the public consultation forming consensus within the working group.

Appendix 9. Local availability of services³⁷

It is recommended that parents are informed or assurances sought that they have retained the information, and that they be given contact details in writing of locally available services or professionals³⁸ enabling parents to be supported and children followed-up, in particular the contact details of:

- professionals or institutions proposing early intervention programmes (CAMSP, SAFEP, SEFISS, socio-medical establishments, etc.) in each approach (audiophonic approach, auditory oral with or without LPC, oral education with signed French or with LSF; visuo-gestural approach with LSF);
- information centres on deafness;
- associations of parents of deaf children and deaf people; it is advisable to leave the timing of this meeting to the families;
- professionals or institutions enabling parents or children to obtain psychological support;
- professionals or institutions enabling audiophonological follow-up of the child (independent or salaried ENT specialists with competency in infant audiophonology)
- professionals or institutions enabling acquisition of hearing aids (hearing prosthesis with experience in the follow-up of deaf children) or technical aids enabling the environment to be adapted to the child;
- places or establishments where the child, before schooling, and his/her parents, if necessary, can experience a social environment where sign language is used (nursery assistant or nursery using sign language, meeting place for deaf and hearing parents, sign language course, etc);
- professionals or institutions (social service assistant) allowing the parents to obtain financial assistance adapted to the particular needs of the child, in particular, for the acquisition of technical aids or the financing of sign language or LPC classes in accordance with the regulations in force;³⁹
- places where health professionals used to the follow-up of deaf children practise (e.g. hospital unit receiving and caring for deaf patients, independent professionals, etc);
- classes, schools or specialised establishments, at the time of schooling;
- specific services such as LSF interpreters or LPC coders.

³⁷

This appendix obtained 83 % favourable opinions during the review phase and was completed after considering the comments from the review phase and the public consultation forming consensus within the working group.

³⁸ If services are not locally available, it is appropriate to provide the contact details of professionals or services available on a departmental, regional or even national level.

³⁹ Decree of 24 April 2002 relating to conditions granting six categories of additional allowance for special education

Appendix 10. Supporting the families⁴⁰

It is recommended that support for the families aims for the following objectives in order to respond to the different aspects of parenthood with a deaf child.

► To be the parent of a deaf child is above all to be a parent

- Give a positive vision of the deaf child's competences and his/her future. Qualitative investigations with parents of deaf children show that the presentation of deafness by professionals as a positive source of new perspectives forms a part of the factors which have assisted parents in their experience of parenthood (see scientific evidence § 2.1).
- Reassure the parents because what they will have to know and do will remain within the scope of competences of what all parents usually do. Identifying with the parents the progress noted at home as time goes by in all the areas of development of the child will reassure parents about the situation; recording by the professional together with the parents helps to objectify the progress made and set milestones for the overall development of the child.
- Encourage dialogue with the parents in order to help them to balance their various roles with respect to the child, and to encourage them to share their experiences and to ask questions. This facilitates partnership relationships between parents and professionals and not dependency relationships.
- Inform the parents about the choices possible, depending on the particular needs of their child (audiophonic or visuo-gestural approach, methods of schooling possible, etc), in order to enable the parents to make enlightened choices necessary for the education of their child.
- Support the parents in their choice and give them the ability to adapt their education project by regularly informing them about the overall progress of the child, and specific progress in communication and acquisition of the language(s) provided.

► To be the parent of a deaf child, one must develop specific parental abilities

- Help the parents to develop parental competences specific to the particular needs of their child:
 - Arrange and adapt the physical, social and linguistic environment of the child to encourage his/her emotional and multisensory development (e.g. maximally open up the space visible to the child, place yourself if possible at the height of his/her gaze, establish visual contact before expressing yourself, reduce the background noise, utilise the information perceived by touch, vibrations etc),
 - Maintain the spontaneity and pleasure of interaction,
 - Become aware of the wealth of visual information, in all forms, to locate, indicate, share and interact,
 - Facilitate shared auditory and visually attentive situations, and lip-reading,
 - Develop methods of communication within the family which facilitate interaction and prioritise the meaning of messages, and do not intrude or focus on correcting messages delivered by the child,
 - Depending on the training programme used by the parents, learn the hand-shapes of LPC (cued speech) or French sign language,
 - Spot the situations in which strategies different to those proposed to hearing children necessitate early implementation due to deafness (e.g. strategy in the case of danger, if hearing perception does not enable the child to be called from a distance; take care not to keep the child away from others, in the family, or any other situation, where more than 2 people are speaking at the same time or not expressing themselves in his/her field of view), or due to using a badly mastered language, or disagreement between children and parents.

► There are many ways to be a parent

- Respecting the fact that there are many ways to be a parent requires adaptation of the actions proposed to the individual situation in each family. The way to be a parent builds over time and

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This appendix obtained 67% - 98% favourable opinions during the review phase and was modified after considering the comments from the review phase and the public consultation forming consensus within the working group.

depends on emotional and psychosocial factors and past memories prior to the child's birth, the values, culture and priorities of the parents, the socio-economic circumstances and the perspective which the parents have of deafness.

- Encourage communication between parents and children, as far as possible through a common language, in order that the values and culture of the family can be conveyed to the child by his/her own parents. This is particularly important for parents of deaf children whose language is not that of the country in which they are living (e.g. immigrant families).
- Adapt the actions proposed to the individual situation of each family, taking care to consider the parents' economic situation in order not to impose on them a rate of follow-up and support that could worsen their economic difficulties. It is recommended that they be informed about social benefits which they can claim from the perspective of developing specific parental competences (e.g. financing of courses in LSF or LPC using benefits proposed by MDPH⁴¹).

► **To be the parent of a deaf child is to be in contact with many professionals**

- Help the parents in their approach by explaining to them the roles and training of the different professionals who follow up the child, the institutions (e.g. role of the MDPH) and the possible services (e.g. interpreter, LSF or LPC courses, etc.).
- Facilitate contacts between the family and the child's peers (deaf children or adults).

One of the consequences of deafness in children is that parents are put in contact with many professionals, and possibly with a community which uses another language from themselves, a situation which they would probably never have met before if their child did not have special needs.

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In accordance with the decree of April 24, 2002 (Special Educational Needs and Disability Act) relating to the conditions for allocation of the six categories of additional allowance for special education, the additional allowance for education of the handicapped child can cover the expenses of training of family members in certain techniques (sign language training courses, work on communication...) insofar as they come within the framework of the personalised programme for the child and of the recommendations of the Committee for the rights and autonomy of disabled persons (CDAPH)

Participants

The following learned societies and professional associations were asked to participate in compiling these guidelines and to provide names of participants in the various groups below:

- Association «Action Connaissance Formation pour la Surdit  » (Association for Action, Understanding, Training for Deafness)
- Association nationale des   quipes contribuant    l'action m  dico-sociale pr  coce (National Centre for early socio-medical action- CAMSP)
- Association nationale des parents d'enfants sourds (National association of parents of deaf children)
- Association R  seau d'actions m  dico-psychologiques et sociales pour enfants sourds (Association Network of medical, psychological and social activities for deaf children)
- Centre technique national d'  tudes et de recherches sur les handicaps et les inadaptations (National Technical Centre on Handicaps, CTNERHI)
- F  d  ration fran  aise de psychiatrie (The French Federation of Psychiatry)
- F  d  ration nationale des sourds de France (The French National Federation for the deaf)
- Minist  re de la Sant   (Ministry of Health)
- Minist  re de l'  ducation Nationale (Ministry of National Education)
- Soci  t   fran  aise d'ORL et de Chirurgie Cervico Faciale (French Society for Otorhinolaryngology – Head and Neck Surgery)
- Soci  t   fran  aise de P  diatrie (French Society of Paediatrics)
- Soci  t   fran  aise de psychologie (French Psychological Society)
- Structure d'accueil et soins en langue des signes (Institution for welcome and care in sign language)
- Union Nationale des Associations de Parents d'Enfants D  ficients Auditifs (National Federation/ Union of Associations for parents of hearing impaired children)
- Union nationale pour l'insertion sociale des d  ficients auditifs (National Union for social inclusion of the hearing impaired)
- Union Nationale pour le D  veloppement de la Recherche et de l'  valuation en Orthophonie (National Union for the development of research and evaluation in speech therapy)

A public consultation was set up to enable all the associations, institutions or organisations to participate in the review phase of the guidelines via a questionnaire made available on the internet (to find out which organisations participated, see document in appendix «Deafness in the child: public consultation and review group- Results concerning the initial programme of recommendations » downloadable from www.has-sante.fr).

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Objectives(s)	<p>To encourage access to language by the deaf child within his/her family, whichever language is chosen (French language or sign language). The questions which the recommendations answer are the following ones:</p> <ul style="list-style-type: none"> • What information should be given to the families and how can their neutrality and completeness be guaranteed faced with the multiple representations of deafness and follow-up of the child? • What actions should be provided to support the families after the pronouncement of deafness? • How can one help the parents to be key players in the follow-up and support of the child? • How can one prevent psychological and relationship problems in the deaf child? • How can one evaluate communication and language in the deaf child? • What actions should be proposed to develop communication and language in the deaf child, whatever language is used: sign language or French language? • In 2009, which institutions provide family support and follow-up of deaf children between 0 and 6 years of age?
Population concerned	Children between 0 and 6 years of age with permanent bilateral deafness with a hearing threshold of > 40 dB HL.
Professional(s) concerned	Professionals involved in family support and follow-up of deaf children between 0 and 6 years old, especially health professionals: hearing-aid specialists, ENT doctors and surgeons, speech therapists, paediatricians and general practitioners, child psychiatrists and other professionals : educators, teachers, psychologists.
Requestor	Ministry of health, youth, sports and community life (Directorate General for Health)
Sponsor	Haute Autorité de Santé (HAS), Guidelines Department
Funding	Public funds
Project management	<p>Coordination: Ms Joëlle André-Vert, project manager, HAS Guidelines Department (head of department: Dr Patrice Dosquet)</p> <p>Secretarial services: Ms Laetitia Cavalière and Ms Émilie Costa</p> <p>Literature search: Ms Gaëlle Fanelli, with the help of Ms Julie Mokbhi and Ms Yasmine Lombry (head of the Documentation Department: Ms Frédérique Pagès)</p>
Participants	Learned societies, steering committee, working group (chair: Prof René Dauman, ENT, Bordeaux) peer review group: see list of participants.
Conflicts of interest	HAS received declarations of interests from the members of the steering committee and working group (see www.has-sante.fr). These were analysed in accordance with the topics of the guidelines. The interests declared by the working group members were considered compatible with their participation in this study.
Literature searches	Covering the period from January 2000 to September 2009 (see literature search strategy in evidence review)
Authors of the evidence review	Ms Joëlle André-Vert, HAS project manager, La Plaine Saint Denis Ms Marie-Thérèse Le Normand, Project Authority, Research Director, INSERM, University Paris Descartes, Laboratory of Cognitive Psychology and Neuroscience (C.N.R.S)
Validation	Notice of the Guidelines approval committee Validated by the HAS Board on December 2009
Updating	Relevance of updating to be considered in 2013
Other formats	The summary of the guideline and the evidence review may be downloaded from www.has-sante.fr
Supporting documents	«Deafness in the child: public consultation and review group- Results concerning the initial programme of recommendations», downloadable from www.has-sante.fr

