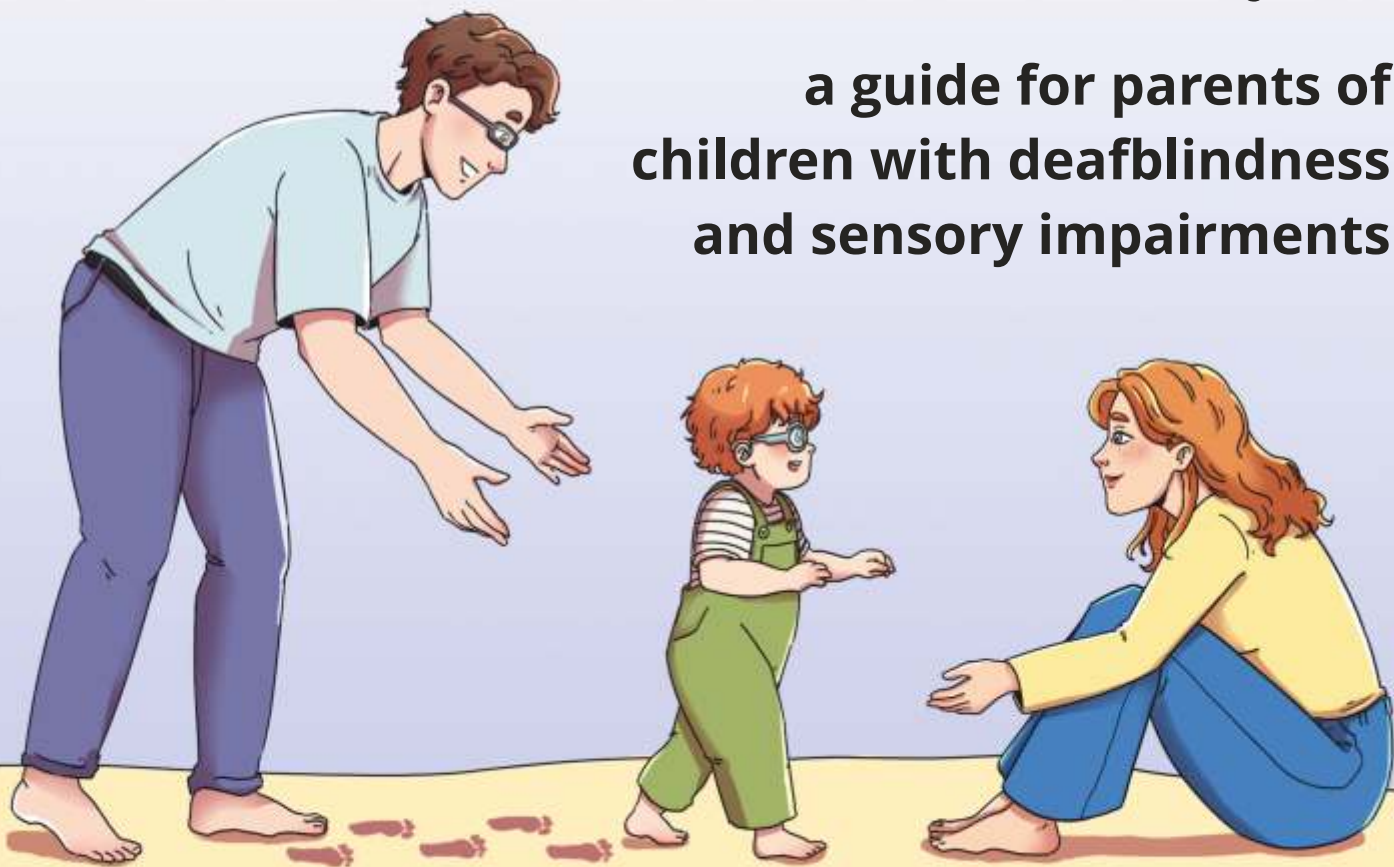


First steps

a guide for parents of
children with deafblindness
and sensory impairments



Bucharest
2024

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**First steps: a guide for parents of children with deafblindness
and sensory disabilities**

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The guide "**First steps: a guide for parents of children with deafblindness and sensory disabilities**" has been developed by **Sense International Romania**, alongside **the School Center for Inclusive Education "Cristal" Oradea**, **the Special Technological High School "Vasile Pavelcu" Iași** and **the School Center for Inclusive Education "Constantin Pufan" Timișoara** under the project of the same name, project selected within **the "Solutions for the Community" campaign**, implemented by **Synevo Romania**



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Dear parent,

This guide is about you and your baby, for you and your baby...

If you are reading these words, it means that a child with deafblindness or sensory disabilities, visual or hearing, has appeared in your life.

It's perfectly normal to wonder how to deal with this situation. It is perfectly normal to feel overwhelmed, sad, angry, confused, to have many questions and few answers. During these times, it is important to know that you are not alone and that there are resources and support available to help you navigate this journey.

Deafblindness is a unique condition involving a severe or total loss of sight and hearing. It is important to understand that in the absence of these two main senses, your child will use other ways of communication and interaction.

Every child is unique and their needs and abilities may vary depending on the degree and cause of their disability. Since you are the person who knows your child best, there are many things you can do to help them develop. As a parent of a child who is deafblind or has a sensory impairment, you may feel overwhelmed by the challenges this experience brings.

With patience, love and support, you will be able to discover your child's abilities, thus opening the door to a fulfilling and successful life. We invite you to read this guide, in the hope that you will find it a source of inspiration and that it will give you confidence in your parenting skills.

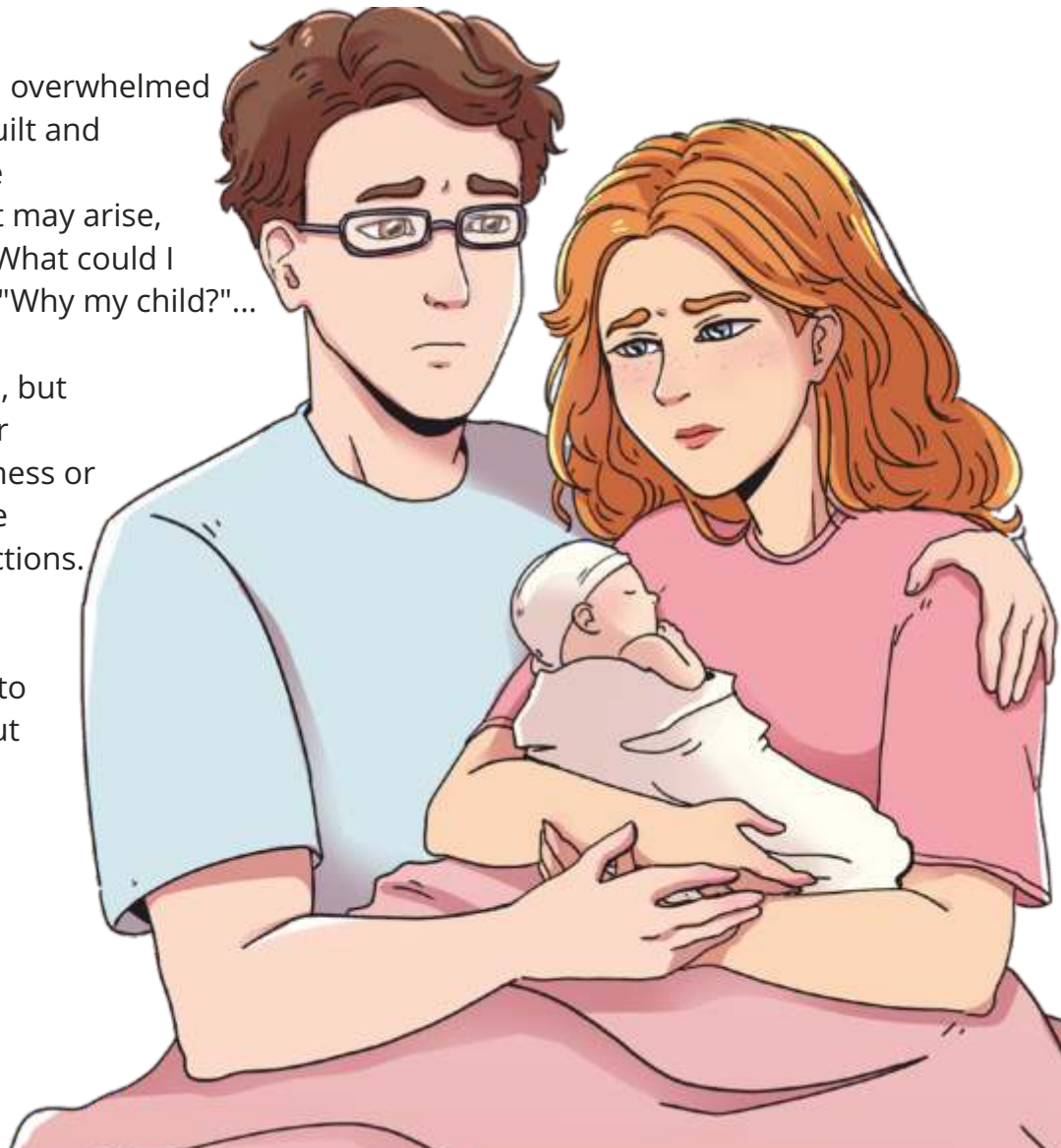
We are with you on this journey and we are convinced that together we can support your child's development.

Recognise and accept your emotions

It's perfectly normal to feel overwhelmed with complex feelings of guilt and loss for "the child you have imagined". Feelings of guilt may arise, along with the questions "What could I have done differently?" or "Why my child?"...

Such questions are natural, but it's important to remember that your child's deafblindness or sensory disability is not the result of your choices or actions.

In these moments, it is essential to allow yourself to feel these emotions without judgement.



Don't hesitate to share these feelings and seek support in your community.

In difficult times, remember that you are not to blame for your child's deafblindness or sensory disabilities.

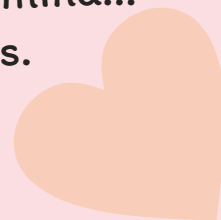
Complex emotions and unanswered questions are inevitable when facing the challenges of having a child with a disability.

Keep in mind that such feelings and thoughts are part of this experience and do not define your quality as a parent or the quality of your child's life.

Accept and validate your feelings, but remember that you are a loving and dedicated parent who is doing everything they can for their child. The trials and difficulties you encounter do not diminish the love and care you have for your child. **Allow yourself to feel these emotions without judgement.**

Be strong, parents of special children are superheroes! Look for a true specialist, be patient with yourself to understand yourself, your feelings, emotions, state of mind... Be with the child at all times.

I.D., parent



Seek support groups for parents

You are not alone in this experience, and it's perfectly okay to seek help and talk about whatever you're feeling. Discussing these feelings in a parents support group can be extremely beneficial.

Talking to other parents who understand and empathise with your experience can be a source of information and help reduce feelings of isolation and guilt.

Caring for a child with deafblindness or sensory disabilities can be extremely difficult, and your stress and frustration is understandable.

Find support and connect with other parents going through the same experience. Together, you will find ways to cope and support your children's development and well-being.

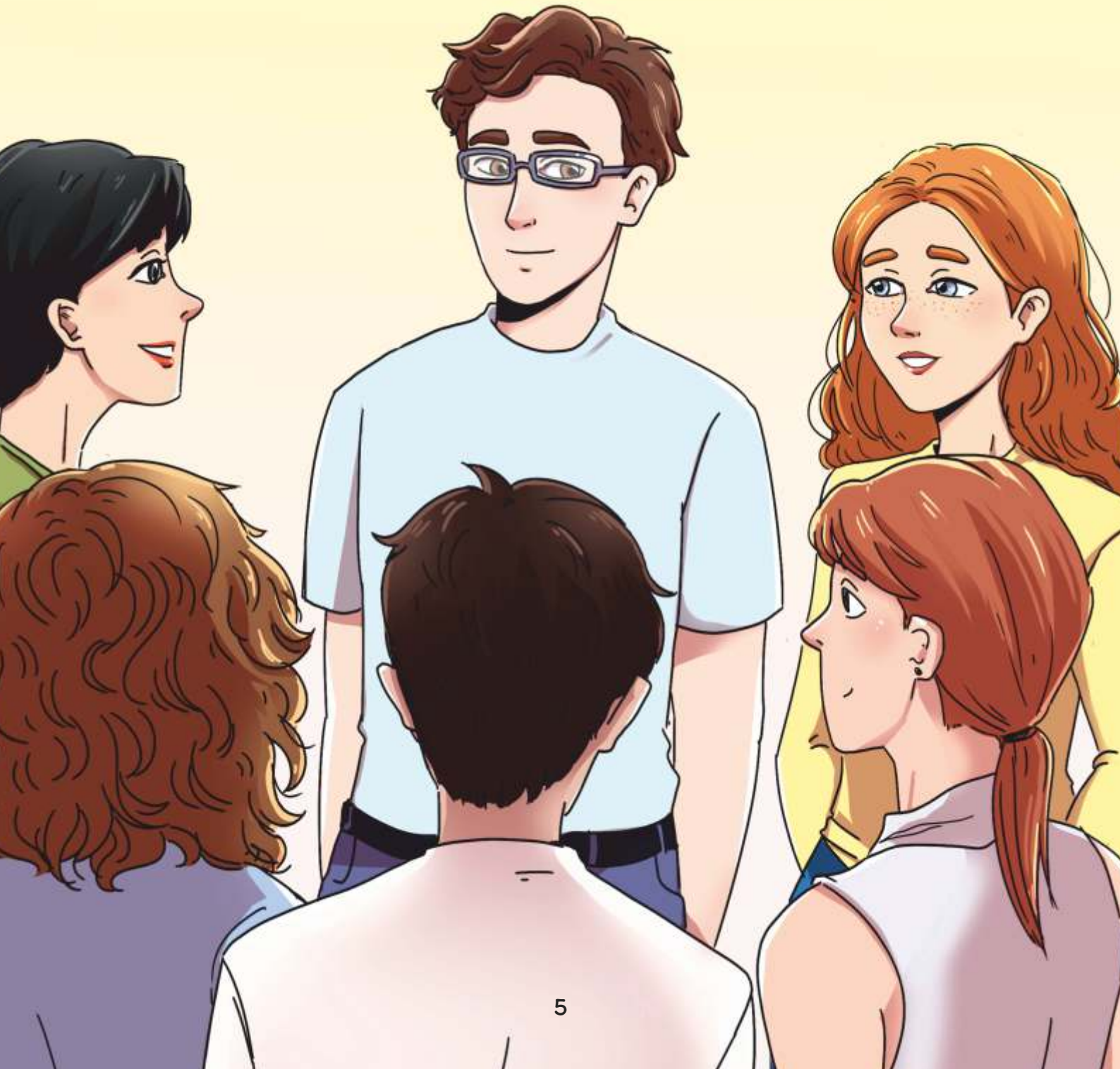
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Do not despair, look for people who share the same experiences.

Seek information from as many sources as possible and give yourself time to accept them.

Don't put pressure on yourself and the baby. Seek specialist support both for you and for him. Start therapy as soon as possible, it can greatly improve your child's life.

D.A., parent



Communicate openly in the family

Communication of a diagnosis involving a severe or total loss of vision and hearing, like deafblindness, can be extremely delicate and emotional.

Talk openly with your partner and other family members about your feelings and your thoughts. That way, you can support each other in accepting the situation. If there are older siblings, approach the situation very carefully, but without hiding it. Here are some tips to manage this complex situation:

When talking with your partner, **choose the right moment** and make sure you are both in a quiet place and time, free of distractions, where you can talk openly.

It's okay to show your emotions. Crying and expressing sadness are natural reactions and can help create a stronger emotional bond.

Be honest with your partner about your feelings. After you share the news, let him/her express his/her emotions and thoughts as well. Listen with empathy and without judgement.

After you've had a chance to talk and process the news together, **start discussing next steps.** Identify resources, specialists and plan how you will tackle this situation together.

Explain to older siblings about the baby's condition in a language they can understand without overloading them with information.

Be honest about the challenges that deafblindness can bring, but emphasise the positives, such as growing up together and learning new ways to communicate.

Show that your love and attention remains constant, even if some aspects of family life change.

Show them how to interact with the baby using gentle touch and talking, even if the visual or auditory response is limited.

Create and encourage activities that are appropriate for a child with deafblindness, such as sensory play or vibrating music. Invite siblings to join and help adapt these games, encouraging them to be creative and find new ways to play together.

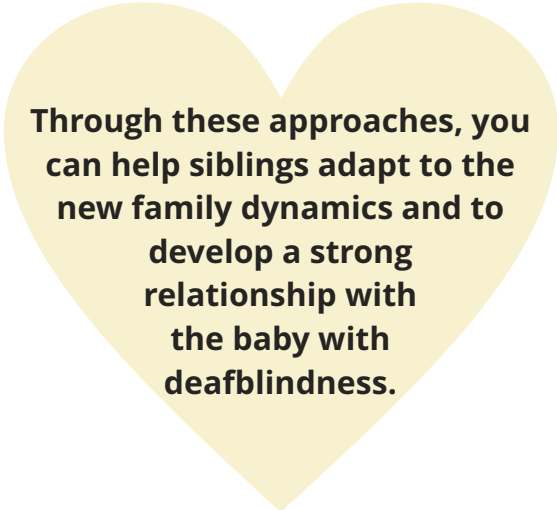
Give older siblings access to resources and information about deafblindness so they can better understand their sibling's condition.

Acknowledge feelings of jealousy or neglect that may arise with older siblings. Give them time and space to discuss their feelings and make sure each child feels seen and heard.

Maintain a regular family routine as much as possible, making sure that the time you spend with each child is valuable. The balance between caring for the newborn and giving attention to the older siblings is essential to maintain harmony in the family.

Provide emotional support to both older siblings and the newborn. Encourage them to express their feelings and concerns, let them know that they are an important part of the family and that they can get involved too.

Create stable and consistent routines that provide safety and comfort for both newborn and older siblings. These can include routines for eating, sleeping and daily activities to help maintain balance in the family.



Through these approaches, you can help siblings adapt to the new family dynamics and to develop a strong relationship with the baby with deafblindness.

Ask for support

Asking for support from family, grandparents and close friends is very important when it comes to caring for a deafblind baby, and this step requires sensitivity, openness and sincerity. To get the most out of grandparents' support, be honest in communicating your needs and expectations while respecting boundaries and their capacity for involvement.

Here are some suggestions for approaching this topic:

Arrange a time to meet with grandparents and close friends to discuss the newborn's situation. Choose a quiet time and place where you can talk without interruption.

Begin by explaining what deafblindness means, how it affects a baby's development and everyday life. Provide information about the child's specific requirements and what types of care are needed.

Be open about the emotions and difficulties you are facing. This can help grandparents and friends understand the seriousness of the situation and the need for support.

Be clear about the types of support you need. This may include physical care of the child, emotional support or practical help such as transport or meal preparation.

Encourage them to spend time with the baby to become familiar with the baby's special requirements and to learn appropriate ways of interacting. It may be useful to organise sessions where you can teach them how to communicate effectively with the child.

Inform them about resources available to families with deafblind children and about the possibility of attending training courses or workshops.

Suggest the idea of forming a support network of family and friends, where tasks and responsibilities can be shared. This will reduce the pressure on parents and will increase the overall well-being of the family.

Be sure to express gratitude for the support and emphasise how important it is for the good of the child and the family.



By adopting an open and informative approach, parents can facilitate a better understanding and a more effective support from grandparents and close friends, which is essential for managing the challenges associated with caring for a child with deafblindness.

Additionally, it is essential to seek support and share these feelings with other parents or professionals in deafblindness. Interact with other families who have gone through similar experiences.

Hearing other parents' stories and strategies can be comforting and encouraging. By talking about your experience, you will discover that you are not alone and that there are resources and support available to you.

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Talk about the diagnosis, because that's the only way you'll know what you have to do, as soon as possible.

Accept the diagnosis, because only then will you be able to help your child.

Have a lot of patience, trust your children and give them much love, be always with them...

P.L., parent

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Accepting the diagnosis is the first important step for a beautiful life. It was meant to be, this is our path and theirs from today forward. You, as a parent, will choose whether the road will be with tears or smiles. Yes, it is normal to cry, but not all the time. Cry, scream, but promise yourself that the day will come when you wipe your tears and say one morning: What can I do for my child? How do I show my child that I love him/her with all my heart?

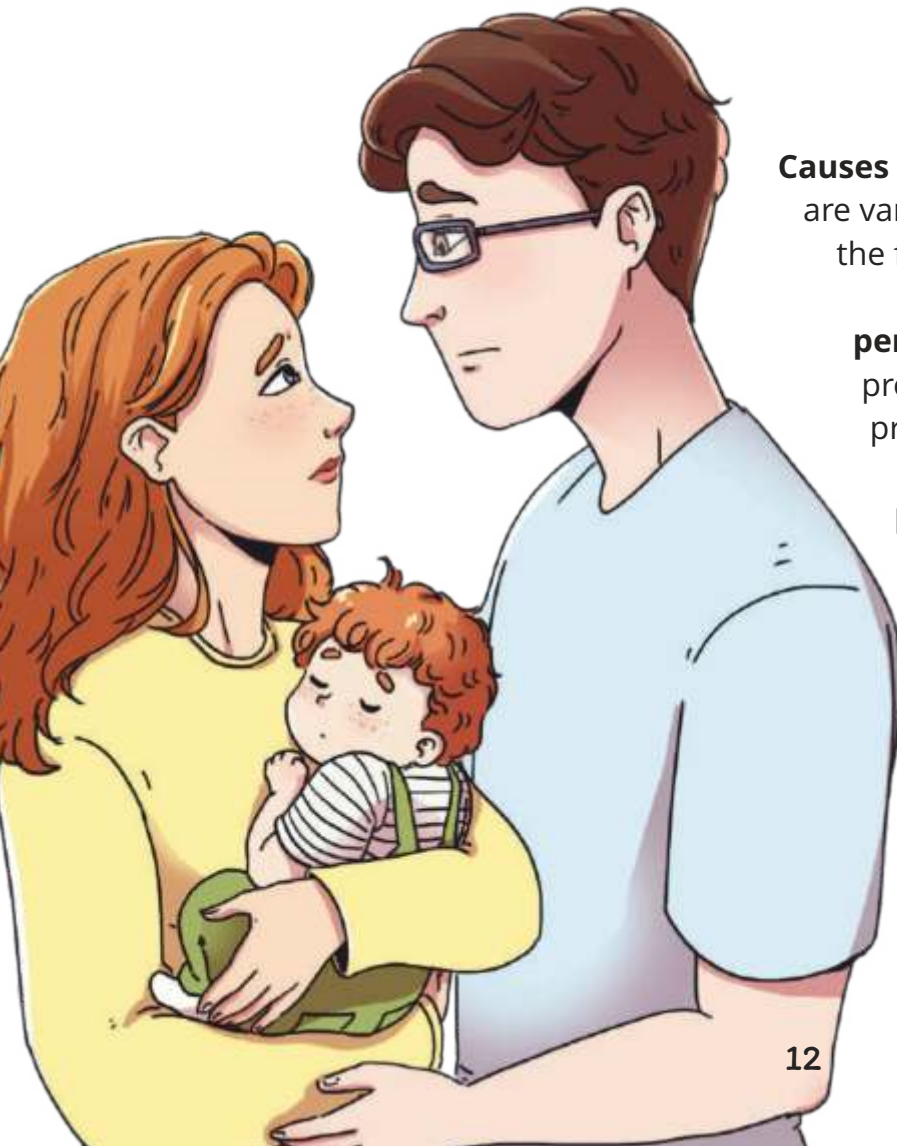
The day you accept the diagnosis, life for your child will be much simpler, easier to live. Acceptance means power. The power to move on with your head high, the power to not give up, the power to pull out the best in your child's potential.

N.A. parent

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What is deafblindness?

Deafblindness refers to the presence of double sensory disability, sight and hearing, in varying degrees, causing difficulties in communication, orientation, mobility and in accessing information.



Causes of deafblindness or sensory disabilities are varied, specialised literature mentions the following as the most common:

perinatal causes (15%) - hypoxia, anoxia, prolonged labour, medical inappropriate procedures;

postnatal causes (5%) - meningitis, encephalitis, head trauma, heart failure;

prenatal causes (50%) - embryofetopathies, cytomegalovirus, rubella virus, syndromes: Down, Usher, C.H.A.R.G.E., Goldenhar, Laurence-Moon-Biedle.

Congenital rubella syndrome

Congenital rubella syndrome not only seriously affects the vision or hearing analysers, but the entire development process. The younger the fetus' age at the time of the mother's illness, the more aggressive the impact of the syndrome can be.

The main symptoms of congenital rubella syndrome are:

- hemolytic anemia, hepatosplenomegaly, mechanical jaundice, meningoencephalitis;
- neurosensory hearing impairment;
- visual impairment (of various degrees, from mild amblyopia to blindness): cataract, pigmentary retinopathy, nystagmus, microphthalmia, optic atrophy;
- intellectual disability (in 55% of cases);
- heart problems (interventricular septum defect, pulmonary artery stenosis);
- neurological or cerebral problems (may be absent, but when present, the degree of damage varies from moderate to severe), microcephaly;
- insulin-dependent diabetes.

C.H.A.R.G.E./Hall-Hittner Syndrome

An acronym that involves several conditions:

C - irian coloboma - an anomaly that occurs in the absence of a substance in the lower part of the iris;

H - heart, various heart defects that can affect 75-80% of newborns with this syndrome, tetralogy of Fallot is common;

A - choanal atresia, blocking the nasopharyngeal communication, caused by the formation of a membrane that prevents air from entering during nasal inspiration;

R - retarded growth - delay in physical and intellectual growth and development;

G - genital - genital hypoplasia, incomplete development of genital organs;

E - ear - abnormalities of the ear and hearing loss.

USHER Syndrome

Usher syndrome type I (USH1) is the most severe form, with children suffering from profound or severe congenital sensorineural hearing loss. Because they are born deaf or with residual hearing only during the first year of life, they do not learn to speak. Constant vestibular dysfunctions are present from birth, and children show delays in motor development, which is why they do not sit unsupported and start walking at a later age than children with typical development milestones. Retinitis pigmentosa (RP) begins in childhood, leading to the progressive narrowing of the visual field simultaneously with the progressive decrease in visual acuity (the first affected being night vision, which leads to nyctalopia).

Usher syndrome type II (USH2) is characterised by delayed and moderate onset of hearing loss. Thus, although the hearing impairment is congenital neurosensory, the remaining hearing varies from moderate for low frequencies to severe for high frequencies (with a tendency to stabilise); for this reason, verbal communication is possible in childhood, especially with hearing aids. Hearing loss can occur between the first and third decades of life. Vestibular function is normal, but nystagmus may be present. The onset of retinitis pigmentosa (nyctalopia, progressive narrowing of the visual field and decreased central visual acuity) occurs either during puberty or later in adolescence.

Usher syndrome type III (USH3) is very rare and is notable for the fact that patients have normal hearing at birth. Subsequently, the hearing loss becomes similar to that of USH2, with major losses in the case of high frequency reception. The rate of progression varies, but in most cases profound deafness is reached. However, acceptable levels of residual hearing in childhood allow the acquisition of oral verbal language in a satisfactory manner. Hearing and sight deteriorate with time, so that in adulthood it will be necessary to use a hearing aid; vision loss is severe and profound. Balance difficulties may appear later.

Down Syndrome

The syndrome is also known as trisomy 21, because it is about mutations that appear on the 21st pair of chromosomes. Typical clinical features in Down syndrome relate to aspects of physical appearance, intellectual disability and health problems.

Common physical features are: epicanthum, hypertelorism, small ears, implanted lower than normal, round and flat face, microgenia, flattened nose, brachycephaly, short and wide hands, transverse palmar fold. The space between the big toe and the next toe may be abnormally large. Vision and hearing problems are found, in various combinations, in more than half of the individuals.

**Be strong and accept that you were chosen because you can.
Ask for and accept all help that is offered to you,
don't isolate yourself from the world...
Disability is not something to be ashamed of,
and you are heroes!**

C.M., parent

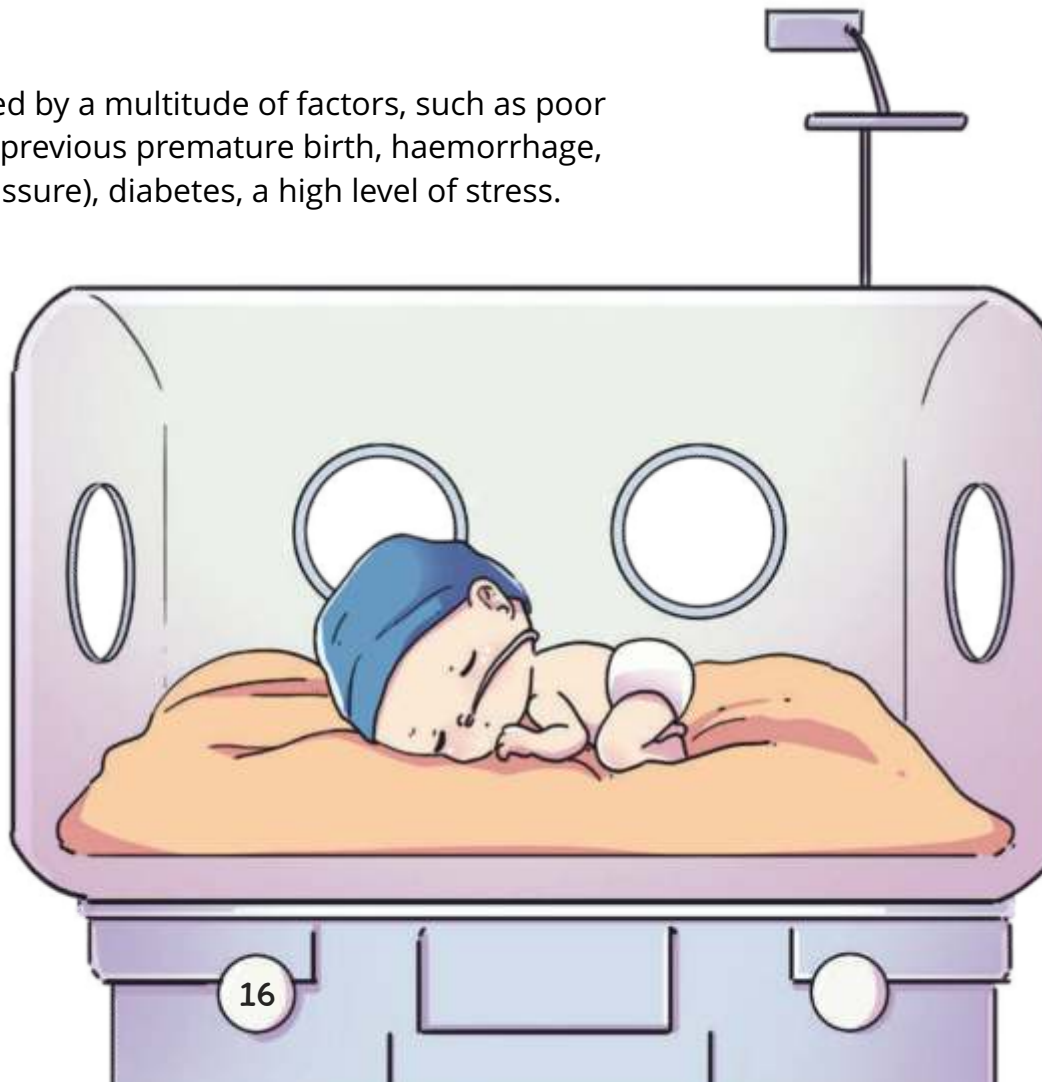
Prematurity

Prematurity is the birth of a baby before the due date. Thus, a premature baby is a newborn who was born before 37 weeks, considering that the normal duration of a pregnancy is 40 weeks. It is important for the neonatologist to pay attention to prematurity, as it is frequently associated with the occurrence of complications and an increased degree of mortality.

Premature birth can be caused by a multitude of factors, such as poor nutritional status, infections, previous premature birth, haemorrhage, preeclampsia (high blood pressure), diabetes, a high level of stress.

There are situations when the cause that led to premature birth cannot be determined.

There is a possibility that the baby will be born prematurely even if the mother followed all the doctor's instructions.



Some women may have a higher risk of having a baby born prematurely. Risk factors that increase the incidence of preterm birth include multiple pregnancy, history of pregnancy with preterm labor, previous miscarriage, a new pregnancy less than a year after birth, maternal age, smoking, drug use, heart disease or renal medical conditions.

Based on the analysis of the size, weight and cranial perimeter, the corrected age of the newborn is determined. For a premature newborn, the corrected age is lower compared to the biological age. This aspect is important for the pediatricians, as they will be able to offer the most suitable recommendations for the harmonious development of the child.

The diagnosis of prematurity is established by the pediatrician. In order for a newborn to be considered premature, it is necessary to consider what week the baby was born. The baby should benefit from a medical team consisting of neonatologist, pediatrician, pediatric neurologist, ophthalmologist.

In this way, an optimal intervention plan is established to ensure the harmonious development of the child. During the first days of life, the baby may need to be cared for in a neonatal intensive care unit. Parents are advised to be around the newborn. Studies have shown that the interaction between parents and children from the first days contributes to the development of the little one.

What is early intervention?

Early intervention means tailored services and programmes to support you in the challenges you face and help you focus on your baby's development.

These services are designed to identify and address as much as possible, as soon as possible, potential developmental delays and provide the support you need to overcome obstacles.

Early intervention specialists can provide activities and strategies adapted for your child with deafblindness or sensory disabilities.



Early intervention is aimed at children between the ages of 0 and 3 who have developmental delays due to visual or hearing disabilities, multiple sensory disabilities or deafblindness, with the aim of compensating them and supporting the child to develop to their maximum potential. The intervention also applies to children between the ages of 3 and 6, who have not previously benefited from specific therapies.

Specialised early intervention services are provided through **specific individual therapy activities**, one-to-one, with the parent as a partner. This means that you, as a parent, will be involved in all stages of the therapy: assessing the child in areas of development, setting goals and developing a personalised intervention plan, carrying out therapy activities and evaluating the child's progress, being guided and supported by specialists in early intervention to continue working with the child at home.

Early intervention activities can take place both in special educational institutions - early intervention support centers, and at the child's home in the presence and with

the active participation of the parent.

Early intervention will always focus on what the child can do.

Thus, knowing the child's functional level is essential for choosing the type of therapeutic activity and the most suitable means of communication.

The types of therapies and activities that your child can benefit from in the early intervention program are: communication activities, sensory and cognitive education activities, orientation activities, mobility and general motor stimulation, emotional and social development activities, physical therapy.

Next, we will briefly describe what each type of therapy consists of and give you some recommendations and strategies on how you can best support your baby's development process in his/her own environment, at home.

Early communication

Communication skills are needed by everyone, impacting all areas of development and the ability to form relationships. The importance of the ability to communicate and relate to others cannot be overstated.

Children with severe disabilities can encounter substantial difficulties in communicating with those around them. For this reason, it is key priority for children who do not communicate verbally, to establish an alternative communication system, as early as possible.

Interacting with your child can be difficult and sometimes frustrating. It's normal to feel overwhelmed and confused by the child's behaviors, especially when it comes to communication and attachment.

Observe and try to understand your child's communicative behaviours. Even if it sometimes seems like he/she doesn't tolerate the interaction, offer him/her support and show your child that you're there.

In the initial stages, it may seem that your child resists interaction, but it is important not to give up and persevere in your efforts to build a relationship with him/her.

Understanding and accepting the specific needs of the child with deafblindness is essential to be able to establish a deep and secure connection with them.

This requires patience, empathy and understanding on your part, but also support from professionals and family.

It's important to notice and try to understand what your child is trying to communicate, even if they don't express themselves in traditional ways. Sometimes the behaviours may be different or seem unusual, but it's important to take the time to understand them and offer support in ways that are accessible and effective.

Also, remember that the interaction between you and your child may be different from the one you have with other children. It can be helpful to seek support and share your experiences and concerns with other parents who are going through the same thing.

Because verbal language can be difficult for deafblind children to use, learning and interpreting non-verbal signals such as gestures, facial expressions and body language are essential. These can be important ways of communication for children with deafblindness. Use not only your voice, but also gestures and gentle touches to communicate with your baby and convey your love and support.

Be present and responsive to your baby's needs and signals. Respond promptly to the child's cries and other signals and try to provide comfort and support when needed.



Stimulating vision

Visual disability is a sensory disability that involves a reduction in vision (of visual acuity) in various degrees, going all the way to total vision loss (blindness).

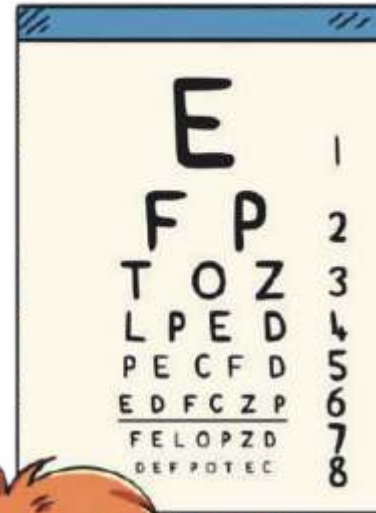
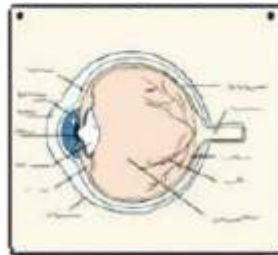
Each visual impairment has its own individual characteristics, but with all types, the following aspects need to be taken into account:

Visual acuity (VA) - this refers to the distance from which objects are seen/perceived;

Visual field (VF) - refers to the total or partial area of vision when the eyes are fixed on a fixed point;

Contrast sensitivity - refers to the ability of the eye to perceive in different shades of grey or shades.

If a person recognises an object at a distance of 10 m, an object that a person with good eyesight would recognise at 100 m, then the visual acuity is 10% or 0.1.



Visual disability can be ocular or cerebral in nature.

The visual disability of an ocular nature can occur as a result of diseases or injuries to the structures of one or both eyes or the optic nerve, which inevitably affects a person's visual function and ability.

This category includes diseases such as: glaucoma, opacification of the cornea, cataract, coloboma, aniridia, optic nerve hypoplasia, albinism, retinopathy of prematurity, optic dysplasia, etc.

Cortical/cerebral visual disability is due to bilateral dysfunction of the optic radiations or the visual cortex or both.

It may coexist with ocular or oculomotor disorders and may be the result of a brain injury during birth or may occur as a result of brain trauma.

There are several causes of cortical visual disability, including: pre- or perinatal cerebral hypoxic encephalopathy; periventricular leukomalacia in children born prematurely; cerebral anoxia (lack of oxygen); brain development defects; intrauterine infections; traumatic brain

injuries; hydrocephalus and cerebrospinal fluid drainage shunts; severe epilepsy.

The World Health Organisation classifies visual impairment into:

Partially sighted - the person has a visual problem and must benefit from specialised services in those situations where the use of visual functions is needed;

Low vision - is a severe visual impairment, not necessarily by limiting distance vision, but also near vision. This term is used when the person cannot read the newspaper at the normal distance (33-40cm), even with the use of optical aids or glasses.

Legally blind - indicates a visual acuity value of less than 20/200 (0.1) in the better-seeing eye with correction, optical lenses or glasses, and a visual field value of less than 20 degrees in the stronger eye.

Ideas and suggestions

The more a child uses their sight, the better they develop their ability to interpret visual information. This is crucial because vision is a developing sense, and early use helps refine the pathways that process visual cues. Vision does not work in isolation. It integrates with other sensory information to provide a comprehensive understanding of the environment. Encouraging children to use sight along with touch, hearing, taste and smell enhances this multisensory integration, leading to better spatial awareness skills and environmental exploration. Integrate visual tasks into your daily routine.

Because a significant part of the brain is involved in processing visual information, visual stimulation from an early age can influence overall brain development and functioning.

Use black and white objects/images at first, colours and high contrast lights to make objects easier to see. Position the items in the child's best field of vision.

Use toys that are visually interesting and also provide sensory feedback such as lights, textures or sounds to encourage the child to use sight along with other senses.

Flashing or fluorescent lights are prohibited for babies with epilepsy because they can trigger seizures.

Photosensitive seizures are triggered by certain flashing light patterns or lights of variable intensity. These can occur while the child is looking at or being exposed to these light patterns. Symptoms can range from abnormal visual sensations to generalised seizures.

Stimulating hearing

Hearing disability implies a deficit in the level of receiving information through hearing. It can appear from the moment of birth for well-determined reasons (congenital hearing loss) or may occur during life (acquired hearing loss). In the case of children, it is necessary to carry out detection tests and diagnosis as early as possible, to be able to intervene and avoid the negative implications of hearing loss on development.

This is possible through the National Hearing Impairment Detection Programme which is carried out at the level of hospitals in the country, a programme through which newborns go through a hearing screening from the first days after birth.

If hearing loss is suspected, the maternity ward refers the baby to a specialised consult (ENT) in order to establish a diagnosis. Depending on the audiometrically determined hearing loss, there are four types of hearing impairment:

mild - loss of reception skills is located in the range of 20-40 dB;

moderate - the loss of reception skills is located in the range 40-70 dB;

severe - the loss of reception skills is located in the range 70-90 dB;

profound - the loss of reception abilities exceeds 90 dB.



Depending on the affected organic segment of the auditory analyzer, there are three types of hearing loss:

Transmission hearing loss - it is located at the level of the peripheral segment of the auditory analyser, that is, at the level of the external ear and the middle ear. This type of loss is called transmission loss because the path that the air wave travels from the outer ear to the neural part is blocked, which has consequences in terms of auditory functionality. This type of hearing loss cannot exceed 70 dB.

Sensorineural or sensorineural hearing loss - is located in the inner ear. The loss can range from mild hearing loss to profound hearing loss or even total loss (cophosis). In reality, cophosis is rare, because almost always the audiologist can identify residual hearing at the level of low frequencies (250-750 Hz).

Mixed hearing loss - it is a combination of conductive and sensorineural hearing loss. This type of disability is diagnosed when there are greater than 10 dB differences between air conduction and bone conduction.

Also, depending on the impairment, the hearing loss can be organic, where the hearing loss is caused by a component of the hearing analyser, or functional, where there is no organic damage, but the person is no longer able to hear due to aging or due to exposure in a noise-polluted environment.

The consequences of hearing loss at an early age are reflected in the formation and development of verbal language. The earlier the diagnosis of hearing loss is made, the greater the chances of its compensation through technical means (hearing aids or cochlear implant) and the formation of verbal language.

Ideas and suggestions

Stimulating the hearing in a baby with deafblindness or sensory disabilities can be a complex process, but there are some strategies you can use to support the hearing development. In addition, adapting the environment to facilitate auditory stimulation is essential.

Consult a specialist for specific advice and recommendations for stimulating your baby's hearing (these differ depending on the baby's age, level of hearing loss, recommended prosthetic method - conventional prostheses or cochlear implant, if the damage is unilateral or bilateral, if it is associated with other conditions, etc.)



Once your child has had a hearing aid or implant activated, **make sure that they wear the device(s) throughout the day** (while awake), that it has batteries and is in optimal working order so that the child benefits from of quality auditory input, consistently.

Talk and sing to your baby regularly.

Even if he/she can't hear clearly, the vibrations of your voice and the rhythm of your speech or songs can be felt by the baby. This gives the opportunity to become familiar with the sounds of the language and begin to understand vocal communication.

Use toys with sounds, simple musical instruments or other objects that make interesting noises to introduce them into the everyday environment.

Stimulation with a variety of sounds and noises can be beneficial for your baby's auditory development.

Use books adapted to the age and characteristics of your child. Nowadays, there is a wide variety of books that you can use to stimulate your child's development: tactile books, sensory books, with different textures, with black and white pictures, without text, with clappers, books with sounds and songs, etc. In addition, daily reading with the child helps to form attachment, develop positive interactions and stimulate the child's language.

Reduces loud and dissonant environmental noises that could be overwhelming or disruptive to your baby. Instead, create a quiet and calm environment where baby can focus on sounds and auditory experiences.

Stimulating touch

Touching and manipulating objects is one of the most important ways in which the child with deafblindness or sensory disabilities learns about the world around him.

Here are some suggestions to help develop your baby's sense of touch and body awareness:

Blow on the child's hands, fan his hands, feet, body. Use real objects that the baby can handle and explore safely.

Use gentle, baby-safe massage oils, such as baby oils. Be careful when using essential oils, especially with babies and small children, as they can be very concentrated and cause side effects. Essential oils, including eucalyptus oil, can have strong effects and trigger seizures in children with this condition, allergic reactions or irritation, especially in children with sensitive skin.

Always position the child where he feels safe, able to touch and hold things easily, using both hands.

Use safe household items such as pan lids, brushes and wooden spoons – often these are the best toys!

Place a variety of objects around the house in a basket or box for your little one to explore. Objects with different textures, such as wood, metal, rubber, paper, sponge, velvet, etc. they are much more interesting than smooth plastic. You can change the objects from time to time so that your child always wants to explore the content. The baby will also use the mouth to explore objects, often by licking or chewing. It should not be discouraged as this is an important way in which they explore and discover the world.

Kinetotherapy

Physical therapy, or movement therapy, will help your baby to develop harmoniously, to move using his own body in the healthiest possible way. The role of physical therapy is to combat the delay in development, to help the child go through the stages of neuromotor development according to the biological age, to correct certain vicious postures and to strengthen the deficient muscles. Physiotherapy activities for babies aim to:

Going through the stages of neuromotor development: 0-3 months, 4-6 months, 7-9 months, 10-12 months - each stage being represented by certain motor acquisitions: head control, doll posture, rolling over, sitting position, walking on all fours. And so on.

Development of postural control - the baby's ability to maintain a stable body position in acquired positions, to be able to maintain an anti-gravity position in space.

Improving coordination, control and balance.

Development of fine motor skills - grasping/manipulating toys and objects (developing forms of prehension - refers to the effective use of all fingers in various hand actions).

Adapting the environment

It is important to adapt the home environment to encourage and support your child's development. For babies with deafblindness or sensory disabilities, additional lighting can make it easier to explore and interact with their environment. It is important to create a well-lit and accessible environment for them.

Dim lighting and shadows can be problematic for babies with deafblindness/visual impairment/vision loss, as they can make it difficult to detect objects and explore the environment.

Make sure you improve the lighting in all important areas of the house to facilitate the interaction of the baby with the world around. In the baby's room, make sure there is enough natural light. Opening the curtains or blinds during the day can bring natural light into the room and give your baby a richer visual experience.

In the baby's play area, make sure there is **enough light to enhance exploration and interaction** with the toys and objects around. You can use desk lamps or colored light projectors to create an environment that visually stimulates the baby.

Make sure the toys and objects in the play area are **contrasting and easy to detect** for the deafblind baby.

Use **toys with varied textures and vibrant colors** to attract attention and stimulate baby's tactile and visual senses. In general, make sure that the environment in which the baby develops is safe and adapted to his unique needs, including his sensory needs. This may include simplifying and organizing the space to make it easier for the child to navigate and interact with their environment.

Recommendations around screen time

TV programs run at a very fast pace (even those aimed at young children), which can affect the child's cognitive, affective and language development. Even more so in the case of children with deafblindness, the recommendation is not to leave the child alone in front of the TV, not to leave the TV on in the room where the child is playing or sleeping.

Both TV and games on a tablet or phone are very visually stimulating, and although your little one may seem very focused or quiet while looking at the screen, the potential harm to your child's development from too much exposure to watching TV or playing games on a tablet or phone is far more significant than the benefits that occupying your child in this way can bring. In addition, the sound quality may not be good enough for little ones to hear clearly what is being said.

For a short duration of a few minutes a day, depending on the age, you can watch a suitable programme with the child, turning the volume down and telling the child, in simple words, appropriate to his/her age and level of development,

what is happening on the screen. Enlist the support of the early intervention specialist to create a stimulating environment where your child has the opportunity to actively explore and learn.

This may include providing adapted toys and materials, as well as providing strategies, new and exciting experiences to help increase the baby's confidence and security, and develop social, emotional and cognitive skills.

Available services and benefits

It is important to be informed about all the rights and services your child can benefit from and follow the necessary steps to obtain them. It can sometimes seem like an arduous process because it involves time and effort, energy and patience to obtain papers, documents and evaluations from several specialists or institutions, but the more and the better informed, the sooner your child and family can enjoy these benefits.



Within the General Department of Social Work and Child Welfare (D.G.A.S.P.C) in the city or county where you live, the Child Complex Assessment Service (S.E.C.C.) operates. The evaluation process of this service aims to maintain, improve or increase the quality of the child's life through the following interconnected actions:

- a. Classification as a disability, which confers the rights provided by the special law
- b. Planning of habilitation and rehabilitation services and/or psychological and educational services with regular monitoring and reevaluation of the progress made by the child, the effectiveness of the benefits, services, interventions and the degree of satisfaction of the beneficiaries.

The necessary documents for the evaluation of the child in order to grant him/her the disability degree are the following:

- the medical certificate with tax stamp completed by the specialist doctor of the hospital where the child is registered, in the original and a copy (in the medical certificate type A5 the complete diagnosis is entered - the main disease, the associated disease and other diseases and the disease code provided by the world classification of diseases, respectively CIM-10);
- synthetic medical record from the family doctor;
- hospital discharge tickets (all existing) and other medical documents additional to the medical certificate (audiogram, spiogram, echodoppler, medical letters, etc.);
- psychological record filled out by a registered, stamped and signed clinical psychologist;
- social work report from the municipality of residence;
- photocopies of the following documents: the child's birth certificate, parents' identity card, marriage certificate or divorce decree (where applicable).

Depending on the stage of the disease, the child can be classified by the assessment committee in one of the following degrees of disability: GRADE 1 (severe, with or without personal assistant/companion allowance), GRADE 2 (pronounced) and GRADE 3 (medium).

It is important to know that access to the Early Intervention Programme, in the counties where these services are available, is not conditional on the Disability Classification Certificate.

It is your decision as a family whether you choose to benefit from the rights and benefits provided by this certificate. However, in order to enroll the child in the Early Intervention Center, the School and Professional Orientation Certificate issued by the County Center for Educational Resources and Assistance (C.J.R.A.E.) of the county you belong to is required.



Documents required for the issuance of the School/Professional Orientation Certificate are:

- copy of the child's identity document (birth certificate);
- copy of the identity documents of the parents/legal representatives;
- copy of the document proving that the person submitting the application is the legal representative of the child (court decision/decision of the Commission for Child Protection); if the parent has changed his/her name: marriage certificate;
- copy of the social survey from S.P.A.S./D.G.A.S.P.C. by sector (validity of the document: 6 months);
- copy of the synthetic medical record from the family doctor (validity of the document: 12 months);
- copy of the medical certificate type A5 from the specialist doctor (validity of the document: minimum 12 months);
- copy of the psychological evaluation form from a clinical psychologist (validity of the document: 3 months);
- psycho-pedagogical sheet (completed by the teacher/leaders, where applicable);
- copy of the matriculation sheet (classes I-XII) or certificate (preschool-preparatory class) attesting the child's enrollment in the educational unit and a certificate attesting the student's enrollment in the respective class;
- for the purpose of extension: a copy of the School/Professional Orientation Certificate;
- in special case: updated Disability Certificate.

* you will notice that, for the most part, they are the same documents as in the case of the Degree Enrollment Certificate, so you can solve both relatively at the same time, with the specification that they are issued by different institutions, respectively D.G.A.S.P.C. (for the degree placement certificate) and C.J.R.A.E. (for the school and professional guidance certificate).

On the basis of the school and professional guidance certificate, the child benefits from specific therapies free of charge, receives a monthly food allowance as well as an amount of money intended for the purchase of clothing, shoes, supplies, granted in 2 installments (the first installment granted between April and June, and the second installment in the October-November period, according to Government Decision No. 564 of 2017).

In addition, if the child with Special Educational Requirements (SER), as well as a certificate of placement in the degree of disability, he/she benefits from a 50% increase in the financial rights granted, according to Law no. 272 of June 21, 2004.

For up-to-date information on the legislation in force granting the rights of children with SER, you can contact the social assistance service of the special education institution in the city/county where you live.



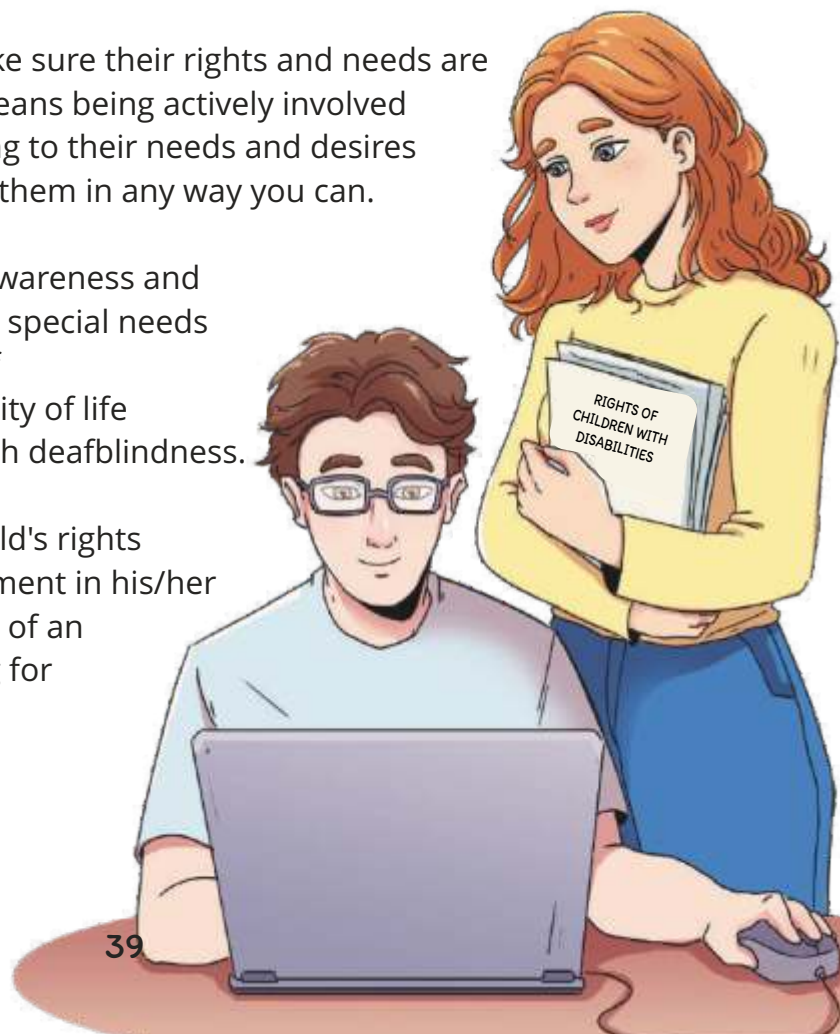
Defending your child's rights

Every child is unique and has their own needs and potential to bring joy and achieve meaningful life. Success and happiness can be defined in many different ways, and as a parent, your role is to be an advocate for your child's rights and needs, making sure they are always respected.

Be an advocate for your child and make sure their rights and needs are met and are always respected. This means being actively involved in his/her life, listening and responding to their needs and desires and being there to guide and support them in any way you can.

Participating in events that promote awareness and improving conditions for children with special needs can be a great way to express yourself support and make a difference in quality of life your child and perhaps all children with deafblindness.

By supporting and promoting your child's rights with deafblindness and active involvement in his/her life, you can contribute to the creation of an inclusive environment and stimulating for its development.



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Sense International Romania is a Romanian organisation established in 2001 with the aim of improving the lives of people with deafblindness and multiple sensory disabilities in our country. It is the only organisation in Romania that actively campaigns for the rights of people with deafblindness.

Through national level programmes that promote early intervention for newborns with sensory disabilities, educating children with deafblindness and offering vocational services, SIR successfully manages to bring a change for the better in the lives of hundreds of people with this type of disability.



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