

# Congenital deafblindness

Supporting children and adults who have visual and hearing disabilities since birth or shortly afterwards



**BARTIMEUS SERIES**

Bartiméus aims to record and share knowledge and experience gained about possibilities for people with visual disabilities. The Bartiméus series is an example of this.

## Colophon

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## Preface

Since 1980, Bartiméus has offered specialised support to people with visual and hearing disabilities, especially those born with visual and hearing disabilities, referred to as congenital deafblindness. Bartiméus staff have had the opportunity to get to know these people intensively over the past 30 years. Many people with deafblindness have lived in the same place for many years and have a permanent and trusted team of caregivers who have been with them during all facets of their daily lives, at both good and bad times. Through the intimacy of this contact, the proximity and the frequent physical contact, caregivers have gained extensive experience in dealing with these people's unique combination of disabilities.

People with congenital deafblindness require special support. As psychologists we have seen firsthand how these people can flourish with the right support and exhibit more capabilities than we had dared to hope for. At the Bartiméus Expertise Centre Deafblindness, we have recorded the knowledge developed in the past 10 years and shared it with other people with deafblindness and their caregivers. Scientific research (partly done in collaboration with Professor M. J. Janssen at the University of Groningen) supports our experience that the quality of life of a person with visual and hearing disabilities can be much improved when their environment is properly modified to suit their need for support.

This book is intended to offer practical tips to parents, caregivers, teachers and professionals involved in supporting people with congenital deafblindness. In our experience, it is never too late to start providing specialised support to these people. With this book we would like to share our experiences with everyone involved with deafblindness.

*Saskia Damen*

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# 1 Introduction

This book describes the support needed by children and adults diagnosed with congenital hearing and visual disabilities. National prevalence surveys in the Netherlands, also conducted in institutions for people with intellectual disabilities (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Meuwese- Jongejeugd, Van Splunder, Vink, Stilma, Van Zanten, Verschuure, & Evenhuis, 2008), have shown that this is a substantial group of people.

In the Netherlands, some children and adults with congenital deafblindness are supported by organisations with services aimed at one of the two sensory disabilities (e.g. schools or homes for people with visual disabilities or hearing loss) or the combination of both disabilities. However, the largest proportion of this group is supported by organisations that provide services for people with intellectual disabilities.

Unfortunately, there is still a lot of ignorance surrounding people with congenital deafblindness, both in and outside the Netherlands. It is a regular occurrence that sensory disabilities are not noticed (Fellinger, Holzinger, Dirmhirn, Van Dijk, & Goldberg, 2009) or do not result in the correct support. Possible consequences include severe developmental delay, behavioural problems and/or social isolation (Van der Burg, Damen, & Evenhuis, 2007; also see the interview with Professor Janssen in the Dutch newspaper *de Volkskrant*: Van Hinthum, 2009).

The parents of a child with deafblindness often have questions concerning their child's education. Professionals working with people with congenital deafblindness regularly indicate a need for advice as well. These professionals include daily caregivers, but can also be teachers, physiotherapists, speech therapists, occupational therapists or psychologists. This book aims to fulfil their need for knowledge by providing information about congenital deafblindness, its impact and its consequences.

The first part of this book gives background information about the term deafblindness, its causes, impact and diagnosis. In the second part, each chapter covers a different facet of support for people with congenital deafblindness. The third part contains suggestions for arranging their environments and addresses the specific skills needed by their caregivers.

# Part I

Background information about congenital deafblindness

## 2 What is congenital deafblindness?

### 2.1 Terms

#### *DEAFBLIND*

The World Health Organization (WHO) uses the term *deafblindness* to refer to people with visual and hearing disabilities. The term encompasses not only people who are completely deaf and blind, but also those with various gradations of visual and hearing disabilities (i.e. deafness combined with partial sightedness, blindness combined with partial hearing loss, and partial sightedness combined with partial hearing loss). On the basis of the norms for partial sightedness and partial hearing loss, this includes people with a visual acuity of less than 0.3 and/or a visual field of less than 30 degrees (Colenbrander, 2010) and a hearing loss of 26 decibels of more in the better ear (World Health Organization, 2001).

In Scandinavia, which has highly specialised support for people with congenital deafblindness, a functional definition of deafblindness is used. This means that instead of using strict norms for the results of vision and hearing tests, they examine the extent to which someone with visual and hearing problems needs a specifically deafblind approach. If that is the case, the person is diagnosed as deafblind (Dammeyer, 2010a).

The term *deafblind* can be confusing because it does not always mean that a person with this diagnosis cannot see and hear at all.

Nevertheless, people with congenital deafblindness, their caregivers and professionals often choose to use the term deafblind or deafblindness. These terms are used to make it clear that living with impaired vision and hearing is a unique and complex form of existence. Having both visual and hearing disabilities involves more than just the sum of the two disabilities; the impact of dealing with both is much greater. We sometimes also refer to this as a multiple disability, meaning that one disability cannot or can only barely be compensated for because of the other disability (Colenbrander, 2010).



*Pieter is partially sighted and deaf, so he falls into the deafblind target group.*



The diversity and complexity of deafblindness are also evident in the definition of deafblindness formulated in 1999 by the Dutch Deafblind Platform ([www.doofblind.nl](http://www.doofblind.nl)):

“Deafblindness is a combination of deafness/partial hearing loss and blindness/partial sightedness. Deafblindness inhibits communication, acquisition of information and mobility. Without modifications, aids and/or support from others, people with deafblindness cannot always participate in daily and social life.”

***Practical example: Els***

*Els is a 43-year-old deaf woman with a severe visual disability. For many years she has been living in a group home for people with varying levels of visual and intellectual disabilities. The caregivers are in the habit of calling the residents to dinner. Els usually responds adequately, except at weekends, when she has to be collected by a caregiver. Observation of Els at mealtimes during the week and in the weekend revealed that her appetite does not change. However, there is no one sitting next to her on the couch in the weekends because the person who normally sits next to her spends weekends at his parents' house. This means that in the weekends Els has no way of knowing it is time to get up and go to the dining room.*

In this example, we note that Els, unlike the other residents, cannot benefit from auditory information because of her deafness. Els's limited vision also means that she cannot observe the behaviour of others at a distance. Close by, she can see and also feel the movement of the person sitting next to her on the couch. This experiential knowledge combined with other indications, like the smell of food and the order of events, lets Els understand that it is time for dinner when she sees and feels the resident next to her get up. When that person is not there, this information is unavailable.

***DEAFBLINDNESS COMBINED WITH A COGNITIVE DISABILITY***

This example with Els illustrates that a person with deafblindness, like anyone else, makes a more or less conscious estimation of a situation based on perceived sensory information: what is going on and what am I expected to do? When doing so, a person's mental capacity, plays an important role.

There is a clear link between sensory disabilities and intellectual disabilities, also called cognitive disabilities. A person with sensory disabilities has limited access to the surrounding world and can develop unclear impressions of that world.

Limited sensory information hinders cognitive development, as this process takes place when children use their senses to come into contact with the world (Gibson, 1966; Vygotsky, 1978). Children learn to make links between similar phenomena by touching the world around them. They develop a mental image of that world and the links between its different aspects. Based on this mental image, children can organise and interpret new information (Piaget, 1957) and, for example, respond adequately to events.

Many people with deafblindness have developed a relatively limited number of concepts and links between concepts due to their limited sensory information. In addition, they have been

able to gain little knowledge and experience with different strategies for coping with the world. As a result, they have not been able to fully develop their cognitive capabilities (Dammeyer, 2011). In addition, impaired cognitive development makes coping with sensory disabilities more difficult.

Assigning meaning to limited sensory information, like a vague photo, is much more difficult if you only have a limited number of meanings (see Section 8.1 on information processing).

Due to the impact of deafblindness on cognitive development, it is difficult to evaluate the cognitive capabilities of someone with congenital deafblindness. Regardless of the level of cognitive functioning, we therefore prefer the term *people with deafblindness* and we do not refer to these people as *people with a cognitive/intellectual disability who are deafblind*.

### **FORMS OF DEAFBLINDNESS**

Depending on the age at which a person becomes deafblind, the deafblindness can be characterised as congenital or acquired. With acquired deafblindness, a distinction can be made between acquisition at an early age and after the age of 55 (elderly deafblindness). There are thus three general forms of deafblindness:

- Congenital deafblindness: the person is deafblind from birth, soon after birth or becomes so within the first year of life. The deafblindness manifests before the start of language development (Dammeyer, 2010a).
- Acquired deafblindness: the person becomes deafblind after the start of language development (Dammeyer, 2010a), which is usually considered to occur during the first year of life.
- Elderly deafblindness: the person becomes deafblind after the age of 55 (Vaal, Gussekloo, De Klerk, Frijters, Evenhuis, Van Beek, & Deeg, 2007). This is the most common form of deafblindness.

This book addresses the challenges inherent in caring for a person with congenital deafblindness. People with other forms of deafblindness may share some of the same challenges or have entirely different ones.

## **2.2 Figures**

The total number of people with deafblindness in the Netherlands can be estimated on the basis of national prevalence surveys. The estimate ranges between 33,000 and 38,000 people (Vaal et al., 2007). Of these people, about 2,000 have a congenital form of deafblindness. Various researchers have indicated that this is probably an underestimate (see the interview with Professor Marleen Janssen by Van Hinthum in the Dutch newspaper *de Volkskrant*, 2009). Within the group of people who receive residential care in institutions for people with intellectual disabilities in the Netherlands, there certainly are people with undetected and/or unrecognised deafblindness (Meuwese-Jongejeugd et al., 2008). In the Netherlands, the visual and auditory acuity of many people with an intellectual disability is first examined at an adult age. It is therefore unclear which sort of deafblindness they have.

## 2.3 Causes

There are several causes of congenital deafblindness. A list of the most important causes is given below:

### *PREMATURITY/COMPLICATIONS AROUND BIRTH*

Children who are born prematurely or suffer a lack of oxygen during birth run a risk of brain damage and associated sensory disabilities. An excessive concentration of oxygen added to the incubator can also damage the developing retina. In addition, the use of antibiotics to combat infections in premature babies can be linked to the development of hearing loss.

### *DISEASES*

Meningitis and strokes are conditions that can lead to congenital deafblindness in very young children. This also applies to other diseases that can lead to brain damage, such as a brain tumour or shaken baby syndrome. Probably the most famous person with deafblindness, Helen Keller, became deafblind after developing meningitis at the age of 19 months. Keller, an American born in 1880, went on to study linguistics at university and was not the first person to receive specialist deafblind education (that was Laura Bridgman). However, she became world famous for publishing her autobiography (Keller, 2004).

### *INFECTIONS IN THE WOMB*

The following diseases are known to be able to cause deafblindness in the foetus if they develop during pregnancy: toxoplasmosis, congenital cytomegalovirus infection and rubella.

Toxoplasmosis is a disease caused by a parasite that is found most commonly in cat faeces and in raw meat of animals such as pigs, goats and sheep.

Cytomegalovirus is a herpes virus commonly found in humans. Rubella (German measles) is a viral childhood disease. If the expectant mother contracts this disease during pregnancy, the baby can suffer severe congenital deformities. This is called congenital rubella syndrome.

### *Congenital rubella syndrome (CRS)*

German measles is an innocuous childhood disease, but if a woman becomes infected with it while pregnant, the foetus can suffer developmental delay and severe deformities (Duszak, 2009; O'Donnell, 1996). The earlier the infection occurs in the pregnancy, the greater the risk of deformities (Spreen, Risser, & Edgell, 1984) and the greater their severity.

Children born with CRS often have abnormalities of their eyes and ears. In addition, they often have intellectual disabilities and medical problems, such as a heart defect and/or growth retardation (Van Dijk, 1982; Duszak, 2009).



*Josy has deafblindness as a result of congenital rubella syndrome.*

At a later age they often develop other medical problems like diabetes, thyroid anomalies and psychological or behavioural problems. These are called *late manifestations* (Munroe, 1999). Researchers have differing opinions on whether these symptoms are specific to the rubella virus or are caused by the combination of growing up with severe, multiple disabilities. Recent research by Dammeyer (2010b) suggests that the latter is more likely.

The Bartiméus and Koninklijke Kentalis organisations in the Netherlands are currently conducting collaborative, long-term research on 60 adults with CRS. This research has resulted in the development of a medical and psychological monitoring system (Kingma, Schoenmaker, Damen, & Van Nunen, 2005) to identify and treat problems at an early stage. The study also revealed that the participants displayed four types of psychological problems (Damen & Van Nunen, 2011):

- a. aggressive behaviour,
- b. mood problems,
- c. autistic-like behaviour and
- d. attention problems.

These problems match descriptions in the literature (see Chess & Fernandez, 1980; Chess, Korn, & Fernandez, 1971; Nicolas, 2000; O'Donnell, 1996). The severity of the psychological problems seems to be associated with the time of infection during pregnancy, the severity of mental disability and age (Suelmann, 2010).

Twenty of the adults with CRS were compared with adults with deafblindness due to causes other than CRS (Van Schadewijk, Wijnroks, & Damen, 2003). This revealed that adults with CRS

display more autistic characteristics and self-mutilating behaviour than participants with other causes of deafblindness.

However, the participants with CRS were more task-oriented than the participants without CRS. When the study was repeated again five years later, the recorded problems were considerably less severe and thus the difference between the two groups had disappeared (Weinstock, 2008). This may be because the participants' caregivers had paid more attention to their psychological well-being.

Rubella vaccination currently forms part of the national vaccination programme in most countries (World Health Organization, 2000). This is the case in the Netherlands, but there are still some countries that do not provide the vaccination. At the end of 2011, vaccination against rubella was provided in 130 of the 195 countries in the world (World Health Organization, 2011). In addition, there are people who do not undergo vaccination, primarily because of religious or anthroposophical beliefs. This means that children are still being born with CRS. Between 1962 and 1965, before there was a rubella vaccine, many children were born with CRS during a worldwide rubella epidemic. This increased the attention paid to deafblindness in care and education (Van Dijk & Nelson, 1997-1998).

## ***SYNDROMES***

The congenital rubella syndrome discussed above is caused by a viral infection contracted during pregnancy. There are also other syndromes that can result in deafblindness, such as CHARGE, Wolf-Hirschhorn syndrome, Zellweger syndrome and Cornelia de Lange syndrome, but these are all caused by a chromosomal aberration. In Goldenhar syndrome, the cause of the deafblindness is still unknown.

### ***CHARGE syndrome***

CHARGE is an acronym for a combination of symptoms seen in a number of children: it stands for coloboma of the eye, heart defects, atresia of the choanae, retardation, genital defects and ear abnormalities and/or hearing loss. CHARGE syndrome results in a recognisable pattern of birth defects with many deformities that differ from person to person. CHARGE syndrome occurs in 1 in 10,000- 12,000 children. CHARGE syndrome has a genetic basis: it is caused by an error in the eighth chromosome. This genetic defect is found in only two thirds of all people with CHARGE, and because of this the diagnosis of the syndrome is based on clinical examination rather than genetic testing.

Diagnosis today distinguishes between major features and minor characteristics. Almost all children with CHARGE have problems with balance. The major features are:

- Coloboma of the eye. Incomplete development of the retina, defects in the iris and/or the optic nerve (in 80-90% of people with CHARGE).
- Atresia of the nose openings (choanae). There is no link between the nasal cavity and the throat opening, making it impossible to breathe through the nose. This also affects the sense of smell in many cases (50-60%).
- Heart defects.
- Developmental delay (retardation). Delay of growth and development (70%).

- Defects in and delayed development of the genitalia, urinary tract defects (50-90%).
- Ear defects and/or hearing loss (>90%).

Most children with CHARGE syndrome do not have all of these symptoms; CHARGE is diagnosed when at least three of the specified six symptoms are present. CHARGE is also diagnosed if two of the major features are present together with three minor characteristics. These characteristics include typical facial features, low muscle tone, cleft lip or palate, difficulty swallowing, kidney defects and oesophageal defects (Blake & Prasad, 2006; Horsch & Scheele, 2011; Jongmans, Admiraal, Van der Donk, Vissers, Baas, Kapusta, & Van Ravenswaaij, 2006).

#### ***Goldenhar syndrome***

With Goldenhar syndrome, the development of the foetus's head and spine did not proceed normally during pregnancy. The cause of Goldenhar syndrome is still unknown. A baby with Goldenhar syndrome may have an asymmetrical face.

Symptoms can also include defects of the ears, eyes and nose. In addition, the lower and upper jaws can be smaller than normal, and the upper lip can be cleft. The spinal vertebrae can be underdeveloped and there may be scoliosis of the spine. There may sometimes be heart and kidney defects (Zelante, Gasparini, Castriota Scanderberg, Dimitri, Criconia, & Gorlin, 1997).

#### ***Wolf-Hirschhorn syndrome (WHS)***

This hereditary syndrome is also called 4p syndrome because part of the short arm of chromosome 4 is missing. The symptoms differ from person to person; known symptoms include problems with feeding, low birth weight, heart defects, growth retardation, muscle weakness, epilepsy and delayed motor and cognitive development (Fisch, Carpenter, Howard-Peebles, Holden, Tarleton, Simensen, & Battaglia, 2012). Deafblindness is found in the syndrome because of defects in the development of the ears and eyes.

#### ***Zellweger syndrome***

This syndrome is a hereditary metabolic disorder that is associated with certain facial features, such as a flat face, a high forehead and a broad bridge of the nose. Along with deafblindness, there are a number of associated medical problems like muscle weakness, liver enlargement, skeleton and kidney defects, and jaundice.

There is often a greater risk of respiratory tract infections. Finally, intellectual disability may be present. Most children with Zellweger syndrome die before becoming toddlers due to the severity and complexity of their symptoms (Steinberg, Dodt, Raymond, Braverman, Moser, & Moser, 2006).

#### ***Cornelia de Lange syndrome***

Cornelia de Lange syndrome is a hereditary developmental disorder. Children with this syndrome can have visual and hearing disabilities along with intellectual disabilities. In addition, they often have characteristic external features like a small head; thin, arched eyebrows that often meet in the middle; long, thick eyelashes; a small, upturned nose; thin lips that bend downwards; low-set ears; a high palate (sometimes cleft); excessive body hair, marble-like skin; and small hands and feet (Basile, Villa, Selicorni, & Molteni, 2007).

## 2.4 Summary

The term *deafblindness* is used to describe people who are blind or partially sighted and deaf or have partial hearing loss. Congenital deafblindness refers to deafblindness manifesting immediately after birth or in the first year of life. The impact of this dual sensory disability is enormous and affects all aspects of how a person functions in everyday life. In particular, communication, mobility and the ability to acquire information are severely affected. An association has been found between deafblindness and cognitive disabilities: as all information is perceived in fragments, it takes a great deal of effort and time to interpret information, and learning processes proceed more slowly. Conversely, cognitive disabilities impede the interpretation of sensory information.

There are different causes of congenital deafblindness. The most common causes are premature birth or perinatal complications, infections in the womb and several syndromes (especially hereditary ones). The different causes of congenital deafblindness were briefly described in this chapter.

### 3 The impact of congenital deafblindness

#### *EXPERIENTIAL EXERCISE*

To get an idea of what deafblindness means, it can help to perform an experiential exercise: blindfold yourself and limit your hearing by inserting earplugs and headphones. You will notice that the world is suddenly no larger than the extent of your reach. You will also become very aware of what you feel and what is happening in your body: the position of your body parts, your respiration, the temperature of the room you are in and the movements of air in the room, and the surfaces you are sitting on and resting your feet on. As you perceive so little of your surroundings and the visual and auditory contact with others disappears, a feeling of isolation and a need for communication and information arise: are there other people there, do they know that I am here, am I missing something, what is going to happen and what is expected of me?



*An experiential exercise clearly reveals how deafblindness affects everyday life.*



### **3.1 Perception and experience of time**

People with deafblindness perceive time differently. In a general practitioner's waiting room, you have visual and auditory clues that ensure you know when it is your turn. While you are waiting, you can amuse yourself by watching or listening to what is going on in the waiting room, or reading a magazine. All these options are unavailable to people with deafblindness, which greatly lengthens the experience of waiting. This applies even more strongly when they do not know exactly where they are or what they are waiting for; tension can increase rapidly under those conditions.

And what happens if someone bumps into the knee of a person with deafblindness as they are walking by? Because the warning system that works with the distance senses (sight and hearing) is unavailable, only the impact senses (taste, scent) are left. People with deafblindness have no warning that someone is approaching and they can therefore be startled by someone bumping into them. This type of contact is also transient and so the meaning of the contact will be unclear. Are they expected to do something? Did they do something wrong? Or was it accidental?

In this example, we sketch a situation in which seeing and hearing are completely absent; the situation can change if a person has partial sight or hearing. The use of sight and hearing can make the above-mentioned waiting room scenario seem less unclear, confusing, lonely and hopeless, but not always. Even if a person has partial sight or hearing, a person with congenital deafblindness receives only small fragments of information compared to the complete sensory information acquired by someone who can see and hear well.

This problem in people with deafblindness is referred to as *fragmentary perception* (Van Dijk & Janssen, 1993). It is a major task to forge these fragments into a meaningful whole. The snippets of information received through the senses can be confusing or give the wrong impression of a situation. It is not uncommon for a person with deafblindness to seem to shut out the fragmentary visual and auditory information received, because the person is busy thinking about what he or she experienced and trying to make connections. The person needs additional processing time; if disturbed while thinking and/or processing, it is easy to lose track altogether and respond inappropriately. The consequence is an acute interruption of the contact, which can result in a negative experience for both the person with deafblindness and the communication partner.

### **3.2 Touch as a source of information**

Touch is an important sense for people who cannot use or can only slightly use their ears and eyes (Andersen & Rødbroe, 2006). Touch can provide a lot of information, but it cannot fully compensate for the distance senses of sight and hearing. The disadvantage of touch is that it cannot provide a complete picture of your surroundings and the people and objects they contain. Thus, people with deafblindness are said to have a "from parts to the whole"

approach in contrast to the “from the whole to the parts” approach of people who can see and hear (Bruce, 2005a). We see the room and the people and objects it contains at a glance. When someone approaches us, for example, we see the whole person. To decide whether we know the person, we concentrate on details, such as the face.

People with deafblindness must always create an idea of the whole based on details. That is much more complicated and takes a lot more time (Bruce, 2005a).

### 3.3 Development and social interaction

The impact of congenital deafblindness is always major. Due to the lack of sensory information, also referred to as *deprivation* (Van Dijk & Janssen, 1993), the development of people with congenital deafblindness is often delayed. This can mean that they do not learn to distinguish between themselves and others, or they may use others as an extension of themselves or treat them roughly. They may not have any or only a limited idea of the daily schedule and the day’s activities and may not recognise associations between phenomena occurring in their lives (Miles, McLetchie, & National Consortium on Deaf-Blindness, 2008). Other people with congenital deafblindness do have some idea of the association between time, activity, place, person and space. They may have difficulty with deviations from the daily routine, though, because it makes them lose their overview.



*Jan Dirk is looking at a ball in the ball pit. It is extremely difficult for him to obtain a complete overview of his surroundings.*

People with deafblindness also face other challenges. Many seem to have difficulty establishing a cause and effect relationship; they exhibit very few problem-solving skills. They have often developed poor independent coping skills and thus remain dependent on care provided by others (McInnes, 1999). Many people with congenital deafblindness also have difficulty communicating their intentions or understanding those of others (Bjerkan, 1996; Rødbroe & Souriau, 1999). A limited range of interests and passivity are both common. Repetition of the same movement, also referred to as *stereotypical behaviour*, is also commonly observed. These behaviours appear to be a means for a person with deafblindness to experience sufficient stimuli in response to the limited sensory stimuli received (Bloeming-Wolbrink, Janssen, De Weerd, Ruijsenaars, Sweep, Eijsbouts & Riksen-Walraven, 2012; Van Dijk, 1991). In response to the difficulty of communicating their intentions, experiencing limited influence over their surroundings or losing their overview, people with congenital deafblindness can display behavioural problems in the form of self-mutilation (Sisson, Van Hasselt, & Hersen, 1987).

All of these factors (lack of overview, poor mastery of skills, problems with communication and problem behaviour) continuously affect their functioning. The impact of deafblindness on cognitive development is covered later in the book (in Section 4.2). The impact on social contact is extensive as well, since the possibilities for social interaction are often limited. It is not easy for people with deafblindness to make real contact with others, to understand them or to make themselves understood.

Social partners (e.g. parents, caregivers and teachers) regularly report problems in their interactions with a child or adult with deafblindness (Janssen, 2003a, 2003b, 2004, 2006). The usual means of contact and communication, like eye contact and speech, are unavailable. Therefore, it is often difficult for seeing and hearing people to recognise attempts to make contact by people with deafblindness and to interpret them correctly. For example, a child with deafblindness can become still in response to feeling the air move as his mother passes by. His mother may not see this reaction or may not realise that it means her child is paying attention to what she is doing and may be waiting for further contact attempts. She will thus not make contact, and the attention of the child with deafblindness will move on. If social partners do not respond appropriately to contact attempts from a person with congenital deafblindness, then that person may respond by rejecting or breaking off the contact (Janssen, 2003a, 2003b; Rødbroe & Souriau, 1999; Goode, 1990).

People with deafblindness who learn how to influence others through their behaviour and emotions often find it difficult to learn how to communicate about different matters in the world. They continue to communicate about what is perceivable here and now. For example, they may ask for a clapping game by sticking out a hand. To be able to communicate about things that are not present in the immediate environment, like an object in another room, a person who is not present or an activity that happened yesterday, they need aids to refer to them.

They require symbols, such as a specific sign or an object serving as a reference. To use these symbols, they need to develop symbolic understanding, an understanding that symbols refer to

something in the real world. Many children with congenital deafblindness do not develop symbolic understanding (Bruce, 2005a; b; Rødbroe & Souriau, 1999).

The examples stated above show how great the impact of deafblindness can be on a person born with deafblindness and his or her social environment. This does not mean that person does not have the ability to develop. A professional with extensive knowledge of deafblindness can test the extent to which the living environment, daily support and daily activities suit a person's complex need for support and can offer recommendations. By using video interaction analysis, those involved with a person with deafblindness can gain better insight into the extent to which the support matches the needs of that person. After adjusting the support, for example, by emphasising touch more in contact with the person with deafblindness, we often see that this person is capable of a lot more than was previously suspected.

### **3.4 Four groups**

It is important to know to what extent a person with deafblindness can see and hear and uses that information in daily life. This allows for adjustment to be made to the monitoring style and environmental factors that match the individual's needs (Siegel-Causey & Great Lakes Area Regional Center for Deafblind Education, 1996). It is important to realise that the sensory capabilities of people with deafblindness are very limited. These limitations can lead to problems with information and communication, as well as with orientation and mobility. People with deafblindness are often classified into one of four groups according to their visual and auditory acuity (Rødbroe & Janssen, 2008; Fellingner et al., 2009):

1. Moderate hearing and profound/severe visual impairment,
2. Profound/severe hearing and moderate visual impairment,
3. Moderate hearing and visual impairment,
4. Profound/severe hearing and visual impairment.

#### ***1. MODERATE HEARING AND PROFOUND/SEVERE VISUAL IMPAIRMENT***

People in this group can use their hearing functionally in daily life, but not their sight. The extent to which these people use their hearing at any specific moment is determined by several associated factors: the nature of the hearing disability, the nature of the sound, whether a hearing aid is being worn or not, the quality of the noise environment (e.g. acoustics, background noise), a person's general state (e.g. level of alertness, tension level, mood) and possible strategies to compensate for information loss (e.g. memory or use of communication aids). To understand the complex association between functional disorders and daily activities, we refer to the International Classification of Functioning, Disability and Health model, also called the ICF model (World Health Organization, 2001).

Although it sometimes seems that a person understands a lot, reference is always made to *residual* hearing, to emphasise that hearing is only partial. In all cases, much information is not picked up by people with partial hearing loss and environmental adjustments are required.

In general, the residual hearing can be optimally used in a calm environment without echoes and with one-on-one contact. Social partners can take partial hearing loss into account by adjusting the context and the environment. For example by:

- asking for a person's attention before speaking
- speaking calmly
- using short sentences
- articulating clearly
- speaking near the better ear or directly in front of the person
- not speaking excessively loudly (hearing aids amplify sounds)
- being predictable and not changing the subject too quickly
- adjusting the noise in the surroundings (e.g. turning off music and TV during contact).

The fact that a person with congenital deafblindness responds to auditory information does not mean that he or she has completely understood the content of the message. Spoken language can have a signal function for some people (knowing that something is being said), but not a symbolic function (knowing what is being said). These functions can be confused in practice. Often people think that a response (e.g. putting out a hand for a drinking cup) is proof that a person can hear well (the message: "here is your coffee"). Certainly if the situation is recognisable for a person with deafblindness, there is a good chance that person will respond adequately, even if he or she has not understood the message. By recognising the situation, a person will guess the correct message without being able to understand the spoken language.

The signalling function of sound is also very important. This can be the purpose of a hearing aid, for example. After all, a person with deafblindness who can use a hearing aid to learn that there are other people nearby may feel less alone. The same applies for a cochlear implant (an implant that transforms sound into electric pulses, which allows some perception of sound).

If someone responds adequately to one sound, this does not mean that person can perceive and correctly interpret other sounds. People who are less able to hear high tones can pick up environmental noises (e.g. bell ringing, door banging) but can partly miss spoken language. For example, it is often unclear who is being addressed. Or people can sometimes hear high voices better than low ones, or vice versa.

People with deafblindness with residual hearing can be hypersensitive to sound. Sounds like coughing or shifting a chair can be extremely uncomfortable for them. This hypersensitivity can cause them to avoid noisy environments or they may display stress reactions in such surroundings. This often has to do with the extent to which all sounds are magnified by the hearing aid (including the background noises). It is important to realise that partial hearing loss is tiring, particularly when a person with deafblindness spends a long time without pause listening intensely and concentrating.

Even if a person has residual hearing, it is important for the communication partner to confirm the auditory information through touch: let someone feel who you are, where you both are

and what is in front of him or her. Supportive means of communication, like objects or tactile signs, can clarify spoken language.

Remember that being asked to listen and touch at the same time may be too much. It is difficult for people with congenital deafblindness to integrate these two forms of information and not everyone will be able to do so. They may concentrate so intensively on exploring an unfamiliar object with their hands that any information they hear may be ignored. It is better to offer information sequentially through different senses than all at the same time.

People with congenital deafblindness require a longer processing time during communication and it is relatively common for them to interpret signals incorrectly. Therefore, take time to make contact and exchange messages. Constantly check that you have understood the person with deafblindness and vice versa. This helps prevent misunderstandings or leads to their early detection and resolution.

***Practical example: Eef***

*Eef is a blind man with very little residual hearing. For years, his caregivers in the community home have approached him using spoken language. During transition situations, Eef had the habit of calling out sentences in a loud voice, like "take a shower now", even when the caregivers had repeatedly told him he was not going to do that.*

*During a video analysis the team discovered that spoken language was not sufficiently clear for Eef. It was thought that he shouted the sentences in an attempt to clarify what activity was next. The team decided to support their verbal explanations by offering Eef tangible objects (e.g. drinking cup, spoon, toilet roll). His shouting subsequently decreased.*

## **2. PROFOUND/SEVERE HEARING AND MODERATE VISUAL IMPAIRMENT**

This group has functional residual vision but no functional hearing. The extent to which these people can use their residual vision depends on their visual possibilities and the visual stimuli offered.

People belonging to this group are sometimes described as keeping a close watch on their surroundings. They focus on perception through vision. Often there is an evident preference for visual stimulation (by themselves or others), such as looking in the light, waving in front of their eyes or looking at brightly coloured or shiny objects. If a person is busy with visual self-stimulation, it can be difficult to get their attention. Patience and repeatedly trying to make contact can help.

It is important to understand that looking is not the same as seeing clearly. Small details disappear for many people with deafblindness with residual vision: one example is not being able to see facial expressions and not being able to follow the direction of someone's gaze. These people rarely point to something; they are more likely to take another person's hand and move it in a certain direction. They may also touch their own bodies to communicate about something that they have previously felt (known as *body pointing*, also observed in blind children; see Preisler, 1991).

The visual attention of people with deafblindness with residual vision is often focused on what is happening close at hand. Interest and alertness can be important components of vision: some people with deafblindness can find all the sweets on the table so they can eat them, while failing to grab a washcloth. When interacting with these people, it is important to consciously draw their visual attention, amplify visual stimuli (e.g. sufficient lighting, short viewing distance, strong contrasts) and give them time to look at (and feel) an object. Also take into account that looking is tiring and that it is not always possible to look at and feel an object at the same time. They need all their energy to use one sense as well as possible. For partially sighted people with profound or severe hearing loss, it is therefore important to take a lot of time to initiate contact, make use of supportive means of communication and check whether you are understanding each other correctly.

***Practical example: Bianca***

*Bianca, a deaf and partially sighted woman, recently went shopping with her caregiver. Bianca held tight to the shopping trolley while the caregiver fetched a product from a low shelf. While doing so, the caregiver bumped into the trolley. Bianca understood this as a signal to return to the community home and started walking back with the trolley. The caregiver stopped her and made a gesture in front of her face: NO, WAIT. Bianca can see large gestures, but did not seem to understand the message because it conflicted with the touch information she had received (the bump against the trolley). Bianca began to panic and started hitting her head. The caregiver wrote in her report: Bianca was not interested in shopping today.*

### **3. MODERATE HEARING AND VISUAL IMPAIRMENT**

The information about hearing and seeing given for the first two groups also applies to this group of people with deafblindness. The extent to which they can utilise their limited visual and auditory capacities depends on many factors. It is important to let these people make use of their abilities in their own ways. For many people with deafblindness, it is difficult to use their senses, also called modalities, at the same time. Feeling an unknown object is so intense, for example, that they cannot look at the same time or vice versa. Often one modality is preferred: one of the senses (sight, hearing or touch) is employed most often. It is also possible that the person is focused more on touch at one point and then switches to looking or listening.

The possibilities for people in this group are greater in general than those for people without functional residual vision or hearing. This often gives the people around them the impression that they can benefit sufficiently from regular methods of communication and support, like spoken language. However, by employing adapted communication aids, often through touch, these people can utilise their capabilities better and develop further.

People with deafblindness who have residual hearing and vision also need more time to gain an impression of an object or situation. Obtaining an impression by touching, examining, listening, tasting and/or smelling is called *exploring*. By stimulating exploration, the perceived world can be expanded. By exploring together, you can give a person with congenital deafblindness an idea of what you can experience together in the surrounding world. Naturally,

the individual's tempo and preference for feeling, smelling, tasting, looking or listening must be respected. The starting point must always be finding the interest and motivation of the other, working with these interests and encouraging a person to expand his or her perception of the world.

***Practical example: Jos***

*Jos is a partially sighted man with partial hearing living in a residential care facility. He walks around all day with a radio in his pocket and visits several office workers for a chat and a cup of coffee. Jos has repeatedly stated his lack of interest in work or other group activities, and so no attempts are made anymore to include him in these activities. Not everyone can talk to Jos, because it is very difficult to understand him; you have to know him well to understand what he means.*

*The number of people who know him well has declined in the past few years, and apparently Jos is not having any luck making new contacts. On days when familiar staff are absent or have no time for him, Jos looks lonely. This has been happening increasingly often. Caregivers have talked to Jos about his interest in doing tasks that would bring him into contact with familiar people in an organised manner and let him meet new people. Jos has said that he would be happy to help several secretaries (even a few he does not know) by carrying the internal post to the reception. He likes the idea of having a familiar caregiver accompany him in the initial period to help him get used to the work and meet unfamiliar colleagues. Jos agreed with his coordinating supervisor that she would start a file to record what Jos finds important in his life and how he usually talks about this (his vocabulary). In this communication book, his caregivers will also record, with his approval, things he experiences and would like to share with others (such as a visit to a soccer game).*

#### **4. PROFOUND/SEVERE HEARING AND VISUAL IMPAIRMENT**

This group relies primarily on touch. This is not the only sensory form of information remaining when vision and hearing are almost or completely absent: smell and taste, and information from the muscles and the balance organ (the proprioceptive system and the vestibular system, respectively) are also used to gather information.

Some completely deaf and blind people are hypersensitive or hyposensitive to taste stimuli. Others are capable of smelling who is in their vicinity. This group of people is sometimes known to concentrate intensely on noticing every movement of air or scent. Some people with deafblindness develop strategies to maximise their chance to encounter people, for example, by standing or lying in the doorway. Only when they can perceive the presence of others do they know that there are other people around and where they are.

Since touch is so important to this group, each touch experience is felt intensively. Wearing certain kinds of clothing can be very disturbing if it is too tight or it itches. This can draw a person's attention to their clothing, as evidenced by a frequent tendency of this group of people to take their clothes off.



Taking their hands can also be considered interference. Try to close your eyes and feel the surface of a table, and then do it again while someone holds or pushes on the back of your hand. You are distracted from the feeling and thus acquire less information. Some people with deafblindness have developed a tactile defence (e.g. due to negative experiences during a hospital visit or medical interventions) that can delay or inhibit the development of the touch sense.

A methodical approach should be used when learning to feel objects and/or doing this together. The method often used with people with deafblindness is the *hand- under-hand method* (Miles, 1997; see Section 8.2 for a description).

Many people with congenital deafblindness enjoy walking barefoot because of the touch information they receive and because they have better contact with the ground. Some prefer to take all their clothes off. Some people who are deafblind prefer to spend the day lying down, perhaps because this gives them maximum contact with the surface. This may produce a feeling of security or it could be due to balance problems. We also see a preference for balance games and objects that vibrate. Since sound is a vibration, musical activities are also suitable for people with deafblindness. Let them feel a guitar or drums or put speakers under a wooden plank that they can sit or lie on. Sound vibrations can also be felt by touching a balloon. Different sorts of *sound banks* are available from specialist organisations (see p.129 for a list of specialist organisations).



*Elco, who has no visual and hearing residuals, is enjoying a bubbling footbath.*

**Practical example: Gerard**

*Gerard is completely deaf and blind. He communicates through signs and tactile symbols. When Gerard is sitting alone on the couch, he is always busy feeling something: the sole of his shoe, the light switch behind him or his stomach and torso. He is trying to prevent understimulation. Gerard is extremely sensitive to the way other people touch him. When caregivers tap him to encourage him to do something, like drink his tea, he will often bite hard on his thumb. Gerard has strongly developed the use of touch: he sometimes clamps his cup in his mouth, leans his head back and blows. By copying this behaviour, we found that this is not stereotypical behaviour but rather functional. Blowing produces air circulation, which clearly tells him how much liquid is still in the cup without him having to stick his fingers in.*

### **3.5 Summary**

Interaction with people with congenital deafblindness is generally difficult. The standard means of contact and communication (speech, eye contact) cannot be used. It is difficult to recognise the initiatives made by these people, and their meanings are often unclear. It takes a lot of time and effort from both the person with deafblindness and their communication partners to build good interactions. Video observations and close examination of interactions can help improve contact and communication, even at a later age.

People with congenital deafblindness have a different form of perception and experience of time. Because information is primarily collected through touch, often only part of a situation is perceived. People with deafblindness need a great deal of time to form a whole picture from the different pieces of information, and there is still a great risk of wrong expectations and misinterpretations. This can lead to frustration and restrictions in contact. It takes additional effort from those around people with congenital deafblindness to follow and understand them.

The environment and supervision of a person with deafblindness must be adjusted to the senses that a person primarily uses. It is important to know the manner in which someone uses residual vision and/or hearing. If people can still hear a bit, the sound in their surroundings can be modified to enable optimal opportunities for hearing. If a person uses their residual vision, contrasts can be amplified and visual information can be provided in a predictable, calm manner. For people who are completely deaf and blind, as well as those with residual hearing and vision, touch is an important sense for acquiring information. Smell and information from the proprioceptive and vestibular systems are also used to collect information about situations.

## 4 Assessment

As part of the professional support for people with disabilities, it is common to perform medical and/or psychological assessments to estimate the extent of their abilities and disabilities if these have not yet been sufficiently diagnosed. In the case of deafblindness, the following types of assessment are relevant:

- **Medical assessment:** physical examination. In particular, this includes estimation of the severity of the visual disability (ophthalmological and visual function examination) and/or auditory disability (audiometry).
- **Psychological assessment:** examination to estimate psychological functioning (see De Zeeuw, 1983).
- **Communication assessment:** examination of the communicative capabilities. Normally, this forms part of a psychological assessment, but we will focus on this aspect separately.
- **Assessment of sensory integration:** examination of the ability to collect sensory information, organise it and use it in daily life. This examination is important for people with deafblindness who are suspected of having a sensory integration disorder (e.g. because they get upset when touching and being touched or seem to have little control of their movements).

To acquire a good overall picture, it is sensible to examine a person's functioning as a whole. This means having all experts collaborate in multidisciplinary assessments. The experts may include a general or educational psychologist, a speech therapist or communication coach, a general practitioner, a caregiver, an audiologist and audiology assistant, an ophthalmologist, an orthoptist, a technical ophthalmology assistant and a physiotherapist or sensorimotor therapist. It is best if these experts are specialists in deafblindness.

The aim of the assessment procedure is to support an individual as best as possible in their daily life. We call these assessments action-oriented (Pameijer, 2002); they produce concrete proposals for parenting, support and/or education. It is also sensible to follow someone for a longer period to get a better picture of their learning capacity (Boers, Janssen, Minnaert, & Ruijsenaars, 2013). A known pitfall is to conclude that someone is only capable of doing what his or her current development level prescribes; this ignores that person's capacity to learn and develop. It is often more informative to determine the next level of development and how this person could achieve that level with support. Dynamic assessment is a suitable method for estimating learning capacity (Haywood & Lidz, 2007): this diagnostic method involves measuring before and after an intervention (Boers et al., 2013). It makes a great difference if a person's current and former support have been geared specifically to that person with deafblindness. If a modification is or was not optimal, then even more care should be taken than usual when making pronouncements about capabilities.

## 4.1 Medical assessment

### *ASSESSMENT OF VISUAL FUNCTIONS*

The ICF model (World Health Organization, 2001) describes a person's health in three areas: physical functions, anatomical features, and activities and participation. Disturbances in functions and anatomical features lead to restrictions in activities and participation.

An assessment of a person's visual functions focuses on measuring the extent of useful vision. Both eyes are examined with properly fitting glasses if the individual needs and can wear glasses (some people with congenital blindness cannot tolerate glasses). We stress that the outcome of this examination does not tell us the extent to which the individual experiences restrictions in his or her activities and participation. A psychological assessment can provide more insight into that aspect.

Poor vision can manifest in two ways. It can result from limitations in visual acuity, also known as vision. Vision is defined as the number of details a person can perceive at a certain distance. A restriction in vision is given as a fraction. A person with normal vision has a vision of 1.0; a person with vision of less than 0.3 is defined as partially sighted or as having a visual disability. For that person, details must be three times larger than normal to be perceived. Vision of less than 0.1 but more than 0.05 is defined as a severe visual disability, and vision of 0.05 or less is defined as functional or complete blindness. The term *functional blindness* is used when there is some residual vision, but it cannot be used in a functional sense. *Blindness* refers to a total lack of vision (World Health Organization, 2001).

A disability related to visual functions can also be caused by a restriction of the visual field. If the visual field is smaller than normal, visual information is lost or is noticed later than usual. A normal visual field extends 90 degrees to each side. Partial sight is defined as a visual field of less than 30 degrees (concentric), and functional blindness or complete blindness as a visual field of less than 2 degrees (Colenbrander, 2010). Often the restricted visual field is described as looking through a bucket without a bottom (for a slight visual disability) or through a toilet paper roll (for a greater visual disability). The visual field restriction may apply not only to the edges of the field; the centre can also be affected. In some syndromes, for example Usher syndrome, the visual field gradually shrinks. That is why it is important to regularly repeat the visual function test.

#### ***Methods for assessing visual function***

Partial sight or a worsening visual disability is not always evident from a person's eyes or behaviour. Certainly in groups at risk, like children and adults with an intellectual disability (Evenhuis, Sjoukes, Koot, & Kooijman, 2009) and older adults (Quillen, 1999), it is worthwhile to measure precisely what a person can see.

For people who are difficult to examine, visual disability can be estimated by observing their looking behaviour during a test involving Teller Acuity Cards (TAC), which are printed with different stripe patterns. The underlying idea is that if the patterns are noticed, there is an

automatic looking response. If a reaction cannot be elicited with the TAC, the next step is often to check whether the person reacts to movements (e.g. a ball with a black-and-white pattern) or to light (e.g. by moving a lamp in front of the eyes).

The TAC test only measures visual detection (seeing that something is there) and not the processing of stimuli (seeing what is there). The TAC test cannot determine whether someone recognises forms. A test that does measure this is the Snellen chart, which has printed letters (Strouse Watt, 2003). But a person who takes this test must be able to read and that is often not the case with people with congenital deafblindness. Testing can then be done with images, for example, with the Kay Pictures Test.

The visual field can also be measured in several different ways. In standard visual field testing, the person being examined is asked to say when he or she can see a lamp flashing. If not, a stick with a ball on the end can be used to try to elicit reactions by moving it side to side and up and down towards the central field of view. This testing yields only general information about the visual field.

We can also check whether someone benefits from stronger visual contrasts. This test involves naming images with decreasing amounts of contrast, meaning that the person being tested must have some ability to communicate.

Finally, an ophthalmologist can examine the eyes for any abnormalities. The ophthalmologist can examine the eyeball using a type of microscope (slit lamp) and can check the retina (reflection) using a special optical lamp.

### **AUDIOMETRY**

Audiometry (measuring hearing) is performed to determine which pitch (frequency) and which volume (decibel) of sound waves a person can perceive. There are roughly three types of partial hearing loss (Kramer, Smits, Goverts, Festen, & Meuwese-Jongejeugd, 2013):

1. **Conductive hearing loss:** the problem lies in the conduction of sound to the inner ear. There is a loss of volume (sounds appear muted).
2. **Sensorineural hearing loss:** the problem lies in perceiving the sound in the area from the inner ear to the cerebral cortex. There is a loss of volume and quality (sounds appear muted and distorted).
3. **Mixed hearing loss:** a combination of conductive and sensorineural hearing loss. The problems lie in both the conduction and perception of sound.

When there are doubts about a person's hearing, the first step is to conduct a hearing screening. The first part of a hearing screening is otoscopy, in which the person's ear is examined for aberrations. The mobility of the eardrum is then measured using a tympanometer, a small device placed in the ear. In addition, the proper functioning of the cochlea is tested by making a click with an otoacoustic emission (OAE) meter. The cochlea is responsible for processing and referring sound to the brain, so a properly working cochlea will return the click sound. A measurement of the returned signal can show whether the cochlea functions properly.

The above-listed examination methods are simple. They involve holding a device briefly in a person's ear, which is usually not uncomfortable. The examination can also be conducted anywhere, even in the person's normal daily environment.

Because hearing problems are not always noticed, it is worthwhile testing the hearing at regular intervals. This certainly applies to people who have been diagnosed with a loss of vision and those with an intellectual disability (Meuwese-Jongejeugd, Van Splunder, Vink, Stilma, Van Zanten, Verschuure, & Evenhuis, 2008). If the result of the hearing screening suggests a problem, a more intensive examination can be initiated.

### ***Methods for audiometry***

Tests to determine the restrictions of hearing are always done without hearing aids and usually when hearing screening suggests hearing abnormalities. The standard audiometry methods (pure tone audiometry and speech audiometry) require the client's active participation (Rodenburg, 1996): with pure tone audiometry, the client is asked to indicate whether the tone is heard, and with speech audiometry, words must be repeated. For people who have difficulty with the examination, an attempt can be made to elicit reactions to tones through conditioning: e.g. repeatedly sending a puff of air against the eyes when a loud stimulus is given. In time, the client will respond to sound by blinking, even without the puff of air. This is a sign that the sound has been heard.

Another method of audiometry for people who cannot indicate what they are hearing is *free-field audiometry*. The client is exposed to different sounds coming through loudspeakers at different volumes and the client's behaviour is then observed. Because this type of examination does not always produce reliable results, some people with deafblindness are examined in hospital by testing the brain's reaction to sound. This method is called brainstem evoked response audiometry (BERA). A disadvantage of this method is that only high tones can be examined. This examination is often conducted under anaesthesia with people with congenital deafblindness because the client must lie still during the examination.

In general, partial hearing loss is expressed as the average volume at which a person begins to hear something, measured at three frequencies: 1000, 2000 and 4000 Hz (the Fletcher Index). A loss of 20 decibels means that everything less than 20 decibels is lost. The figure 20 decibels is called the threshold value or the hearing loss. The following classification is commonly adopted for hearing (Kramer et al., 2013):

- Mild hearing loss (20-40dB): there is difficulty understanding speech under certain circumstances.
- Moderate hearing loss (40-60dB): there are more evident problems with understanding speech, especially with background noise. Speech can be understood with enough volume and articulation.
- Severe hearing loss (60-80dB): speech cannot be understood without special measures.
- Extreme hearing loss (80-90dB): speech cannot be understood, even with hearing aids.
- Deafness (90dB plus): again, no speech can be understood, even with hearing aids.

Audiometry is done in a completely quiet room, but in daily life there is almost always background noise. This noise negatively affects the above-mentioned values.

In the process of adjusting a hearing aid, it is important to see what increasing the noise does to the extent of hearing. To estimate the effect, a client's hearing is measured while he or she wears the hearing aid. This does not measure the hearing limitation, but what the person can hear with the hearing aid.

## **4.2 Psychological assessment**

### *COGNITIVE ASSESSMENT*

An assessor's aim when measuring intelligence in a child or adult is to discover that individual's capacity to understand the world and cope with it. Aspects of intelligence include acting intentionally, processing information and selecting relevant information (American Psychiatric Association, 2000). Individuals act intentionally when they carry out an action to achieve a chosen goal.

In general, information processing is considered a process in which individuals filter the information they receive through their senses, arrange and compare it with existing knowledge, store it in their memory and then use it to prepare and conduct a response (World Health Organization, 2001). We cannot measure information processing, but we can measure the result of information processing in the form of behaviour. We can also estimate intelligence from a person's behaviour. An intelligence test compares an individual's presentation (behaviour) with the behaviour of others (the control group). The result indicates the extent to which the person deviates from the mean in the test.

The above explanation shows how difficult it is to measure intelligence in someone who is deafblind, because intelligence is estimated based on behaviour. Since intelligent behaviour exhibited by people with deafblindness can appear different to intelligent behaviour exhibited by people who can see and hear, we cannot compare them. When a person who can see wants to avoid bumping into obstacles, he or she person looks around. A person with deafblindness may start walking very slowly. Slowing down is an adequate response in this case, but is often not associated with cleverness.

The relationship between perceivable behaviour and intelligence – the ability to comprehend the world – is not always evident in people with deafblindness.

First of all, they acquire only a limited amount of information. This makes it more difficult and time-intensive to build up knowledge. A particular experience may easily be unfamiliar, making it difficult to select an adequate response. Second, as the acquired information is fragmentary and presented only briefly, the working memory is exerted to a greater extent. The link between what you do and the resulting effect is therefore less obvious for people with deafblindness than for people who can see and hear. It is possible that a person may have the

potential capacity to understand the world but that this is not sufficiently evident. This capacity may also not be fully developed (yet).

Performing psychological assessments of people with deafblindness is complex and should, therefore, only be done by a multidisciplinary team with extensive knowledge and experience in the field of deafblindness.

From the literature (Snow & Van Hemel, 2008) it seems that statements about the capacities of a person with deafblindness must take into account factors that also apply to very young children who do not yet use language or use it very little:

- The results of psychological assessments do not adequately reflect the later possibilities of very young children who do not yet use language. The outcomes say little about these children's real capacities and about what they are capable of learning (Snow & Van Hemel, 2008).
- Individual experiences play a major role in influencing the outcomes of psychological assessments. Children living in a stimulating environment score much higher than children who are not greatly stimulated. This does not mean that the children's potential capacities really differ (Snow & Van Hemel, 2008). This also applies to a great extent to people with deafblindness. We always have to consider the amount of deafblind-specific education and supervision they receive now and have received in the past during their development.

#### ***Assessment methods***

In standard intelligence tests, tasks are given verbally and a verbal answer is expected. Even tasks that require a participant to perform an action are given verbally (Snow & Van Hemel, 2008) and demand a lot of the participant's visual capacity. The standard tests used to measure intelligence in children (the Wechsler Preschool and Primary Scale of Intelligence and the Wechsler Intelligence Scale for Children) and in adults (e.g. the Wechsler Adult Intelligence Scale) are thus not suitable for people with deafblindness. The standard norms for children who can see and hear cannot be used either.

Intelligence tests for children with a visual or auditory disability are more suitable in theory. In the Netherlands, for example, there is the ITVIK, developed for blind children of primary school age (Dekker, Drenth, & Zaal, 2007). There is also a non-verbal intelligence test, the SON, for children from the age of two- and-a-half years (Tellegen & Laros, 2011; Tellegen, Winkel, Wijnberg-Williams, & Laros, 1998). As far as we know, none of these tests have been checked for their suitability for children with deafblindness.

Despite the lack of standardised tests, psychologists and educators try to estimate the potential of people with deafblindness in terms of cognition, learning, and knowledge and information processing (Siegel-Causey & Great Lakes Area Regional Center for Deafblind Education, 1996). An international working group has been researching the measurement of cognition in people with congenital deafblindness so that guidelines can be developed. This working group has found a solution in the systematic observation of the person with deafblindness during interactions with the social environment (other people) and physical environment (objects) (Ask



Larsen & Damen, in preparation). An important precondition is that sufficient consideration is given to the person's deafblindness during these interactions. This means that every contact is one-on-one and that the social partner has enough skills to cope with someone who is deafblind.

It is important to optimise the interaction first, before conclusions can be drawn based on observations about the individual's capacities. Statements about the individual's behaviour and functioning must also consider the extent to which the interaction does justice to this person. This means that we can only get an impression of the level of functioning if the person with congenital deafblindness can make him or herself optimally understood in contact with others. The assessor must therefore know a lot about the specific support needed for people with deafblindness.

In research into behaviour that gives an idea of information processing, it is important to examine how much touch information a person with deafblindness can absorb. This means that the individual must understand object permanence (i.e. understand that something continues to exist even if it cannot be perceived). We call the capability to retain touch information the *tactile working memory*. This capability can be tested by asking someone to remove forms from a puzzle in the reverse order in which he or she felt the assessor put them in shortly before. Nicholas (2012) stresses the importance of charting the tactile cognition of people with deafblindness by observing their daily functioning, for example, by considering whether a person can find objects that were previously put away somewhere. To obtain an idea of the cognitive capacity, we can also look at whether a person is capable of sticking to a goal without being distracted. The extent to which someone can do this says something about their higher cognitive functions, especially planning and memory (Hartshorne, Nicholas, Grialou, & Russ, 2007).

The "Child-guided strategies: The Van Dijk approach to assessment" (Nelson, Van Dijk, Oster, & McDonnell, 2009) also focuses on obtaining information about the learning capacity of people with deafblindness, especially children and adolescents. In this assessment method, the assessor conducts an assessment by interacting with the child. By building up this interaction and offering different materials, the assessor observes how a person responds and explores. This provides information about the person's learning capacity, interaction and communicative capabilities, and about which compensations the person uses (e.g. touch, residual vision and/or hearing). The following aspects in particular are considered:

- a. capability to maintain and change a certain level of alertness
- b. extent to which someone is open and oriented to the environment
- c. preference for learning channels
- d. capability to learn routines and remember and anticipate them
- e. capability to fit new experiences into existing frameworks
- f. problem-solving strategies
- g. memory
- h. capability to become attached to others and interact with them
- i. communication possibilities



*Maaïke's learning capacity was examined using the Van Dijk approach to assessment (child-guided strategies).*

The method has evolved from a purely cognitive model to one based on different explanatory models, including the neurobiological model, social learning model, transactional model and attachment theory (Nelson et al., 2009). Publications about this method (MacFarland, 1995) stress the importance of the manner in which the assessor approaches the child. It is also important to always conduct the assessment in the presence of a person familiar to the child. The assessor must first build up a relationship of trust, inquire about the child's interests and always give the child enough time to process experiences. On the basis of results, the assessor can advise on how to promote the child's development (Nelson et al., 2009). This method has proven to be valid and appears reliable (Nelson, Janssen, Oster & Yayaraman, 2010).

### ***ASSESSMENT OF BEHAVIOUR AND FUNCTIONING***

Aspects of a person's functioning and behaviour in daily life are examined to assess his skills or adaptive behaviours. A person's developmental age is determined by comparing the person's functional skills with the average age at which children usually display these skills for the first time.

For a person with deafblindness, assessment methods are sometimes used that were originally developed for young children or people with an intellectual disability. In general, there are three types of assessment instruments:

1. Questionnaires about activities and developmental milestones for primary caregivers of young children (e.g. the KID-N; Schneider, Loots, & Reuter, 1990).
2. Observation instruments for people with an intellectual disability that explore specific areas, such as social life skills (e.g. the SRZ; Kraijer, Kema, & De Bildt, 2004, or the Vineland-Z; De Bildt & Kraijer, 2003).
3. Standardised tests or ordinal scales used to estimate a child's developmental age (e.g. the BSID-II; Van der Meulen, Ruijter, Lutje Spelberg, & Smrkovsky, 2002, or the Southern Californian Ordinal Scales of Development (SCOSD); Ashurst, Bamberg, Barrett, & Bisno, 1985).

It is important to understand that examination instruments for young children or people with an intellectual disability are not standardised for deafblindness.

Development scales intended for children with a single disability are thus more useful, but still not sufficiently adjusted and standardised. These include the Reynell-Zinkin for children with a visual disability (Reynell & Zinkin, 1979) or the modified versions of the BSID-II for children with a visual or hearing disability (Van der Meulen et al., 2002).

When an assessor starts working with a young child, the following must be taken into account: how familiar the assessor and the planned activity are to the child, the assessor's own responsiveness, and the child's condition (amount of tension and alertness). This also applies to people with deafblindness. In the best case, the assessor works with people the child knows and starts not with what is threatening but with things that are familiar and strongly motivating (Snow & Van Hemel, 2008).

### ***Methods for assessing the functioning of people with deafblindness***

In addition to the commonly used instruments for young children and adults with an intellectual disability, several instruments have been specially developed for people with deafblindness. These are discussed below.

#### ***Carlier-Asuza***

Stillman (Stillman & Battle, 1985) created this development scale in 1974 to estimate the functioning of children with deafblindness in the following areas: motor development, perception, independent coping skills and language skills. The scale was tested with children with deafblindness in the USA and proved to have sufficient quality (McInnes, 1999).

#### ***FSSI (Functional Skills Screening Inventory)***

This is a domain-specific behaviour checklist that can be used to investigate the skills that an individual displays in everyday life. According to McInnes (1999), the checklist can be used to determine the support and education needs of the individual with deafblindness, and can be used in setting goals and measuring progress in skills. The scale can be used with children with deafblindness aged six years and older.

#### ***Developmental profile for people with deafblindness***

The "developmental profile" of Nafstad and Rødbroe (1999) is a method to estimate the functioning of an individual with deafblindness by recording the individual's interactions with a familiar person on video and observing them. The development profile has four aspects: social interaction, proximity, exploration and communicative expressions.

### ***PSYCHOLOGICAL AND PSYCHIATRIC DISORDERS***

Diagnosing psychological and psychiatric disorders is complicated because it is difficult to gain access to the mind of a person with deafblindness. Their behaviour can be explained in various ways. For example, aggression towards someone else can mean that a person feels misunderstood or is experiencing physical discomfort, or it can be associated with depression, attachment disorder or autism.

Autism is a common diagnosis in deafblindness. With both deafblindness and autism, perception is characterised by details and problems with making connections. The behaviour of people with deafblindness can resemble that of people with autism, but does not necessarily suggest its presence. One example is the strong need that people with deafblindness have for predictability and thus rigidly sticking to rituals. Stereotypical behaviour and problems with contact can also be explained by the dual sensory disability. The difference with autism is that by adjusting the supervision style, this type of problem can often be reduced in people with deafblindness. This is not the case with autism (or much less so). Diagnosing autism in people with deafblindness is difficult and demands extensive knowledge and expertise (Hoevenaars-Van den Boom, Antonissen, Knoors, & Vervloed, 2009).

***Practical example: Elsie***

*Elsie is a 13-year-old girl with CHARGE syndrome. She is completely deaf and partially sighted. She lives at home and goes to a special school for deaf children. She is a lively and active girl who often has difficulty concentrating, which is typical for children with CHARGE. Both her parents and her teachers state that it is difficult to get her attention. Elsie was examined in an observation and treatment centre, where the diagnosis of autism was made.*

*Several years later, the diagnosis had to be revised since Elsie had made great strides in her social and communicative development. By working with an interaction and communication coach specialised in deafblindness, Elsie's teachers and parents ensured that contact with Elsie was better suited to her needs and capabilities. It was apparently important for Elsie's social partners to expressly ask for her attention before communicating a message; they do so by making gestures in the air, adjusting the tempo and giving her more support by touch.*

*Since then, people's impression of Elsie has changed. Instead of seeing her as an autistic girl who is difficult to reach, her parents and teachers now consider her to be open to contact and quite capable of communicating her intentions if other people allow for her visual and hearing disabilities.*

### **4.3 Communication assessment**

All people try to communicate their intentions in their own way, consciously and unconsciously. People with congenital deafblindness cannot generally use spoken or written language, so they often need other means of communication to express their intentions and understand the intentions of others. For example, aids like pictograms, tangible objects, tactile symbols on swell paper, Braille and signs (4-hands) can support communication.

Before using these aids, we first recommend that the support needs of a person with congenital deafblindness be identified and clearly formulated. This also involves an assessment of a person's possibilities for communicating. If it is unclear how a person expresses him or herself or what he or she understands of the environment, this is a good reason to conduct a communication assessment. If an assessment then indicates that communication aids could be

helpful, the chosen aids must match the person's abilities, especially his or her communication possibilities. If there are problems with contact, it is better to first work on improving that contact. Aids should only be used after it is clear how someone communicates and what the development possibilities are in that area.

### ***Assessment methods***

The following instruments are suitable for establishing the communicative functions and possibilities of an individual with congenital deafblindness.

#### Weerklank communication profile

The Weerklank communication profile (Oskam & Scheres, 2005) consists of several diagnostic instruments:

- An extensive questionnaire to clarify the personality.
- A communication framework to estimate the level of communication. A distinction is made between three levels:
  - The most fundamental level is the *situation level*, meaning that a person understands what is happening based on concrete sensory information.
  - The next level is the *signal level*, where the person recognises signals (e.g. a single word, photo, object or pictogram) and links them to an expectation regarding the current situation.
  - The highest level is the *symbol level*, where a person understands the principle of reference and can use terms outside the concrete situation. The person is able to use abstract symbols (e.g. spoken language or sign language) to a greater or lesser extent in communication.
- An experience-based classification framework developed by Timmers-Huijgens. This framework distinguishes between four levels of experience-based classification: physical classification (responding on the basis of experience, there are no expectations), associative classification (simple links are made, deviation from routines is difficult), structuring classification (more complex links are made, the person can deviate from routines) and constituting classification (something unique and personal is added to existing structures). Experience has shown that people with congenital deafblindness can rarely use this last level.
- A function framework, which gives insight into the way in which someone deals with communicative functions (e.g. asking questions, looking for information and refusing).

On the basis of the results of the communication profile, a communication plan can be prepared that includes the needs for support and the goals. Parents, caregivers and/or teachers play an important role in completing the communication profile since they know the person with congenital deafblindness the best. This active role in completing the communication profile produces more knowledge and awareness among the communication partners of the client.

### ***Communication matrix***

Rowland developed a digital questionnaire called the “communication matrix” (Rowland & Freid-Oken, 2010) to investigate different communicative functions, like refusing and asking for seconds. People who are directly involved can specify for each function how an individual with congenital deafblindness expresses him or herself (e.g. through behaviour or signs). This can produce an impression of this person’s communication level comparable to the levels used in the Weerklank communication profile.

### ***Vocabulary list and communication book***

In addition to the above-mentioned means of assessment, it can be interesting to record all the terms that a person with deafblindness has been known to use (i.e. vocabulary). All those involved can then learn to recognise and use the form of communication expressed by the person with deafblindness. The lexicon is usually recorded in a communication book or a personal communication passport, in which the terms are linked to the manner in which they are communicated (e.g. a description or drawing of the gestures or tangible objects). Attention must be paid to non-verbal communication as well, for example, by describing, photographing or filming the person’s facial expressions and body language. Video analysis is used to learn and see the non-verbal signals.

## **4.4 Assessment of sensory integration**

People with congenital deafblindness can have problems with sensory integration (SI). This means that there are problems with the way sensory information is recorded, organised and used by the brain. *Sensory integration disorder* is an umbrella term used to cover several distinctive disorders affecting the way in which people use their senses (Stock Kranowitz, 2005). SI tests are usually conducted by a specialised occupational therapist or physiotherapist. The tests present various types of sensory stimuli (e.g. movement, sound or touch stimuli) and the person is observed as he or she copes with these stimuli.



*Communication book.*

It is essential to determine which specific type of SI disorder a person has in order to be able to choose the correct therapy. For example, if someone has problems with their sense of touch, the therapy will focus on reducing their tactile resistance. This therapy could consist of rubbing the arms and legs daily with sponges and cloths of different textures.

## **4.5 Summary**

Assessments are used to determine the extent of a person's disabilities and which functioning capabilities a person has. This chapter discussed medical, psychological and communication assessments. The results of these assessments must be multidisciplinary to produce a complete picture.

Medical assessment focuses on testing people's vision and hearing. Various means are available, depending on the possibilities for communication with the person with deafblindness. A rule of thumb is that the less clearly a person can indicate what he or she sees or hears, the less specific the result will be.

The goal of a psychological assessment is to obtain an image of a person's cognition, learning, and knowledge and information-processing capabilities. Psychological assessment employs descriptive tests and questionnaires for caregivers. Various assessments can be performed and video observations can be used for diagnostic purposes. The usual tests are not suitable and/or standardised for people with congenital deafblindness.

Communication assessment is important for obtaining insight into the way in which someone with congenital deafblindness expresses him or herself, and what he or she is capable of learning. Examination of the communicative functions is important so that the right aids can be selected and appropriately introduced.





# Part II

Insight into daily functioning

## 5 Support needs

People with congenital deafblindness live in a world of touch and proximity. They have to try to understand the world based on fragmentary impressions, and there is a great risk that they may suffer a severe delay in their development. Being withdrawn and problem behaviour are noted regularly due to the lack of positive experiences in social contact and communication (Durand & Berotti, 1991; Janssen et al., 2004).

People with congenital deafblindness require lifelong support, so it is important that caregivers have insight into their daily functioning. This information can be used to formulate their specific support needs, which are then used to adjust the care required. In daily functioning, the following focus points can be distinguished:

1. physical well-being
2. psychological well-being
3. stimuli and information processing
4. interaction and communication
5. acquiring knowledge and skills
6. orientation and mobility

Chapters 6-11 describe these six focus points and the subsequent support needs. Chapter 12 describes the environmental requirements and Chapter 13 addresses the aids used to improve sight and hearing. The final chapter, Chapter 14, covers the role of people supporting someone with congenital deafblindness. Social partners (e.g. parents, caregivers and teachers) have to be very sensitive and need specific knowledge and skills for dealing with people who live in a world of touch and proximity. Many social partners indicate that they need support with these issues.

## 6 Physical well-being

For children and adults with congenital deafblindness, their own bodies are an important source of security. Physical discomfort can disturb this sense of security. Many people with congenital deafblindness cannot easily indicate that something is bothering them or what physical need they are experiencing. In comparison with people who can see and hear, there is much less distraction from physical sensations, so these sensations can have a very different (often stronger) effect on mood and behaviour than expected. Unmanageable behaviour can be a sign that a person with deafblindness feels misunderstood about what he or she does or does not want, but it could also reflect physical discomfort. This chapter will explore the role and influence of physical functioning.

### 6.1 Elementary needs and physical discomfort

Physical discomfort can have a major influence on a person's well-being. In the daily education, supervision and care of a person with congenital deafblindness, a lot of attention must be paid to optimising that person's physical well-being and preventing physical discomfort.

#### *ATTENTION TO BASIC NEEDS*

Attention should be paid to individual needs in the following areas: eating and drinking, personal hygiene, comfortable temperature, optimal lighting (if partially sighted), as little disturbing background noise as possible (if partially deaf), a pleasant way of being touched, a pleasing scent, as few disturbing touch stimuli as possible (e.g. no drafts, people walking behind you), comfortable clothing (e.g. no gaps, more or less fitting) and sexual needs.

Elementary needs can vary from person to person. What form of touch does a person like? Do they prefer a firmer or softer touch? Contact on the hands or lower arms? Having someone blow air on their face or letting them feel vibration through the ground or couch before initiating touch? Making contact with warm, dry hands? Does it matter if you are a woman or a man? If someone prefers to walk barefoot, is the floor surface and temperature appropriate? Observing a person's interactions can be an important means of answering these questions and discovering what a person with deafblindness does or does not like.

Paying attention to physical well-being does not mean that the caregiver must always automatically take care of the person's basic needs without communicating about this. Small signals that indicate needs such as thirst or hunger can be seized as opportunities to initiate contact. For example, when a person stretches out a hand because he or she expects to be given a cup, first help the person make the sign for drink. Immediately afterwards, offer the cup containing the drink (also see Section 9.3 on signs).



*Marjolein enjoys the feeling of water and wind on her face. Physical contact with the caregiver is essential for maintaining a feeling of security.*

A clear preference or rejection can also form a topic of conversation. For example, if a person with deafblindness gets used to tangible objects for bathing and showering, we can gradually observe if he or she can choose between them. Even when a caregiver knows that a client prefers a bath, offering the client the choice allows him or her to experience the ability to make his or her own choices.

### ***OPTIMALISING THE QUANTITY OF STIMULI***

There is a great risk that people with congenital deafblindness will be understimulated due to their lack of visual and auditory stimuli. As a result, a person may actively start searching for stimuli. Because a person's own body is an important source of stimuli (since it is always available and gives a perceptible result), a person with congenital deafblindness is likely to resort to self-stimulation. This carries the risk that a person will become less open to external influences, and it can have a negative effect on learning (Van Dijk & Janssen, 1993).

Many people with deafblindness also need more processing time than people who can see and hear. If this is not properly taken into account, there is a risk of overstimulation. In that case as well, a person can resort to self-stimulation.

In our view, self-stimulation need not be corrected with behavioural therapy measures, but the underlying cause should be sought. The "Child-guided strategies: The Van Dijk approach to assessment" can help gain insight into the processing of stimuli. This approach recommends first offering a single stimulus and then gradually adding more (Nelson et al., 2009). If a person with deafblindness is overstimulated, this will become evident through the changes in that person's behaviour (Nelson et al., 2009). Fewer stimuli will then have to be offered or the

person with congenital deafblindness will have to be given more processing time. In the event of understimulation, we recommend searching for an appropriate pastime and ways of involving a person more in the world (see Section 12.3 about daily activity programmes).

People with deafblindness can be hyposensitive or hypersensitive to certain specific stimuli. Even if there appears to be enough time to process stimuli and they are given the right amount of stimuli, people can still respond in a hyposensitive or hypersensitive manner. Tactile defence, for example near the mouth or of the hands, is seen regularly. It can be advisable in cases like this to consult a sensory integration (SI) therapist who can examine the processing of all sensory and motor information and links within this process. If a form of hypo- or hypersensitivity is involved, this can then be treated.

Obtaining advice on sensory integration becomes even more important when the hypo- or hypersensitivity interferes with daily care, eating and drinking, contact with the person with deafblindness, or a specific therapy (e.g. wearing a hearing aid).

#### ***IDENTIFYING AND PREVENTING PHYSICAL COMPLAINTS***

It is worthwhile ascertaining whether someone with congenital deafblindness experiences physical complaints, what is causing these complaints and how they become evident. The first step involves close observation by people who know the person with deafblindness well. Often, people with deafblindness express pain signals in a manner that is not obvious, such as exhibiting self-stimulatory or problem behaviour or hitting the sore spot. Hypotheses can be formulated and tested in multidisciplinary consultation with a behaviour expert, the primary care physician and/or a physician specialised in treating people with intellectual disabilities. Information about a person's behaviour in relation to pain or physical discomfort can be used the next time to spot the problem earlier.



*Jeffrey can influence the intensity of stimuli himself in his rocking chair.*

**Practical example: Louise**

*Louise is a severely visually impaired and deaf young woman who lives in a community home for people with deafblindness. Louise likes to lie on the waterbed, and over the last half year her caregivers have worked specifically on contact with her by lying next to her at a set time and imitating her initiatives.*

*Louise has begun to increasingly value these contact moments. During one such contact moment, Louise hit her toe hard against the wall when turning around. Her reaction was to stick her finger in her mouth and then place it on the sore spot. Her caregiver noted this behaviour, laid her hand under Louise's, pointed to the toe and made the sign for THAT, HURT. Afterwards, the caregiver shared this experience with her colleagues and they began to notice that Louise always indicates pain in this same specific manner: she licks her finger and puts it on the sore spot. This knowledge and the good observation of her behaviour led to the caregivers talking more often about pain with Louise and trying to reduce her pain with a cold cloth or painkiller.*

When it is known that someone is suffering physical discomfort, an attempt can be made to prevent the discomfort. For example, a laxative or fibre-rich diet can be provided for someone who is known to suffer from frequent constipation.

Discomfort due to a cold, allergies or menstrual cramps can also be alleviated.

## **6.2 Energy**

Daily activities for people with deafblindness take a lot of energy and the chance of becoming fatigued is much greater than for people who can see and hear.

People with deafblindness can often only partially contribute to activities (both daily and less common activities). There is a great risk of overstimulation at the start of an activity and of them withdrawing at the end. The following conditions can be formulated to promote participation in activities:

- A good alternation between activities and rest in the daily activities programme.
- Information from the person with deafblindness can be used to select certain activities and to determine what part that person will play in them and the support he or she will need. For each individual situation, the caregiver should seek the limits of what a person can do.
- A person's levels of energy can vary from day to day and moment to moment. Skills or possibilities to participate can also vary accordingly. For example, a person who is feeling good can put on his or her own socks, but when that person is stressed, he or she may only manage to get the tip over their toes. A caregiver's sense of observation, sensitivity and flexibility are essential to an activity's success.

## **6.3 Circadian rhythm**

Often, people who are completely blind have a disturbed circadian rhythm. When it gets dark at night, no signal is transmitted from the retina to the pineal gland. In people who can see,

this gland produces the hormone melatonin when it gets dark, which makes them sleepy. The production of melatonin begins as soon as dusk falls and reaches its peak after about six hours. At the peak, people are normally in the deepest part of their sleep. From that peak on, melatonin production slowly declines until about six hours later, early in the morning, when melatonin production ceases. The production period lasts about 12 hours and remains dormant for 12 hours.

If the pineal gland is not activated at just the right moment (due to the visual disability), the body does not automatically manufacture melatonin. People with deafblindness can therefore benefit from having melatonin administered at dusk. The administration of melatonin must always be supervised by a doctor so it can be adjusted properly to an individual's melatonin level in the blood and the rate at which he or she breaks it down. Lamps can also stimulate the production of melatonin in some people, depending on the function of the retina. For some people with deafblindness, an active daily programme (especially one focusing on outdoor activities) and a calm preparation for going to sleep are important aids in helping to uphold their circadian rhythms.

## **6.4 Summary and advice for caregivers**

The body is an important source of information for people with congenital deafblindness. If someone feels good, activities and tasks run relatively smoothly. Paying attention to an individual's basic needs, offering the right amount of stimuli, supporting a good balance of energy and creating a circadian rhythm help create the right conditions for success.

People with deafblindness often express physical discomfort or pain using signals that are difficult to understand. This can also result in self-mutilation and/or increased self-stimulation. If there are changes in a person's behaviour, that person's physical well-being should always be examined.

We offer caregivers the following advice regarding physical well-being:

- Investigate what someone with congenital deafblindness finds pleasant in terms of taste, scent, touch, sight, hearing and temperature. Try to accommodate them where possible and communicate to them about it.
- Investigate the quantity of stimuli the person needs to feel challenged without becoming overwhelmed. Also explore the extent to which the person wishes to and can contribute in daily situations and activities.
- Ensure a good balance between rest and activities in the daily programme.
- Try to prevent physical discomfort and be alert to signs of physical discomfort.
- Document the manner in which the person indicates pain and physical discomfort.
- Support people with congenital deafblindness in finding a circadian rhythm by creating a challenging daily programme and providing melatonin where necessary.

## 7 Psychological well-being and social relationships

A strong attachment is an important requirement for psychological well-being. It gives a person a feeling of basic trust, also known as a *secure base*. This chapter concentrates on a secure base in social relationships.

A secure base used to be considered a characteristic of a person: once it had been disturbed, it did not seem possible to restore it. However, it has become clear that a secure attachment can be built up even after the *sensitive phase* (Hinde, 1972). Research by Sterkenburg, Janssen and Schuengel (2008) showed that children with multiple disabilities and an attachment disorder can build new relationships through a psychotherapeutic method based on attachment theory. Earlier research by Janssen and colleagues (2003b; 2006) revealed that those raising children with deafblindness can be effectively supported in improving the quality of interactions with these children. Research by Damen, Kef, Worm, Janssen and Schuengel (2012) showed that this is also the case for adults with multiple severe disabilities.

There is a clear link between a secure base and a person's social-emotional functioning. An inadequate security base can cause a person to turn inwards, reject contact and seem anxious or abandoned. When the secure base is strong, a person feels self-confident. A person is resilient because of the knowledge that help and support are available if needed and he or she experiences a secure base and a safe haven (Cooper, Hoffman, Power, & Marvin, 2005).

There is also a relationship between a secure base and social relationships. If a person does not trust other people, this affects the establishment of social relationships. In this chapter, we first pay attention to building a secure base and then to social relationships.

### 7.1 Building a secure base

To support people with congenital deafblindness in experiencing, maintaining and nurturing a secure base, it is important to know how normal attachment develops. Based on her work with adopted children, T. Bakker-Van Zeil found five building blocks that are essential for building a trust relationship and thus a secure base (Foundation Adoption Services; *Stichting Adoptievoorzieningen*):

*BUILDING BLOCK 1: Basic trust*

*BUILDING BLOCK 2: Trust in others*

*BUILDING BLOCK 3: Self-confidence*

*BUILDING BLOCK 4: Independence*

*BUILDING BLOCK 5: Creativity*

This chapter describes the principles of each building block and what this means for caring for a person with deafblindness.



### ***BUILDING BLOCK 1: BASIC TRUST***

A person with deafblindness does not feel completely safe, even in the presence of people who know him or her well. The action plan for building block 1 is:

- Only allow the person to come into contact with a few people who offer one- on-one contact, who are unconditionally and perceptibly available, and who consistently respond to signals from the person with deafblindness.
- Provide a familiar, safe place.
- Offer a predictable activity that can motivate someone with congenital deafblindness. In this phase *being together* is important in the interaction, while *doing something together* may be too much.

### ***BUILDING BLOCK 2: TRUST IN OTHERS***

A person with deafblindness does have experience (positive or negative) with togetherness, but does not have much experience with doing things together. Supervision should focus on further nurturing relationships with familiar people by:

- Keeping familiar, trusted people as the basis
- Keeping a familiar, safe place as the basis
- Adjusting the content of interactions, from being together to doing something together.

The world of someone with congenital deafblindness becomes a bit larger in this phase; not because more people come into contact with the person or because the person has explored more spaces, but because the activity changes.

Activities aimed at doing something together could include interaction games, like clapping games, drumming and mirroring. A caregiver and person with deafblindness could also do small, daily recurring tasks together, such as those involved in eating, drinking and getting dressed. It is important when doing so to stimulate a person to take the initiative in contact, and to respond to signal behaviour (e.g. the signals used to indicate what a person does or does not want).

When it appears that the person with deafblindness is less able to actively participate in the interaction, the focus can shift from doing something together to being together. This can also be temporary, for example, due to physical discomfort.

#### ***Practical example: Johan***

*Johan is a middle-aged man with congenital rubella syndrome. He has a fixed daily programme that reflects his interests and capabilities. One part of his routine is walking outdoors. Usually, he takes a long walk with a caregiver, with breaks to explore the surroundings by touching: Johan and his caregiver touch the trees and what is lying on the ground (e.g. leaves, branches). Johan often selects a few branches to take home and keep.*

*However, when Johan has a cold (which happens regularly), he does not want to walk far and he cannot be tempted to explore. Caregivers have noticed that if they try to convince him to explore, he ends up sitting on the ground and it is almost impossible to get him back up. He sometimes also starts hitting himself. When Johan pulls on his caregiver to indicate that he*

wants to continue walking, the caregiver accepts this and makes tactile gestures: *YOU AND ME, WALKING, GOOD.*

### **BUILDING BLOCK 3: SELF-CONFIDENCE**

A person with deafblindness may feel comfortable with familiar people and actively participate in contact with them, but not be comfortable when in contact with others.

The support for this building block concentrates on teaching the person with deafblindness to feel comfortable with less-familiar caregivers and less-familiar activities and spaces, and to know that the familiar caregivers are available if the person needs them. The approach looks like this:

- Familiar people are available and several people are around.
- A familiar basic place is accessible, but more activities are done in other places.
- Familiar and unfamiliar activities take place in different areas.

It is important that there are always familiar people around for people with congenital deafblindness and that these people are available at stressful times. In this phase, it is also helpful to have means of communication that can help the person with congenital deafblindness prepare (e.g. for what is coming and who is present). It is also helpful if that person has a means to attract a caregiver's attention or ask a question. People with congenital deafblindness gain a feeling of security from fixed routines.

#### ***Practical example: Siebe***

*Siebe is a 50-year-old man who is completely deaf and blind. When family members and caregivers greet him, they let him feel a fixed feature of theirs, such as a moustache or glasses. Siebe understands this and after the first meeting will often feel the other's feature spontaneously to make sure he knows whom he is communicating with. The personal features are thus a suitable communication aid for him. The difficult aspect is that Siebe and his social partners can never communicate in this way about someone who is not present. It was decided, therefore, to combine the personal features with signs for names.*

*The sign for the name of the caregiver Evelien is a tap to the neck because she has a dimple there (which is her personal feature). When Evelien greeted Siebe, she not only let Siebe feel her dimple, but she helped him to tap his own neck. This name gesture had a useful function six months later when Evelien left for another job.*

*Siebe started tapping his neck regularly and caregivers responded by making gestures for *EVELIEN* (tapping neck) *AWAY* and *EVELIEN, WORK, HERE, NO*. Siebe took a long time to think about this and eventually no longer asked about Evelien.*

### **BUILDING BLOCK 4: INDEPENDENCE**

At this stage, a person feels comfortable with familiar and less familiar people and in different situations, but does not have enough confidence to take control in both familiar and unfamiliar situations (if given the chance). People who are not yet fully independent may still wait for an indication from a caregiver, such as a tap on the hand (called a prompt), before they start the next action. Not being able to take control does not mean that the client cannot ask for help.

One example of a person who has reached this building block is a middle-aged man with deafblindness who dropped a screw. He bent down to search and then clapped his hands to ask for help. When his caregiver came over and asked WHAT, the client made the gesture for LOOK and took the caregiver's hand and drew it down to the ground. The client clearly has control in this interaction.

The support in this building block focuses on allowing the person with congenital deafblindness to feel competent enough to take control. The approach looks like this:

- Stimulating active participation.
- Gradually reducing the use of physical reminders (*prompts*) and, if possible, gradually reducing the support provided (*scaffolding*).
- Giving control to the person with deafblindness (e.g. by waiting before initiating the following step and letting him or her specify the next step or skipping a step and solving the problem together).
- Labelling and making compliments when the person with deafblindness takes control.
- Prevent the client to make mistakes and not labelling inadequate actions (*mistakes*) as the client's fault, but transform them into the desired action (*errorless learning*).
- Together with the person with deafblindness, telling others what he or she did and recording important milestones in a remembrance book.

### ***BUILDING BLOCK 5: CREATIVITY***

At this stage, the person feels comfortable with both familiar and less familiar people in different situations and has enough confidence to take control in familiar situations, but gets upset quickly when the situation is different than expected and tends to let others make decisions. Support for this building block focuses on increasing the person's self-confidence. As a result, a person with deafblindness can better cope with unexpected situations and develops the ability to design his or her own life. The approach looks like this:

- Communicating about concepts like *expectation, idea, wish* and *feelings*
- associated with whether the expectations are fulfilled.
- Labelling the emotions and letting them know that all emotions are allowed.
- Helping them cope with negative emotions.
- Helping them solve problems themselves (self-management).
- Helping them develop strategies to cope with times when expectations are not met.
- Helping them formulate wishes for their own life and finding ways to fulfil those wishes.

## **7.2 Building social relationships**

When building social relationships with people with congenital deafblindness, attention must first focus on their families. The involvement of professionals in the lives of these people does not mean that their social relationships must be dominated by professionals. On the contrary, family members have lived with the person from a young age and offer the possibility for maintaining a lifelong relationship, while caregivers and teachers tend to come and go. Nevertheless, professionals can play an important role in supporting the relationship between a

person with deafblindness and his or her relatives and helping to nurture them and, if necessary, build them up.

It is important that professionals remain open to the experience gained by the family members, even when the professionals see the person with congenital deafblindness more often than the family. It is also useful for many family members to be informed honestly about topics they wish to be informed about.



*Firoz and his caregiver are playing an interaction game. This is an activity they both enjoy.*

The information can help them contribute to the support given to their child, brother or sister.

When building a social network, attention must also be paid to supporting the contact with housemates, fellow pupils or other people with whom the person with congenital deafblindness comes into contact. Certainly when communication systems differ or a situation becomes unsafe or unclear for the person with deafblindness, an intermediary may be required. The advice here is not to interfere too quickly. Two people with congenital deafblindness are sometimes perfectly capable of finding a way to communicate with each other. In addition, volunteers can play an important role in designing and supporting social contacts and activities.

### **7.3 Summary and advice for caregivers**

People build their secure base through social relationships. A person's social- emotional functioning depends strongly on this secure base. If the secure base is inadequate, the person can withdraw, reject contact and/or seem anxious.

Building a secure base often occurs naturally in a child's development. This situation is different for people with congenital deafblindness, where it is often evident that the secure base is inadequate. There are special intervention programmes available to improve the relationships of people with deafblindness, even for adults.

This chapter described the development of a secure base according to five building blocks: basic trust, trust in others, self-confidence, independence and creativity. This chapter also considered support for relationships between someone with congenital deafblindness and his or her family members.

We offer caregivers the following advice regarding psychological well-being and social relationships:

- Offer positive contact experiences in contact by adjusting to the behaviour, emotions and interests of the person with deafblindness.
- Take into account the phase(s) of attachment development the person is in.
- Involve the family and other members of the person's social network in building up social relationships.

## 8 Processing stimuli and information

The world of a person with deafblindness consists of stimuli from and outside his or her own body and from elements that are close enough to feel, smell and taste. The world can be considered unpredictable and unsafe to a great extent as stimuli from the surroundings are not recognisable. There is a great risk of deprivation due to understimulation and lack of stimuli (Van Dijk & Janssen, 1993). If there is a lack of stimuli, people with deafblindness will stimulate themselves (Van Dijk, 1968), often by using their own bodies. They can develop complex patterns of self-stimulation that offer a sense of security, but can also lead to withdrawing their attention from the outside world. Stimuli from outside can feel like a disturbance to them if they are occupied with their own bodies, and can lead to them responding by rejecting communication. For many people with deafblindness, the longer they are left to live in their own world, the harder it is to entice them out again.

### ***Practical example: Sandra***

*Sandra is an 11-year-old girl living in a small community setting for children with severe multiple disabilities. She has very little residual hearing and sight and uses a wheelchair. She is often occupied with rubbing her hands and she gives the impression of being focused inwards. She often responds by rejecting touch. At the request of her caregivers, Sandra was examined by a psychologist with specific knowledge of deafblindness using play observation. This psychologist was able to make contact with Sandra after lying next to her on her bed for a considerable amount of time and imitating Sandra's expressions, like her movements and sounds. Sandra became increasingly aware that someone was paying attention to her and finally began to respond. At a certain moment, Sandra also clearly took the initiative by raising her head to ask for help to get up so she could better see a bear with flashing lights.*

Often people with congenital deafblindness have had very few opportunities to learn that there are other people around, and that those people have their own needs and emotions. As a result, others are used *instrumentally* to satisfy their own needs, and little distinction is made between themselves and the other. For example, a person with deafblindness will sometimes use the caregiver's hand to stroke his or her own head.

People with congenital deafblindness are heavily dependent on caregivers to obtain sufficient external stimuli. The caregiver has to bring the world to the person with deafblindness. People with deafblindness usually need more time to discover and process. Caregivers can offer stimuli in a way that is orderly and measured and let the client feel which activities they are carrying out by inviting a client to place his or her hands on their own hands. If a caregiver communicates about these experiences using natural gestures, he or she gives meaning to the world and allows someone with congenital deafblindness to experience how to cope with the world.

Just like for the rest of us, contact with other people means that you form part of a social group. Through contact with other people we not only learn from the experiences of others (e.g. how to prepare coffee) but we also learn about social customs and cultural values. People

with congenital deafblindness require a great deal of physical contact; if a caregiver cannot be felt, that caregiver is usually thought to be “gone”. If the caregiver does not make regular physical contact, social isolation develops and the person with deafblindness will then turn inwards. Caregivers have an important task in preventing social isolation and teaching people with deafblindness that there are other people around with whom they can have positive contact. That is why it is important that caregivers clearly let clients know that they are nearby and are available for the client.



*Jenny is having someone do her make-up. Although she cannot see the result, she is enjoying the experience.*

## **8.1 Acquiring and processing information**

When describing the impact of deafblindness in Section 3.2, we stated that people with congenital deafblindness only perceive fragments (Van Dijk & Janssen, 1993): they only acquire pieces of information and must make a whole picture based on those pieces. This is exactly the opposite of what people who can see and hear perceive (Bruce, 2005a), as described in Section 3.3. This means that information processing takes longer for people with deafblindness and more repetition is required for them to obtain knowledge. It is difficult for a person with congenital deafblindness to gain an overview of people, spaces and activities. If small things change, a person with congenital deafblindness can lose the entire overview.

To understand how sensory disabilities can influence information processing, it can help to know the steps involved in this process. According to Nelson and colleagues (2009), these include the following: 1. perceiving a stimulus, 2. orienting to a stimulus, 3. comparing a stimulus with existing patterns, 4. getting used to a stimulus, 5. integrating a stimulus and 6. remembering a stimulus.

Before a stimulus can be processed, a person must not only perceive it, but must also have the time to process it by orienting him or herself towards it and comparing it with other, familiar stimuli. If the stimulus is unknown, the next step is to add the experience to the existing knowledge or revise that knowledge.

The last step is for a person to store the new experience in his or her memory. A weak or transient stimulus, like a blurry visual stimulus, can give insufficient input for a person to complete all of the steps involved in the information- processing procedure.

Another problem is that people with congenital deafblindness cannot learn by watching or listening to other people. There is also less *discovery learning* because they cannot see or hear the results of their actions.

Caregivers of people with congenital deafblindness can support their clients' information processing by helping them familiarise themselves with their surroundings by feeling those surrounding. In daily dealings with a person with deafblindness, caregivers constantly need to be searching for ways to clarify what is happening in a situation and letting their client know what can be expected. This requires a caregiver taking someone with congenital deafblindness by the hand, for example, to let that person feel where he or she is and who else is there. The caregiver can then use tactile gestures and signs to describe what is happening.

People with congenital deafblindness quickly become dependent on their caregivers. They best understand a situation if there is a recognisable structure involving a familiar person, time, activity and space. New activities are important to help expand a person's world, but must always be closely linked to what is familiar. People with congenital deafblindness gain control over their lives when they have a recognisable and well-structure daily programme, ordered living areas and a familiar manner of interaction and supervision.

***Practical example: Lidwien***

*Lidwien is a five-year-old girl confined to a wheelchair. She is completely deaf and has very little residual sight. She lives at home with her parents and little brother and attends a day care centre for children with multiple disabilities. She was assessed there according to the Van Dijk method (Nelson et al., 2009) by a psychologist specialised in deafblindness, to examine her learning capacities. Whenever Lidwien is placed on a thick mat, it is evident that she immediately tries to gain an overview of her surroundings by sliding around. When the assessor tickled her hand and then waited, Lidwien immediately tried to find out where the hand went. When the assessor lay down next to her, Lidwien ensured a constant check of her presence by keeping her leg over the assessor's leg. She also grabbed after a disappearing lighted object.*

*During the discussion of the assessment report, caregivers stated that they were not aware that Lidwien was so occupied with obtaining an overview of place, space and person and how important touch is for her to obtain this information. Her parents and caregivers agreed to pay more attention in helping her feel where she is and where objects in her immediate*



*surroundings are located. They will also let her feel characteristic features of other people, like glasses or a ponytail, so she can experience who is making contact with her.*

## **8.2 Stimulating touch: hand-under-hand method**

Although touch can be an important means of support for people with congenital deafblindness to gain information, communicate and make contact, they are not always aware of their ability to use touch. A caregiver can invite someone to feel objects by placing an object in their one hand and putting their other hand under the hand of the person with deafblindness so they can feel the object together. Hand-under-hand contact makes touching the object less scary.

The hand-under-hand method (Miles, 1997) is a friendly method because the other can always remove his or her hand. Make sure that the hand of the person with congenital deafblindness is not restricted in any way (e.g. held by the caregiver's thumb). In the same way, a caregiver can also feel what the person with deafblindness is touching: place your hand lightly on or just next to the hand of the person with congenital deafblindness and copy what he or she is doing. This creates a shared focus through the sense of touch.



*Signs can be felt using the hand-under-hand method, in which the listener loosely places his or her hands on the speaker's hands.*

By observing the person with congenital deafblindness closely while exploring together, we can discover which types of tactile stimuli are pleasant or unpleasant for this person. For example, some people do not like touching materials that do not have a clear beginning and end, like shaving cream. They often tend to prefer hard materials. Others prefer soft, bendable materials (e.g. plastic toy animals you can squeeze), vibrating materials, wind (blower) or running water. When touching a specific object, a person with congenital deafblindness may focus more on touching one particular part of that object because they find that part more interesting. Systematically and repeatedly feeling certain parts of an object can allow a person with

congenital deafblindness to obtain an overview of that object. Some people also do this when feeling a face.

***Practical example: Gino***

*Gino is a 13-year-old boy who is deaf and partially sighted. Originally, communication with Gino primarily involved making signs in the air and drawings, but caregivers discovered that these means were inadequate for continuing the contact. Especially when eating his fruit snack in the afternoon, Gino appeared to be withdrawn and hardly responded to the caregiver's attempts to get his visual attention. Caregivers therefore decided to use more touch in their communication. They invited Gino to use hand-under-hand contact to pour drinks with them and choose from the different types of fruit.*

*Since then, contact has improved. Gino has become much more active and appears to enjoy being with his social partners. A nice example is the moment when Gino became fascinated by squeezing a plastic bottle while pouring out lemonade. The caregiver lightly put her hand on top of Gino's and an exchange of alternating actions started: first Gino squeezed the bottle and the caregiver felt it, then the caregiver squeezed the bottle and Gino felt it. During this activity Gino was highly concentrated, and at the end he had a broad smile on his face.*

### **8.3 Summary and advice for caregivers**

As people with congenital deafblindness are dependent on physical touch sensations to collect experiences, there is a great risk of understimulation and a lack of stimuli. This leads them to self-stimulate, making it more difficult to initiate contact with others. Caregivers can draw a person with deafblindness into the surrounding world by bringing the world to that person in an orderly and comprehensible manner. Physical proximity and availability are important requirements for this.

By communicating calmly about what is happening, the caregiver can support a person with deafblindness in processing information. Communicating and exploring objects together should preferably be done using the hand-under-hand method, in which one communication partner feels what the other says and feels. The "listener" is free to withdraw his or her hands.

We offer caregivers the following advice about stimuli and information processing:

- Give a person with congenital deafblindness the chance to participate by offering him or her external stimuli. Explore the surroundings together using touch, to foster understanding and create an overview. Use the hand-under-hand method.
- Be available, so that a person with congenital deafblindness can find you if he or she needs support.
- Make sure there is a recognisable and structured daily activity programme, a recognisable and well-structured manner of support and orderly living areas. This allows a person with congenital deafblindness to gain more understanding and control over his or her life.

## 9 Interaction and communication

*Interaction* is the term used to refer to the process in which two or more individuals influence each other's behaviour (Janssen et al., 2003a).

*Communication* is a special form of interaction in which individuals transfer and share meanings (Janssen et al., 2003a) such as an intention, message, emotion, experience, opinion or idea. Interaction is required for communication. In other words, people must first make contact before they can exchange meanings.

Each person is born with a natural need to share their emotions and intentions with others (Trevarthen & Aitken, 2001; Tomasselo, Carpenter, Call, Behne, & Moll, 2005). Gradually, children learn how to do this better (Trevarthen & Aitken, 2001). An important skill is negotiating about meaning when the communication partners do not or do not fully understand each other. Very young children already seem capable of showing others whether they feel understood or not and of adjusting their expressions to ensure that the other person understands them (Golinkoff, 1986). Children develop communication skills in particular by being in frequent contact with adults and learning to use language to exchange intentions.

### 9.1 Impediments to interaction and communication

Children with congenital deafblindness experience fundamental problems in sharing their intentions and emotions with other people (Bjerkas, 1996; Bruce, 2005a,b; Andersen & Rødbroe, 2006). Spoken and written language are not suitable for them, but it seems difficult to teach them to refer to something by using signs, like tactile gestures. Many children with deafblindness develop no symbolic understanding, which means they are often misunderstood and can only communicate about objects or people that are present (Bruce, 2005).

People with congenital deafblindness who develop symbolic understanding often appear to continue to use communication to ask about something or someone. They seem to have gained little experience with exchanging thoughts (also see Rødbroe & Souriau, 1999). This leads to others experiencing communication with them as functional and hardly personal, in contrast to, for example, communication with people who became deafblind at a later age.

Education given to children with a sensory disability has always focused a lot on the development of symbolic understanding and the use of symbols. In education for deaf children, there have been strong proponents of children learning the spoken language and proponents of children learning sign language. Over time, educators grew to understand that the environment must adjust to the child's possibilities and not focus on a particular means of communication. This vision is known as *total communication* and focuses on the adequate use of means of communication (Oskam & Scheres, 2005).

Research into young children with deafblindness has shown that communication problems are not only the result of unsuitable means of communication. Children with a visual disability show fundamental problems with contact immediately after birth (Fraiberg & Fraiberg, 1977),

which subsequently influences their complete development. More recent strategies for raising children with deafblindness focus on improving the affective involvement and reciprocity in the contact between these children and their communication partners. For example, communication partners may choose to imitate the child's expressions (Hart, 2006; Nafstad & Rødbroe, 1999) or make *co-active movements* (Marschark & Spencer, 2011; Van Dijk, 1991). In co-active movement, the parent or caregiver of a person with deafblindness moves together with him or her in close contact. This allows the communication partner to clearly feel when the person with deafblindness takes initiatives, which can then be immediately responded to. This helps a person with deafblindness to become aware of their own intentions and learn that these can be shared. Below we describe several other methods for improving interaction and communication.

## 9.2 Improving interaction and communication

### *CONTACT METHOD*

The Contact intervention method focuses on improving reciprocity between people with deafblindness and their communication partners (e.g. caregivers, parents, teachers). The programme's effectiveness has been demonstrated in several studies (Janssen et al., 2003b; 2004; 2006; Damen et al., 2011). The most important ingredient of the Contact method is coaching the communication partners and having them evaluate video recordings of themselves in interaction with the person with congenital deafblindness. The coaching involves aspects taken from the interaction model for people with deafblindness (Van den Tillaart, 2001) and focuses on the following aspects:

- a. recognising the signal repertoire (communicative behaviour) of a person with congenital deafblindness,
- b. adjusting one's own behaviour within the interaction to the person with congenital deafblindness, and
- c. adjusting the interaction context (the environment) in a way that promotes the interaction.



*Jan Dirk and his caregiver are talking about the plans for the rest of the day. The hand contact confirms for Jan Dirk that the caregiver is paying attention to him.*

An intervention is always initiated by the identification of a need relating to interaction and/or communication. This need is then formulated into a number of intervention goals that cover one or more aspects of interaction: initiatives, confirmation, answers, attention, assigning turns, regulating tension, sharing emotions and acting independently. The intervention is conducted by a coach working with the social partners, using training and video interaction supervision.

The Contact programme has been used at Bartiméus since 2004 in research with children with deafblindness and with children and adults with a visual and intellectual disability. It appears to be an effective way to improve interaction (Damen et al., 2011). In 2009, a follow-up study was initiated into the effects of the Contact programme. This study expanded the Contact programme to include an intervention aimed at promoting shared meanings and emotions in communication between people with congenital deafblindness and their communication partners (Damen, Janssen, Schuengel, Huisman, & Ruijsenaars, in preparation). The communication partners were first trained using the original Contact programme developed by Janssen, which improved their interactions. They were then taught using the communication section to learn how to:

- a. adjust the communication context so the person with congenital deafblindness can gain meaningful experiences and have the possibility to share them,
- b. recognise meaningful experiences, communicative signals and emotions and respond to them in a manner suitable to the person with congenital deafblindness,
- c. initiate a symmetric dialogue and stimulate variation in topics, and
- d. negotiate about meaning to uncover the meaning and relevance of communicative signals from a person with congenital deafblindness.

***Practical example: Joey***

*Joey is an eight-year-old boy with CHARGE syndrome who is deaf and partially sighted. He sits in a class with deaf children but his teachers have noticed that Joey cannot always keep up: he is easily distracted and often does not understand the assignments. During video analysis (using the Contact method), his teachers and parents noticed that they often communicate too quickly.*

*Communication improved when they took more time to first gain Joey's attention before telling him something with signs and then gave him the opportunity to respond. His teachers now also use gestures to give him additional information about a situation and ask him to repeat what they have said. This has led to an improvement in Joey's communication with signs. Talks with Joey are getting longer and cover a wider range of topics. His mother has now also succeeded in talking to him about his school day.*

**HEARTBEAT**

People with congenital deafblindness need individual contact with a caregiver to undertake an activity. But how do you establish contact if you do not know where to find the caregiver? Many people with deafblindness wait and resort to self-stimulating behaviour or "call" the caregiver by using self-mutilation.

In 2010, a project was started at Bartiméus that uses the “Heartbeat” method, in which a person with deafblindness can call a caregiver. The client is trained to push a button when he or she needs contact. Vibrations in the device (in the rhythm of a heartbeat) then let the client know whether the caregiver is approaching. This informs a person with congenital deafblindness that his or her request has been heard and a caregiver is on their way. If client notice that their requests are responded to consistently, they may take more initiatives to make contact and adopt a less passive attitude. This augments their control over their own life.

### 9.3 Aids for better communication

There are many aids available for people with deafblindness; the choice of aid depends strongly on the abilities of the person with congenital deafblindness. This concerns not just the extent to which the person can hear, see, feel or smell, but also the person’s communication level. In general, the lower the communication level, the more concrete the means must be. Section 4.3 describes how and with what means a communication assessment can be done.

Means of communication refer to something or someone. For people with deafblindness, tangible objects used as a means of reference must have a clear connection to what is being referred to. For example, a cup refers to drinking. The connection between drinking and a cup is strong because you can easily guess the meaning from the characteristics of the reference object (the cup). If the communication level is higher, the means of communication can be more abstract.



*Pictograms are used to describe the day's events.*

Language is an abstract reference means because it does not directly indicate the literal meaning. We have agreed that a chair is called "chair", but it could just as easily have been called "table".

Communication aids can also be relatively abstract. One example is the four-handed sign for computer (a C that you move back and forth over your arm) or the tactile symbol for water (wavy lines). Gestures vary in the extent to which they are concrete. We use the word *sign* for signs from official Sign Language. The word *gesture* is used for personal gestures or home signs. The latter almost always have a clear relationship to the reference subject but are often only understood by the person with deafblindness who uses them and people in that person's immediate surroundings.

A number of examples of communication aids are given below, arranged on the basis of the required visual, auditory or tactile abilities. We emphasise that the use of communication aids must always follow an individual communication plan and occur under the supervision of a speech therapist or communication coach who has experience with deafblindness.

### ***PICTOGRAMS/PICTURES/PHOTOS***

For people with some residual vision, images or pictograms can be a good support or replacement of verbal communication. The advantage with these aids is that the meaning is clear: new people usually know immediately what is meant. The disadvantage is that often not all information can be communicated with these aids. For example, it is difficult to indicate with images that your mother was ill yesterday and you needed to go there, which is why you could not visit the person with deafblindness.

There are several things to note when using pictograms or images. The depictions must be concrete and recognisable for a person with deafblindness. For instance, you should not use photos of an inflatable pool to talk about an indoor swimming pool. In addition, the images should contain very few details and be set against a neutral background, so they are clear for people with a visual disability. For example, drawn images could have an especially thick outline and light background. An orthoptist can provide individualised advice about how to make illustrations clear. Photos are more concrete than pictograms or images, but they are often too complicated in visual terms and have too little contrast for people with a visual disability.

### ***TANGIBLE OBJECTS***

Tools that refer to a specific situation or event are called tangible objects. There are two kinds of tangible objects: concrete and abstract.

#### ***Concrete tangible objects***

The most recognisable form of tangible objects are the tools that are used in daily life and are offered to prepare a person for an activity. For example, a child with deafblindness may be playing in his bedroom, when his mother makes contact and offers his cup as a sign that there is something to drink. The child can take the cup and join his mother in the living room for a drink. This form of tangible object is offered to people who have difficulty understanding more abstract forms of communication.



*Concrete tangible objects are offered to communicate about an activity.*

Communication research (see Section 4.3) using the Weerklank communication profile (Oskam & Scheres, 2005) has shown that this communication takes place at the *situation level*. Offering objects in a situation in which they would normally be used is the easiest form of communication. The objects offered are recognisable as they have previously been used for the same purpose (e.g. a towel, a ball from the play area, a spoon, a toothbrush). Scents can also be used for support, for example a swimsuit that still has a faint smell of chlorine can be presented to a person with deafblindness to let him or know that swimming is next on the activity programme. With people who seem to clearly understand the meaning of an object, communication partners can try extending the interval between the moment when the object is offered and the activity it refers to. In the above example, the cup was offered in the bedroom and not in the living room, where the drinking takes place. Nevertheless, the meaning was clear and the child followed.

The advantage with this communication is that a person with congenital deafblindness can indicate whether he wants to do a particular activity without having to bring the caregiver to the situation or be brought into the situation himself. It is possible to communicate about a situation outside the directly perceivable surroundings. In the example above, the child could also have indicated that he preferred to keep playing for a while by giving the cup back and returning to his game. When teaching this form of referral, it is important to make a clear link between the tangible object and what is being referred to. This requires considerable empathy, patience and repetition.

#### ***Abstract tangible objects***

People with deafblindness who have a greater capacity for abstraction function at the symbolic level, where there are more possibilities for using tangible objects (e.g. for subjects that cannot be explained concretely, such as a name or the time). In addition, concrete objects can be large and unwieldy; smaller materials are easier to carry around and use in a plan system. To ease the transition from concrete tangible objects to abstract ones, a familiar part of a larger object can

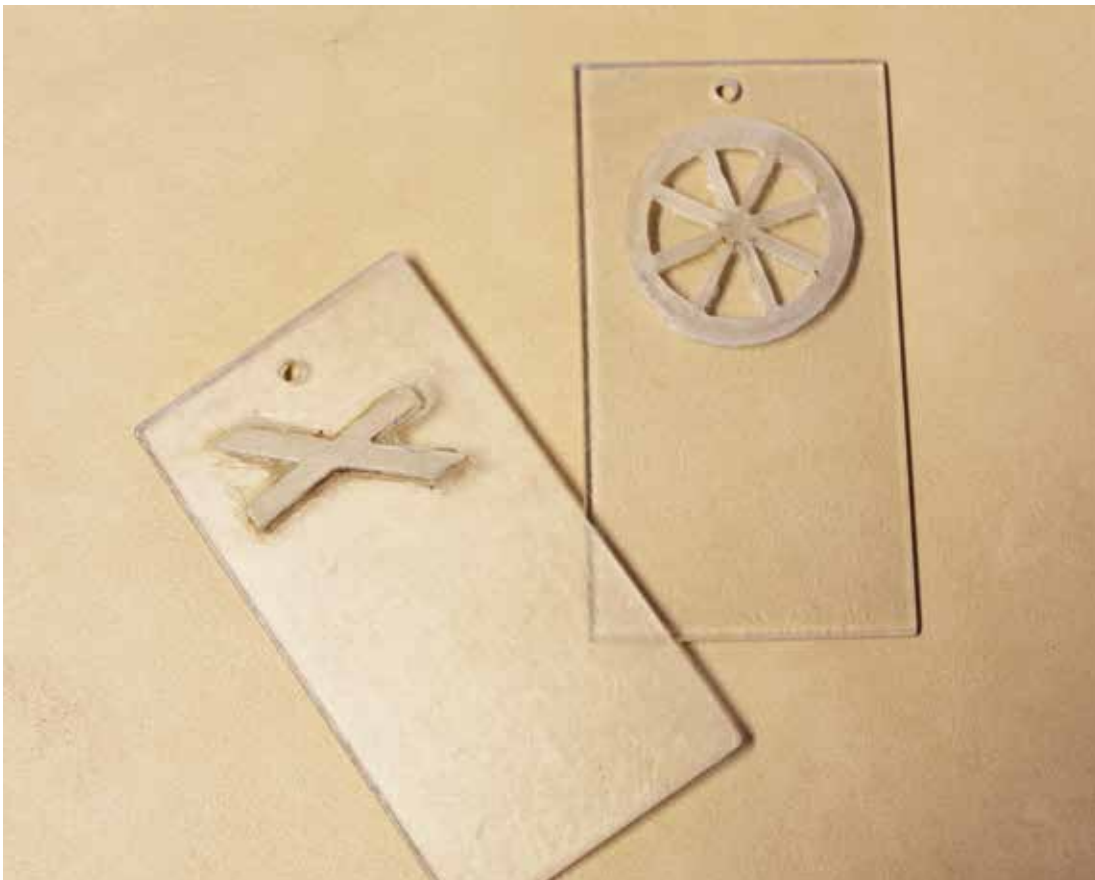


be selected. When this method is trained, the client is first offered the part in combination with the real object (e.g. by including a piece of nappy or toilet roll to refer to the time to change nappies or go to the toilet). This type of tangible object is often used by people functioning at the *signal level* (Oskam & Scheres, 2005).

## SIGNS

Deaf and severely hearing impaired people have their own language: sign language. This enables them to communicate at the same level as people who can use spoken language. Different sign languages are used in different countries. An example is British Sign Language (BSL). A derivative is the use of signs from a sign language vocabulary to support the spoken language.

Normally, signs are traced in the air. People with congenital deafblindness who cannot or can only barely perceive those signs may feel the signs reciprocally, which is called *four-handed signs*. The person who is "speaking" holds their hands under those of the listener, who feels the signs. Speaker and listener can alternate by changing the position of their hands. Through touch contact, a person with deafblindness can feel which signs are being made. People with congenital deafblindness must have symbolic understanding to be able to fully master sign language.



*Abstract tangible objects can be used to talk about abstract matters.*



*Jenny is using signs to communicate about eating.*

People with congenital deafblindness can often sign, but may not always master the full sign language. They may use a selection of signs for regular daily occurrences and concepts (e.g. eating, drinking, showering, sleeping, you, me, waiting, done, finished). A person with congenital deafblindness may also know sign systems that are derived from or a precursor of the official sign language. These systems often have simpler motor elements and a clear location on the body, making them easier for a person with congenital deafblindness to learn. A person may also develop their own signs, called personal or idiosyncratic gestures or home signs. Often their meaning is only known to that person and his or her closest communication partners.

A supplement to sign language is social haptic communication. Variables that are difficult to describe in regular sign language or that require many signs to describe (e.g. meanings from intonation and touch, the atmosphere or description of the space, forms of large objects) are communicated by touching the body, especially the back and/or arm (Lahtinen, Palmer, & Ojala, 2012).

### ***FINGER SPELLING***

The hand alphabet is sometimes used to communicate with people with deafblindness, but few of these people will completely master finger spelling because of the level of abstraction

involved. Individual letters are often used in combination with a signs (e.g. to specify a name). For example, a caregiver named Els has curly hair, so the sign for her name is a finger-spelled E with a curl drawn afterwards.

### ***PLAN SYSTEMS***

A plan system can give a person with congenital deafblindness a better overview of the sequence of events within a unit of time. Depending on the level of communication, the unit of time can be long or short. Some people can only conceive of one or two activities after each other, while others can survey an entire year.

The simplest form of a plan system is a calendar box, which is a long, vertical box with sections in which tangible objects can be placed. The object that refers to the first activity is placed on the far left, and the subsequent sections indicate which activities come next. Aside from signs and finger spelling, almost all tactile and visual means of communication are suitable for a plan system. For example, pictures, photos, pictograms, tools and other tactile symbols can be hung on a plan board or taped in a diary.



*Stephan and his caregiver are talking about the week using a plan system.*

### ***COMPUTER/AT AIDS***

Technological advances are progressing faster than we can follow in this book and possibilities involving assistive technology (AT) are tremendous. Computers can be fitted with a Braille reading line or be activated with a touch screen or special buttons, but this can be too complex for many people with congenital deafblindness. It is important that an AT aid matches the user's communication level and fills a clear need. We advise contacting an expert in this field, like a computer accessibility consultant from a specialised organisation (see list of addresses on p.129). A multidisciplinary approach can help to find the most suitable technical aid.

### **Practical example: Kees**

*Kees is a 50-year-old man who is completely deafblind as a result of congenital rubella syndrome. Kees understands signs derived from Dutch Sign Language for daily recurring terms. He does not know abstract terms or numbers and he has difficulty surveying longer periods. Visits from his father and stepmother are very important to Kees and he often asks about them. They come on average once every two months. When Kees used to ask for DADDY, he often received the answer MANY SLEEPS to indicate that it would still be a while. This did not satisfy him, so his caregivers looked for a method to help him understand how many sleeps there were until his family visited. They decided to try a counting frame. The balls at the top indicate the number of nights; once a night has passed, the ball is moved down to the bottom.*



*An iPad can also function as a means of communication.*

*The next time that Kees made the gesture for DADDY the caregivers showed him the balls on the counting frame and signed THIS MANY SLEEPS, DADDY. This was repeated several times. When Kees woke up the next morning, a caregiver moved one of the balls together with him and he felt the remaining balls. Again he received the message: THIS MANY SLEEPS, DADDY. On the day when his father and stepmother were coming to visit at the coffee break, Kees and his caregiver touched the counting frame and felt that there were no more balls. His caregivers told him NOW EAT THEN DRINK COFFEE, DADDY. He seemed to understand this because he broke into a smile.*

## **9.4 Summary and advice for caregivers**

Interaction and communication are essential for exchanging ideas and feelings. People with congenital deafblindness experience fundamental problems in contact with others. Though the standard means of communication are not suitable for them, there are different ways to improve their interaction and communication possibilities.

Many communication aids and methods can be used (perhaps with some modification) to communicate with a person with congenital deafblindness. In the Contact method (Damen et al., 2011; Janssen et al., 2003a, 2003b, 2004, 2006), caregivers are coached to respond more sensitively to signals from a person with congenital deafblindness and to create the right conditions for optimal interaction and communication. A person with congenital deafblindness can use a Heartbeat device to call caregivers who are not in the immediate vicinity.

A communication assessment can determine a person's communication level and learning capability. This chapter reviewed various ways of supporting communication, such as pictograms, pictures and photos, tangible objects, signs, finger spelling, AT aids and plan systems.

We offer caregivers the following advice about interaction and communication:

- Communication assessment can clarify the possibilities of and aims for communication and support the choice of aids.
- Ensuring good interaction with a person with congenital deafblindness is a precondition for optimal communication.
- As the communication partner, be available for the person with deafblindness so that person has an opportunity to communicate.
- When communicating, try first to involve a person with congenital deafblindness more in the daily routines. Then create opportunities to talk about events in the past or in the future.

## 10 Acquiring knowledge and skills

People learn through interactions with the world around them (Geenens, 1999). Ours is primarily a social world and, through contact with others, children learn how to cope with the world and what it means to be human. They see and hear how other people act and are invited to participate. Sometimes it seems as if skills develop on their own as a child tries something repeatedly and learns in the process, like learning to roll over. Sometimes a child needs more explanation or instruction from an adult to master a skill, such as when learning to tie shoelaces.

Mastering a task or skill becomes interesting when it has a positive consequence for the child: the child gains admiration, more freedom or authority. A child who cannot yet crawl and reach a toy animal will do everything he or she can to move towards the animal and grab it. The child's temperament helps determine how much persistence that child will display.

The above examples clarify how important social contact is and also tells us that interest and motivation play a role in acquiring skills. If you as the caregiver want to help somebody learn tasks and skills, then it is important to keep this in mind. It is also important to understand that new knowledge must always build on what a person already knows and can do. Only then can the new information be integrated with the existing knowledge.

### 10.1 Increasing knowledge and skills

If you want to support a person with deafblindness in acquiring knowledge and skills, you first have to optimise the contact between that person and his or her social environment. It takes exceptional effort from all those involved with a person with congenital deafblindness to provide optimal possibilities for that person to express him or herself. People in this person's surroundings will have to do their best to understand him or her and make themselves understood (also see Chapter 9 about interaction and communication).

Second, the focus must lie on eliciting optimal participation in the activity from the person with deafblindness. There is a great risk that people with congenital deafblindness will submit to an activity, which is called *learned helplessness* (Stipek, 1988; Warnez, 2002). To really involve people with deafblindness and let them participate, another focus is required. Instead of taking control, the caregiver should invite the person to participate, to indicate the next step and to gradually do parts of it on his or her own. For people with congenital deafblindness who have mastered a routine, a part can be deliberately left out (a *mismatch* can be incorporated) to stimulate them to indicate this and to solve the "problem" together with the caregiver.



*Irene has learned to exchange her empty basket for a full one at work.*

One way to teach specific skills to people with congenital deafblindness is *backward chaining* (Slocum & Tiger, 2011). This is a learning strategy that means “working backward down the chain” and involves teaching a person to do a part of an action independently, starting with the last step before the end of the action or activity. They then work backwards step by step to the beginning, or as far as possible. The advantage of this method is that the reward (the result of the action or activity) is close by at the beginning of the learning process. Also, later in the learning process, the person with deafblindness will still know which steps to take to achieve the result.

For example, backward chaining can be used to teach the action “drinking lemonade”. The caregiver first plots the steps that must be followed between taking hold of the cup and drinking the lemonade. The person with deafblindness then learns to carry out the last step first (drinking). Once he or she can do that well, the step before the last is also learned (getting the cup), and then the last three steps. The caregiver works backward until the person with deafblindness has mastered all the steps from beginning to end. The learning involves demonstrating, doing things together and then a person doing things on their own.

## **10.2 Problems in acquiring skills**

Some people with deafblindness are not successful in learning by demonstrating, doing things together and then doing them alone, not even when learning in steps and taking time for each step, as in the above example of backward chaining.

There may be restrictions in carrying out the activity, such as motor or memory problems. It is important not to give up too quickly, but to first search for ways to adjust the activity. It is

important to observe a person with deafblindness, which will quickly lead to points for evaluation. It is also important that you do not stress inadequate actions, but prevent the person to make mistakes by transforming these actions into adequate actions. We call this *errorless learning*. This approach helps lessen the chance of the mistaken reaction being stored in a person's memory instead of the correct reaction (Haslam, Bazen-Peters, & Wright, 2012).



*Jan Dirk is partially sighted and can sort by colour. This makes stacking rings an interesting activity for him.*

It is also possible that the person with deafblindness has little interest or motivation to do what is asked. One solution could be to make the activity or parts of it more interesting. For people who can make cause-effect connections, this could involve attaching a reward to the completion of the task. For people who cannot make cause-effect connections, conditioning may help. A long walk can be made more interesting by pausing at set times and playing an interaction game.

***Practical example: Rika***

*Rika is a middle-aged woman who is completely deaf and blind due to her premature birth. She lives in a community home for adults with congenital deafblindness. Rika is not toilet-trained; though attempts were made in the past to teach her to use the toilet, they were not successful. However Rika gives the impression that she has control over her body. Because she is having increasing difficulty wearing incontinence products, her caregivers decided to once again try to teach her to use the toilet. The training took the form of conditioning: her caregivers took her to the toilet at set times during the day and rewarded this action with a cookie. In the beginning she was given a cookie for just sitting on the toilet, but later she had to use the toilet to earn her reward. Rika eventually learned to use the toilet.*



### **10.3 Summary and advice for caregivers**

Three points must be kept in mind when teaching knowledge and skills. First, people learn through contact with others. Other people are required when learning most skills or tasks: to demonstrate, to encourage or to support the learning process. This makes it important that a person with deafblindness and the people around him or her understand each other clearly. Second, interest and motivation play a major role in learning new skills (and the speed of doing so). A person with deafblindness has to be involved as much as possible in the conduct of a task or activity, and his or her participation must be rewarded (create experiences of success). Finally, new knowledge must build on existing knowledge. A good way to teach a person with congenital deafblindness a certain action or activity is backward chaining.

We offer caregivers the following advice about acquiring knowledge and skills:

- Find out which tasks or activities are interesting or rewarding (or could be rewarded) for a person with deafblindness to learn.
- When teaching, make sure to devote your full attention and support to client. You must be available and be able to communicate optimally with a person with congenital deafblindness.
- Use backward chaining to teach an action: teach the last step of an action first, then the last two steps, and so on.
- Give the client time to learn and use the time for close observation. Adjust the activity as necessary to make the learning process easier.
- Do not stress any mistakes that are made but transform them into adequate actions (errorless learning).

## 11 Orientation and mobility

Many people with congenital deafblindness have difficulty orienting themselves. They have no sight or hearing to entice them to go out in the world, so they tend to take little initiative to walk somewhere or explore. Like blind people, they can be anxious about entering a space on their own or losing contact with the safe place where they are (Gunther, 2004). Other people must show them the added value potentially inherent in movement. Mobility offers possibilities for activities, independence in daily activities or the ability to inform others of their wishes and needs (communication).

To learn how a room is arranged, a person with congenital deafblindness can explore the room with someone else: learn where things are, find the recognition points and discover which set paths are best for walking through. An important starting point for this exploration is willingness; a person should be guided, not dragged somewhere. The exact extent of this depends on the person's preferences and abilities.

People with deafblindness who do dare to move around and who can orient themselves can be easily upset when something unexpected occurs. That is why they also need caregivers who are available and who can provide support if necessary. Orientation and mobility require intensive support for all people with deafblindness. This support can also involve aids or specific training.

### 11.1 Following fixed routes

Both seeing and hearing people and people with deafblindness prefer to use fixed routes. In principle, each person with congenital deafblindness needs specific supervision with orientation and mobility, both outdoors and inside. To document the capacity for orientation, every change of location (e.g. from the couch to the dining table) must be considered a route. To be able to identify a route, a person with congenital deafblindness needs recognisable orientation points that show whether he or she is on the right route. Depending on the person and the space, this varies from a single point to complete guidance.

Which type of supervision and how much supervision does a person need? The first and most important step in answering these questions is observation. By making observations, a caregiver receives important information about what a person with congenital deafblindness needs to learn a route.

The following aspects should be considered:

- Recognition points. Which potential recognition points are already available in the space? This involves fixed components of a space, such as cupboards, couches, doors or windows. Sometimes a person with deafblindness needs additional recognition points (e.g. guide rails or a wall decoration) to make orientation easier.
- Orientation. How does a person with deafblindness orient him or herself and how much supervision does he or she require? A caregiver also needs to examine how the person moves and what this means for orientation. For example, many people with deafblindness find it stressful to lose contact with the surface they are walking on, so they tend to shuffle along rather than step.
- Use of touch. Which parts of his or her body does the client use for activities (e.g. hands, arms, feet, residual vision, residual hearing)? There may be some resistance to the use of touch: a person with deafblindness may not like having his or her hands held because then this limits their ability to feel objects, or a person may not like having dirty hands or walking on soft or uneven surfaces. Tactile resistance can be caused by a disturbance in sensory integration (SI). An SI therapist can examine this and treat it if possible.
- Dynamics. Which other people use the space and how much does that influence the mobility of a person with deafblindness? The recognition points and routes used by others may also need to be taken into account.

After the orientation and mobility of a person with congenital deafblindness are examined, a plan should be prepared for learning one or more routes. Attention must be paid to mapping and possibly adjusting the physical environment.

Spaces should be recognisable for a person with deafblindness and the surroundings should be safe and free of obstacles. In addition, the plan must cover an agreed form of support that is adjusted to the needs and capabilities of a person with congenital deafblindness.

In principle, learning a route follows the same steps listed above: the caregiver demonstrates how it is done, the client and caregiver do it together and then the client does it independently. The speed of learning a route differs from person to person. Some people with congenital deafblindness learn quickly, and a caregiver can start moving away after walking a route together just two times.

Others may take months to learn a certain route. Some people will always need intensive assistance, but even they can still learn to recognise routes. For example, this becomes apparent when a person turns around near the couch to sit down although he has not yet felt the couch. This is also a form of orientation capacity, which allows a person with congenital deafblindness to participate in mobility and communicate about wishes and needs. However, even then, it remains important to devote specific attention to orientation and mobility (McInnes, 1999).

**Practical example: Yvonne**

*Yvonne is a middle-aged woman who is completely deaf and blind and who did not seem to have an overview of her everyday environment. Her caregivers provided physical support when she walked and Yvonne never took any initiatives. When a new caregiver examined Yvonne's file, she noted that Yvonne had been able to walk independently before the community group home had been rebuilt. She also used to take the initiative to walk to the rocking chair by herself. This had all changed after the renovation.*

*The caregiver discussed this in a team meeting and expressed the suspicion that Yvonne had never learned to walk a new route. The team decided to walk a fixed route through the home from then on and to encourage Yvonne to feel various tangible observation points along the way. After six months, the caregivers noted that Yvonne started taking the initiative by pulling them in a certain direction, for example, when asking about a bath or the rocking chair.*

Sometimes it is necessary to change one or more routes, but as a general rule it is important to avoid change as much as possible. It is already complicated enough for people with congenital deafblindness to move around in a familiar environment. Even a small change, like moving a cupboard that happened to be a recognition point on a route, can have major consequences for their independence and self-confidence.

## **11.2 Support style**

A person with congenital deafblindness usually needs to use their whole body to move around. This leads to a very personal preference in support style. For someone with residual vision and/or hearing, it is sometimes possible to make indications at a distance. Often, however, a caregiver has to be within touching distance.

As regards support, it is important to start with the idea of helping a client maintain or achieve as much independence as possible. Therefore, it is important that a person with deafblindness feels safe enough to explore and to experiment. There are different ways to accompany a person with congenital deafblindness:

- **Swinging arm.** The caregiver and the person with congenital deafblindness walk hand in hand, leaving one hand free to feel around.
- **Elbow-hand.** The elbow of the person with deafblindness is supported with a hand. By steering the elbow, the caregiver can help determine the direction. The person with congenital deafblindness has both hands free to feel with.
- **Shoulder.** The caregiver has his or her hand on the shoulder of the person with deafblindness, who can freely move both hands and arms.
- **Hand or arm underneath.** The hand or arm of the person with deafblindness is lightly supported by the caregiver, on a spot where the person with deafblindness finds comfortable. This allows the client a great deal of independence while knowing that someone is available.

- Behind/in front. The person with congenital deafblindness walks behind the caregiver and holds onto his or her elbow or shoulder. This offers a lot of support and physical contact. In addition, the risk of bumping or jerking is greatly reduced because the two people walk exactly the same route.
- With an object. A person with congenital deafblindness and the caregiver both hold onto the same object (e.g. a stick, thick rope or hoop). With some forms of tactile resistance, this is considered more pleasant than direct contact. This can also help to increase independence at a later stage.
- Other forms of accompaniment can be discovered or used, as long as the starting points remains the same.

Independent of the style of accompaniment, a caregiver must ensure that a person with congenital deafblindness can always let go when he or she needs to. This allows the client to communicate about the speed of walking, the environment he or she is in and the intensity of the contact.

### 11.3 Aids for orientation and mobility

There are many aids on the market to help people who are blind or deaf. Several of these aids are also suitable for people with congenital deafblindness and those in their surroundings. When choosing an aid, the same principles apply as when choosing a support style: it must match a person's abilities and preferences and must help increase that person's independence.



*Eelco is walking down the hall. Because he is walking behind his caregiver, there is little risk of him bumping into something.*

This field is characterised by rapidly advancing technological development and innovation, making it impossible to provide an up-to-date review here. There is a list of addresses and websites at the back of this book associated with aids for orientation and mobility. The most important aids used by people with congenital deafblindness are guide rails, glasses and/or hearing aids, modified lighting, white canes and tactile orientation boards. These aids can be fully adjusted to an individual's abilities and needs and are described below.

### ***GUIDE RAILS***

In places where a person with congenital deafblindness spends a lot of time (e.g. at home or at a day care centre), guide rails can be valuable assets for promoting mobility. Guide rails generally resemble horizontal handrails. Guide lines (e.g. ridged tiles on the floor) can also be used.

A guide rail serves two purposes. First, it provides a firm place to hold on. Many people with deafblindness enjoy having something or someone they can physically lean on. A guide rail is also relatively easy to find again if a person stops, lets go and then wishes to continue on. A guide rail leads a person with deafblindness to another room. The risk of bumping into something or getting lost is practically nil because the rail does not move and should be free of obstacles. Secondly, guide rails can provide information about location (e.g. by hanging or sticking a tactile orientation object on the rails next to a room). Many people with congenital deafblindness benefit from the use of guide rails or lines, both inside and outside.

### ***GLASSES AND/OR HEARING AIDS, MODIFIED LIGHTING***

Hearing aids and glasses are of course useful for more than just orientation and mobility. They are valuable aids in acquiring more information about the environment. Therefore, we recommend that they always be used when moving around.

The same applies to lighting if there is any residual vision. Good illumination ensures that visual abilities are used optimally. Therefore, strong contrasts and optimal lighting should always be available for people with partial sight. Different specialised organisations have advisors in the field of lighting and room layout who can help; see the address list at the back of this book.

### ***WHITE CANES/GUIDE DOGS***

People with congenital deafblindness use various types of long canes, guide canes and identification canes. They sometimes also use guide dogs, which can give them a greater sense of independence in orientation and mobility.

People with congenital deafblindness often prefer to use a white cane with a rolling tip rather than ticking it against the ground, because the tip is in permanent contact with the ground. A person with congenital deafblindness usually knows only a few routes, and it is generally difficult for him to move "freely" using only a white cane. Some support must always be around, nearby or at a distance, to ensure that a person with congenital deafblindness does not get lost when something unforeseen arises.

### *TACTILE ORIENTATION BOARDS*

Most people have a nameplate and house number by the front door. That is a typical form of a tactile orientation board: a referral sign, used not only outside but also inside the house. A tactile orientation board is an object that indicates where a room is located. The board is hung up next to or close to the room concerned (Van Welbergen, 2009).



*A tactile orientation board for the bathroom.*

A tactile orientation board helps a person with congenital deafblindness to orient him or herself and continue walking on that basis. A system of tactile orientation boards is primarily used when a familiar situation is about to change (e.g. an impending removal). By introducing tactile orientation boards in familiar situations, a caregiver can help a person with congenital deafblindness to use the same tactile orientation boards to recognise the same type of room in a new place.

Naturally, it is important to introduce tactile orientation boards systematically for a person with congenital deafblindness. This means that the boards are hung in a recognisable location and at a convenient height, preferably where a person with deafblindness would already be feeling for orientation. The first few times a tactile orientation board is used, the caregiver must introduce the object by feeling it together with the person with deafblindness. Thus, the tactile orientation board can also serve as a topic for further communication about the room or route.

## **11.4 Specific training**

Specialised organisations for people with visual or hearing disabilities offer training and support in the field of orientation and mobility. These services are also offered to people with congenital deafblindness and their caregivers. Mobility trainers can estimate the extent of help and support a person needs and can then offer practical tips, advice or training to him or her and/or people in his surroundings.

This allows them to make orientation and mobility improvements.

## **11.5 Summary and advice for caregivers**

Orientation capacity and mobility are generally severely impaired by congenital deafblindness. When moving around, people with congenital deafblindness are often dependent on others. The extent of support needed differs from person to person and depends on their sensory functions and learning capacity. Some people with congenital deafblindness can only orient themselves when close to a caregiver, while others only need help to spot changes and obstacles. This chapter described how to measure the amount of support a person needs. In addition, several options for support were outlined, and the most important categories of aids were described.

We offer caregivers the following advice about orientation and mobility:

- Ensure that a person with congenital deafblindness has enough time and space to move around. Invite a person (do not pull) and allow him or her to set the tempo of movement.
- When teaching routes, incorporate the person's preferences and what he or she already knows and can do in terms of mobility.
- Always make sure that glasses and/or hearing aids are used when moving around and that the lighting is adequate.
- Create tactile orientation points and/or install guide rails on commonly used routes and let a person feel them.
- Be aware that a person with congenital deafblindness will always need some form of support.



# Part III

Design of the environment

## 12 Housing and daily activity programme

The most important places in anyone's life are their home and place of work/daily activities. Since this is where they spend the most time, it is very important for people with congenital deafblindness to feel safe, free and comfortable in these places. Only then can there be optimal well-being, which enables learning and development. In the vast majority of cases, this means that adjustments will be required to meet a person's specific needs.

### 12.1 Supported living

Homes for people with congenital deafblindness must be adjusted to their needs, which means that they must contain aids for orientation and communication. Supported living also means that enough trained caregivers are present to offer individual support. Inside the home, the caregivers must be able to observe a person with deafblindness and maintain a line of contact. This means that caregivers must be available for contact and the person with deafblindness must be able to make contact when needed.



*Irene is sitting in her own chair in the communal living room. The chair is kept in a fixed place against a wall, making it easy for Irene to find it.*

Experience has shown that a group of four to six people with deafblindness is the right sized living arrangement. This allows possibilities for social interaction while also offering sufficient oversight. A person's own bedroom serves as a place for individual activities, or a place to calm down. A person must be able to find the other rooms and the caregivers from this room. In addition, the entire living environment must be orderly and a place where a person with deafblindness is stimulated and challenged to participate in daily life as much as possible (see Section 12.2).

Research has shown that specialised programmes for pupils with deafblindness involving highly qualified professionals have a better influence on the development and well-being of these pupils than inclusion projects or ambulatory support in general (Chen, 2004; Giangreco, Edelman, & Nelson, 1998; Goetz & O'Farrell, 1999). This is in line with the experience of experts in the Netherlands: a modified environment and specialist support are essential to realise and sustain contact development.

People with deafblindness have a different need for support than people who are not deafblind. Experience has shown that in an environment where only one or two people with deafblindness lives, it is generally impossible to meet those individuals' special need for support, which leads to behavioural problems and/or a lack of development. It seems that people with congenital deafblindness can develop enormously if they receive specialised support in a modified environment (Damen & Kingma, 2003).

## **12.2 Adjustments to the environment**

People with congenital deafblindness perceive the environment in fragments. It is difficult for them to understand the connections in their surroundings. If they succeed, the effort takes a lot of time and energy. That is why it is important to ensure that the living environment is as orderly as possible. The following aspects are important:

- Rooms and their layout must be recognisable. This is done by setting furniture, objects and people (e.g. sitting corner, table arrangement) in permanent places, paying attention to the characteristic scent of a room or adding tactile orientation points (e.g. tactile orientation board, ridged tiles, tactile markings and guide rails).
- It is best if different functions take place in different rooms (e.g. eating, sleeping, daily activities, showering and toileting). When arranging a room, this must be taken into account.
- The floor must be recognisable and predictable. For people with deafblindness it can be disturbing when the floor surface is not flat or when it changes suddenly (e.g. because of loose carpet). The floor offers many possibilities to support orientation by giving different rooms their own type of floor (e.g. tiles in the bathroom, laminate in the living room and carpet in the bedroom).
- People with congenital deafblindness must be enabled to walk the same routes repeatedly, both inside and outside their home. This broadens their overview, even for people who require constant support when moving about.

- The homes for people with congenital deafblindness should preferably be located close together, so caregivers are able to exchange knowledge and experience and further adjust the immediate surroundings.
- There should be a good auditory environment for people with residual hearing. People with partial hearing loss need good acoustics and as little background noise as possible (e.g. no TV or washing machine). A good acoustic environment is especially important for individual conversations. In general, the worst acoustics are found in large and tiled rooms, and the best in small rooms with carpet and curtains (e.g. a bedroom). Experts can evaluate the acoustics of a living space and make suggestions for improvement.
- There should be good lighting and contrasting colours for people with residual vision. For example, mood lighting is often insufficiently bright for these people to see well. The distinction between a doorpost, wall and door can be amplified by painting the doorpost in a contrasting colour to the wall and door. The use of brightly coloured plates and cups can help define a person's place at the dining table. We recommend having an expert examine living spaces for light quality and use of contrast and give advice about lighting and layout.



*Firoz is orienting himself in his home with the help of his caregiver.*

**Practical example: Dina**

*Dina is a young woman with deafblindness who was soon to move from her parents' house to a residential group home for adults with congenital deafblindness. Dina's parents wanted to prepare her for this move but did not know how to do this properly, as Dina lives emphatically in the here and now. They discussed their worries with the psychologist at the new residential group home. The expert asked the parents about familiar aspects in Dina's current environment: they listed her own couch, the woollen bedspread and the lavender scented oil sometimes used to massage her.*

*It was decided to incorporate these elements in the new environment and to use them more in the parental home. A lavender room scent was purchased to use daily in Dina's bedroom and the same material as her woollen bedspread will be hung next to the door to her room at touch height to let her know where she is. Her parents wanted to purchase new furniture for Dina, but it was recommended that they do this either long before the move or not at all. This applied especially to her bed and couch and less so to her clothing closet, because she does not use it herself. Her parents were also advised not to wash her bedspread just before the move but to take the unwashed sheets along so the scent will be familiar to her. On the morning of the move, her parents helped her put her bedspread and pillows in a large box and moved these with her to her new room.*

## **12.3 Daily activity programme**

A worthwhile set of activities to fill the day is an important need for people with congenital deafblindness. It offers possibilities to promote personal well-being, maintain social contacts and gain new experiences. In addition, a daily activity programme and leisure activities have a more direct purpose: preventing boredom and "an empty existence". A daily activity programme contributes to individuals' development and opens up the worlds of people with congenital deafblindness.

To produce a worthwhile set of activities for people with congenital deafblindness, it is necessary to ensure a basic level of safety and predictability, and to adjust to the possibilities and needs of the moment. In the daily programme, the emphasis lies on being together and experiencing and doing things together. This demands a great deal of individual availability and support. There must be an appropriate balance between activity and rest. In addition, it is important to offer surprising elements and variety, to prevent rigidity of routines.

The daily activity programme should take place in set rooms and give different activities permanent locations (e.g. music in a music room, work in a special room, a gymnasium or a solarium). If necessary, these places can be marked with a tactile orientation board. This gives a person with congenital deafblindness an idea of what to expect before they enter a room.

Daily activities can be offered to either individuals or a group, depending on the need for support. Suitable activities could be sensopathic in nature (e.g. a Snoezelen multi-sensory

environment, massage, footbath) or promote participation (e.g. cooking, shopping), play and creativity (e.g. music, stories) or movement (e.g. walks, cycling, swimming). Some people with congenital deafblindness also require more work-like activities, which can include simple production work (e.g. packing, sorting) or doing chores (e.g. carrying out boxes). Gardening can also be a worthwhile, work-like activity. When choosing activities, consideration must be given to the individual's abilities and wishes, which derive from the advice for caregivers given in Part II of this book.



*Stephan is filling children's surprise eggs with toys. He enjoys this work-like activity.*

## **12.4 Integrated daily programme**

Transitions take a great deal of time and energy for many people with congenital deafblindness. This applies to all transitions: change of place, of activity, and of caregivers. That is why it is most comfortable to have the least number of caregivers between the time they get up in the morning and the time they go to bed. It takes people with deafblindness a lot of time and energy to get used to another person. Because of their limitations around transitions, an integrated form of living and daily activities or integrated daily programme is more suitable for most people with congenital deafblindness than a strict separation of the living and working domains.

In an integrated daily programme, the living space is the central point where all activities start and end. Both activities inside (e.g. cooking, making the bed) and outside (e.g. cycling, going to the garden or an activity room) the home are done with the regular caregiver. This limits the

number of changes between caregivers, while giving a person with deafblindness a worthwhile set of activities. In this way, an individual's needs and changing energy levels can be flexibly adjusted for.



*Jenny is making coffee for herself and the other people she lives with.*

The daily programme focuses on having people with deafblindness actively participate in a normal daily routine, like taking care of themselves, preparing meals and doing the laundry. There is also space for activities (work) that they find worthwhile and fun. The activities can take place in or outside the home, depending on the nature of the activity and the capabilities of the person with deafblindness. The emphasis is placed on maximising the person's involvement in all activities and on interaction and communication. This enables the individual to share experiences and prevents social isolation. An integrated daily programme offers possibilities for meeting the individual's need for support when designing the activity programme.

***Practical example: Lieke***

*Lieke is a 13-year-old girl with CHARGE syndrome. She is deaf and partially sighted. She lives with her parents and older sister. Lieke really likes doing things with other people and enjoys helping with daily chores. Her mother noticed that Lieke was able take a more active role in this when given clear information about the next steps to take. Her mother now draws these steps for her and discusses them one by one.*

*She did this when introducing a new task: collecting the laundry from the line, putting it in the laundry basket and folding it neatly. Lieke was enthusiastic when her mother signed, "COLLECT TOGETHER LAUNDRY". She looked with interest at the drawings her mother used to explain what comes next, nodded and pointed to the line outside. While collecting the laundry, she smiled as her mother explained that some clothing could not be collected yet (THAT NO, THAT WET) while some could (THAT YES, THAT DRY). Lieke has now learned to distinguish between wet and dry and to use gestures for YES and NO to tell her mother which laundry can go in the basket.*

## **12.5 Summary**

Deafblindness has a major influence on the optimal layout of an environment. People with congenital deafblindness require modifications and aids for orientation and communication, both in the home and in other places they visit regularly, like the day care centre. These places must be arranged in a recognisable fashion with fixed places for certain activities. Change should be avoided as much as possible. In addition, it is important for caregivers to be present and easily accessible. Caregivers too require good lines of sight to be able to supervise and provide prompt support.

The daily activities of people with congenital deafblindness should take place in a fixed, recognisable structure. Surprising elements are important to prevent rigidity. People with deafblindness should take part in all activities, both in daily life and in movement-oriented work or leisure activities. Stress should be placed on interaction and communication to promote social contacts. Because transitions can quickly lead to unclear and uncertain situations, they should be made as simple as possible by preventing caregiver changes and taking the time to make transitions together. All daily activities should be able to take the changing energy levels of people with congenital deafblindness into account.



## 13 Aids

Deafblindness is a disability that affects all areas of a life. The lack of hearing and sight cannot be compensated for by the other senses (i.e. touch, smell, and taste), so all aids that could contribute to greater independence or improved participation must be used as much as possible. However, this is usually not straightforward.

There are many different types of aids, but unfortunately they are not all suitable for all people with congenital deafblindness. Therefore, it is important to be aware of the available aids so that a sound choice can be made.

Aids for people with deafblindness can be roughly classified into a few categories. Most are intended to amplify the senses (distance senses, especially), simplify communication with others and improve independence with orientation and mobility. This book describes various aids in Sections 9.3 (aids to improve communication) and 11.3 (aids to help orientation and mobility). These are meant as illustrations, to give examples of the kinds of aids that are available for people with deafblindness.

New aids are regularly introduced on the market, so keeping up to date with the latest developments is important. This can be done in many ways, such as visiting different websites or contacting specialised organisations. There is a list of addresses in the back of this book.

People with congenital deafblindness need assistance to use most aids. Therefore, an aid cannot be used to replace assistance, but should be considered a means of support to enable functioning that is as independent as possible with the help of a caregiver. This chapter describes the support that is needed to learn to use and continue using an aid.

### 13.1 Hearing aids and/or glasses

It is important to know if and how to make optimal use of any residual vision or hearing. These senses help a person with congenital deafblindness to come into or remain in contact with daily reality and with other people. Therefore, special attention must be paid to glasses and hearing aids that amplify the person's existing sight or hearing. This section will not describe the aids themselves, but will focus on the support needed to use them properly. For descriptions of glasses and hearing aids, you can visit the websites listed in the back of this book.

The adjustment and use of glasses or hearing aids must be properly supervised, which requires several different disciplines. Adjustment must be based on recent hearing and visual measurements and on the aims for the use of that aid. In addition, an individual's personal situation must be taken into account. For example, when adjusting a hearing aid it is important to know whether the wearer is often in a noisy environment.

It takes time to adjust to wearing glasses or hearing aids. Since a person with deafblindness is not used to wearing such an object on his body, he may not immediately notice its benefits and

may even be overwhelmed by the increased quantity of stimuli. The caregiver must be able to motivate a person with congenital deafblindness to try the aid. This can involve a situation that appeals to this person, such as first wearing the glasses or hearing aids only during a daily activity. A caregiver can also create a pleasant, challenging (but within bounds) situation, such as only using the hearing aid when making music. In any case, the caregiver can best respond to the individual's signals during a one-on-one assistance situation. The success of using the aid can be evaluated by predetermining the aims for use of the aid and the criteria that confirm that these aims have been realised.



*Josy wears glasses and can therefore play with light and colour.*

Occasionally, adults with congenital deafblindness have been given a hearing aid or glasses in the past but have rejected those. This may have occurred during a period when the person's vision or hearing was worsening, which in itself is a time of great anxiety and uncertainty. This is no reason not to try again. People with congenital deafblindness can accept an aid years later, when it is offered in a different way or because the person has changed.

While a person with deafblindness is adjusting to the aid and also afterwards when using it, it is important to do regular multidisciplinary checks to promptly solve any problems. Just cleaning a hearing aid's earpieces and regularly testing the batteries takes time and demands great care. It is sensible to involve people from several disciplines and experts from specialised organisations when offering hearing aids and evaluating their use. Supervision for people learning to wear a hearing aid involves an audiologist and a hearing care professional, as well as a speech therapist, a communication coach and an educational or general psychologist. A multidisciplinary approach is also required when a person first starts wearing glasses: a technical ophthalmology assistant, orthoptist, ophthalmologist, communication coach and ambulant caregiver should all be involved.

**Practical example: Leonie**

*Leonie is a middle-aged woman who is deafblind as a result of congenital rubella syndrome. She lives in a community for adults with congenital deafblindness.*

*There were no exact hearing measurements available for Leonie because she could not be examined. Since the building where the audiometry tests are performed is the same building where her general practitioner and dentist are located, Leonie seems to associate that place with unpleasant experiences and therefore refuses to cross the threshold of the building. Because her family and her caregivers agreed that an audiometry test would not present a burden for her (she only had to respond to sounds), they decided to take her into the building by another route. This strategy succeeded and the testing went well. The hearing care professional visited her in her community home to make the earpieces while her caregivers distracted her with clapping games. To help her adjust to the hearing aids, they were introduced during an individual music activity in the Snoezelen multi-sensory environment room. Leonie responded well to this. The more the musical activity was repeated, the more pleasure Leonie began to take in using her voice. She now enjoys reciprocal imitations of sounds with her caregivers.*

## **13.2 Adjusting to an aid**

As with introducing any new thing into the life of a person with congenital deafblindness, an aid should be chosen carefully and offered in a way that suits the person's individual needs. This creates the best likelihood of success. There are various points to consider when introducing aids to people with congenital deafblindness. See the doctoral dissertation by Meuwese-Jongejeugd (2006) about hearing rehabilitation in the care of people with an intellectual disability and the hearing rehabilitation model of Bartiméus (Damen & Kingma, 2006; Kingma, Schelfhout, Damen, Makker, Kuik, & Van Zanten, 2005). Learning to keep glasses on can be practised with a special adjustment programme for glasses. A caregiver can read the programme book to clients with deafblindness; it discusses the different aspects of wearing glasses in a positive manner (Appeldoorn-Witte, Asjes-Tydeman, & Marskamp, 2010).

The most important points when starting to use an aid are to:

- Formulate a clear goal for the use or introduction of the aids. What is the aid meant to achieve? How is it meant to improve or enrich the user's quality of life?
- Make sure the measurements of vision, hearing and cognitive functioning are up-to-date. The rule of thumb is that people with an intellectual disability should have a hearing screening every five years. The hearing of partially sighted people without an intellectual disability should be tested after the age of 50. Once a person is diagnosed with a hearing problem, tests must be repeated every two to three years. The visual function of partially sighted people should be tested every three years. A psychological assessment (to determine level) can be done every five years in adults; with children, it is worthwhile to test more often.

- Observe the person with congenital deafblindness in daily situations. In which area does this person have specific needs? What are this person's wishes in terms of aids? What are the minimal requirements for the aid (e.g. mobility, ease of using the aid and the fragility of the aid)?
- Look at assessments from the different disciplines and use the collected data to decide which aid(s) would work best. Sometimes an aid can be further adjusted to a person's capabilities and preferences.
- Prepare an action plan for introducing the aid. Consider the best situation and time of day to offer it. Be aware of the person's alertness and motivation. Take into account the practical applicability in this situation and the ultimately desired result.
- Introduce the aid, regularly evaluate the action plan and adjust it as necessary.

The success that a person with congenital deafblindness will have with using an aid in daily life is partly determined by the caregivers. They play a major role in offering the aid, maintaining the aid, supervising the person during the use of the aid and so forth. When caregivers see the added value of the aid, they are more motivated to offer it and do so more consistently. It is therefore very important to inform them about an aid's proper use.

As there are not many aids for people with congenital deafblindness, other methods can also be selected. Caregivers must be aware of what is available and whether a device could be used by a person with congenital deafblindness or that person's social partners in providing support. It is also important to establish the aim of the use first and to be well informed about a person's capabilities and preferences. Then a multidisciplinary action plan can be prepared and the aid can be introduced.



*By wearing a hearing aid, Irene gets more information about her surroundings. Even if she does not understand people around her, she hears when things happen nearby and can respond.*

### **13.3 Summary**

Aids can be a great help for people with congenital deafblindness. They offer possibilities for participation and a greater amount of independence.

Unfortunately, most aids need modification to be suitable for this target group. Aids, or their use, must be adjusted as much as possible to the individual with deafblindness. In addition, aids are primarily meant to support the assistance provided by professionals. People with congenital deafblindness will always require appropriate assistance.

Aids are primarily employed to promote the use of the senses (distance senses, especially) and to improve information processing, interaction and communication and/or orientation and mobility. Because the available aids are constantly changing, it is worthwhile to follow developments on the market. See the address list at the end of this book for details.

The introduction of an aid requires special attention. As it is often impossible to explain the usefulness of an aid to people with congenital deafblindness, and they will have to experience its function and added value for themselves. This takes creativity, time and persistence on the part of caregivers. This chapter described various issues involved in introducing an aid.

## 14 The caregiver: characteristics and role

All people with congenital deafblindness are greatly dependent on others due to the complexity of their disabilities. Intensive help and support are essential in all facets of daily life. This is often provided by caregivers, especially as a person with deafblindness gets older and can no longer live at home.

This extensive dependency can lead to the development of an unbalanced assistance situation in which the caregiver takes over more tasks than necessary from the person with deafblindness. Specific skills are needed to evaluate an individual's need for support. The support to be provided is very specialised and demands knowledge and a great degree of empathy, patience and perseverance.

### 14.1 Physical contact

Touch is the most important sense used by people with deafblindness to collect information (Lonkhuyzen, 2004). This may involve the hands, but generally the whole body is used. Physical contact is a fundamental and essential requirement in providing adequate support. Especially with people who are completely deafblind, each and every contact takes place through the body, but also for others with congenital deafblindness physical contact is the most important means to arrive at activity and communication.

Young babies find touching others to be an easy and natural process. Babies are held, lifted up, hugged and played with. This is important for their sense of security, but it also allows them to make contact and communicate (Trevorthen & Aitken, 2001). This natural form of touch gradually fades into the background as children grow older (Hertenstein et al., 2006). But for adults with congenital deafblindness, it remains just as important to have physical contact as it is for young children. This also gives them a feeling of trust and security. At the same time, it is often the only or one of the few ways they can express their wishes and needs or collect information.

Caregivers of people with congenital deafblindness should frequently make a lot of physical contact, not only using their hands but their whole body as well (Lonkhuyzen, 2004). They must find a balance between accepting tactile contact, including from people who are less familiar to them, and preserving boundaries, both their own and other people's. This is not an easy task and it is recommended that the subject be regularly discussed during peer review sessions and/or team meetings.



*Physical contact is used to share reciprocal emotions.*

## **14.2 Proximity and availability**

A caregiver needs to be close by to be able to see the often difficult-to-read signals from a person with congenital deafblindness. The caregiver also needs to be available to be able to respond to these signals. Using the hands to communicate makes it impossible to converse with several people at the same time, so all contact should take place in a one-on-one assistance situation. Even though most people with congenital deafblindness live in a group, in practice there are still many individual contacts. This means that a high level of caregiving is necessary to provide the essential level of support.

People with congenital deafblindness are heavily dependent on help from others in all situations. A caregiver is almost always needed to provide support for all tasks. Sometimes a person can ask for help themselves (e.g. by making a sound); sometimes the caregiver has to notice that help is required. Thus, it is important that the caregivers remain in the same room as the person with deafblindness and that there are clear lines of sight.

Caregivers must always be aware of privacy: the person with congenital deafblindness is always being watched and listened to. There are very few moments when he or she can do something unseen. The caregiver can develop a tendency to offer support too quickly or take charge when something is going wrong. But people with deafblindness must try things for themselves and discover things themselves. This may require waiting patiently and “sitting on your hands”.

### 14.3 Observation skills and empathy

As already stated, people with congenital deafblindness are heavily dependent on help from others, especially professional caregivers. They need others to establish exchanges and activities. The caregivers must be able to perceive, interpret and effectively respond to signals from the person with deafblindness. This is called *sensitive responsiveness* (Ainsworth et al., 1978; Van IJzendoorn, 1994). A sensitive caregiver is capable of perceiving and interpreting even small signals. He or she is able to empathise with the world in which a person with congenital deafblindness lives. Responsiveness means that the caregiver can respond to the signals in a way that the person with congenital deafblindness understands.

Thanks to sensitive responsiveness, the person can experience a sense of trust, which allows him or her to develop further.

The caregiver must also be able to examine his or her own role and influence. Getting to know each other and nurturing a professional relationship demands care and time. It often takes more than a year before a person with congenital deafblindness and a caregiver get to know and trust one another (Janssen, 2012). This is unsurprising given the heavy dependence in the relationship, but the implications are quickly underestimated. It takes a great deal of patience and perseverance from both people to build a balanced relationship during all the times they are together. This relationship is essential to promoting the growth of a person with deafblindness in terms of communication, independence and resilience.

#### ***Practical example: Jacco***

*Jacco is a 19-year-old man with Goldenhar syndrome who lives in a home for children and young adults with congenital deafblindness. Jacco is in the last year of school and will soon make the transition from school to work in a social workplace. He is described as a sociable person who enjoys contact with others. He has a special relationship with one person, his teacher David, who has been working with him intensively four days a week for the past few years. The conversations between Jacco and David are clearly different than those with Jacco's other social partners: they do not concern only practical information, like the next activity, but they also include experiences, wishes and emotions. For both Jacco and David, Jacco's leaving school means an emotional parting. David decides that he does not want to lose touch with Jacco and becomes his permanent volunteer visitor.*

### 14.4 Knowledge

A caregiver must have specialised knowledge about congenital deafblindness. This can mean knowledge in the field of psychological and medical problems associated with deafblindness and the syndromes which can lead to deafblindness. Other important aspects include knowledge about how people with congenital deafblindness function, the special ways they express themselves through behaviour or the phase of life they are in: these are all needed to recognise and respond to their need for support. Attention must be paid to all facets of functioning. Knowledge about interaction and communication is the primary component:



caregivers should know the basic principles of interaction and alternative forms of communication.



*Caregivers can augment their knowledge and skills in interaction and communication through video interaction.*

Various agencies for people with hearing and/or visual disabilities offer training in these topics. There is basic training in deafblindness and courses in communication and mobility. See the address list at the back of this book for details

## **14.5 Social network**

Constructing and maintaining a social network demands special attention from the caregivers. Given their problems with interaction and communication, the networks of people with congenital deafblindness are often small. Contacts with other professionals and agencies cannot take place without help from a caregiver who understands how the person with deafblindness communicates and can interpret it. The caregiver can serve as an intermediary between a person with deafblindness and others, helping to expand the expertise of the person's social network so that the person can develop relationships him or herself. Without professional support, a person with congenital deafblindness runs the risk of having a very limited social network, with all the associated consequences (e.g. fewer new experiences, fewer possibilities for exchange, deprivation).

## 14.6 Summary

With the correct support, a person with deafblindness can continue evolving and developing. It is therefore important that caregivers develop knowledge about deafblindness and skills in supporting people with congenital deafblindness. They can follow training programmes at institutes for people with hearing and/or visual disabilities.

Learning to support individuals with deafblindness takes a lot of time and patience and demands empathy. Caregivers must be able to offer lots of physical contact. They must be able to interpret signals that are difficult to read and respond to them (sensitive responsiveness). They must be close by and available, without taking charge (or wanting to) of all the activities performed by a person with deafblindness. Caregivers and their clients must be given and take the time to get to know each other. Building a trusting relationship is essential to being able to offer suitable support in all areas of life.

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## About the Authors

Saskia Damen, an educational psychologist, has been working at Bartiméus since 1997, where she has gained extensive experience in the care of people with deafblindness. In 2006, she and others established the Bartiméus Expertise Centre Deafblindness, which still exists today. In 2007, she was one of the first graduates of the Master's programme in Communication and Deafblindness at the University of Groningen (RUG). She began her doctoral studies at the RUG under the supervision of Professor M.J. Janssen in 2008 and expects to receive her PhD in 2013.



*Saskia Damen*

Mijkje Worm, a developmental psychologist, has been caring for people with deafblindness at Bartiméus since 2002. She began her career providing daily care and support at a residential group home for people with deafblindness. Since 2004 she has worked as a behavioural expert, advising professionals both within and outside Bartiméus about how they can better support people with deafblindness. She has also made significant contributions to various research studies and is associated with the Bartiméus Expertise Centre Deafblindness.



*Mijkje Worm*

## Addresses of organisations for people with deafblindness in the Netherlands

### **Bartiméus**

Oude Arnhemsebovenweg 3  
3941 XM Doorn  
PO Box 340  
3940 AH Doorn  
+31 34 352 6911  
info@bartimeus.nl  
<http://www.bartimeus.nl>

Bartiméus devotes itself to improving the quality of life of blind people and people with partial sight by providing personal advice, support and knowledge transfer. This also applies to people with a combination of visual and hearing disabilities, with or without an intellectual disability. Bartiméus searches for the best forms of support together with the client, and integrates the latest insights into their work. Bartiméus has several locations throughout the Netherlands. In Doorn, Bartiméus provides small-scale living communities, work, day care and communication training. Bartiméus is also available for assessment and temporary stays.

### **GGMD voor Doven en Slechthorenden (mental health care social services for deaf people and people with partial hearing loss)**

Büchnerweg 3 (headquarters)  
2803 GR Gouda  
+31 80 0337 4667  
contact@ggmd.nl  
[www.ggmd.nl](http://www.ggmd.nl)

GGMD voor Doven en Slechthorenden is a national professional service provider for deaf people and people with partial hearing loss, sudden deafness, age-related deafness and deafblindness. Its key functions are social work, career guidance, living group supervision, parent support, training advice, communication training and information services.

### **Kalorama, Centre for People with Deafblindness**

Nieuwe Holleweg 12  
6573 DX Beek-Ubbergen  
PO Box 85  
6573 ZH Beek-Ubbergen  
+31 24 684 7777  
info@kalorama.nl  
[www.kalorama.nl](http://www.kalorama.nl)



The Centre for People with Deafblindness forms part of the Kalorama Foundation. The centre provides supervision, support, care and part-time treatment for adults with deafblindness. The main themes of its services include supported living and living group supervision; at people's homes and on site at Kalorama, support and training in self-sufficiency, mobility and communication (e.g. sign language lessons and computer instructions), daily programme activities and contact with other people with disabilities.

**Royal Kentalis**

Theerestraat 42

5271 GD Sint-Michielsgestel

PO Box 7

5270 BA Sint-Michielsgestel

+31 73 558 8111

info@kentalis.nl

www.kentalis.nl

Royal Kentalis offers a wide range of treatment, support and supervision for people with deafblindness. It has gained considerable expertise in providing advice and support, assessments, education, rehabilitation, family support, supported living arrangements, daily programme activities, support with finding work and support through the resources for deafblind caregivers. In addition, Royal Kentalis offers other products related to hearing, sight and communication.

**Royal Dutch Visio (Koninklijke Visio), Centre of Expertise for Blind and Partially Sighted People**

PO Box 1180

1270 BD Huizen

+31 35 697 3200

info@visio.org

www.visio.org

Visio supports partially sighted and blind people with their questions about life, learning, living and working with a visual disability. For example, Visio gives advice on aids, offer practical training and supported living arrangements, working and emotional processing. Some clients also have an associated physical or intellectual disability.

At the various Visio locations, the focus is on what the client needs, and any combination of disabilities is taken into account. People with deafblindness can also call on the Visio services for rehabilitation and advice, education, support, supported living arrangements and daily programme activities.

**Oogvereniging – DoofBlinden (Eye Association – deafblindness)**

info@doofblinden.net

www.doofblinden.net

Oogvereniging - DoofBlinden is a patient group of the Eye Association for and by people with deafblindness and their families, caregivers and other supporters.

Oogvereniging - DoofBlinden promotes the interests of people with deafblindness and their supporters. The Deafblind patient group works closely together with the Eye Association, an interest group for people with a visual disability. The website offers you contact other people with a disability as well as information, advice and special interest group projects.

**Talant**

PO Box 303

8440 AH Heerenveen

+31 51 364 3800

<http://www.talant.nl>

Talant is a small, accredited specialist facility for people with deafblindness who also have an intellectual disability.

## Addresses of some service providers outside the Netherlands

### **Würzburg Institute for the Blind (Blindeninstitut Würzburg)**

Ohmstrasse 7  
97076 Würzburg  
+49 09 312 0920  
info@blindeninstitut.de  
www.blindeninstitut.de

The Würzburg Institute for the Blind offers services to people with visual disabilities. The organisation has a school for children with deafblindness that features small classes and a strong emphasis on learning communication skills.

### **Helen Keller National Center for Deaf-Blind Youths and Adults**

141 Middle Neck Road  
Sands Point, NY 11050  
+01 516 944 8900  
www.hknc.org

The Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) on Long Island, New York, offers individual diagnostic assessments and training programmes for people with deafblindness from across America. The HKNC also hosts a rubella network group in which people with congenital rubella syndrome and professionals serving them can participate. The HKNC also organises American and international seminars for professionals.

### **Spermalie Royal Institute (Koninklijk Instituut Spermalie)**

Snaggaardstraat 9  
8000 Bruges, Belgium  
www.spermalie.be

The Spermalie Royal Institute is an organisation for children with sensory disabilities. They have a special section for children with deafblindness, which offers integrated supported living and education.

### **Sense**

London Office  
101 Petonville Road  
London N1 9LG  
+44 845 127 0067  
Supporterservices@sense.org.uk  
www.sense.org.uk

Sense is a charitable organisation in the UK that offers support to children and adults with deafblindness. They have various community resource centres that offer a variety of activities and programmes for people with deafblindness. Sense also offers specialised housing facilities, individual counselling, parenting support and vacations and outings. In addition, Sense offers diagnostics, advice and support for people with deafblindness.

**Mo Gard**

S-612 93 Finspang, Sweden

+46 0012 23600

[https://www.facebook.com/mogard.folkhogskola?hc\\_location=timeline](https://www.facebook.com/mogard.folkhogskola?hc_location=timeline)

Mo Gard is a Swedish organisation that provides services to people with deafblindness. They have housing facilities, provide training and offer interpreters for hire. In Finspang they have houses that are specially designed for people with deafblindness.

## Addresses of knowledge centres in the field of deafblindness

### **Bartiméus Expertise Centre Deafblindness**

Oude Arnhemsebovenweg 3

3941 XM Doorn

PO Box 340

3940 AH Doorn

+31 34 352 6911

doofblind@bartimeus.nl

<http://www.bartimeus.nl>

At the Bartiméus Expertise Centre Deafblindness, you can find answers to all your questions about deafblindness. The expertise centre is a multidisciplinary team that includes ambulant caregivers, behavioural experts, a speech therapist and a general practitioner specialised in intellectual disabilities. We offer concrete support, advice and coaching for individual development plans, training, presentations, publications and scientific research.

### **Deafblind International (Dbi)**

11-13 Clifton Terrace, Finsbury Park

N4 3SR London,

UK [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org)

[www.deafblindinternational.org](http://www.deafblindinternational.org)

### **International Expertise Centre Deafblindness Kentalis**

c/o Kentalis Centre for Expertise/ Deafblind Knowledge Team

Theerestraat 42

5271 GD Sint-Michielsgestel

+31 73 558 8111

[A.Eikelboom@Kentalis.nl](mailto:A.Eikelboom@Kentalis.nl)

International collaboration at this expertise centre ensures development and distribution of expertise in the field of congenital and early acquired deafblindness. Its themes include the exchange of knowledge related to communication methods, training, new construction projects, profiles in caregiving, assessments and research projects.

### **Landelijke Intervisie Doofblindenzorg (National intervision Group Deafblindness)**

c/o Anne Schoone [A.Schoone@kentalis.nl](mailto:A.Schoone@kentalis.nl)

This network of Dutch professionals in deafblind care organises peer reviews and themed meetings twice a year.

**National Consortium on Deafblindness**

Western Oregon University 345 N. Monmouth Avenue Monmouth,  
OR 97361 United States of America  
[www.nationaldb.org](http://www.nationaldb.org)

The NCDN is a consortium subsidised by the U.S. government that aims to improve the quality of life for children with deafblindness and their families. On the website you can find a digital library where literature can be downloaded and recent publications are tracked.

**Nordic Center for Welfare and Social Issues (NVC)**

Slotsgade 8  
DK-9930 Dronninglund  
Denmark  
+45 96 47 1600  
[nvcdk@nordicwelfare.org](mailto:nvcdk@nordicwelfare.org)  
[www.nordicwelfare.org](http://www.nordicwelfare.org)

The NVC collects and compares experiences from the Scandinavian countries in the field of health care. In Denmark there is a division of the NVC that specifically deals with knowledge development about deafblindness. They organise courses, produce publications and manage a library.

**Research Centre on Profound and Multiple Disabilities**

Grote Rozenstraat 38  
9712 TJ Groningen  
+31 50 363 6566  
[M.Cazemier.van.den.Berg@rug.nl](mailto:M.Cazemier.van.den.Berg@rug.nl)

The aim of the research centre is to collect and disseminate scientific knowledge in close collaboration with professionals working in the field of people with severe multiple disabilities. The research centre focuses specifically on two target groups: people with severe intellectual and multiple disabilities (ZEVMB) and people with congenital or acquired deafblindness (DB). The research centre forms part of the Department of Pedagogy & Educational Science at Groningen University. The ZEVMB research group is headed by Professor Carla Vlaskamp (together with Dr Annette van der Putten) and the DB research group is headed by Professor Marleen Janssen.

**University of Groningen, Department of Pedagogy & Educational Science, Master of Communication and Congenital Deafblindness**

Grote Rozenstraat 38

9712 TJ Groningen

+31 50 363 6575

[a.m.arendshorst@rug.nl](mailto:a.m.arendshorst@rug.nl)

[www.rug.nl](http://www.rug.nl)

RUG offers this master's degree in collaboration with Deafblind International. It is a unique educational programme in which students acquire theoretical and methodological skills for analysing communication in complex situations. The methods they use can be applied in research and intervention.

## Addresses and websites for aids and modifications in the field of deafblindness

### **Barry Emons Modified Toys**

Hoefslag 11  
5411 LS Zeeland (NL)  
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### **Centre for Consultation and Expertise (CCE)**

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3526 AA Utrecht (NL)  
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CCE aims to give people with special needs a dignified life and takes action when they have severe behavioural problems, their quality of life is severely compromised or their regular caregivers cannot find solutions. Since 2006, CCE has focused its attention on the group of people with dual sensory disabilities.

### **Nederlands Gebarencentrum (Duth Sign Centre)**

Gebouw Rijnhaeghe 2  
3981 GB Bunnik (NL)  
+31 30 656 5407  
[info@gebarencentrum.nl](mailto:info@gebarencentrum.nl)  
[www.gebarencentrum.nl](http://www.gebarencentrum.nl)

The Dutch Centre for Sign Language is the national centre of expertise for Dutch Sign Language (or NGT) and Dutch with Gestures (or NMG). The website contains a sign language databank. It also provides an overview of publications on NGT and NMG. The centre for sign languages also offers courses in sign language.



**Optelec Nederland, Optelec Tieman Groep**

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Optelec provides simple and effective solutions that improve the quality of life of people with a visual disability and dyslexia.

**Stichting Koninklijk Nederlands Geleidehonden Fonds (KNGF; Dutch guide dog association)**

Amsteldijk Noord 2

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**Worldwide Vision**

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www.worldwidevision.nl

Good aids often form an essential condition for integration in our surroundings. Worldwide Vision is specialised in marketing articles for older adults and for people with a visual, hearing and/or reading disability.

**www.allaboutvision.nl**

This English website aims to provide independent and reliable information in the fields of vision, ophthalmology and ophthalmological modifications and corrections.

**www.doofblind.nl**

This website offers information for and about various target groups with a hearing and visual disability. It is an informative site, which also allows visitor to ask questions to the editors.

**[www.hoorprofs.nl](http://www.hoorprofs.nl)**

Hoorprofs is a group of independent hearing care professionals who have formed an association. The website considers in detail the different forms of hearing loss, the procedures for requesting a hearing aid, the differences between hearing aids and all the latest developments. It also contains a range of useful tips.