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SYNDROME AND INTERVENTION GUIDES (O2)

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SYNDROMES

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1. Severe Autism

Communication strategies

Children with a severe autism spectrum disorder can have serious speech alterations or total lack of speech. In addition, their ability for communicative intention is low or non-existent, which can cause considerable problems to teach the communication strategies. Despite that, their level of language comprehension is usually better than the language expression.

In this regard, the stimulation by speech therapists or specialists in language disorders is recommended.

The intervention strategies which should be taken into account are:

- In the case of people with a low level of communicative intention, work in parallel to establish it.
- It is basic and essential to know those stimuluses which motivate the child in order to use them as positive behavioural reinforcements.
- We must have a list, as large as possible, of reinforcements and check that the child's pleasures have not eventually changed.
- Overinterpret signs of affected people. React to their movements, actions, indications, looks, sounds or vocalizations to give them a communicative sense, relating it to the context of the present situation.
- Use **Augmentative and Alternative Communication Systems (AAC systems):** forms of expression different from spoken language, which aim to increase the communication skills or compensate (alternatives) the communication and language difficulties of many disabled people.
- Adapt the various symbol systems depending on the characteristics of each person (according to their cognitive, linguistic and motor skills). Depending on the development level of the AAC systems, we can use anything from tiny objects or photos of real objects to pictographs.
- Positively reinforce all starts of communication and the use of AAC systems.
- We will promote communication learning if they find it easy and it is carried out in natural contexts.
- Take advantage of the spontaneous appearance of any sign or gesture to refer to an object or an action. These are not incompatible with the AAC system in which you are working.

- Encourage the use of basic signs which support the word: first teach specific signs referred to particular objects as ‘bread’ or ‘ball’ and then general actions like ‘eat’ or ‘play’.

- The real photos are helpful to schedule activities.

- The pictographs may help to generalize concepts.

- Keep established routines through schedules with pictographs.

- Use technical aids.

- Use sign language.

In situations where you do not know the affected person, it is recommended:

- To ask the family about the communication system which they usually use.

- If they use an AAC system with pictographs or photos, ask them to have it always on hand to use it.

- If the person uses a gesture system, ask the family a brief summary to interpret them.

- Whenever possible, proceed with the activities which have been carried out with the person, with the help of visual aids (real object, photos of objects or pictographs).

Related behavioral problems and how to address them

Children with severe autism usually show the following behavioural problems:

- Opposition behaviors:
    - Act calmly and with a soft voice, because they react to what we tell them and the way we say it.
    - Crouch down, place yourself on a par with them and stay with them to make the communication easy.
    - Explain how we want them to behave, by accompanying our explanation with a visual aid.
- Tantrums and hetero or self-aggressive behaviors:
    - Act calmly and do not react by increasing their anxiety or anger.
    - Try to find out which is the cause of their anger.
    - Look at any sensory problem.

    - If the problem is the place (too much noise, too many people, etc.), take them away from the situation.

- Problems to adjust their behavior to social norms:

    - Do not take for granted that they will know how to act in a situation, even if they have experienced similar situations before.

    - It is necessary to explain things in good time and remind them how to behave in a particular situation.

    - Focus your attention on positive aspects of their behavior.

- They find it difficult to change or go from a task or situation to another:

    - Whenever possible, anticipate the changes with the help of visual aids

2. Infantile Epileptic Encephalopathies. Dravet Syndrome

Communicative strategies:

The degree of neurological affectation of patients suffering from epileptic encephalopathies is variable. In the case of **Dravet Syndrome**, which implies a serious cognitive deficit, the language area is affected to a greater level, with comprehension being better developed than expression.

Patients have trouble communicating, understanding the environment and forming social relationships. From that point of view, it is vital to seek the help of speech therapists or language disorder specialists.

Recommended action strategies:

- Use Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating (alternating) the communication and language difficulties of many disabled people. These systems will also help increase their interest in the environment as well as their communicative intent.

- Positively reinforce the start of communication and the use of AAC systems.

    - Depending on the level of development, you can use miniature objects, pictures of real objects or pictograms in the AAC systems. The purpose is to tailor the different symbol systems to the characteristic features of each patient (taking into account their cognitive, linguistic and motor skills).

- Encourage the adoption of basic signs which support the use of words: the first step focuses on teaching specific signs that refer to certain objects, such as ‘bread’ or ‘ball’, then extend to include general actions, such as ‘eat’ or ‘play’.

- Make the most of any spontaneous gesture or sign to refer to an object or action. These are not incompatible with the applied ACC System.

    - Over-interpret the patient’s gestures, in other words, respond to their movements, actions, instructions, looks, noises or vocalisations, giving them a communicative sense and associate them with the context of the present situation.

- Some songs can be associated to actions such as eating, playing or sleeping in order to anticipate and increase their level of comprehension (listening to these will make the patient foresee what will happen and thus will reassure him/her).

- Use the Augmentative and Alternative Communication Systems to schedule and time the activities.

- Use technical support.

In situations where the patient is not known:

- Ask the family about the communication system they usually use.

- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.

- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.

- Whenever possible, focus on the activities carried out with the patient by using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to face them:

Patients suffering from Drave Syndrome or other types of infantile epileptic encephalopathies may often present behavioural problems as a result of their lack of understanding of the environment and their limited resources to be able to express what they feel.

Understanding how, and why, they act the way they do will help us empathize with them and will thus help us eliminate situations which provoke disruptive behaviour or the interaction with them in difficult situations.

The most prevalent behavioural problems could be:

- An increase in the level of frustration may cause agitation, anxiety or aggressive behaviour towards him/herself or other people.

Some possible strategies to address them are as follows:

- Create scripts in which they can visually see what is going to happen, how they have to behave and, should they have trouble, who can help them.

- Teach and reinforce basic rules. They need to be reinforced and generalized through the use of visual support so that the patient remembers how they have to follow them.

- Positively reward the moments when they are relaxed and their behaviour is appropriate.

- In critical moments, it is important to try to divert their attention and make them focus on a stimulus or object that might relax or distract them.

- Talk to them calmly and slowly in moments of extreme agitation or anxiety. Use a soft tone and do not shout or raise your voice.

3. Cerebral Palsy (CP) in Children Dystonic Tetraparesis

Communication strategies

One of the associated difficulties in children with CP is the delay in language acquisition, or, indeed, its absence. Despite these difficulties, they can communicate and their level of language comprehension remains better than the expressive one. Sometimes, even if their expressive language is correct, motor difficulties in the orofacial area make their speech unintelligible.

In this regard, the stimulation by speech therapists or specialists in language disorders is recommended.

It is important to take into account the following recommended intervention strategies:

- Take advantage of any movement, action, indication, look, sound or vocalization to give them a communicative sense related to the context of the present situation.

- Use **Augmentative and Alternative Communication Systems (AAC systems):** forms of expression different from spoken language, which aim to increase the communicative skills or compensate (alternatives) the communication and language difficulties.

- Adapt the various symbol systems depending on the characteristics of each person, according to their cognitive, linguistic and motor skills. Depending on their developmental level we will be able to use photos of real objects or pictographs.

- It is important to bear in mind the difficulties in motor functions when implementing the AAC system.

- We must positively reinforce all starts of communication and the use of AAC systems.

- Take advantage of the spontaneous appearance of any sign or gesture to refer to an object or an action, since they are not incompatible with the AAC system you are using.

- They will learn how to apply more efficiently the augmentative communication if it is taught in natural and functional contexts.

- If there appear basic signs which support the word, we must encourage them.

- Use real photos to schedule activities and pictographs to generalize concepts.

- Keep established routines through schedules with pictographs.

- Use technical helps (support products).

- Bear in mind that their posture or movements can easily make them lose visual contact with other people and with the support they use to communicate.

In situations where you do not know the affected person, it is recommended:

- To ask the family about the communication system which they usually use.

- If they use an AAC system with pictographs or photos, ask them to have it always on hand to use it.

- If the person uses a gesture system, ask the family a brief summary of what the gestures mean.

- Whenever possible, proceed with the activities which have been carried out with the person, with the help of visual aids (real object, photos of objects or pictographs).

Related behavioral problems and how to address them:

There is a great variability at the behavioural level among people affected by cerebral palsy.

The behavioural problems which most frequently occur are listed below:

- Aggressive and self-injurious behavior:
    - Try to find out the cause of this behavior so you can change it.
    - Act calmly and do not react by increasing their anxiety or anger.
    - Try to distract them and to establish an incompatible behavior.
- Abulia (passivity or lack of initiative):
    - It is important to keep them active, to encourage them and to prevent sensory deprivation.

4. Angelman Syndrome

Communicative strategies

The linguistic ability of patients suffering from Angelman Syndrome is very limited. Most patients are either unable to acquire spoken language or learn very few words. Comprehension is less affected, so they may understand more than they express. Adequate work done by a speech therapist or a language disorder specialist may increase their communicative resources in a considerable way, resulting in a better adaptation to the environment and minor frustration.

Suggested action strategies:

- Work on communication with Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating (alternating) for the communication and language difficulties of many disabled people.

- Take into account the fact that they learn to use augmentative communication more effectively in natural and functional contexts.

- Depending on the level of development, you can use miniature objects, pictures of real objects or pictograms in the AAC systems. The purpose is to tailor the different symbol systems to the characteristic features of each patient (taking into account their cognitive, linguistic and motor skills).

- It is important to over-interpret the patient's gestures, in other words, respond to their movements, actions, instructions, looks, noises or vocalisations, giving them a communicative sense and associate them with the context of the present situation.

- Try to increase their gestures and spontaneous expressions. These are not incompatible with the applied AAC System.

- Facilitate comprehension:

- Use simple, clear language and speak slowly.

- Use real pictures in order to explain activities and events.

- Set their routine schedules and calendars so that the patient understands them better.

In situations where the patient is not known:

- Ask the family about the communication system they usually use.

- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.

- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.

- Whenever possible, focus on the activities carried out with the patient by using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to face them

Communication limitations, hypersensitivity to stimuli, routine or sleep changes, any medical cause, etc. are some of the causes that may lead to behavioural problems from patients affected by Angelman Syndrome.

It is important to understand what their needs are and what causes this inappropriate behaviour in order to deal with it.

Most common behavioural problems are:

- Agitation.

- Hyperactive behaviour (decreases as they get older).

- Self-aggressive and aggressive behaviour (hair pulling, clothes pulling, biting).

- Tendency to put things in their mouth.

Guidelines to deal with them:

In general, positively reinforce adequate behaviour and try not to pay attention to disruptive behaviour, suggesting positive alternatives.

- Agitation.

    - Set fixed routines. Carry out measures which involve creating an organized, predictable, calm routine and a structured environment in these people's lives in order to reduce agitation.

    - Remove disturbing elements that may increase the degree of agitation.

    - Talk to them slowly and calmly. Use a soft tone and do not shout or raise your voice.

- Hyperactivity.

    - Positively reinforce the moments when he/she is calm and his/her level of activity is adequate.

- Anticipate their motor necessities, providing them, whenever possible, with activities that require moving.

- Self-aggressive or aggressive behaviour.

  - When it happens, try to divert their attention and make them focus on a stimulus or object that might relax or distract them.

  - It is very important to identify those situations that lead to the patient's discomfort and activate mechanisms to eliminate them. Aggressive episodes must not be reinforced with too much attention.

  - Act calmly and do not react so that his/her anxiety or anger increases.

- Tendency to put objects things in their mouths.

  - Be aware of the fact that every object given to them must be safe.

  - It is advisable to use single-element objects that do not contain small pieces on which they may choke.

5. Cornelia de Lange Syndrome

Communicative strategies

Patients suffering from Cornelia de Lange Syndrome (CdLS) usually present a notable delay in the development of language and communication skills, which is increased in those mildly affected.

Comprehension is better developed than expression and, in the event of patients using language, this tends to be repetitive and hardly enables them to hold a conversation. Patients have trouble understanding some nuances and pragmatic aspects of language.

Their difficulties to coordinate and produce the necessary motor movements to speak must also be taken into account.

In this sense, we should consider the following communicative strategies:

- Provide stimulation with the help of language disorder specialists.
- Introduce sign language or alternative techniques aimed at reinforcing the communication ability. Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating the communication and language difficulties of many disabled people.
- Tailor the different symbol systems to the characteristic features of each patient (taking into account their cognitive, linguistic and motor skills). Depending on the level of development, you can use miniature objects, pictures of real objects or pictograms in the AAC systems.
- Make the most of any spontaneous gesture or sign to refer to an object or action. These are not incompatible with the applied ACC System.
- Take into account the fact that they learn to use augmentative communication more effectively in natural and functional contexts.
- Encourage the adoption of basic signs which support the use of words: the first step focuses on teaching specific signs that refer to certain objects, such as ‘bread’ or ‘ball’, then extend the signs to include general actions, such as ‘eat’ or ‘play’.
- It is important to over-interpret the patient’s gestures, in other words, respond to their movements, actions, instructions, looks, noises or vocalisations, giving them a communicative sense and associate them to the context of the present situation.
- Use real pictures to schedule activities and prevent other developments.

- Keep fixed routines through the use of schedules and pictograms. The schedules and calendars must be set in order for the child to understand them better.

- Use technical support.

In situations where the patient is not known:

- Ask the family about the communication system they usually use.

- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.

- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.

- Whenever possible, focus on the activities carried out with the patient by using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to address them:

Some situations may lead CdLS patients to present disruptive behaviour: changes in their routine, communicative frustration, hormonal changes, sleep changes, any medical cause, etc.

- Generally, it is important to understand the CdLS patient's necessities as well as the cause of the disruptive behaviour in order to be able to act upon it.

- Self-harm:

    - When patients feel overcome by environmental stimuli, they might injure themselves. It is strongly advised to remove all unsettling objects that may intensify the possible self-destructive behaviour.

    - In these instances, it is important to try to divert their attention and make them focus on a stimulus or object that might relax or distract them.

- Agitated behaviour and anxiety:

    - It is important to speak calmly and slowly. Use a soft tone and do not shout or raise your voice.

    - Positively reward the moments when they are relaxed.

    - Anticipate their motor necessities, providing them, whenever possible, with activities that require moving.

    - Take measures to help reduce the level of anxiety in these people's lives. A structured, predictable and calm routine as well

as an organized environment seem to work best for children suffering from CdLS.

6. Kleefstra Syndrome

Communicative strategies

Most people suffering from Kleefstra Syndrome display moderate to severe intellectual deficit associated with a notable language disability. Some of them learn single, useful words and are sometimes able to put words together. The use of Augmentative and Alternative Communication Systems is an important tool for this kind of patients, helping them to express their needs and thoughts. Their level of comprehensive language is usually higher than their expressive one.

The communication strategies that can be considered as follows:

- Work with a speech therapist or a language disorder specialist in order to increase their communicative resources.

- Work on communication with Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating (alternating) the communication and language difficulties of many disabled people. These systems will also help increase their interest in the environment as well as their communicative intent.

- Tailor the different symbol systems to the characteristic features of each patient. Depending on the level of development, you can use miniature objects, pictures of real objects or pictograms in the AAC systems.

- Take into account the fact that they learn to use augmentative communication more effectively in natural and functional contexts.

- Make the most of any spontaneous gesture or sign to refer to an object or action. These are not incompatible with the applied ACC System.

- Over-interpret the patient's gestures, in other words, respond to their movements, actions, instructions, looks, noises or vocalisations, giving them a communicative sense and include them in the context of the present situation.

- Positively reinforce the start of communication and the use of AAC systems.

- Facilitate comprehension by talking slowly and using short sentences as well as words accompanied by gestures, images or other kinds of support.

- Keep fixed routines through the use of schedules and pictograms. The schedules and calendars must be set in order for the patient to understand them better.

- Use technical support.

In situations where the patient is not known you should:

- Ask the family about the communication system they usually use.
- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.
- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.
- Whenever possible, bring forward the activities carried out with the patient using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to face them

Usual behavioural problems that patients suffering from Kleefstra syndrome may display are: aggressions (biting, hitting, hair pulling), self-destructive behaviour, invasion of other people's personal space, etc.

They may have unpredictable mood swings, a feeling of insecurity, intolerance of routine changes, etc. Disruptive behaviour may be produced by one of these causes or, for example, a medical issue; puberty may lead to an increase in this hard-to-handle behaviour.

Obsessive-compulsive disorders, stereotyped movements and behaviour caused by the autism spectrum, especially during childhood, have been described.

Specific guidelines to address them

- Aggressive or self-aggressive behaviour.
- It is important to try to divert their attention and make them focus on any stimulus or object that might relax or distract them.
    - It is very important to identify those situations that lead to discomfort of the child and activate mechanisms in order to decrease their appearance. Aggressive episodes must not be reinforced with too much attention.
    - Acting calmly and not reacting so that his/her level of anxiety or anger increases.
- Invasion of others' personal space.
    - Remove him/her with a calm but firm attitude from anyone's personal space.
    - Using visual support, explain to him/her what he/she must not do and what he/she can do in those situations.

7. Lennox Gastaut Syndrome

Communicative strategies

The Lennox Gastaut syndrome represents a kind of epileptic encephalopathy, usually appearing in early childhood and persistent in adulthood. Most of the patients present cognitive damage, intellectual disability and serious problems in the language and communication areas.

It is important to consider the following recommendations in order to maximize the patient's communicative potential:

- Get help from a language disorder specialist to make communication as functional as possible.
    - Use augmentative/alternative techniques to improve their communication ability in terms of comprehension and expression. These techniques are included in the Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating the communication and language difficulties of many disabled people.
- The AAC system must be tailored to each individual, as well as to the degree of cognitive damage and level of development of their motor and linguistic skills. Different symbols can be used in this sense: miniature objects, pictures of real objects or pictograms.
- It is important to remember that they will learn to use the AAC systems more effectively in natural and functional contexts.
- Positively reinforce communicative activities.
- Give the patients' gestures and spontaneous expressions a communicative sense.
- React to the patients' movements, actions, instructions, facial expressions, noises or vocalisations, giving them a communicative sense and associate them with the context of the present situation.
- Encourage the use of basic signs to emphasise words.
- Use simple language and talk slowly in order to facilitate comprehension.
- Use technical support.
- Set fixed routines with schedules and pictograms.

In situations where the patient is not known you should:

- Ask the family about the communication system they usually use.
- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to make use of it.
- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.
- Whenever possible, focus on the activities carried out with the patient using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to address them

The Lennox Gastaut syndrome is often linked to hyperactivity, aggressiveness and autistic features which lead to behavioural problems.

These recommendations could be considered:

- Agitation, anxiety and hyperactivity
    - Avoid stressful environments which may lead to an increase in the level of frustration, agitation and nervousness.
    - Facilitate a calm, organised and familiar environment.
    - Focus on daily actions and activities (always with the help of visual support: pictograms, pictures, images, etc.) in order to reduce the patient's anxiety towards new events.
    - Positively reinforce the moments when he/she is relaxed and his/her level of activity is appropriate.
- Tantrums and aggressive/self-aggressive behaviour
    - Act in a calm way in order not to increase his/her anxiety or irritation.
    - Try to find out what is causing his/her aggressiveness.
    - Avoid unnecessary frustrations whenever possible.
    - Find alternative activities to avoid the patient hurting himself/herself, thus distracting him/her.
- Autistic symptomatology and oppositional behaviour
    - Act in a calm way and use a soft tone of voice, as the patient reacts to what we say, but also to the way we say it.

- It is important to come down to the level of the patient, at the same eye level, in order to facilitate communication.

- Explain to the patient how you want them to behave, using visual support as we show it.

8. Mowat-Wilson Syndrome

Communication strategies

Speech is usually absent in children with Mowat-Wilson syndrome. Those who develop some language skills will have a severely impaired speech. If speech develops, it is usually delayed until mid-childhood or later. Despite this difficulty, many of them can communicate through gestures, and they understand more than they are able to express.

Therefore, stimulation by speech therapists and specialists in language disorders is essential to help them reach the level of communication that matches their cognitive skills.

Recommended intervention strategies:

- Giving meaning to the signs they make. Reacting to their movements, actions, signs, glances, sounds, or vocalizations in order to give all of these a communicative meaning associated with the context of the current situation.

- Using Augmentative and Alternative Communication systems (AAC systems): these systems are ways of expression other than speech. They aim to increase communication skills and/or to make up for the communication and language problems.

- Adapting the systems of symbols that have been chosen depending on each individual's characteristics (based on their cognitive, linguistic, and motor skills). Depending on the level of development, we can use miniature objects, photos of real objects, or pictograms.

- Positively reinforcing every start of communication, as well as the use of AAC systems.

- In order to simplify the use of AAC systems, they should learn how to use them in natural and functional contexts.

- Taking advantage of spontaneous appearances of any sign or gesture to refer to an object or action, as they make communication easier and are not incompatible with the AAC system used by the patient.

- Encouraging the use of gestures to support words: teaching specific signs referred to particular objects like "water" or "bed" first, and then to general actions like "to drink" or "to sleep".

- Real pictures are useful to schedule activities, and pictograms to generalize concepts.

- Timetables with pictograms are useful to establish routines.

- They can use sign language.

When one does not know the person affected, it is recommended to:

- Ask the family about the communication system that they normally use.
- If an AAC system with pictograms or photos is being used, ask the family to bring it along in order to use it.
- If the person uses a system of signs, ask the family for a short summary in order to interpret these.
- When possible, anticipate the activities that will be involve the person by using visual media (real object, photos of objects, or pictograms).

Associated behavior problems and how to address them

People affected by Mowat-Wilson syndrome usually have a placid, happy, and smiley appearance.

Even so, certain aspects of their behavior must be taken into account:

- They present hyperorality (insertion of objects in the mouth) and may even ingest non-edible things:
    - We should ensure that every object given to them must be safe.
    - It is recommended to use one-piece objects with no small pieces on which they could choke.
- Hyposensitivity to pain:
    - It is very important to pay attention to any change in their behavior which can give us the impression that they feel unwell. An increase in irritability is an example of this.
    - Do not trust their reactions to falling or being hit, it may seem that they have not been hurt, but they can be injured.
- They tend to invade the personal space of other people:
    - With a calm, yet firm, attitude, move them away in order for them not to invade the other's personal space.
    - Using visual media, explain to them what they should do in those situations.
- They present tactile defensiveness:
    - Tactile defensiveness is the tendency to react negatively and sensitively to touch.
    - Find out which sensations make them react this way so that you can avoid them.

- Do not overload them with tactile stimuli (do not touch them unless it is necessary).

9. Phelan-McDermid Syndrome

Communication strategies

One of the most frequent characteristics of people with Phelan-McDermid syndrome is absent or delayed speech. They may be able to communicate through gestures, and they understand more than they are able to express.

In this regard, stimulation by speech therapists and specialists in language disorders is essential.

Recommended intervention strategies:

- Reacting to their movements, actions, signs, glances, sounds, or vocalizations in order to give all of these a communicative meaning related to the current situation.

- Using Augmentative and Alternative Communication systems (AAC systems): ways of expression other than speech. They aim to increase communication skills and/or make up for the communication and language problems that many disabled people face.

- It will be necessary to adapt the systems of symbols depending on each individual's level of cognitive development. We should also bear in mind their linguistic and motor skills. Depending on each individual's characteristics, we could use photos of real objects or pictograms on AAC systems.

- Positively reinforcing every start of communication, as well as the use of AAC systems.

- They will learn how to use augmentative communication more efficiently in natural and functional contexts.

- We can take advantage of spontaneous appearances of any sign or gesture to refer to an object or action. They will help emphasize communication and are compatible with AAC systems.

- Encouraging the use of basic signs to emphasize words: teaching specific signs referred to particular objects like "cookie" or "ball" first, and then to general actions like "to eat" or "to play".

- Using real pictures to schedule activities, and pictograms to generalize concepts.

- Keeping routines established by timetables with pictograms.

- Using technical aids.

- They can use sign language.

When one does not know the person affected, it is recommended to:

- Ask the family about the communication system that they normally use.
- If an AAC system with pictograms or photos is being used, ask the family to bring it along in order to use it.
- If the person uses a system of signs, ask the family for a short summary in order to interpret these.
- When possible, anticipate the activities that will involve the person by using visual media (real object, photos of objects, or pictograms).

ASSOCIATED BEHAVIOR PROBLEMS AND HOW TO ADDRESS THEM

Many of the problems which normally appear are related to communication issues.

- Children with Phelan-McDermid syndrome take longer to recognize social norms, and parents have trouble teaching them the most socially appropriate behaviors:
    - Before placing the children in a social situation, explain to them what they should do.
    - Support the explanation with visual media (drawings).
- Some of these children may pull or chew your hair, pinch, or bite themselves.
    - Introduce alternative behavior to keep them from hurting themselves. Using a teether is an example.
- Most of these children tend to insert things in their mouths and chew various objects or clothing.
    - Use a teether to keep them from inserting inappropriate objects in their mouths and chewing them.
- Many of them tend to get anxious in social situations and avoid eye contact when possible:
    - Respect the time that the children need to adapt to our presence and feel comfortable.
    - Do not force them to make eye contact with us unless it is absolutely necessary.

- Sometimes they refuse to wear clothes:
    - They can be very sensitive to the feel of certain clothing items. If we notice that a stimulus is not pleasant, we must not force them to touch that kind of fabric.

10. Pitt-Hopkins Syndrome

Communication strategies

While many people with Pitt Hopkins syndrome are unable to speak, they can make themselves understood with gestures, and they understand more than they are able to express. Those who are able to speak will use words or short sentences.

In this regard, stimulation by speech therapists and specialists in language disorders is suggested.

Recommended intervention strategies:

- Overinterpreting the signals from people affected with this syndrome. Reacting to their movements, actions, signs, glances, sounds, or vocalizations in order to give these a communicative meaning associated with the context of the current situation.

- Using Augmentative and Alternative Communication systems (AAC systems): these ways of expression are different from speech. They aim to increase communication skills and/or make up for the communication and language problems that many disabled people face.

- Adapting the various systems of symbols depending on each individual's characteristics (based on their cognitive, linguistic, and motor skills). Depending on the level of development of the AAC systems, we can use miniature objects, photos of real objects or pictograms.

- Positively reinforcing every start of communication, as well as the use of AAC systems.

- Taking advantage of spontaneous appearances of any sign or gesture to refer to an object or action. These are not incompatible with the AAC system on which the patient is working.

- Giving due consideration to the fact that they learn how to use augmentative communication more efficiently in natural and functional contexts.

- Encouraging the use of basic signs to support words: teaching specific signs referred to particular objects like "bread" or "ball" first, and then to general actions like "to eat" or "to play".

- Using real pictures to schedule activities and anticipate events, and pictograms to generalize concepts.

- Keeping routines established by timetables with pictograms.

- Using technical aids.

When one does not know the disabled person, it is recommended to:

- Ask the family about the communication system that they normally use.

- If an AAC system with pictograms or photos is being used, ask the family to bring it along in order to use it.

- If the person uses a system of signs, ask the family for a short summary in order to interpret these.

- When possible, anticipate the activities that will involve the person by using visual media (real object, photos of objects, or pictograms).

Associated behavior problems and how to address them

The most frequent behavior problems are:

- Excitable behavior and anxiety:

    - It is important to talk to them slowly and calmly, using a soft tone of voice and not shouting or raising your voice. If you can avoid it, it is better not to touch the person, as they can easily feel attacked.

- Self-aggressions:

    - When environmental stimuli overwhelm them, they can harm themselves.

    - When this happens, it is important to try to distract them and invite them to focus on any stimuli or object that can calm them down.

- Hyperactivity:

    - Positively reinforce the moments when the person is relaxed and their activity level is appropriate.

    - Anticipate their mobility needs and, when possible, provide activities which require movement.

11. MECP2: Rett Syndrome

The alteration in the methyl-CpG binding protein 2 (MECP2) gene has been related to Rett syndrome. This syndrome consists of a regressive disorder which occurs from 6 to 18 months of life and entails the loss of speech and the ability to coordinate limb movements. Despite these difficulties, their language comprehension is better than the expression and they have a great communicative intention.

Due to motor difficulties, especially hand movements, it is very uncommon that a girl should respond positively to the use of sign language. Therefore, we must concentrate more on the following:

- Overinterpret signs of people affected by the syndrome. React to their indications, **looks, sounds**or **vocalizations** to give them a communicative sense, relating it to the context of the present situation.

- They effectively understand the use of real photos, pictographs and simple symbols.

- Depending on the hand function which they possess, they can use push buttons, tablets and iPad, mouse alternatives, etc., through which they can make requests.

- Bear in mind that the **communicative intention**, the understanding of situations and the social connection do not seem to stagnate or decline, unlike what happens with the use of language.

- Work will basically be done by using the communicative look or pointing with the look.

- They learn how to use more effectively the augmentative communication in natural and functional contexts.

- When you attempt to use new methods or mechanisms, it is better to restrict their use to specific times of day or particular activities.

- Positively reinforce all starts of communication and the use of Augmentative and Alternative Communication (AAC) systems.

- Use real photos to schedule activities and pictographs to generalize concepts.

- Keep established routines through schedules with pictographs.

- Develop organization systems and mechanisms. Train people in their environment.

In situations where you do not know the affected person, it is recommended:

- To ask the family about the communication system which they usually use and ask them to be always approachable.
- They are very sensitive to all non-verbal communication, gestures, tones, staging, etc.
- Whenever possible, make progress with the activities which have been carried out with the person, with the help of visual supports (real object, photos of objects or pictographs).

Related behavioral problems and how to face them

There is much variability among the affected girls and, without being able to refer to a specific phenotype, we can say that they stabilize from 5 or 6 years of age. They are usually very calm, with an affable and affectionate character. They enjoy familiar social environments and are well-behaved, have a healthy attachment, have an appealing look and a very characteristic hand movement.

Even so, it is worth mentioning some points regarding their behavior:

- Frustrations can lead to tantrums, crying and self-injuries (head banging, scratches and, above all, biting):
    - Try to avoid the unnecessary frustrations as far as possible.
    - Distract them from the situation which caused the frustration and focus their attention on another stimulus or activity.
- Difficulty to control anxiety, relax or calm down:
    - Speak slowly, in a warm and calm voice.
- They find it difficult to move from one situation to another:
    - As far as possible, anticipate always the changes with pictographs or some kind of visual support.
- Excessive caution in some situations and environments:
    - Wait the time it takes for them to feel comfortable and safe. Respect their rate of adaptation.
- Inconvenience in noisy and crowded environments:
    - Try to avoid big crowds.
    - Take them away from the stressful situation.

- Resort to headphones to decrease the noise or to music players.

12. Síndrome de Usher

Communicative strategies

There are many types of Usher Syndrome, depending on the age of onset of the symptoms, the degree of cochlear and retinal affectation and the evolution of the clinical manifestations. However, people suffering from this syndrome require some sort of communication support and appropriate training. In general, we could say that the patients are born with hearing impairment or that they develop hearing loss and gradually lose their sight.

Given the diversity of patients, the communication system that can be used also varies. Some suggested action strategies could be:

- To teach the sign language.
    - To teach the tactile sign language.
    - To teach the Braille system.
- When using sign language: signs must be delivered at a normal speed, their configuration must be clear, the sentences must be brief and a certain comfortable distance from the speaker must be kept.
- In the case of visual loss, they could continue using sign language if their interlocutor is placed within their (usually narrow) visual field and if both the signs and the face of the speaker are well lit.
- If this is not enough, they could use a tactile communication system (hands-on signing).
- To use technical support.

In situations where the patient is not known, you should:

- Ask the family about the communication system they usually use.
- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.
- When there is no visual loss, try to focus on activities with the patient using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to face them

Generally, Usher Syndrome does not involve many behavioural problems. Nevertheless, the following action strategies might be useful:

- When patients feel overcome by environmental stimuli, they might present agitated behaviour and anxiety:

- It is important to speak calmly and slowly.

- Try to identify the situations which cause anxiety or discomfort in these patients in order to reduce the possibility of any inappropriate behavior arising.

- It is advisable to keep a routine and have a structured environment to offer safety and avoid disruptive behaviour.

13. West's Syndrome

Communicative strategies

The language-communication area is usually affected in West's Syndrome patients. In several cases, either they do not develop spoken language skills properly or those skills are not functional, although they create and use strategies which enable them to communicate. A case can, therefore, be made for applying Augmentative and Alternative Communication Systems (AAC Systems).

Recommended action strategies:

- To provide stimulation with the help of language-disorder specialists.
- To keep in mind that the main objective is to achieve functional communication.
- To use augmentative/alternative techniques aimed at reinforcing the communication ability in order to facilitate language expression and to increase and improve both language comprehension and the understanding of the environment. Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating the communication and language difficulties of many disabled people.
- The communication system must be individual and tailored to each patient in a way that it allows him/her to have a functional relationship with the surrounding environment.
- Depending on the level of development, you can use miniature objects, pictures of real objects or pictograms in the AAC systems. The purpose is to adapt the different symbol systems to the characteristic features of each patient (taking into account their cognitive, linguistic and motor skills).
- To positively reinforce successful communication-driven activities.
- To take into account the fact that they learn to use augmentative communication more effectively in natural and functional contexts.
- To over-interpret the patient's gestures, in other words, to respond to their movements, actions, instructions, looks, sounds or vocalisations, giving them a communicative sense and including them in the context of the present situation.
- To try to widen their own gestures and spontaneous expressions (they are not incompatible with the applied AAC system).

- To use simple and clear language (simple sentences and direct orders) and to speak slowly.

- To set visual schedules and calendars for their routines so that the patient understands them better.

- To use technical support.

In situations where the patient is not known, you should:

- Ask the family about the communication system they usually use.

- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.

- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.

- Whenever possible, enhance the activities that involve the patient by using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to face them

The main symptomatology of West's Syndrome is often accompanied by behavioural problems, such as hyperactivity, nervousness, anxiety, tantrums and aggressive and self-aggressive behaviour, including Autism spectrum's characteristic behaviour. These problems may be the result of a variety of factors, such as physical discomfort deriving from medical illnesses, emotional distress or the inability to communicate, which are the most prevalent.

Some concrete suggestions to address these symptoms could be:

- Excitability, anxiety, hyperactivity, nervousness.

    - Avoid a stressful environment, which increases the patient's frustration and therefore his/her agitation and nervousness, so try to create peaceful, organized and familiar surroundings whenever possible.

    - Facilitate the spatial and temporal structuring through the anticipation of daily actions, activities and incidents (relying on visual material: pictograms, images, pictures, etc.) in order to reduce the patient's anxiety towards new events.

    - Positively reinforce the moments when the patient is relaxed and his/her activity level is appropriate.

- Tantrums and aggressive/self-aggressive behaviour.

    - Try to uncover the causes of this behaviour in order to be able to act upon them.

- Try to prevent unnecessary frustration whenever possible.
- Behave calmly so as not to increase the patient's level of anxiety or irritation.
- Try to distract the patient and introduce alternative behaviour in order to keep him/her from hurting himself or herself.

14. Microdeletion and Microduplication Syndromes with Serious Language Affectation

Communication strategies

One of the most common characteristics is the delay in language acquisition or its absence altogether. Nevertheless, they can communicate with gestures and their language comprehension is better than their expression.

In this regard, the stimulation by speech therapists or specialists in language disorders becomes basic and essential.

In these cases, the recommended intervention strategies are:

- Overinterpret their movements, actions, indications, looks, sounds or vocalizations to give them a communicative sense. This must be related to the context of the present situation.

- Use **Augmentative and Alternative Communication Systems (AAC systems):** these systems consist of forms of expression different from spoken language. Its aim is to increase the communicative skills or compensate (alternatives) the communication and language difficulties.

- It is important to consider the characteristics of each person to develop symbol systems depending on their cognitive, linguistic and motor skills. In this regard, we can use photos of real objects or pictographs.

- It is important to consider the difficulties with fine motor skills when implementing an AAC system.

- We must positively reinforce all starts of communication and the spontaneous uses of the AAC system.

- They will learn how to use more efficiently the augmentative communication in natural and functional contexts.

- If there appears any sign or gesture to refer to an object or an action spontaneously, we must promote their use, since they are not incompatible with the AAC system.

- Encourage the use of basic signs which support the word. We will start first with specific signs referred to particular objects as ‘bread’ or ‘ball’ and then we will move to general actions, such as ‘eat’ or ‘play’.

- Real photos may help to schedule activities, while pictographs may help to generalize concepts.

- Use of technical aids.

In situations where you do not know the affected person, it is recommended:

- To ask the family about the communication system which they usually use.
- If they use an AAC system with pictographs or photos, ask them to have it always on hand to use it.
- If the person uses a gesture system, ask the family a brief summary to interpret them.
- Whenever possible, proceed with the activities which have been carried out with the person, with the help of visual aids (real object, photos of objects or pictographs).

Related behavioral problems and how to address them

People affected by these syndromes may show:

- Tantrums, crying and self-injuries caused by feelings of frustration:
    - Try to avoid unnecessary frustrations as far as possible.
    - Distract them from the situation which caused the frustration and focus their attention on another stimulus or activity.
    - Act calmly and do not react by increasing their anxiety or anger.
    - Try to find out the cause of their anger.

15. Deafness Associated with other Causes of Intellectual Disability

Communicative strategies

We refer to **syndromic deafness** when it is associated with abnormalities in other body areas. There are more than 400 genetic syndromes linked to hearing impairment. Furthermore, there are different types of syndromic deafness associated with intellectual disability.

Patients with syndromes such as Treacher Collins Syndrome, Goldenhar Syndrome and Charge Syndrome suffer from hearing, visual or cognitive impairment, a situation which complicates access to language and communication.

Sometimes, the hearing loss is not serious enough to label it 'deafness'. However, any degree of hearing loss may affect speech and language development. In this sense, the help of speech therapists or language disorder specialists might be very useful.

- Treacher-Collins Syndrome:

Some of the characteristic features of this syndrome, apart from hearing loss and a possible cognitive deficit (in a few cases), may affect speech and language development. Anatomorphologial problems, for instance, will lead to joint problems in speech and will modify the quality of sound and intelligibility.

- Goldenhar Syndrome:

This syndrome (a variant of hemifacial microsomia) is characterized by the presence of a wide range of signs and symptoms which may vary in patients depending on the seriousness of each case. Some of these symptoms, such as hearing loss, possible visual problems and intellectual disability (which is seen in 5-15% of the cases) will lead to damage in speech and communication.

- Charge Syndrome:

This is one of the genetic syndromes linked to visual and hearing loss.

The linguistic or symbolic systems used by patients suffering from this syndrome are not necessarily the same when they communicate or receive information. Some use different kinds of communication systems at once, and the way these systems are used may change in future. This situation requires an ability to adapt to the patient's changeable sensory and cognitive skills.

This syndrome implies the existence of certain significant abnormalities, apart from visual and hearing deficits and intellectual disability, which may range from mild to serious. They also pose difficulties in speech and in acting out the signs (low muscle tone, poor tactile perception, small mandible, dyspraxia, etc.).

The following communicative strategies might be useful:

- Introduce sign language or alternative techniques aimed at reinforcing the communication ability. Augmentative and Alternative Communication Systems (AAC Systems): ways of expression that are different from spoken language and are aimed at increasing communicative skills and compensating for the communication and language difficulties of many disabled people.

- The communicative system must be individual and tailored to each patient in terms of their characteristics and cognitive, linguistic and motor skills. We can use different symbols in AAC systems: miniature objects, pictures of real objects or pictograms.

- Make the most of the spontaneous appearance of any gesture or sign to refer to an object or action (they are not incompatible with the applied AAC system).

- Encourage the learning of augmentative communication in natural and functional contexts whenever possible.

- Positively reinforce the moments when the patient starts to communicate or uses AAC systems.

- It is important to over-interpret the patient's gestures, respond to their movements, actions, instructions, looks, noises or vocalisations, give them a communicative sense and associate link them to the context of the present situation.

- Compile visual calendars and schedules of their routines so that the patients understand them better. These systems provide the patients with communication and safety support.

- Use real pictures to schedule unusual activities and anticipate new events.

- Use technical support.

Specific strategies for patients suffering from deaf blindness (or Charge Syndrome):

- Choose the most adequate communicative system in terms of acquired learning, residual vision or hearing, the necessary skills to manage certain devices, etc. **Hand sign language** is the most common, but amongst the most well-known systems are:

    - Oral systems and lip-reading.

    - Sign language.

    - Signs in constricted or moderate field of vision.

- Braille and Moon.
- Alphabetical blocks.
- Tactile sign language.
- Written notes.
- Electronic communication (which must enable the use of Braille or use large letters).
- Individualised signs.
- Tadoma (usually used as an additional source of information).

A combination of the above mentioned systems can be used.

When using sign language: signs must be delivered at a normal speed, their configuration must be clear, the sentences must be brief and a certain comfortable distance from the speaker must be kept.

In situations where the patient is not known you should:

- Ask the family about the communication system they usually use.
- If an AAC system with pictograms or pictures is used, ask the family to always have it on hand in order to be able to use it.
- In the event of the patient using a gesture system, ask the family for a brief summary of them in order to be able to interpret them.
- Whenever possible, bring forward the activities carried out with the patient using visual material (real objects, pictures or pictograms).

Associated behavioural problems and how to address them

Patients suffering from hearing impairment that is associated with other causes of intellectual disability may present behavioural problems, such as self-harm, aggressiveness towards other people or defying them. Perseverative behaviour in young patients or obsessive-compulsive behaviour in adults has also been described in Charge Syndrome, which may cause problems in their environment.

These difficulties can be derived from different situations: frustrations caused by communication problems, physical pain or discomfort, cognitive impairment (in some cases), problems associated with the change or start of certain activities, etc.

It is important to bear in mind that their behaviour has a communicative function. Therefore, it is also important to understand the communicative purpose behind the inappropriate behaviour and help the patient find more adequate communicative methods in order to achieve their goals.

Based on the above, the following recommendations might be useful:

- Do not get angry, threaten or hurt.
- Help the patient find a more appropriate method to enable communication.
- Ignore the inappropriate behaviour, thus protecting the patient and other people from any harm, and favour a kind of behaviour that is aimed at reducing inappropriate behaviour. Aggressive impulses must not be reinforced with excessive attention.
- Be patient.
- Act in a calm way and do not react in a way that increases the patient's anxiety or irritation.
- Try to identify the situations that lead to anxiety or discomfort in these patients in order to reduce the possibility of existence of inappropriate behaviour.
- Set a routine and create a structured environment to provide safety and avoid disruptive behaviour.
- Teach and reinforce basic rules. These must be reinforced and generalized with the help of visual support aimed at making the patient remember how they have to follow them.

COMMUNICATION

COMMUNICATION

1. Some general considerations about communication with severely intellectually disabled individuals

If we start from the idea that communication and language skills are essential for taking part in every aspect of daily life, school, and community (Light & McNaughton, 2012) as they allow us to express our needs, desires, to share information, and to connect with other people, it is understandable that the absence of these skills will result in limited communicative exchanges, if any. People who do not have these skills present what is called Complex Communication Needs (CCN).

The severe intellectual disability that affects people with various syndromes or with some kind of pathology (e.g. autism spectrum disorder) is accompanied by CCN. The latter implies the absence of functional communication, which causes problems when people suffering from this try to manage their feelings and degree of excitement. These levels may shoot up, so CCN sufferers may react excessively to certain stimuli. The reactions can vary, ranging from extreme irritation right through to emotional withdrawal.

Although sensory integration therapies are recommended, no study has shown their positive effects. It is normally helpful to meticulously observe the person in order to determine when they are overexcited or mentally blocked, and to respect the way they are and adapt ourselves to the way they can face and overcome the situation (Jordan, 2012: 197).

Most of the situations described as aggressive might be caused mostly by the panic they experience when things do not go as expected, so most of the reactions are predictable. Since these behaviors cause very uncomfortable situations in the social field and limit the disabled patients' living conditions, it is important to find effective solutions. Therefore, according to Jordan (2012: 203), it is advisable to address them as a form of communication; this will help us choose a strategy to develop a behavior which will replace the violent one. If we find out that it is a defensive reaction to fear or anger, relaxation techniques can be very useful to address such behavior rather than trying to restrict it.

Jordan (2012: 203) points out the following factors which are worth considering in order to change the patients' behavior:

1. Changing the conditions in which they live
2. Teaching them an alternative
3. Changing the consequences of their behaviour

She suggests the following example: if a student scratches another person in a meeting, we should try to find out why he did it, because of the noise or because he wants to leave. We must teach him to express what he wants in other ways or make the session of the meeting shorter, so that it can be extended over time with more positive results. The author also notes that some severely disabled individuals perform actions

on purpose to elicit the other person's anger. Therefore, the best way to communicate and calm down the subject should be based on understanding the reason of their actions and reactions and adopting positive approaches, which are the most effective and useful for interpreting behavior as a form of communication, whether it is or not.

That way, we try to teach them a more acceptable way of expressing what has been identified as the role which the previous, unwanted behavior played.

Some tips to carry out the positive intervention

Problematic behavior is best controlled through comprehension strategies, stress reduction, and teaching with positive support.

We have to keep in mind, for example, that certain places can disturb disabled people and adversely affect their behavior, as they associate them with previous stressful situations. Certain sounds or even some colors can also unsettle them.

People with severe intellectual disability may experience anxiety when adapting to new people, especially when the latter's display uncharacteristic behavior. If the person introduced as a caregiver, monitor, teacher, etc. shows a defiant attitude, it is difficult for the disabled person to accept them. Mentally disabled people are especially sensitive to the tone of voice and they generally accept a new person if they interact with them like others who regularly interact, educate, or carry out leisure activities with them and to whom they are well adapted, also if we talk to them calmly and provide security.

Effective communication using various methods has been discussed in many manuals and scientific papers. A number of authors conclude that the most ethical approach is to consider these people as true communicators (Tetzchner and Jensen, 1992), and they support the need to use total communication approaches (Calculator, 2013) based on both conventional and more subtle methods.

The compendium of guides that appear in this project aims to provide clear and useful information on the characteristics of different pathologies and the possible intervention of teachers, therapists, interpreters, health workers, leisure monitors, and any other professional who needs to communicate with severe mentally disabled people.

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2. The most usual scales used for the appraisal of intelligence and language from early childhood

Scales	Areas	Age of application	
BAYLEY SCALES OF INFANT DEVELOPMENT (BSID)	Mental and Motor Development in Infants	Mental Scale: receptive/expressive language and non-verbal solution of problems/attention	From 2 months to 2.5 years
BRUNET-LEZINE SCALE	Area of perceptive-manipulative development Area of social development Area of language Area of cognitive development		From birth to 3 years
BATTELLE DEVELOPMENTAL INVENTARY (BDI)	Development and diagnosis of possible deficiencies and delays	Personal-Social, adaptive, motor, communication and cognitive	From birth to 8 years
McCARTHY SCALES OF CHILDREN'S ABILITIES (MSCA)	Cognitive and motor abilities (fine or gross)	Perceptive-manipulative verbal and numerical abilities, memory, motor coordination and laterality	From 2.5 years to 8. years
KAUFMAN ASSESSMENT BATTERY FOR CHILDREN (K-ABC)	Intelligence, problem-solving, information	Problem-solving, knowledge, abilities	From 2.5 to 12.5 years
STANFORD-BINET INTELLIGENCE SCALE (Fourth Edition)	Verbal and non-verbal intelligence	Verbal reasoning, Abstract/Visual reasoning, Memory	From 2 years
WECHSLER INTELLIGENCE SCALE FOR CHILDREN (WISC) AND PRESCHOOL AND PRIMARY SCALE OF INTELLIGENCE (WPPSI)	Intelligence	Manipulative (non-verbal) IQ and verbal IQ	From 4 to 6.5 years From 6 to 16 years

GESSELL DEVELOPMENTAL SCHEDULES	Intelligence	Motor behavior Adaptive behavior Language Personal-Social	From 4 months to 3 years
OBSERVATIONAL DEVELOPMENTAL SCALE		Motor, sensory, affective, contact and communication	

- **GENERAL LANGUAGE TEST**

  - **PLON-R. Prueba de Lenguaje Oral de Navarra- Revisada [Navarra Oral Language Test, Revised].** It is a test used for screening or quick detection of the development of oral language. Application age: from 3 to 6 years of age.

  - **Batería de Lenguaje Objetiva y Criterial [Screening Objective and Criterial Language Battery].** It measures four basic language constituents: morphology, syntax, semantics and pragmatics. It does not measure phonology. Application age: from 5 to 14 years of age.

  - **Illinois Test of Psycholinguistic Abilities (ITPA).** Assessment of psycholinguistic functions involved in the communication process and, consequently, detection of learning disorders. Application age: from 2.5 to 10.5 years of age.

- **SPECIFIC LANGUAGE TESTS:**

  - **INDUCED PHONOLOGICAL REGISTER**. This test assesses phonology in induced expression and in repetition. Application age: from 3 to 7 years of age.

  - **EXAMEN LOGOPÉDICO DE ARTICULACIÓN [SPEECH THERAPY EXAM OF ARTICULATION] (ELA-ALBOR)**. It is used for assessing the phonological constituent of language. Application age: from 4 to 6 years of age.

  - **SPEECH INTELLIGIBILITY TEST**. A test of register and measurement of the speech intelligibility in children or adults with serious alterations (deafs, dysarthrics…).

  - **TEST OF METALINGUISTIC ABILITIES**. Appraisal of the developmental grade of metalinguistic abilities at the beginning of the systematic learning of reading and writing.

  - **EVALUACIÓN DE LA DISCRIMINACIÓN AUDITIVA Y FONOLÓGICA [Assessment of Auditory and Phonological**

Discrimination]. It is used to detect possible alterations, from approximately 3 years of age, which could arise from deficits in the field of auditory discrimination, in order to treat them promptly.

- **BOEHM TEST OF BASIC CONCEPTS**. It is used to appreciate the children's command of some concepts which seem essential for learning achievement during the early years. Application age: from 4 to 7 years of age.

- **PEABODY PICTURE VOCABULARY TEST**. It assesses the lexis of the individual. From 2.5 years of age.

- **TOKEN TEST**. It is used to evaluate the syntax and the understanding of orders which grow in difficulty. It can be used in children.

- **TEST OF SYNTACTIC ABILITIES (TSA)**. The development of morphosyntax in children. As the title itself shows, the test is intended to evaluate the morphosyntactic constituent of language. Application age: from 3 to 7 years of age.

- **READING AND WRITING TEST:**

  - **PROLEC.** Assessment of reading processes. It obtains a score of the children's reading ability and information about the strategies used by each child when reading a text, as well as about the mechanisms which are not working adequately and therefore, do not allow them to read well. Application age: from first to fourth year of primary school.

  - **PROLEC- SE [Reading processes assessment battery in secondary school].** It assesses the main processes involved in reading: lexical, syntactic and semantic. Application age: from first to fourth year of secondary school.

  - **PROESC.** Assessment of writing processes. Assessment of the main processes implied in writing and error detection. Application age: from third year of primary school to fourth year of secondary school.

  - **READING COMPREHENSION TEST.** It is used to determine the level of reading comprehension. Application age: from 6 to 7 years of age.

  - **DYSLEXIAS AND DYSGRAPHIAS.** Theories, clinical forms and exploration.

  - **EXPLORATION OF INDIVIDUAL READING DIFFICULTIES. EDIL-1.** Assessment of three aspects of reading: accuracy, comprehension and speed. Given the scores achieved in these variables, it is also possible to assess a general

reading level. Application age: children with a starting reading level or with higher levels but showing difficulties in this aspect.

- **Batería Diagnóstica de la Competencia Básica para el Aprendizaje de la Lectura [Diagnosis Battery of the Basic Competence for Language Learning].** It is used to measure the ability to learn written language. Application age: from 4 to 6 years of age. It is also used with an idiographic character in older children with difficulties in learning written language.

- **BADIMALE. Batería Diagnóstica de la Madurez Lectora [Diagnosis Battery of Reading Maturity].** Application age: from 5 to 6 years of psychophysic development.

- **ECL. READING COMPREHENSION ASSESSMENT**. Assessment of the reading comprehension level in schoolchildren. Application age: from 7 to 16 years of age.

- **INTELLIGENCE TEST:**

  - **McCARTHY (MSCA)**. Measures different cognitive and motor behaviors in six scales: verbal, perceptive-manipulative, numerical, overall cognitive or general intellectual Rate, memory and motor functions. Application age: it is suitable for children from 2.5 to 8.5 years of age.

  - **WISC**. Measures an Intelligence Quotient (IQ). It also offers the manipulative (non-verbal) IQ and the verbal IQ independently.

  - **WPPSI**. Measures an IQ. Moreover, it offers the manipulative (non-verbal) IQ and the verbal IQ independently.

  - **RAVEN, Progressive Matrices.** It is aimed to measure one of the 'g' factor constituents identified by Spearman, the ability for relations. Application age: children, adolescents and adults.

  - **TONI-2.Test of Non-verbal Intelligence**. It adds an interpretation of the problem-solving ability, by deleting the influence of language and motor skills as far as possible. Application age: individuals from 5 to 85 years of age.

- **K-BIT**. **Kaufman Brief Intelligence Test**. It is a battery designed to measure the verbal and non-verbal intelligence. Application age: from 4 to 90 years of age.

- **k-ABC**

- **EVOLUTIONARY DEVELOPMENTAL SCALES:**

  - **Portage guide to early education.** It covers 5 developmental areas plus a section about how to stimulate a baby. The areas are: socialization, self-help, cognition, language and motor development. Application age: from birth to 6 years of age.

  - **Brunet-Lezine**. Psychomotor developmental scale of early infancy. Measures 5 aspects: postural control, language, sociability, hand-eye coordination and a global score. Application age: from one to 30 months of age.

  - **The Carolina Curriculum**. Assessment and exercises for infants and toddlers with special needs. Application age: from birth to 24 months.

  - **McCarthy (MSCA)**. Measures different cognitive and motor behaviors in six scales: verbal, perceptive-manipulative, numerical, overall cognitive or general intellectual Rate, memory and motor functions. Application age: it is suitable for children from 2.5 to 8.5 years of age.

Notes on the exploration of the cognitive maturity in infancy

It is not uncommon for the child to show related problems and, for this reason, apart from cognitive maturity, the following must be taken into account:

1. Personality and the way in which it shows, if its affectivity is defensive or it establishes a good contact, by observing the defensive mechanisms which prevail.

2. The toddler development, and the verbal and manipulative level in first infancy, from scales of proven reliability.

3. The presence of inhibitory disorders, blocks and serious or minor relational alterations must be ruled out.

4. Psychomotor maturity level, by ruling out the presence of difficulties such as instability, slowness or attention deficit. At the same time, more specific areas must be objectified.

ASPECTS RELATED TO LANGUAGE

It is common to differentiate between receptive language (which refers to the receptive language function implied in the interpretation of auditory stimulus and in the understanding of the meaning of words and sentences) and expressive language (related to the ability to remember words, organize them in accordance to the linguistic rules of the language, and express the ideas in a sequential way).

Deficits in the receptive language result in general difficulties in being able to understand, whereas deficits in the expressive language are usually at the origin of school problems, voice alterations, tone and verbal fluency being the most frequent.

The linguistic development follows the evolutionary course set out below:

The faltering appears towards 6 months of age (6-9 months), with a syllable emission; the expression implies here a double emotional and expressive role. Towards 9 or 10 months, the first words appear as meaningful units.

The linguistic period covers the holophrastic stage, from 10 to 18 months of age. Words used as sentences, which means a word used to indicate an action. Imitative language is used.

A single word is used for some objects, new words are gradually acquired by generalization. We draw a distinction between a claiming intonation for asking and a signal for indicating.

Towards 18-24 months, the first simple sentences appear, composed by emissions of two words, the understanding of which is given by the context.

The language jargon or telegraphic speech emerges with sentences from 3 to 5 words.

There is omission of articles and prepositions in general; all the indicators are deleted. The language evolution from 3 to 6 years increases from 1000 to 2500 words, depending on the age, developing as follows:

Different use of you and I. Use of sentences, and answering simple questions.

Acceptance of general answers. Social communication. Fantasy. Some functional dyslalias tolerated.

Language independence extended to other fields.

The syntax of the expressive language must be correct.

Pronunciation errors should not occur. Likewise, if functional dyslalias appear, it is important to address these promptly, since they will affect the correct learning of reading, writing and language.

3. Linguistic and communicative acquisition with cognitive disability

According to Brodin and Rivera (2001) [i], the communication process used to be described as the transmission of information between a transmitter and a recipient. However, the context and characteristics of the participants have become equally important nowadays, since communication is developed thanks to the interaction with the surroundings. Indeed, we are all born with the ability to communicate, but we need interlocutors to encourage that receptive-interactive process. Communication can therefore be defined as:

- all the verbal and non-verbal behaviors executed in front of other people;
- all the behaviors which a transmitter can carry out when he wishes to share a message with a recipient;
- and all those activities which have a deliberate aim.

From this point of view, the game is an example of a situation of communicative interaction. The nature and degree of the different disabilities often adversely affect the ability to communicate. So far, no study has explained how people with different disabilities interact and how the disabilities may affect the communication process. Sometimes, is it possible to replace some faculties with others, but not completely.

In the communication process between the disabled child and the adult, the latter usually tends to speak without waiting for answers or without allowing enough time for the answer to come. The adult thus takes up the lion's share of the interaction, and the answers of the disabled child are reduced proportionally.

a. Communicative interaction in child development

While the value of early stimulation in the development of disabled children is unquestionable, it requires a planned intervention. Shared activity is essential to facilitate the communication of these children. They will develop if they are active participants in the activity instead of being passive recipients of the stimulus. And it is exactly through the game when conditions for learning happen (Brodin and Rivera, 2000).

b. Communication and language acquisition

Language is defined as a way of expressing feelings, thoughts and necessities with the body, gestures, mimicry and signals, or even through speech and writing. Language and communication are, therefore, concepts that reflect different phenomena. People with multiple disabilities lack verbal language, but they communicate through body movements, gestures and signals.

Deficiencies result in many difficulties in the development of preverbal guidelines, as it is very difficult to identify and interpret ways of alternative communication which babies with deficiencies develop. Those with visual and hearing

deficiencies progress slowly and require even more interaction with an adult who can attribute intentions to their actions. When the adult is capable of understanding the alternative ways available to a baby with deficiencies, there is no reason why the communication development should be changed.

c. Language and communication disorders in people with intellectual disabilities

According to Piaget (1964), people with cognitive disabilities show language problems in proportion to the degree of disability (mild, moderate, severe or profound), given the strong interrelation between thinking and language (Piaget, 1964).

- The receptive, or semantic, level is more advanced than the expressive level, although the receptive level has its own set of problems, due to memory deficits. Sometimes, it distorts language because they it gets one or two words of the sentence, or words which sound similar make language difficult. That is why the message is sometimes lost. These difficulties appear at all levels.

- In the expressive level, a poor and hypofluent lexis and the phenomenon of overextension (only one word used to make more than one object or concept) can be noticed. In addition to these, there are word alterations, which lead to additions, omissions, repetitions, fragmentations, corruptions, inversions and sound substitutions, which give rise to other words or series of meaningless sounds.

- The morphosyntactic level has a low average length of sentence, composed of content words only, i.e. without connectives (articles, pronouns, etc.). Tenses are a weak point, showing a lack of consistency between subject and verb (Roces, 2008).

- As the pragmatic level is one of the most reduced, this often leads to mistakes in answers to simple questions, especially questions referring to ‘who’ and ‘what’, which require a more complex understanding. These people usually answer with the last word of the question. These difficulties are less common as the linguistic level increases (Monfort and Monfort, 2010).

- The described difficulties cannot be generalized for all cognitively disabled people, because we can find many who do communicate properly and others who do not even intend to establish any communication.

d. Communication and cognitively disabled language development

The Swedish researcher Gunnar Kylén (1983) defines the communication process as everything that happens when someone, consciously or not, performs actions which can be interpreted by other people and which entail changes to their surroundings. The communication process can be divided into pre-symbolic or pre-linguistic communication and symbolic communication. This model is very useful to describe the cognitively disabled communication process, especially in children who communicate in a non-verbal way. Many experts agree that the assessment of this

process is very difficult, as there are no appropriate tests or scales. So far, the scale of Uzgiris & Hunt (1975) has been considered the most appropriate.e. La comunicación en niños con pluridiscapacidades

e. Communication in children with multiple disabilities

Parents usually interpret their children properly, but they often worry about other people who are not capable of understanding them. In fact, those who do not receive an answer to their attempts of communication end up refusing to communicate. It can be asserted that children with multiple disabilities use different non-verbal ways to communicate, such as sounds, body movements and gestures. Research into alternative and complementary communication focuses on people with motor difficulties or mild cognitive disabilities (Calculator, 1988; Mirenda, 1990). There are still few studies into severe cognitive disability and multiple disabilities. The most interesting ones have been carried out by Light, Calculator, Lloyd and Mirenda in Canada, The United States and Holland.

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4. Total communication

The human brain stands out for its semiotic capability. The ability to communicate with other human beings is innate, but it is developed from childhood through contact and communication with humans, first with the parents and with those caring for the child.

Thanks to the senses of hearing, sight, touch and smell, which send information to the brain, human beings are able to process and understand different types of signs. At the same time, they are able to emit signs through their voice, eyes and body and to make themselves understood.

Peirce, the American semiologist (Peirce & Deledalle, 1978), drew a distinction between three types of signs: indexes (gestures that signify by cause and effect), icons (images) and symbols (e.g. alphabet letters). Especially icons, and symbols even more, have attracted the attention of our Western culture. The world of icons (related to the sense of sight) has an analog nature: they mirror reality through realistic or abstract (but never arbitrary) drawings. However, the world of symbols (related to the sounds emitted by the voice) possesses an arbitrary and digital nature. Symbols, which were only auditory at the beginning, refer to certain realities through mediation of a meaning or concept, but in most cases this is due to mere convention. That is what we call human language, which progressively adopted graphic representations (alphabets). Along with it, there are also other languages consisting of graphic symbols, such as mathematics (it lacks an external referent) or the musical notation system (it lacks a concept).

Educative systems around the world privilege literacy teaching in their respective mother tongue as a base for any subsequent learning (see Faber Benítez & Jiménez Hurtado, 2004). However, these systems pay much less attention to the development of image interpretation and representation skills. Peircean "indexes" belong to the kinesic world, about which little is spoken (Poyatos, 1993). Children are simply taught not to point the finger, a gesture perceived as impolite. Body language is neither commonly taught nor paid attention to, and when attention is paid, it seems to be only to suppress it.

Children are just like mirrors, they adopt the semiotic skills of others through daily interaction with them: they learn to talk, reason, draw, to interpret drawings and photos, and later on to read, to use the musical notation system and to do math. In this way, they finally learn to combine analog and digital skills (Thibault, 2010).

Nonetheless, the semiotic capabilities vary from one person to another. Some have fully functional cognitive skills; others have them more limited due to congenital deficiency, accident or disease. Each of us encounters limits at some point. It is impossible to speak all languages of the world, regardless how intelligent one is. Others are limited by a sensory disability, which forces them to use alternative semiotic systems: Braille tactile writing system in visual impairment cases or sign language in hearing impairment cases. The so-called translators and interpreters are responsible for removing barriers and rendering the conversation from one language to another so communication succeeds.

There are also people who suffer from greater or lesser degrees of cognitive deficit, which prevents them from mirroring the behavior of others and using language

in a way considered “natural”. In these cases the barrier appears much sooner, at some point during the symbol system acquisition, long before mastering graphic representation. Communication must then be simplified, and if possible, in an analog way (with images) and by using body language (e.g. pointing the finger).

The differences in the semiotic capability among humans are remarkable. However, literate people are those who have enjoyed a higher status for more than twenty centuries.

Nonetheless, the social context in which we communicate has profoundly uring the twentieth century. First, it has been the century of great technological revolutions. The invention of the telephone, television, computer, video and the Internet in the nineties has taken us to a globalized world. A time when information can be shared with the whole planet, bridging distance through real-time interaction from any place in the world, even from mobile devices (O’Hagan 1996; O’Hagan & Ashworth 2002). Not only communication channels have been revolutionized; but also the semiotic modes; language (written and spoken), music or static and dynamic images. All of them are being combined with each other, resulting in progressively sophisticated applications (Kaltenbacher, 2004).

Secondly it was the century of human rights, in which the inclusion of people with disabilities and their rights have received increasingly attention. As well as the right to take part in the same activities that non-disabled people (UNO, 2006). Technological progress provides a range of possibilities to remove at least some of the barriers that people with cognitive disabilities find while communicating with others. And also vice versa, the barriers that relatives, teachers, friends and neighbors have to face. The end of the century meant the threshold to a world with constant multimodality. At the same time, that “multimodality” was not the opening to an unknown dimension, but the rediscovery of the enormous wealth and complexity of human semiotic capability (Muntigl, 2004). Without exception, each of us rely on the daily access to every semiotic dimension within the reach of our species. We seem to overvalue written language and undervalue the rest. Therefore, a call for greater inclusion is also enriching for those who live without cognitive disabilities.

The methodology for this project do not intend the revision of literature, doing experiments, nor describing the state of affairs. The intention is to apply the knowledge of experts in order to develop a range of tools, aiming for the benefit of every person involved.

The first target group are people with cognitive disabilities, who can benefit from applications using augmentative and alternative communication. Such applications are intended to people with specific syndromes (whose descriptions appear in a series of sheets). These patients could make use of analog material (organized into categories). It may include verbal communication (to reinforce speech acts) and non-verbal communication, such as pointing the finger (or taking the other person’s hand to point at an image displayed in the application), as well as looking into the other person’s eyes (De Rijdt, 2013; Sergeant, 2013, 2016).

The second target group are people working as oral communicators; specially interpreters. In order to enrich the way they communicate with interlocutors, they should be aware of ways of communicating beyond spoken language. Indeed, in a world

where inclusion is increasingly important, we should be ready for situations involving communication with interlocutors suffering from permanent cognitive disability. The same applies in cases where the interlocutor does not speak the language concerned; interpreters should be more conscious of alternative systems to convey messages. Including pictures and pointing the finger as supporting material (Bührig, 2004). In other words: making use of non-verbal communication to express communicative content, and of course, bearing in mind that the analog material must be culturally appropriate.

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5. Multimodality and interpretation

Recent research in the field of interpretation, such as Angelelli's (2004) and Bancroft's (2015) support the argument that, in practice, the interpreter plays an active role partially motivated by a quest for social justice by being able to give a voice to all who are entitled to access public services. Much of the work in the field of community interpreting focuses on research methods from a multimodal perspective in search of evidence of active participation of the interpreter not only through textual analysis, but also by examining a series of nonverbal means of communication (such as eyes, gestures and body language, etc.). Studies such as Pasquandrea's (2011), Davitti's (2012) and Bührig's (2004) have managed to provide us with new approaches to useful resources for the interpreter in the interaction.

Communication through multimodal resources is a process in which a joint interaction is carried out (auditory, visual, tactile and gestural) and where people and devices are involved in an accessible form.

With regard to interpretation services in social environments, Yuste Frias (2010) explains that the proper conduct of palliative care given to a patient depends on a very high percentage of the work of the interpreters. This author proposes an approach to the everyday reality of the pressing needs of translation and interpretation in healthcare services to the immigrant population with the use of pictograms: text and image will build icons and textual entities so that the foreign pregnant woman "understands properly what the health professionals are trying to communicate to her". In cases of people with hearing impairment, and always depending on factors such as age, education and degree of hearing loss, Civera y Orero (2010) and Jimenez Hurtado, Seible, and Soler Gallego (2012) also note the importance of the use of icons and, in general, multimodal environments to mitigate the consequences of deafness not only socially and emotionally (loneliness, isolation) but also cognitively (caused by isolation intellectual impairment, difficulty developing abstract hypothetical thinking) and verbally (poor vocabulary and difficulty understanding complex syntactic structures).

Bührig's work (2004) on the medical interpretation in hospitals and multimodal resources emphasizes the enormous potential of this perspective. Bührig (2004: 232) presents medical interpreting cases where the physician provides the necessary explanations to patients to grant their informed consent for surgery. The communicative exchange was done by an explanation based on diagrams with the body parts and through short sentences, which the interpreter transmitted to the patient. This use of different means of communication helps patients to expedite the understanding and, therefore, to facilitate the work of doctors and nurses (Nadir Weibel, et al, 2013). A good number of computing applications are used to support medical interpretation, generally focusing on the use of pictures and pictograms (Verdugo, 2013).

If this is applied to an interaction with users who also have a severe disability that affects their communication skills, a multimodal approach is absolutely essential and requires the training of interpreters based on interdisciplinary approaches such as total communication (Calculator, 2013), which includes the signed speech, the use of pictograms, images and photographs. Although the approach to, and study of, multimodal communication traditionally involved psychology, speech therapy or pedagogy, it is still part of human interaction and of any field in community interpreting

(legal, educational, medical, etc.). Thus the new lines of research could affect the proactive training of professional interpreters, leading to integrated multimodal approaches for maximum optimization of interaction in community interpreting and the opening up of new paths for communication with the most vulnerable users in society, including the severely disabled.

In this sense, Napier (2015: 139-140) considers a closer collaboration between oral interpretation and sign language as a new line of research in interpretation.

Successful communication is a powerful tool to ensure the rights of those who are most disadvantaged because of illness and disability and to promote equity.

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6. Hearing impairment/deafness

A hearing impairment can have different characteristics and degrees – from a slight hearing loss to a profound one without any hearing ability left.

Type and degree of hearing impairment / deafness

Basically one distinguishes between two types of hearing impairment: conductive and sensorineural hearing loss (hearing loss in the inner ear). A third type of hearing loss is the mixed hearing loss, a mixture of conductive and sensorineural hearing loss. In case of a conductive hearing loss the sound does not reach the inner ear. With technical or medical help, the hearing may be recovered partly or even fully. The discomfort level[1] for people with normal hearing or conductive hearing loss lies at 120 dB (decibel). The cause for a sensorineural hearing loss lies within the inner ear, the acoustic nerve or the brain cells. In this case, technical or medicinal help can only be helpful partly or not at all.[2] In both types of hearing loss a loss of loudness is happening[3]. Additionally, hearing losses in certain frequency ranges (high-frequency, middle-frequency, low-frequency) cause changes in tones which distort the speech. The discomfort level of people with sensorineural hearing loss lies beyond that of normal hearing people. This is the reason why they are more sensitive regarding sounds[4].

The three types of hearing loss are classified into different degrees. The foundation of this classification are benchmarks created through speech and tone audiograms. The degrees vary from slight hearing loss to deafness.

Average Hearing Loss in Decibel (dB)[5]	Degrees of hearing loss
< than 30 dB	slight
30 to 60 dB	moderate
60 to 90 dB	severe
90 to 120 dB	Profound with some hearing left
> 120 dB	deafness

A hearing impairment does not have anything to do with not hearing faint sounds, but rather sounds cannot be put in order and merge with the surrounding noises.

Causes of hearing impairment

There are varioud causes for a hearing impairment. It can develop pre- or perinatal (during birth), postnatal or during the course of one's life. Possible reasons for an inherent hearing loss are:

- heredity
- illness of the mother during the pregnancy, e.g. rubella, toxoplasmosis
- complications during the pregnancy / birth, e.g. premature delivery or lack of oxygen

A later appearance of hearing impairment might be caused by the following:

- inflammatory otitis media with complications
- Otosclerosis (a type of calcification of the ossicles)
- infections through viruses or bacteria (e.g. rubella, measles, mumps, influenza, meningitis, shingles, diphtheria, scarlet fever, typhus)
- accidents
- sudden deafness (acute hearing loss)
- noise exposure
- age-related hearing loss[6]

For other causes of hearing impairment you may look up http://www.hearingloss.org/ .

Deaf people and their sign languages

Within the deaf community there are two different groups:

- Adults that lost their hearing after learning to speak are called postlingually deaf. Most of the time they are integrated in the world of the hearing and also have a hearing family. Often one does not even recognize that he or she is hearing impaired.
- People that are hearing impaired since birth or before the third year of age are called prelingually deaf. Prelingual means, in contrast to postlingual, that the hearing impairment happened before gaining speech competences. Such people learn to speak through sight and sense. Their voice sounds nondescript and cannot be put into place. The learning of speech takes a lot of time and energy.

Worldwide, one of 1.000 children is born deaf. 10% of these children have deaf parents and use sign language as their mother tongue. For the other 90% sign language turns into the preferred language. For them, sign language can be learned naturally and is a way of communicating without borders or lost information. Sign language offers them a possibility to express themselves in detail.

Every country has its own sign language, e.g. Austrian Sign Language (ÖGS), German Sign Language (DGS), American Sign Language (ASL). Sign language consists of combined hand-signs connected with facial expressions and inaudible spoken words or syllables (mouthings) or gesticulation with the mouth. Sign languages are natural languages and have their own grammar.

It is estimated that about 500 000 people in the EU use their national sign language as their first language. In Austria, Austrian Sign Language is the preferred

language for about 10 000 people. Austrian Sign Language was officially acknowledged by the constitution in 2005.

In each country, there is not necessarily just a single sign language, but rather dia- and sociolects. Some national sign languages form language families, which derive from historical and present exchange within the deaf community and the adoption of different signs from one sign language into the other. At big international conferences, "International Signs" (IS) are used. This is not a language of its own, but an artificial language to help communicate across borders, much like Esperanto.

Sign languages are manual-visual languages. This means, that a sign consists of different components. The hands are used in different angles (hand orientation), forms (handshape) and directions in various places of the so-called signing space (movement and location), but also the facial expressions have a grammatical function. A typical prejudice is that sign languages are purely iconic (i.e. pictures) and you can only depict simple and general issues. This is of course not true. Sign languages are full languages and can express complex and abstract issues.

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Tips for the usage of signs during communication: http://www.tinysigners.eu/

Contact with deaf people

If you want to get the attention of a deaf person, you had best touch the person on the arm or shoulder with your hand. One should not appear behind a deaf person, because he or she might be frightened. If the deaf person is farther away, a wave of the hand should suffice. If you are in the same room, it is also possible to stamp on the ground. If there is a larger group, you should get the attention by turning the light off and on again.

If you are not capable of using sign language, the deaf person has to read lips. In this case it is important to stand in front of the person so he or she is able to read the lips. You should try to talk a little slower than normal with normal volume. If you try to speak very distinctly, the mouthing might be distorted which makes the spoken words unreadable. Short and complete sentences are preferable, strong dialects should be avoided. If one is unsure if someone might have misunderstood something, you should ask again or write down what is unclear.

Gestures and facial expressions can be used because often iconic hand movements are understood by both hearing and deaf people. Facial expressions should be used naturally and not turn into grimacing.

Spoken language can be read from the lips, but it is very exhausting and only about 30% of the communicated words are transferred, and only in perfect conditions (lighting, known context and dependent on the communication partner). The whole content often has to be concluded out of context, which often leads to misunderstandings. The learning of speaking is exhausting and time-consuming for most prelingual deaf people. The results are often rather poor. Also, the learning and understanding of writing is difficult.

If you are in regular contact with a deaf person, you should try to learn their sign language or at least ask for signs and phrases that are frequently used, like "hallo", "how are you?".

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Deaf culture

Deaf people are confronted with communication problems daily – at home, at school or at work. Additionally, hearing people are often inconsiderate about their impairment. This way they easily get isolated and like to spend their time with like-minded people. Meetings of the deaf community emerged and different activities (sports, culture, education, church service) are available. Because of this strong community and their own language, one speaks of "Deaf culture".

There are national and international (also EU) deaf associations. For example, in the EU the "European Union of the Deaf" (EUD, http://www.eud.eu/) is committed to further Deaf people and sign languages within the EU. The worldwide parent organization is called "World Federation of the Deaf" (WFD). Deaf associations and organizations are a protected space, where deaf people can communicate without feeling underprivileged, as it is often the case when talking to hearing people. The exchange of news and information and the contact with others is important. With regard to the history of deaf people and their sign languages, prejudices have remained to this day because of the little-known information about deaf people and their culture.

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[1] The discomfort level is considered the lowest strength of an acoustic stimulus, which is considered to be discomforting while hearing. This level depends on someone's one sensitivity. It is below the level of pain and depends on the frequency. Source: http://de.wikipedia.org/wiki/Unbehaglichkeitsschwelle
[2] Vgl. http://www.schwerhoerigen-netz.de/MAIN/schwerhoerig.asp?inhalt=broschuere06

[3] Loudness is a psychoacoustic term, depicting how test subjects assess the "perceived" noise of sound. The assessed sound depends on the sound pressure level, the frequency spectrum and the runtime performance of the sound. Source: http://de.wikipedia.org/wiki/Lautheit

[4] Vgl. Wolf, Jilg und Corales, 1992
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