HAUTE AUTORITÉ DE SANTÉ

QUICK REFERENCE GUIDE

Deaf children: family support and follow-up of children aged 0 to 6 years

- Provision made within schools excluded -

December 2009

OBJECTIVES

- To maintain and develop all forms of communication, verbal or non-verbal, between the deaf child[1] and those around him
- To encourage the development of the deaf child's language within his/her family, whichever language used, French or French sign language (LSF)
- To prevent mental health disorders in the deaf child

Except if the grade is specified, this guideline is based on expert consensus within the working group following comments of the members of the peer review group and participants in the public consultation.

GENERAL KEY POINTS

- Due to the fact that the population of deaf children and their families are heterogeneous, individual follow-up and support are necessary.
- «During the education and schooling of deaf children, freedom of choice between a bilingual communication, French sign language and French, and a communication in French, is a right» (Law no. 2005-102).
- In order to act in the best interests of the child, due to the social representations' diversity of deafness in France - because of complex social, historic, ethical, political and regulatory factors - it is necessary that everyone considers his/her own deafness representation and that of his/her interlocutors in order to ensure a quality interaction.
- Access to various early intervention programmes, audiophonic or visuo-gestural must be supported within each health administration region, in order to respect the right for parents to choose between a bilingual or monolingual education project.

WHEN SHOULD AN INTERVENTION PROGRAMME BE INTRODUCED?

An early intervention programme for all children and their families should be provided before the child reaches 1 year of age (grade B).

This programme should be adapted to the particular needs of the child and the education project chosen by the parents.

When implementing early intervention programmes, a place should routinely be given to parents.

Particular attention should be paid to brothers and sisters, to whom specific support must be provided if necessary.

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[1] Deaf child: child with permanent bilateral deafness with hearing threshold > 40 dB HL, whatever the cause.

WHICH EARLY INTERVENTION PROGRAMME SHOULD BE IMPLEMENTED ACCORDING TO THE PARENTALEDUCATION PROJECT?

The different early education programmes

Before 3 years of age, there are two early intervention approaches (audiophonic and visuo-gestural). These are fundamentally different in that they either do (audiophonic) or do not (visuo-gestural) stimulate the auditory pathways as early as possible, in order to promote the development of spoken French.

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

- to reinforce the correct skills within the family;
- to maintain and develop all forms of communication, verbal or non-verbal, between the child and those around him;
- to promote the development of at least one language, French and/or LSF;
- as with any child, to gradually introduce written French, especially starting with everyday situations (reading stories, hand-writing, etc.).

Education with «Communication in French» may be provided in two forms, depending on the main types of communication used prior to 3 years of age: French supported either by French Cued Speech ([in French: langue parlée completée] LPC) or by signed French.

Education with «Bilingual communication», and thus LSF acquisition, can be considered within the framework of the two approaches. The prejudice that early acquisition of sign language delays the acquisition of spoken language has not been scientifically validated (absence of controlled studies).

Table 1. Choosing an early intervention programme according to the parental education project

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)

From the current state of knowledge, and in the absence of consensus between stakeholders, it is not possible to recommend one type of early intervention programme above another for children with a hearing threshold of > 70 dB HL.

KEY POINTS

INFORMING PARENTS TO ENABLE THEM TO CHOOSE AN EARLY INTERVENTION PROGRAMME

It is recommended that parents are informed clearly about the following points:

- The level of spoken language or sign language obtained mainly depends on these 3 factors: the language used at home with the child according to education project of the parents, the hearing threshold of the child (for spoken language) and the presence or absence of associated disorders.
- Stimulation and auditory training before the child is 2 makes it possible to attain a higher level of spoken language than that obtained by children who have not had the benefit of stimulation and hearing training before this age.
- A linguistic environment in sign language proposed before 5 years of age makes it possible to attain a higher written level and sign language level than that obtained by children without associated disorders for whom sign language is proposed after 5 years of age, when spoken language is not acquired.
- The vast majority of deaf children with a hearing threshold of < 70 dB HL acquires and exclusively uses a spoken language. On the other hand, deaf children with a hearing threshold of > 70 dB HL acquire and use either:
  - a spoken language exclusively,
  - for the majority of them, two languages (spoken language and sign language),
  - sign language exclusively.

Main recommendations specific to an audiophonic approach

Arbitrary or iconic gestures (cued speech, isolated LSF signs, family codes) should be provided in support of oral: early intervention programmes to deaf children should no longer be provided exclusively in spoken French without the support of additional gestural back-up.

Parents who have chosen a cued speech programme should be suggested that they learn the LPC hand-shapes and use them at home, if possible before the child starts school (grade C).

Auditory pathways should be stimulated using conventional bilateral amplification devices, in any child with permanent bilateral deafness whose hearing threshold is > 40 dB HL in the 3 months following diagnosis (or before 1 year of age if the diagnosis is made in the first 6 months of life).

Possible parental fear of encountering difficulties of acceptance within the family or social group should be taken into account, as the hearing aids make the deafness visible, when it was not previously so.

When the child presents with criteria indicating the possibility for a cochlear implant[2], in cases of congenital deafness or deafness acquired before the development of spoken French, the parents should be informed before the child reaches 18 months of age, and as soon as possible if the child is older, that:

- the cochlear implant offers the possibility of stimulating auditory function,
- the anticipated impact on auditory perception and spoken language development will be better if the implant is inserted before the child is 2 years old (grade C).

Auditory training should be provided by a specialist professional twice a week if the hearing threshold is < 70 dB HL, 3 to 4 times a week if the hearing threshold is > 70 dB HL, to develop interest in, then knowledge of the world of sound (daily noises and voice recognition).

The expressive abilities of the child should be developed by working specifically on breathing and voice control and by encouraging the child's expression in spoken French during everyday activities.

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[2] See annexe 6 of the guideline to understand the indications for cochlear implant.

- **Main recommendations specific to a visuo-gestural approach**

Communication from the different sensory afferents that remain functional should be given priority, especially visual and not from deficient afferents.

Play activities and encounters in LSF should be provided in the child's living places, at least for 5 hours per week, if possible by different people, deaf or hearing.

Qualified deaf professionals trained in teaching the language and in relationship and educational aspects, should be part of the reception teams.

In order to place the deaf child in an LSF environment with equivalent conditions of stimulation, transmission and language communication with respect to spoken French as those provided for an ordinary child, it is necessary:

- that those with whom the child interacts, especially his/her parents, brothers and sisters or nannies, know or learn this language;
- to check whether or not the family should be given assistance in learning this language, and especially to distinguish whether the family that signs, uses signed French or LSF;
- depending on the situation and as a function of the identified needs, to provide the family LSF with courses or support in communication in real situations in the child's daily life environments.

HOW CAN COMMUNICATION AND LANGUAGE BE EVALUATED?

The deaf child's communication and language should be evaluated every 6 months up to 3 years of age, then every year, by mean of standardised tests if they exist, adapted to the child's development.

The evaluation should be carried out in each language provided to the child and should ensure that the follow-up enables assessment of how the child's abilities have developed at least in the following areas:

- communication during everyday activities;
- understanding of words and syllables, signs, phrases and stories;
- expression of words and syllables, signs, phrases and stories.

The family should be explained to the possible delay in the acquisition of spoken French compared to the norm in hearing children, in the case of an audiophonic approach.

Parents should be alerted if this delay increases during the course of the follow-up, and then propose additional assessments in consultation with teams specialised in developmental disorders and consider if there is a need for adapting and/or changing the linguistic programme.

WHAT SUPPORT AND INFORMATION SHOULD BE GIVEN TO THE PARENTS?

Initially consider the need for information relating to the overall development of the child, as is provided for all children: taking care of a deaf child within his family, is above all taking care of a child.

When a professional addresses a deaf person (child or parent):

- he/her should as far as possible address them in the language used by the addressee: it may be necessary to resort to an interpreter if needed;
- he/her should ensure that conditions are favourable for quality communication with a deaf person.

The information given to parents should be supplemented with suitable information for the child, according to his/her age and cognitive development. Special attention must be paid to the siblings and specific information may be provided to them.

SUPPORT ADAPTED ON A CASE BY CASE BASIS

Supporting the families requires the intervention of many professionals and civilians (parents' social network, associations) in order:

- to convey a positive vision of the deaf child's abilities and future;
- to encourage the parents to share their experiences and ask questions, in order to facilitate partnerships between parents and professionals and not dependent relationships;
- to inform and support the parents in their choice, and give them the means to adapt their education project by regularly informing them about the overall development of their child and the specific development of acquisition of whichever language or languages is/are provided;
- to help parents to:
  - develop specific parental competences necessary for the deaf child;
  - know what local resources are available (associations and services) and understand the procedure by explaining the different roles and training of the professionals or institutions.

HOW CAN POSSIBLE MENTAL HEALTH DISORDERS BE PREVENTED IN THE CHILD?

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 may cause relationship difficulties or reactional behavioural problems.

Whatever the hearing threshold of the child, one should be vigilant in order to detect as early as possible the appearance or presence of behavioural problems or mental disorder.

WARNING SIGNS

The following non-specific signs can reveal difficulties, even psychological suffering in the deaf child:

- gaze disorders (fleeting or too persistent),
- frequent unexplained tears,
- deterioration in psychomotor development,
- sleep problems (difficulties falling asleep) or appetite disorders,
- delay in achieving toilet-training,
- withdrawal, sadness or agitation,
- separation anxiety in excess of the normal period,
- a persistent delay in language acquisition,
- attention disorders,
- a sudden or progressive change in behaviour, relationship difficulties with children of the same age.

In the case of recently observed behavioural or psychological disorders:

- monitor the child's hearing and adaptation to his/her environment (change in the hearing threshold, adaptation and functioning of equipment, school adaptation, especially with inclusion, etc.);
- if need be, refer the child and his/her parents to a psychologist or psychiatrist, if possible one who knows deafness specificity. When the main language used by the child is LSF, recourse to a team using this language is recommended.

Facilitating the acquisition of a common type of communication, either spoken or signed, between deaf children and their hearing or deaf parents is associated with better psychological development of the deaf child (grade C).

WHAT ARE THE PLACES FOR MEETING, SUPPORT AND FOLLOW-UP?

There are numerous places (medical, socio-medical, social organisations, independent professionals associations, etc.) for meeting, support and follow-up. The diversity of institutions and services is necessary to enable the support and follow-up to be adapted according to the particular needs of the child and education project.

Within each institution and region, the provided approaches and the specific programmes available to the children or families should be identified. A national census of the institutions would be useful.

The coordination between the early intervention programmes and the child's living and schooling environment should be organised in order to ensure continuity of communication between the professionals either within an organisation, through an informal network or an outpatient seting.

This document presents the essential points of the clinical practice guideline:
«Deaf children: family support and follow-up of children from 0 to 6 years, provision made within schools excluded »
- Clinical practice guideline – December 2009.
This guideline [in English] and the evidence report [in French] are available for consultation in their entirety at **www.has-sante.fr**